Classification: Official



Interim service specification:

Interim specialist service for children and young people with gender incongruence

9 June 2023

1.	Service name	INTERIM SERVICE SPECIFICATION Interim Specialist Service for Children and Young People with Gender Incongruence
2.	Service specification number	
3.	Date published	8 June 2023
4.	Accountable Commissioner	NHS England

5. Summary

The Service will provide care to children and young people, and their families, who express gender incongruence and who are likely to benefit from clinical support.

The Service will adopt a holistic, multi-disciplinary integrated approach to assessing and responding to an individual's needs in view of the range of co-presentations that may typically present in this patient cohort, and the range of complexities relating to gender identity development. The most appropriate clinical pathway in the best interests of the child or young person will be determined through an integrated multidisciplinary team (MDT) approach, fully involving the child or young person and their family.

Providers delivering The Service must be an established specialist tertiary paediatric unit with a strong partnership with mental health services; be an established academic centre with a strong track record of research in children and young people; and have robust safeguarding frameworks in place.

The clinical management approach should be open to exploring all developmentally and psychosocially appropriate options for children and young people who are experiencing gender incongruence. The clinical approach should be mindful that this may be a transient phase, particularly for pre-pubertal children, and that there will be a range of pathways to support these children and young people and a range of outcomes.

Not all children and young people who present with issues of gender incongruence will require direct interaction with The Service; in many cases the most appropriate care can be provided locally including with additional support and consultation by The Service. A significant proportion of children and young people who are concerned about, or distressed by, issues of gender incongruence experience coexisting mental health, neuro-developmental and/or personal, family or social complexities in their lives. The relationship between these presentations and gender incongruence may not be readily apparent and will often require careful exploration. Where children and young people present with co-existing conditions or presentations, these will normally be addressed by the appropriate local service alongside this Service.

The primary intervention for children and young people who are assessed as suitable for The Service is psychosocial (including psychoeducation) and psychological support and intervention; the main objective is to alleviate distress associated with gender incongruence and promote the individual's global functioning and wellbeing. The approach for onward referrals to endocrinology clinics are described in separate NHS England clinical commissioning policies for puberty suppressing hormone treatment and gender affirming hormone treatment.

6. Population and/or geography to be served

6.1 Population Covered

The defined patient cohort is children and young people up to their 18th birthday who are:

- Registered with a General Practitioner in England or who are otherwise the commissioning responsibility of NHS England; AND
- Who were under the care of the Gender Identity Development Service at the Tavistock and Portman NHS Foundation Trust; OR
- Who were on the NHS waiting list for the Gender Identity Development
 Service managed by the Tavistock and Portman NHS Foundation Trust; OR

 Who are referred to The Service because gender incongruence concerns may be present and which exceed the scope and expertise of local services.

Terminology

Gender incongruence of childhood (ICD11 HA61)

"Gender incongruence of childhood is characterised by a marked incongruence between an individual's experienced/expressed gender and the assigned sex in pre-pubertal children. It includes a strong desire to be a different gender than the assigned sex; a strong dislike on the child's part of his or her sexual anatomy or anticipated secondary sex characteristics and/or a strong desire for the primary and/or anticipated secondary sex characteristics that match the experienced gender; and make-believe or fantasy play, toys, games, or activities and playmates that are typical of the experienced gender rather than the assigned sex. The incongruence must have persisted for about two years. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis".

Gender Incongruence of Adolescence and Adulthood (ICD11 HA60)

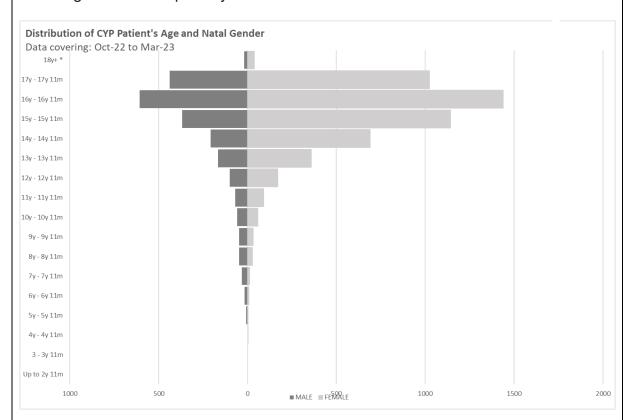
"Gender Incongruence of Adolescence and Adulthood is characterised by a marked and persistent incongruence between an individual's experienced gender and the assigned sex, which often leads to a desire to 'transition', in order to live and be accepted as a person of the experienced gender, through hormonal treatment, surgery or other health care services to make the individual's body align, as much as desired and to the extent possible, with the experienced gender. The diagnosis cannot be assigned prior to the onset of puberty. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis".

6.2 | Minimum population size

Estimates for the proportion of adults or children with gender incongruence vary considerably. This reflects a number of factors such as: variable data reporting by providers; differences in diagnostic thresholds applied and inconsistent terminology; the methodology and diagnostic classification used – population surveys give a much higher estimate than numbers based on service use; and the year and country in which the studies took place. Few studies have taken place in the United Kingdom, and there are no published studies in young children.

Published estimates for the proportion of people who are gender diverse range from 0.3% to 0.5% of adults, and around 1.2% of people aged 14-18 years. The number

of referrals is currently likely to be around 1 per 2000 population per year. The current referral profile suggests that the majority of referrals will be of adolescents following the onset of puberty.



Eligible Patient Cohort

The Service will assume a share of the responsibility for: the existing open caseload; and existing national waiting list of children and young people who are waiting to access a specialist gender incongruence service.

New referrals will continue to be made to NHS Arden & GEM Commissioning Support Unit (The CSU) who will hold the national waiting list on behalf of NHS England until referrals may be passed to a new provider in chronological order.

Young people aged 17 years and who are unlikely to be seen by The Service by the time of their 18th birthday may be transferred to the waiting list of an NHS-commissioned Gender Dysphoria Clinic for adults. In such cases, the Gender Dysphoria Clinic will honour the original referral date to the children and young person's service for the purpose of access into the adult service.

7. Service aims and outcomes

7.1 | Service aims

Pending the establishment of a new national service specification that will describe all elements of the new regional service, this interim service specification describes a model for delivery that will:

- Tailor an individual care plan following a standardised approach to assessment, formulation and care planning
- Provide psychosocial land clinical interventions for children and young people with gender incongruence, including support for the family
- Provide advice in respect of and, onward referral to endocrine intervention services
- Support local services in meeting the gender incongruence needs of children and young people where appropriate through professional liaison and collaboration
- Through professional liaison and collaboration support local services to meet the wider needs of children and young people (including mental health, neuro-developmental and safeguarding) and in risk mitigation
- Build research capabilities to conduct high quality studies across the clinical pathway
- Build and document the history and nature of gender incongruence to establish evidence-based practice

7.2 Outcomes

NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely
Domain 2	Enhancing quality of life for people with long-term conditions
Domain 3	Helping people to recover from episodes of ill-health or following injury
Domain 4	Ensuring people have a positive experience of care
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm

Service defined outcomes/outputs

- To deliver a plan that maximises capacity, delivers assessments and delivers the full pathway of care.
- To provide continuing high-quality data:
 - Workforce plan including vacancy status reported monthly
 - A monthly SPC Chart on first consultations by region, age, biological sex and aggregated
 - A monthly SPC Chart on work in progress (WIP) by region, age, biological sex and aggregated
 - A monthly SPC Chart on discharges by region, and aggregated
- Evidence of engagement with children, young people and families in design and review of service delivery
- Collection and reporting of children and young people's experience of the service
- Build Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) for routine deployment no later than one year following service initiation

7.3 Audit and evaluation

The Service will take part in continuous data collection, reporting and audit to support the NHS in developing a better understanding of the relevant patient cohorts; and for the purpose of evaluating and enhancing the benefits and value of the service model; and for the purpose of building research capabilities to conduct high quality studies across the clinical pathway.

NHS England will commission a third party to support a Learning Healthcare System working with designated providers to build standardised workflows, apply continuous improvement and to create a standard data set for service evaluation through audit and research.

8. Service description

8.1 Future Service model

The future service model will be developed while this interim service specification is used to initiate the service development. Providers are encouraged to adopt a

range of service provision strategies within a structured framework to determine which approaches should be standardised into the workflow.

As a developing area of clinical practice, commissioned providers must actively participate in an ongoing programme of quality improvement to enable continued refinement of models of patient access, assessment, treatment delivery and follow up. This will include:

- Proactive and visible clinical leadership within each service
- Strong links with primary and community care services
- Enhanced data collection, reporting and audit
- Sharing of data and learning between commissioned providers and with national commissioners
- Identification, sharing and rapid adoption of good practice
- Contributing to the prioritisation and focus of national service and quality improvement programmes and initiatives
- Active participation in and delivery of quality improvement initiatives, both at provider level and through a co-ordinated national network approach
- Regular review of service level data at each stage of the pathway and service user feedback, with prompt delivery of any resulting actions for improvement, including where inequalities in access or outcomes are identified

It is important that the opportunity is taken to gather further evidence on the safety, potential benefits and harms of medical interventions.

In addition, well-structured research programmes will be developed through a National Children and Young People's Gender Incongruence Research Oversight Board to include for example: epidemiology; prediction; the course of gender querying; and outcomes of psychological treatments to reduce distress.

Commissioned centres must:

- Contribute to the identification of study and treatment evaluation priorities through participation in the National Children and Young People's Gender Incongruence Research Oversight Board
- Deliver research and evaluation programmes within the service and in partnership with other commissioned service providers

 Ensure an enhanced data set is collected from assessment through to follow up to facilitate research and evaluation, including for those whom, following assessment, it is determined would not benefit from intervention by the Service

Providers will build clear relationships with the range of services and skills across all Integrated Care Systems within the regional catchment.

8.2 Current Pathways

Referrals into the service will be through a National Referral Support Service [DN Insert Link to Specification once approved].

The provider will deliver The Service through an integrated MDT. An individualised pathway will be determined in the child or young person's best interests by, among other things, the clarity, persistence and consistency of gender incongruence, the presence and impact of other clinical needs, and family and social context. An individual care plan will be tailored to the specific needs of the individual following careful therapeutic exploration; this plan may require a focus on supporting other clinical needs and risks with networked local services. The care plan will be regularly updated at least every six months while the child or young person remains in the service.

Standardised Assessment

All children and young people who are seen by The Service will receive a standardised comprehensive assessment that will identify and develop a shared formulation of a child or young person's needs based on a comprehensive, holistic assessment including developmental history, history of gender incongruence and associated needs and risks. Assessments should be respectful of the experience of the child or young person and be developmentally informed. Clinicians will meet families with diverse needs and at different stages in thinking about their gender. This could include where: long-standing social transition has already been made; or no social transition has been made, but the child/young person expresses certainty around a different gender identity; or the child/young person expresses uncertainty and confusion around feelings about gender and distress. Families may have unity around the use of names and pronouns, whereas in others, this may be causing conflict and concern.

The objectives of the process of assessment will be:

- Establish a positive clinical relationship, clinician approach and stance e.g., modelling curiosity, holding balance and neutrality; including sensitivity and flexibility to issues around pronouns, names and language
- Set the context, explain the rationale for a holistic needs assessment and manage expectations
- Seek agreement to understand different areas of the child/young person's life, including wider family/networks
- Identify or confirm significant co-existing conditions or challenges
- Establish next steps in relation to the young person's gender querying / gender incongruence – including the respective contributions from local healthcare (and other multi-agency) services and the nationally commissioned Service
- Identify and signpost to supportive resources for psychoeducation and/or transition pathway options
- Develop an initial, 'working' formulation to guide care planning and next steps

The Service will adopt a holistic, multi-disciplinary integrated approach to assessing and responding to an individual's needs. The most appropriate clinical pathway in the best interests of the child or young person will be determined through an integrated MDT approach, fully involving the child or young person and their family.

There is an increased prevalence of mental health needs in children and young people who present to gender identity services (such as depression; anxiety; risk-taking behaviours) and these children and young people will have spent many years on the waiting list. There is also thought to be an increased prevalence of neurodevelopmental disorders in children and young people on the waiting list. In view of the range of co-presentations that may typically present in this patient cohort the MDT will include expertise for the direct assessment of autism, attention deficit hyperactivity disorder and other forms of neurodiversity.

Initially there will be a focus on understanding the expression of gender incongruence and identifying associated physical and mental health and neurodevelopmental needs; and on identifying and responding to clinical risk, including mental health and safeguarding needs. The Service will identify and initiate action on immediate health and support needs, including in relation to coexisting conditions and, in some cases, safeguarding concerns.

Assessment should seek to understand the holistic needs of the child or young person and their family. This process should determine whether there are any co-occurring and/or contributory elements of the individual's presentation that are affecting their psychosocial wellbeing or functioning and require support as the basis of an individual care plan.

Clinicians should remain open and explore the child or young person's experience and the range of support or treatment options and their implications that may best address their needs, including any specific needs of neurodiverse children and young people.

Assessments will focus on:

- Subjective sense of the child / young person's identity over time
- Their expression of gender identity across different contexts over time and different settings
- Their hopes and expectations and that of their family members/carers and their stance towards the child / young person's gender identification
- Any steps that have been taken along a gender transition
- Developmental needs including cognitive functioning and capacity of the child / young person, and their understanding of gender
- Associated physical mental health and neurodevelopmental needs and their relationship with gender incongruence
- Risk including mental health, safeguarding including risk of vulnerability and exploitation and impact of any unregulated medication
- Psychosocial functioning and impact of the gender incongruence (eg on educational attendance and progress, or experience of bullying or harassment)
- With adolescents sexual orientation; psychosexual development and any sexual experiences
- Assessment of family functioning and quality of relationships within the family, including children and young people in care (or kinship care or who have been adopted) and the wider community
- Exploration of parent/carer and family views on the child or young person's gender identity journey and family support
- Peer relationships and wider social support
- Family's spiritual, cultural, or religious beliefs

 Protective factors – strengths and resources that the young person and family are able to build on

Outcomes of the process of assessment

- Presentations, pathways and outcomes for this cohort will be individualised in the best interests of the child or young person, who is introduced to the service team and service offer, with a focus on promoting or maintaining the child or young person's overall wellbeing and global functioning.
- A child or young person with mental health or neurodevelopmental needs and / or risk-taking behaviours that require immediate intervention will be supported to access this through professional liaison and care navigation with local services including health, social care and education. The Service should confirm collaborative care arrangements for further assessment and treatment with local services through professional liaison. A significant number of children and young people with very complex needs may also be Looked After or may not live with their birth family and may require the active involvement from children's social care and/or expert social work advice.
- Identification of co-existing conditions or needs will lead to an exploration of the relationship between the presentation and gender incongruence through an integrated approach by MDT members.

Support to Local Professionals Following Assessment

The service model will reflect that not all children and young people with gender incongruence will need to be seen directly by The Service or, may only need to be seen for an initial or brief assessment by the Service. The process of assessment will seek to identify children and young people for whom consultation and active support through local professionals is appropriate, 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, the resources available locally, and through a process of clinical prioritisation.

The Role of Formulation

Formulation is a process used by a range of professionals to summarise and integrate a broad range of information gathered in an assessment. A formulation is a set of hypotheses about an individual's difficulties, which links theory and

evidence with practice. It is developed collaboratively with the young person and their family, and should inform and guide subsequent support and intervention.

The process of assessment and formulation should conclude with a set of recommendations in relation to a care plan. This will include potential pathways of psychosocial support, recommendations on therapeutic interventions, parent/carer support options as well as wider recommendations for further support that might be accessed from the local professional networks. It should also include clear pathways around discharge where appropriate.

The Service will make a recommendation on the need for further support and information, incorporating the views and wishes of the child, young person and parents/carers and referring professionals, and make recommendations for a specialist explorative assessment in relation to the medical pathway if appropriate.

The outcome of the process of assessment including formulation of needs and risks will be confirmed in writing with the GP and referrer and shared with the family.

Psychoeducation

Psychoeducation material for children and young people, parents/carers and local professionals alike will include information on gender identity development including research evidence and how to support an exploratory approach that allows their child or young person time and opportunity to consider different options in a flexible and non-judgemental context.

Children and young people who are seen by The Service, and their parents/carers, will receive psychoeducational information that is appropriate to their needs. Parents, carers and families, (including siblings) will have the opportunity to access additional resources including facilitated group discussions with peers on a similar pathway.

Social transition as a part of a clinical intervention

Social transition is something that should be led by the young person with family input.

For the purpose of this interim service specification the reference to 'social transition' is intended to refer to the support offered by NHS clinicians to children, young people and their families who have decided that the child or young person will present in public fully with a gender identity different to that of their natal sex in all forms and aspects of their daily lives – rather than less profound forms of gender

diverse expressions, behaviours or interests such as engaging in activities or presentations socially defined and typically associated with another gender presentation.

The ability to express individuality – and autonomy to change and adapt that expression over time – can be important to a child or young person's development of the self and to their overall wellbeing. However, due to the social and psychological implications that social transition may have, advice about social transition should be seen as informing a significant decision when it forms part of an individual's care.

While there are different views on the benefits versus the harms of early social transition, it is important to acknowledge that it is not a neutral act - and that information is needed about long-term outcomes to support decision making. Information and discussion about this with the MDT is an important part of supporting a child or young person in The Service.

At the point of presentation to The Service some children and young people will have already socially transitioned or be in the process of effecting a social transition, while others may be considering this. The Service will support a shared decision-making process - it is important that the risks and benefits of social transition are discussed with the child or young person and family, referencing best available evidence. Decisions will be individual, and the agency to make the decision rests with the young person, along with their family.

The Service's MDT will engage children and young people and their families in an in-depth process of discussion and thinking around the decision of social transition. The MDT will support a consideration of: how this will fit within the broader holistic approach to addressing the child or 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 including autonomy to change or cease social transition if the gender incongruence changes or abates. This interim service specification recognises that pre-pubertal children have different needs to older adolescents and that the detail of the different clinical approaches across the age ranges will develop as the services evolve and the evidence becomes available.

Direct work with pre-pubertal children, and their families

The clinical approach in regard to pre-pubertal children will reflect opinion that exploration of gender diversity in childhood is an expected aspect of general human

development, and that diverse gender expressions in children cannot be assumed to reflect gender incongruence.

Some children will remain stable in a gender identity they articulate in early life that is discrepant from natal sex and for others it will be a transient phase. While intensity of early gender incongruence in children may be an important predictor of persistence of gender incongruence, gender trajectories in prepubescent children in particular cannot be reliably predicted and may evolve over time.

Generally, the clinical approach will focus on a careful observation of how gender incongruence develops as puberty approaches and is reached. The therapeutic approach for younger and pre-pubertal children is not directed at gender incongruence itself but instead focused on other clinical presentations and needs, or familial/social circumstances that may impact on the child's psychological health and gender incongruence.

The level and timing of intervention will be commensurate to the individual's needs and may range from advice by The Service to the family and professional network where there are no concomitant issues, to more intensive clinical interventions that seek to address other clinical diagnoses delivered by local secondary services with support, advice and consultation by The Service.

Psychological support and interventions provided directly by The Service will focus on children whose presentations are persistent and who have impaired functioning, with the aims of alleviating or preventing the onset of emotional problems, behavioural problems and social relationship problems, improving psychosocial health and global functioning. For younger pre-pubertal children, local services will often be the most appropriate source of continuing direct psychological support and intervention, with or without consultation support from the Specialist Service.

Support will be offered as part of the collaborative care agreement with local services and may be provided by the local and/or specialist service and, could be offered through individual / family work or group work.

In cases where a pre-pubertal child has effected, or is effecting, a social transition (or expresses a wish to effect a social transition) the clinical approach has to be mindful of the risks of an inappropriate gender transition and the difficulties that the child may experience in returning to the original gender role upon entering puberty if the gender incongruence does not persist into adolescence.

However, some children state that they want to make a social transition to their preferred gender role long before puberty, which means that increasing numbers of children may have made a partial or full social transition prior to the first attendance with The Service.

In summary, for pre-pubertal children the clinical approach and advice applied by The Service will be supportive and non-judgemental, balancing on a case-by-case basis a watchful approach overall with a more individualised approach in cases where the child's level of global functioning may be maintained or improved through a carefully observed process of exploration of social transition. Where social transition is occurring or is being considered by the family, The Service will support the family in weighing the potential benefits, challenges and risks.

Direct work with adolescents and their families

Psychological support and interventions provided directly by The Service, including family therapy/work, will focus on alleviating or preventing the onset of emotional problems, behavioural problems and social relationship problems, improving psychosocial health and global functioning, while responding to co-existing needs and conditions.

Clinicians should remain open and explore the young person's experience and the range of support or treatment options and their implications that may best address their needs, including any specific needs of neurodiverse children and young people. The overall aim is to reduce distress in the individual; support the development of positive self-image and self-esteem; promote the individual's global functioning; facilitate understanding and acceptance within the family unit.

Interventions with adolescents should be at a level commensurate with the needs of the individual. More intensive clinical interventions may be needed that seek to address other clinical diagnoses and will be delivered by local secondary services with support, advice and consultation by The Service.

Factors that could influence the complexity and length of the intervention include:

- Unstable or escalating mental health problems
- Ongoing risk issues, and safeguarding issues
- Levels of emotional and cognitive maturity
- Concerns with regard to competency or capacity to understand and consent
- Family conflict about how to proceed

Not all adolescents will want or benefit from social transition. Where social transition is occurring or is being considered by the young person and their family, The Service will support the young person and family in weighing the potential benefits, challenges and risks.

In view of the potentially profound impact of social transition on the young person's life the provision of approaches to support social transition will be considered in cases where expressions of gender incongruence or gender diversity have been persistent; and the young person expresses a clear wish to affirm their gender transition and fully understands the implications of affirming a social transition (informed consent); and where the proposed approach is considered by The Service as necessary for the promotion or maintenance of the young person's overall health, wellbeing and social functioning. In these cases the clinical approach will involve a focus on exploring or supporting (as appropriate to the individual) social transition through psychological support and interventions, family work/therapy and guidance for the local professional network. Young people and their families will be supported in making difficult decisions regarding the expression of a gender role that is consistent with their gender identity, including the timing of changes to gender role and possible social transition.

The Service will aim to maintain a therapeutic relationship with young people and their families throughout any subsequent social changes or physical interventions. This ensures that decisions about gender expression and the treatment of gender incongruence are thoughtfully and recurrently considered. The same reasoning applies if a young person has already socially changed gender role prior to being seen by The Service.

Referrals for assessment for endocrine interventions

Separate but linked NHS England clinical commissioning policies will define the use as part of the NHS commissioned service of i) puberty suppressing hormone treatment; and, ii) masculinising / feminising hormones from around the age of 16 years.

Prescribing from unregulated sources and unregulated providers

Children, young people and their families are strongly discouraged from sourcing puberty suppressing or gender affirming hormones from unregulated sources or from on-line providers that are not regulated by UK regulatory bodies.

If a child or young person has already been started on **puberty suppressing hormones** outside of NHS protocols by the time that they are seen by the NHS, The Service may consider assuming clinical responsibility for prescribing through NHS protocols if The Service's MDT jointly concludes with the related endocrine clinic that this is an appropriate harm reduction measure. In such cases administration of puberty suppressing hormones would need to be stopped for a brief period of time to allow baseline investigations to be undertaken by The Service. If the patient is felt to be appropriate to be restarted on treatment after assessment by The Service treatment may be resumed in accordance with NHS protocols, including the requirement for the patient to be enrolled in the formal research protocol.

If a young person has already been started on **masculinising** / **feminising** hormones outside of NHS protocols, The Service will consider (jointly with the related endocrine clinic) a continuation of prescribing through NHS protocols as a harm reduction measure where ALL of the following criteria are met:

- Evidence of a comprehensive documented assessment by a multidisciplinary team that includes a medical practitioner with specialist expertise in gender incongruence in children and adolescents; and
- Evidence of continued psychological support through engagement with the MDT; and
- Administration of puberty suppressing hormones was commenced not before Tanner stage 2; and
- Masculinising / feminising hormones commenced after at least twelve months on puberty suppressing hormones; and
- Masculinising / feminising hormones were commenced not before approximately 16 years of age; and
- Evidence that impact to fertility was discussed with the young person before initiation of the hormones.

Where the Service is not able to accept responsibility for prescribing puberty suppressing hormones or masculinising / feminising hormones the Service will not offer clinical supervision for the management of the endocrine intervention and will not enter into shared care arrangements with a health professional who is making recommendations for prescribing / is prescribing to the child or young person. In such cases The Service will make the child or young person and their family aware of the risks, contraindications and any irreversible or partially reversible effects of the interventions; and will make the GP or local health professional (as appropriate)

aware and suggest that the GP or local health professional considers what safeguarding protocols may be appropriate for the individual child or young person's wider circumstances including the extent to which the parents / carers are able to protect or safeguard the child or young person. Safeguarding procedures may be necessary regardless of the endeavours and best intentions of the parents / carers in reducing risk of harm.

Safeguarding protocols should be initiated immediately where the child or young person is at risk of immediate, serious harm.

It would also be important for the GP or local health professional to explore what regulatory bodies may need to be informed if healthcare professionals registered with a UK professional body are prescribing medication contrary to NHS protocols.

Transition to adult services and discharge

The Service may provide support to young people up to their 18th birthday.

The Service will review the needs and progress of the young person in relation to their gender incongruence and the goals of treatment and will step down or discharge their care to local primary care or secondary care services as appropriate.

For young people who have been seen by The Service and who are approaching their 18th birthday The Service will co-ordinate a transition and support plan with the professional network specific to the young person's needs. A transfer may be made to an NHS-commissioned Gender Dysphoria Clinic from 17 years of age where the young person meets the access criteria.

A co-ordinated transfer to appropriate local adult services will be needed where complex presentations continue.

8.3 Essential Staff Groups

The key clinical leadership role will be through a medical consultant with significant experience in the developmental needs of children and adolescents.

The MDT will have (or have access to) the following competencies and experience (see also <u>Appendix A</u>). Practitioners will need access to clinical supervision across a range of clinical areas (e.g., psychological, mental and physical health, safeguarding and gender identity development) to support their roles.

- Multi-agency working including provision of consultation, liaison and advice for complex cases, and care navigation
- Expertise in child safeguarding and assessment and management of risktaking behaviours
- Childhood and adolescent development, including cognitive, social and sexual development; gender identity development and gender expression
- Paediatric medicine, including psychological health
- Child and adolescent mental health, including expertise in assessment and formulation, delivery of evidence based therapeutic interventions, trauma informed approaches; and family work/family therapy
- Cognitive Behavioural Therapy
- Neurodevelopment disorders including learning disability and autism spectrum conditions
- Gender incongruence
- Expertise in sex development, and endocrine intervention
- Expertise to support children and young people who may be Looked After or in Special Guardianship or who may be adopted.

8.4 Essential equipment and/or facilities

The provider must have in place premises that are appropriate to ensure effective delivery of the services described in this service specification; and in an age-appropriate environment that children and young people regard as safe and welcoming. Providers will be mindful that the majority of individuals are likely to be of an age following the onset of puberty.

8.5 Interdependent Service Components – Links with other NHS services

The Service must be expert in working with a wide variety of agencies. It is expected that close working will be needed in particular with Children and Young People's Mental Health Services, child health and neurodevelopment services, voluntary community services, education professionals, children's social care and with general practitioners.

The Service should also be competent in their understanding of and close working with children and young people with social care needs – including adopted children and young people, and children in care, and in working with schools and colleges to facilitate wellbeing and full access for their education.

Collaborative care arrangements

Referrers, together with local healthcare services, will agree with The Service collaborative care arrangements particularly in relation to the young person's mental health, neurodevelopmental needs and / or risk-taking behaviours. Local services including children and young people's mental health services, paediatric healthcare services and local authorities will continue to provide the care that they would routinely offer young people and families as part of local or national commissioning arrangements across relevant care pathways. It is not the expectation that The Service will address these broader needs.

Collaborative care arrangements should be clarified through professional liaison and confirmed in writing with all stakeholders including the young person and parents/carers.

8.6 Additional requirements

The provider must have in place:

- A robust system of clinical governance that ensures, inter alia, all clinical staff are trained in assessing and meeting the health needs of children and young people including those on the waiting list, have access to clinical supervision, and are deemed competent to deliver the interventions as per their role; this will include a documented approach to safeguarding that is consistent with NICE guideline NG76.
- A robust system of corporate governance, including a nominated senior manager, that demonstrates effective management, guidance, oversight and accountability by the host organisation; and supported by experienced communications and engagement teams.
- Arrangements in place to ensure that the service delivers culturally
 appropriate and trauma informed care and support; individuals must be able
 to access services in a way that ensures their cultural, language and
 communication needs do not prevent them receiving the same quality of
 healthcare as others.
- Sufficient administrative and managerial support needed for efficient and timely delivery of services.

- Arrangements in place (including ongoing training) to ensure that all staff in public-facing roles have cultural sensitivity towards children and young people who may be gender diverse.
- Arrangements in place to ensure that service design and improvement is co-produced with experts by experience and promotes equality, diversity and inclusion., This should include routine outcomes and experience monitoring and be able to demonstrate how improvement is achieved via means that are accessible, transparent and inclusive.
- Arrangements in place to ensure that feedback, comments and complaints by individuals and their families are acknowledged investigated and responded to promptly; and that the means to complain are publicised and accessible.

8.7 Commissioned providers

Providers delivering The Service must be an established specialist tertiary paediatric unit with strong links to mental health services and have established academic partnerships.

NHS England will establish a framework for a co-ordinated and collegiate approach across all of the new regional services - focusing initially on development of the model and then moving to issues of operational delivery, service development, improvement and audit. This approach will help to ensure continuity of provision for children and young people if they move across sub / regional boundaries.

Providers will co-operate as part of a clinical network with other designated providers to support sharing of best practice, quality improvement and research processes and consistency against the service specification and model of care.

8.9 Links to other key documents

This interim service specification supersedes service specification E13/S(HSS)/e Gender Identity Development Service for Children and Adolescents (2016)

Other key documents:

NHS England <u>Service Specification</u>: Gender Identity Services for Adults (Non-Surgical Interventions); 2019 as <u>amended</u>; 1719

The Cass Review Interim Report, February 2022

NHS England <u>Statement</u>: "Implementing the Recommendations of the Cass Review", July 2022

Appendix A MULTIDISCIPLINARY TEAM COMPETENCIES AND EXPERIENCE

Gender Incongruence in Children and Young People under 18 years of age

- Understanding of the wider social context in which specialist health services for gender incongruence operate; and specifically, understanding of the operation of specialist NHS services for gender incongruence in the context of recent judicial, regulatory and commissioning decisions
- Understanding of the contested debate around different management approaches for responding to children and adolescents who have gender incongruence; and the limited evidence base to inform clinical approaches and service delivery; and limited data on outcomes
- Understanding of the various reasons why professionals may make a referral to specialist gender incongruence services
- Understanding of the current NHS pathway for children and young people up to 17 years
- Understanding of diagnostic formulation currently DSM-V moving to ICD-11) on the NHS pathway of care
- Understanding of how gender incongruence presents in children and young people, and the resulting mental health and psychosocial needs of children and young people on the NHS pathway of care including while they are on the waiting list
- Understanding of approaches to care that are delivered by NHS specialist gender services, and support needs and support options for children and young people who have degrees of gender incongruence
- Understanding of the intended outcomes for children and young people who are seen by NHS specialist gender incongruence services
- Understanding of the relationship / interface between:
 - The Service and Adult Gender Dysphoria Clinics
 - Specialist NHS gender incongruence / dysphoria services and primary care
 - Specialist NHS gender incongruence / dysphoria services and other statutory services

Multi-Disciplinary Clinical Leadership team

In addition to specific expertise in gender identity development and incongruence, the clinical leadership team of The Service should include strong, consultant level expertise in:

- Paediatric healthcare including child development and endocrinology
- Psychological healthcare including child cognitive and emotional development, psychological interventions and therapy, including consultation and liaison approaches to healthcare delivery
- Mental health diagnoses and intervention, including pharmacological interventions and in-patient mental healthcare
- The psychological and mental health aspects of healthcare for children
 & young people with physical healthcare need
- Neuro-developmental conditions, including autism and attention deficit with hyperactivity disorder (ADHD)
- Consent and mental capacity in a child development context where there may be a complex and contentious aspects.

	 Designing, monitoring and redesigning or improving effective, efficient and responsive care pathways in collaboration with experts by experience
Knowledge and	Awareness of a range of mental and physical disorders; and knowledge of
Experience of	models of intervention and their application in practice. Including knowledge
Specific	and experience of:
Presentations	
and	 Neurodevelopment disorders including autistic spectrum conditions
	 Mental health disorders including depressive conditions; anxiety and
Interventions	trauma; eating disorders
	 Endocrine conditions including Disorders of Sex Development
	 Pharmacology, particularly in the context of gender incongruence
	Range of risks that may present in the child or young person including
	deliberate self-harm; exploitation; high risk behaviours; substance abuse
	 Family contexts for children and young people that include being a child
	in care, or kinship care (including special guardianship) or being
	adopted
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Child and	 Knowledge of development in children and young people; including
Young Person	normative development; social and behavioural development; sexual
Development	development; gender identity development and gender expression
	 Understanding of the differences in sexual identity and gender identity,
	and expression
	 Knowledge and understanding of mental health problems in children and
	young people
	 Knowledge and understanding of neurodevelopment disorders in
	children and young people
	 Knowledge of the physical development of children and young people
	Knowledge of the needs of young people who are moving from
	paediatric to adult services
	 Understanding of mental and physical health problems in children and
	young people in the context of impact to:
	- Educational attainment
	- Social development including formation of peer relationships
Family	 Understanding of normative family development
Development	 Understanding of mental and physical health problems in children and
and	young people in the context of impact to family relationships
Relationships	, , , , , , , , , , , , , , , , , , , ,
izeiauonanipa	Understanding of parents with additional needs and impact of their
	mental and physical health needs to children and young people
Assessment,	Ability to contribute to assessment, formulation and diagnosis while
Formulation	acting in a consultation role to the professional network (including
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and Diagnosis	specialist mental health assessment)
	 Ability to contribute to risk assessment and management while acting in
	a consultation role to the professional network
Cultural	Cultural competence and understanding of equality and diversity
Competence	principles
	 Understanding of the wide diversity of children and young people who
	are referred to specialist gender incongruence services
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	Understanding of the social, emotional and mental health needs of
	relevant groups in the local communities who share protected
	characteristics
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Multi-Agency Working	 Ability to work within and across different agencies (health; education; social services; youth justice; other) and an understanding of how these agencies operate including the local voluntary sector Understanding of the role of education services in supporting children and young people with gender incongruence (supporting full access to the curriculum and pastoral support including, vulnerable children policies; toilet and changing room policies; pupils with special education needs and, addressing, exclusion, bullying and harassment) Ability to act in a coordinating and consultation role in case work,
	working with professionals across different services and agencies
Safeguarding / Professional	 Recognise and respond to concerns about child protection and safeguarding Knowledge of legal frameworks relating to children and young people Knowledge of and ability to work within relevant professional and ethical guidelines Knowledge of, and ability to work with, issues of confidentiality, consent and capacity