

Independent review of gender identity services for children and young people

Engagement report



"There's going to be a lot of listening – listening to those who have experience either as a young person, a family member, or a professional in the field".

Dr Hilary Cass

Chair, Independent review of gender identity services for children and young people

Purpose

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This report provides an overview of the range of activity undertaken to engage with service users, clinicians and other stakeholders over the course of the independent review of gender identity services for children and young people (the Review).

Context

One of the principles underpinning the approach to the Review was that there would be extensive and purposeful stakeholder engagement, including ensuring that children and young people could express their own views through a supportive process.

The Review met with teams that had conducted comparable reviews and inquiries, and support and advocacy groups, to learn from them the best ways to ensure that the views of people affected were captured.

The Review tried to create spaces for open honest debate about the issues relating to the provision of these services. It was not always possible to facilitate discussions that brought together people with very different perspectives, not necessarily because there was no common ground, but there was an expressed concern that people would not feel able to speak openly. Opportunities for people to contribute needed to be carefully navigated and well planned.

The Review was commissioned to look at the future clinical and service model, and took an iterative approach, releasing information, findings and advice when there was sufficient clarity and clinical agreement about the way forward. Independent review into gender identity services for children and young people

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In response, NHS England began to implement changes to the clinical service offer in parallel to the Review conducting its work. This included its decision to decommission the Gender Identity Development Service (GIDS) and move to a new regional service model (Phase 1 providers).

This added a layer of complexity to the work of the Review as the clinical landscape shifted. GIDS staff, those accessing the services and support and advocacy groups were understandably feeling unsettled at this time and the public, political and media debate further impacted the situation.

The sensitivity of the subject matter, coupled with the fierce public debate meant that some young people, parents and clinicians were reluctant to speak to the Review unless there was an agreement of anonymity. This has meant that the Review was not able to be as fully transparent as it intended to be, and this has restricted the amount of information the Review could make publicly available.



Principles

The following principles underpinned the Review's engagement.

COLLABORATIVE: Developing recommendations through an iterative process of facilitated discussion and consensus building, based on the evidence available, placing the interests of the children and young people at its centre.

PROACTIVE: Taking a "no surprises" approach, keeping stakeholders involved and informed throughout the lifetime of the Review through regular updates and engagement opportunities.

OPEN & ACCESSIBLE: Using different methods to engage with stakeholders in a manner that made them feel safe and supported and allowed quieter voices to be heard, balancing open access methods with more targeted engagement with those closest to/most affected by the services.

PURPOSEFUL & COORDINATED: Clearly defining the purpose of different engagement activities and how learning would be used to inform the recommendations. Engagement would not duplicate, the work of the Review's academic researchers.

RESPECTFUL: Informed through on-going dialogue with a broad range of stakeholders, acknowledging and allowing expression of the different views and opinion across the spectrum of stakeholders, but not tolerating disrespectful, threatening or abusive behaviour. See our <u>Terms and Conditions page</u>.



Approach and activities

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The Review sought to create a range of opportunities where people felt confident and comfortable to share their experiences and views.

Most of this activity was delivered by the Review team directly, but for some of the more structured activity the Review worked with or through specialist organisations or groups that already had a relationship with children and young people with lived experience.

Overall, the Review has met with over 1,000 individuals. Some were one-to-one meetings, some were bespoke meetings on a particular topic and others focussed on building awareness and improving understanding of the issues among interested parties and organisations.

Two categories of stakeholders were prioritised in the engagement programme:

- People with relevant lived experience (direct/primary or as a parent/carer) and organisations working with LGBTQ+ children and young people generally; and
- Clinicians and other relevant professionals with responsibility for providing care and support to children and young people, both within specialist gender services and beyond.



Independent review into gender identity services for children and young people

Methods

The engagement programme included:

Focus Groups

Collecting insights, thoughts and feedback in small group discussions (less than 15 people) looking at set questions.

Listening sessions

Semi structured 1-to-1 discussions for the chair to hear directly from young people, parents, clinicians & other

Clinical workshops

Thematic discussions where participants contributed to drive thinking on a particular topic area to coproduce potential recommendations.

Round table discussions

Facilitated discussions of 15 – 20 people to explore specific aspects of the review in greater depth based on presented evidence & emerging thinking.

Surveys

Collecting insights, thoughts and feedback from targeted audiences on specific questions.

Engagement meetings

Meetings with organisations or groups – some held at regular intervals, others one-off or adhoc.

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Engaging people with lived experience

"I have spoken to transgender adults who are leading positive and successful lives, and feeling empowered by having made the decision to transition. I have spoken to people who have detransitioned, some of whom deeply regret their earlier decisions. I have spoken to many parents, with very different perspectives." Cass Review Final Report (2024)

The Review was advised that to hear from the young people at the heart of the Review, opportunities needed to be created where they felt safe and could be supported before, during and after their contribution. Also, that they should be engaged around topics where there was a genuine ability to inform and influence decisions.

Hearing directly from the children and young, their parents/carers and the support and advocacy groups working with them, provided valuable insight into the ways in which services were currently delivered and experienced as well as their expectations of, and aspirations for NHS services.

This contributed immeasurably to the Review's understanding of the positive experiences of living as a transgender or gender diverse person, as well the uncertainties, complexities and difficulties faced by those trying to navigate through services and available support.



Listening sessions (Lived experience)

The Review Chair. Dr Cass, held weekly listening sessions to hear directly from people with lived experience.

Listening sessions were held with people with direct/primary lived experience (individuals who identify as transgender, non-binary, gender fluid and/or who have been through a period of genderquestioning) or secondary lived experience relevant to the Review (a parent/carer of a gender-questioning child or young person).

Listening sessions were promoted through support and advocacy groups, clinicians working with gender-questioning children and young people and, when appropriate, were offered to individuals who contacted the Review directly.

Because some people were anxious about being identified, the Review agreed that the sessions would be confidential, and all learning gained would be anonymised.

These confidential sessions provided the Review with invaluable insight into the ways in which services were currently experienced.

They contributed to the Review's understanding of the positive experiences of living as a trans or gender diverse person as well as uncertainties, complexities and challenges faced by children, young people and their families/carers.



Personal Narratives

When the Review first began, the intention was to have an open call for evidence to capture people's experiences and personal testimonies through an online platform. However, several stakeholders cautioned against this approach for the following reasons:

- There would be no way to verify the information being submitted
- Unlike in the case of formal public inquiries, there would be no legal status for the information being provided.

With no formal process or capacity to analyse the submissions and validate their authenticity, the Review concluded that it would not be appropriate to collect a large volume of potentially sensitive information that it would not be able to effectively process.

Some individuals did choose to send the Review written submissions describing personal experiences of gender services or gender identity exploration. All submissions were treated as confidential and read by the Review to see if they raised issues that were consistent with what had been heard from other sources, or if they introduced relevant new information. If the latter, the individual was invited to attend a listening session.



Lived experience focus groups

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The Review commissioned (through an Expression of Interest process) support and advocacy organisations to facilitate focus groups to better understand the experiences, thoughts and ideas of young people and adults (aged 14-30) with lived experience.

The Review wanted to ensure that participants felt comfortable and confident to speak freely and could be supported before, during and after the sessions. The following host organisations were commissioned to deliver the groups:

- 42 Street
- Gendered Intelligence
- The Kite Trust
- The LGBT Foundation
- Mermaids
- The Proud Trust

Each organisation was commissioned to deliver three focus groups, two of these organisations also conducted surveys and some held one-to-one conversations.

There were 127 engagement episodes across the focus groups, one-to-one interviews and surveys. Some host organisations engaged with the same group of individuals across all three focus groups. Other organisations engaged different participants for each of the focus group sessions.

This means that the number of "engagement episodes" i.e. the count of people participating in focus groups, is a slightly higher than the number of individuals participating.



<u>Three sets of questions</u> were explored with the young people. These focused on:

- 1. experiences and thoughts on the existing NHS services available to them
- 2. hopes and ideas for future services
- 3. thoughts on wider support outside the specialist services.

Each hosting organisation submitted a report of the feedback from the focus groups, interviews and surveys. They also provided transcripts of each of the groups.

The Review team then had a meeting with the organisations that had hosted the focus groups to agree common themes. These were incorporated into a summary report.

More information and all the reports are available at:

https://cass.independent-review.uk/contribute-to-thereview/lived-experience-focus-groups/



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Learning from lived experience roundtable

In November 2023, following the completion of the lived experience focus groups, the Review hosted a roundtable discussion "learning from lived experience".

The roundtable brought together some of the young people with direct lived experience who had participated in the focus groups, policy leads from support and advocacy groups, clinicians (including from the phase 1 providers of the new regional children and young people's gender services), NHS engagement leads, Gender Identity Development Service (GIDS) staff and members of the Cass Review Assurance Group.

Key themes from the lived experience focus groups were circulated to the group ahead of the meeting and further insights were presented to the participants during the meeting.

The roundtable focused on two questions:

- 1. What do the insights from the lived experience focus groups mean for future services?
- 2. How should the voice of service users be embedded into the new services?

To allow for full and frank discussion, the roundtable operated under the Chatham House Rule meaning that information disclosed during the meeting could not be explicitly or implicitly attributed to an individual.



Key points from the discussion

The roundtable participants agreed that the key messages identified through the focus groups were an accurate reflection of the high-level issues. The discussion also identified some additional points that the group thought was important to highlight.

- Gender-affirming care comprised a wide range of interventions and services, some of which could be delivered outside of specialist services.
- Clinicians needed to be non-judgmental, respect the young person's sense of themselves and be open to any and all outcomes. They should ask the young person what they want to achieve from the service.
- More support around gender expression, social transition, and exploration was needed.
- Waiting lists needed to be reduced significantly so that young people could receive effective care.
- Medical professionals needed better training about how to work sensitively and effectively with trans, non-binary and gender questioning young people.
- There needed to be better communication and more emotional, physical and social support while people are waiting for services.
- The transition to adult services could be problematic, some participants suggested having an overlap service for 16–25-year-olds.



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- Local healthcare and gender healthcare services needed to work more closely together.
- Increasing trans visibility, including having trans and nonbinary people within the workforce would help support better relationship building and understanding of how to work with trans and gender questioning young people.
- The NHS needed to provide trustworthy information for young people. Resources should be provided for parents, carers and families also.

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Engagement with support and advocacy organisations, charities and campaign groups

The Review identified a core group of support and advocacy organisations where support of gender-questioning young people was their primary function or a significant element of their work.

- Mermaids
- Stonewall
- LGBT Foundation
- Gendered Intelligence
- Proud Trust
- Bayswater Support Group
- GIRES (n.b. GIRES withdrew engagement with the Review in 2023).

The Review met with these organisation every six weeks throughout the lifetime of the Review. Separate meetings were held with each organisation to encourage open and frank conversations and to ensure that each group were able to raise issues specific to their membership/clients.

This regular two-way communication provided the Review with a better understanding of how service users experience services, the challenges that they faced and the impacts of policy changes. It was also an opportunity for the Review to test things that it was hearing and emerging thinking, and for the organisations to raise issues of concern and highlight opportunities to reach genderdiverse and gender-questioning young people.



Meetings with other organisations

In addition to the rolling programme of meetings with the core support and advocacy groups, the Review met with other related charities and advocacy groups.

Some of these meetings were at the instigation of the Review and others were at the request of the organisation. Many of these meetings were similar to the listening sessions in that organisations wanted to share their thoughts with the Review.

Other meetings focused on a specific issue or were arranged to help the audience to better understand the work of the Review.

A list of organisations engaged is included at the end of this report.

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Engagement with clinicians and other professionals

"I have spoken to a very wide range of clinicians and academics. Clinicians who have spent many years working in gender clinics have drawn very different conclusions from their clinical experience about the best way to support young people with gender-related distress." Cass Review Final Report (2024)

The Review received a high level of clinical input which took a variety of forms including listening sessions, group events and workshops (for example to test thinking on the proposed future service model).

Presentations and discussion with different professional groups at conferences or training sessions helped raise awareness of the Review and the dilemmas surrounding clinical care and to understand the thoughts and experiences of the broader workforce.

The team regularly met with senior clinical leads of GIDS and also attended two all staff meetings to talk to the GIDS workforce about the Review and take their questions. Several GIDS staff also attended listening sessions to share their individual thoughts with the Review.

There were also regular meetings with the heads of relevant Royal Colleges and professional bodies.

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Listening sessions with clinicians and associated professionals

The Review held listening sessions with clinicians and other professionals who wished to share their individual experiences and thoughts.

These sessions were usually at the request of the individual, although some specific clinical views were sought to develop the knowledge and understanding of the Review on specific issues.

In common with the lived experience listening sessions, professionals engaged in these sessions on the understanding that their participation would be kept confidential, and any comments utilised by the Review would not be identifiable.

Professions of people attending listening sessions included:

- Clinical psychologists
- Clinical researchers
- Educational psychologists •
- Endocrinologists
- GPs
- Neuropsychologists
- Nurses
- Occupational Therapists

- Paediatricians
- Psychiatrists
- Psychotherapists
- Safeguarding leads
- School nurses
- Speech & Language therapists
- Social Workers
- Teachers



Clinical Expert Group

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A Clinical Expert Group (CEG) was established to consider the strength of the evidence and findings from the Review's research programme and assist the Review in achieving clinical consensus where evidence was not available or limited.

Membership included clinical experts on children and adolescence in relation to gender, development, physical and mental health, safeguarding and endocrinology. It included senior clinicians working at the Tavistock and Portman GIDS, and clinicians from the new regional gender identity services for children and young people, as well as staff working in other paediatric and child and adolescent mental health services.

The CEG considered findings from the University of York's systematic reviews:

- characteristics of the cohort
- guidelines and assessment methods, including detailed review of Swedish and WPATH guidelines
- psychosocial interventions
- social transition
- puberty blockers
- masculinising and feminising hormones
- results of qualitative research

They also considered the purpose, essential components, domains, formulation and individualised care plan of a holistic needs assessment.



Review

Professional panel and workshops with primary and secondary care clinicians and associated professionals

One of the issues highlighted through early engagement with stakeholders was how to approach the challenging problem of establishing an infrastructure outside GIDS. The first step in this was to better understand the capacity, capability and confidence of the wider workforce and how this could be built and sustained.

To get a benchmark of capacity, capability and confidence among the wider workforce, the Review established a professional panel of primary and secondary care clinicians and associated professionals. This work also explored these professionals' thoughts on the role of primary and secondary care clinicians in the assessment process.

The Review recruited 102 self-nominating panel members via the Royal Colleges and professional bodies. The panel ran for six weeks with weekly activities set that participants could complete independently via an online platform. Two workshops were also held with sub-sets of the panel to discuss the learning from the previous weeks' activities.

The exercise was not about seeking to resolve the tensions, change minds or force a conclusion, but rather explore where shared values may exist and where collaboration and cooperation might be possible.



Activities were designed to capture an understanding of:

- Experiences of working with gender questioning children and young people and panel members' confidence and competence to manage their care.
- Changes they may have experienced in the presentation of children and young people with gender-related distress.
- Areas where professionals felt they required more information in order to support gender-questioning children and young people.
- Where professionals currently went to find that information.
- The role of different professions in the care pathway.
- The role of professionals in the assessment framework.
- What participants felt should be included in an assessment framework across the whole service pathway.

The summary report from this work is available at:

https://cass.independent-review.uk/wpcontent/uploads/2022/03/REPORT-Cass-Review-professionalpanel-FINAL.pdf

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Survey of Gender Identity Development Service (GIDS) staff

Following the conclusion of the professional panel the Review undertook an online survey of gender specialists – clinicians and associated professionals who predominantly or exclusively worked with children and young people who needed support around their gender identity.

The survey link was sent by email to all staff working in GIDS. It was also circulated to a number of former GIDS clinicians who had previously been in touch with the Review.

The survey contained some service specific questions, but also sought to test some of what the Review had heard from specialists through the listening sessions and from primary and secondary care professionals engaged in the professional panel activities.

Responses were received from 33 current and former gender specialists. While this is a relatively small sample, the quality and fullness of the responses received was high and the exercise yielded valuable insight and feedback.

The summary report from this work is available at: https://cass.independent-review.uk/wpcontent/uploads/2022/03/Gender-specialists-questionnairereport_FINAL.pdf



Key learning

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The professional panel and gender specialist survey yielded valuable insights from clinicians and professionals both within and outside the specialist gender service. It contributed to early thinking of the Review and highlighted some lines of enquiry that needed to be explored further.

There were a number of consistent messages arising from these activities:

- The current long waiting lists that gender-questioning children and young people and their families/carers faced were unacceptable for all parties involved, including professionals.
- Many professionals in the sample said that not only were gender-questioning children and young people having to wait a long time before receiving treatment, but they also did not receive appropriate support during this waiting period.
- Another impact of the long wait that clinicians reported was that when a child or young person was seen at GIDS, they may have had a more fixed view of what they needed and were looking for action to be taken quickly. This reportedly could lead to frustration with the assessment process.
- When considering the more holistic support that children and young people needed, gender specialists further highlighted the difficulties that children and young people face in accessing local support, for example, from Child

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and Adolescent Mental Health Services (CAMHS), whilst being seen at GIDS.

- It was clear from the professionals who took part in these activities that there was a strong professional commitment to provide quality care to gender-questioning children and young people and their families/carers. However, this work indicated that levels of confidence and competence do vary among primary and secondary care professionals in our sample.
- Concerns were expressed by professionals who took part in the panel about the lack of consensus among the clinical community on the right clinical approach to take when working with a gender-questioning child or young person and their families/carers.
- To support clinicians and professionals more widely, participants felt there was a need for a robust evidence base, consistent legal framework and clinical guidelines, a stronger assessment process and different pathway options that holistically meets the needs of each genderquestioning child or young person and their families/carers

There were also several areas identified where there were different views expressed either among participants of the panel and/or the survey responses and/or in the views of primary and secondary care professionals and those of the gender specialists.

• There was not a consistent view among the professionals participating in the panel and survey about the nature of gender dysphoria and therefore the role of assessment for children and young people experiencing gender dysphoria.

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- Some clinicians felt that assessment should be focused on whether medical interventions were an appropriate course of action for the individual. Other clinicians believed that assessment should seek to make a differential diagnosis, ruling out other potential causes of the child or young person's distress.
- There were different perspectives on the roles of primary, secondary and specialist services in the care pathway(s) and what support or action might best be provided at different levels.
- While there was general consensus that diagnostic or psychological formulation needed to form part of the assessment process, there were differing views as to whether a mental state assessment was needed and, if it should, where in the pathway it should be undertaken and by whom.



Review

Engagement with clinicians working in gender care

Much of the clinical experience of working with these children and young people resided among staff with experience of working in GIDS. The Review drew on the insight, knowledge and experience of GIDS' staff in several ways.

Since the early stages of the Review, the team established fortnightly meetings with clinical and managerial leads from GIDS, providing space to hold open conversations and discuss challenges and ideas.

Dr Cass attended two all staff away day sessions with GIDS staff and an away day with endocrine staff at UCLH to discuss progress of the Review and take their questions and comments. Dr Cass also observed at two endocrine clinic sessions to better understand how those discussions were conducted.

Senior clinical staff from GIDS participated in workshops hosted by the Review and two senior clinicians from GIDS sat on the Review's Clinical Expert Group (CEG).

Many of the GIDS clinicians (both current and former) shared their experience and thoughts in one-to-one listening sessions and their insights were valuable in building the Review's understanding of the challenges of and opportunities for developing a new clinical approach and service model.

The Review also engaged with clinicians working in gender services in other countries.



Review

Focus groups with gender specialists

In Autumn 2023, as the Review was working towards developing its final recommendations, it hosted a series of focus groups with GIDS staff to draw on their knowledge and experience to test and develop emerging thinking on a number of key areas.

The Review worked with GIDS senior clinical staff to ensure that all staff working at GIDS were offered the opportunity to join one of the focus groups. Each group had between 12 – 15 participants and ran for 1.5 hours.

Each focus group had a specific topic area:

- i. Workforce and training. Explored the ideal skills mix of a team and transferable skills among the wider workforce. It also looked at how GIDS staff built their confidence and how training should be organised.
- **ii. Packages of care.** Explored thoughts on the support and interventions that should be offered and the interface with local services.
- iii. Pathways and wider system working. Explored thoughts on the proposed networked service model and how a step-up or step-down model of care would work.

Thematic roundtables

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Roundtable discussions were facilitated with topic experts in a range of associated areas to explore specific questions in greater depth.

In addition to the "learning from lived experience" roundtable described earlier, roundtable discussions were held on:

- The networked service model (May 2022)
- Intersection of mental health, psychosexual development and gender-related distress (September 2023)
- Safeguarding (September 2023)
- Supporting the wider workforce (October 2023).

Participation was by invitation and was based on the professional expertise that the individual could bring to the discussion. The majority of participants had not previously contributed to the Review.

To allow for full and frank discussion, the roundtable operated under the Chatham House Rule meaning that information disclosed during the meeting may not be explicitly or implicitly attributed to an individual.



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Roundtable: The networked service model

The objective of this roundtable, held in May 2022, was to build a shared agreement about the key features of the operating model for the proposed regional gender services for children and young people to inform the development of a new model of care for children and young people needing support around their gender identity. This took place following the publication of the Review's interim report that set out that:

- Regional centres should be developed to become direct service providers, assessing and treating children and young people who may need specialist care as part of a wider pathway.
- Each regional centre would need to develop links and work collaboratively with a range of local services within their geography.
- Clear criteria would be needed for referral to services along the pathway from primary to tertiary care.
- The proposed regional services should have regular coordinated national provider meetings and operate to shared standards and operating procedures with a view to establishing a formal learning health system.
- Regional training programmes should be run for clinical practitioners at all levels.



Key messages

Participants joined breakout groups exploring questions relating to the operating model, service pathways and workforce.

The operational model:

- There was general agreement that a networked model with regional hubs working closely with local services was the most appropriate approach.
- There needed to be a Multi-Professional Team (MDT) approach with specialist skills reflecting the needs of the patient population (child and adolescent health, gender, mental health, neurodiversity and paediatrics).
- Information needed to flow seamlessly between organisations to avoid people having to tell their story multiple times.
- There should be a focus on early help, responding quickly to early questions (first line interventions and triage) before referral to regional hubs. People shouldn't be forced onto a specialist pathway.
- As regional hubs may feel distant to the local population, there would need to be centres of expertise but extended to local areas. The regional hubs could provide an advice/consultation function between professionals to advise on referrals and, where appropriate, support care being held locally.



Pathways through from referral to discharge:

- What each individual needed from a service would differ so there needed to be different pathways to manage different needs and presentations a move from linear pathways to multiple pathways. This may include providing information and advice, consultation, liaison, assessment and treatment elements.
- The regional services would need to have a clear focus (an agreed assessment framework), including clear pathways in and out of the service and into adult services. Defining the pathways would define the workforce.
- Services would need to be flexible to reflect that there were different points in the development of the child/young person when more or less clinical support and different types of support would be required, so the individual should be able to step-up or step-down from different points in the pathway. There needed to be a route to discharge patients back to local services but people needed to know that they could re-enter the service when needed.



Workforce

- There needed to be a national approach to training, including training on complex referrals, risk, safeguarding and managing complexity.
- Recruitment needed to demonstrate how individuals could upskill in various roles within the regional hub.
- There needed to be opportunities for staff to move easily between local and regional services.
- There needed to be consideration of how staff would be supported, and clinical supervision provided.

The outputs of the discussion helped to further inform the proposed model of care described in the letter Dr Cass sent to NHS England in July 2022. NHS England also took this learning to inform the interim service specification for the regional services.

You can access the letter at: <u>https://cass.independent-</u> review.uk/wp-content/uploads/2022/07/Cass-Review-Letter-to-NHSE_19-July-2022.pdf

Review

Roundtable: Intersection of mental health, psychosexual development and gender-related distress

The aim of this roundtable, held in September 2023, was to draw on the clinical and/or academic experience of participants in different areas of expertise, and to explore their thoughts on:

- explanations for what might be contributing to the increasing numbers of children and young people presenting with gender dysphoria
- what factors may underlie the change in the case mix, and
- whether these changes were being seen in other areas of clinical practice.

Expertise represented included those with a relevant research background and/or direct clinical experience on the following topics:

- Adolescent brain development
- Autism spectrum disorder / neurodiversity
- Body dysmorphic disorder (BDD)
- Children and young people's mental health services and their development
- Differences in sex development (intersex)
- Eating disorders
- Epidemiology and statistics of mental health
- Gender care of adults
- LGBTQ+ mental health and equality, diversity and inclusion
- Medically unexplained symptoms
- Obsessive compulsive disorder (OCD)



- Psychological and sociological determinants of health and illness
- Self-harm and suicide
- Sexual abuse
- The impacts of social media
- Tics and Tourette syndrome

Key points raised in the discussion

Background mental health issues

- Child and adolescent mental health had been deteriorating over the last two decades with presentations of increased anxiety, depression and self-harm most evident in teenage girls.
- Clinicians reflected that questions around identity, including gender identity, were now more often part of a patient's clinical presentation, even if it was not the primary concern.
- The pandemic had made life harder normal peer interaction was impeded and there was less social interaction generally, and a shift from in-person interaction to online social interaction.
- Across different clinics there had been an increase in teenage birth-registered females presenting with suicidal ideation and/or self-harm. A common denominator was undiagnosed autism spectrum disorder (ASD). These young people often had good cognitive ability and are articulate.

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Their distress may present as OCD or disordered eating patterns or through bodily manifestations.

- Research had shown a 70% increase in young females presenting for self-harm but the reason behind that was complex and not well understood. There was emerging evidence that social media may be one of the major contributors to this increase.
- The Millennium Cohort Study showed that social media had many downsides for young people, including cyber bullying and presenting unrealistic expectations of life and body image. Conversely, social media had provided previously unheard voices space to be heard.

Parallel / associated presentations

- Clinicians were seeing increasing numbers of patients presenting with bodily manifestations of distress in their clinical areas e.g. tics, BDD, eating disorders. The predominant rise was in adolescent birth-registered females.
- There were particular similarities in patients presenting to BDD clinics. This was manifesting as profound distress. There was a higher female to male ratio (3:1). Many also had ASD. It was relatively rare for individuals to present with BDD before puberty. For many patients their preoccupation was not gender related, but clinicians did also see patients where there was a gender related preoccupation.

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- In medically unexplained symptom clinics, young people also presented with physical symptoms that were a marker of underlying stress or distress and could not be explained by a recognised underlying disease.
- There had been a dramatic increase in complex multifaceted presentations over the last decade, with some individuals having gender presentations as part of a broader series of issues.
- There was some commonality in presentation and risk factors across many of the different conditions discussed. It was also helpful in identifying differences. There may be multiple or different routes into gender dysphoria.
- Distress that is not heard / noticed manifests in the body. The online world created a supportive space for young people to be able to communicate their mental health in a way they did not necessarily feel they could explain to others.



Roundtable: Risk and Safeguarding

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This roundtable, held in September 2023, drew participation from designated safeguarding leads from different part of the country, clinicians from the developing regional gender services, professionals from children's social care, and chairs or members of national safeguarding networks and panels.

There were several aspects of safeguarding relevant to planning care for these children and young people:

- A significant proportion of children and young people who were concerned about, or distressed by issues of gender identity, experienced co-occurring mental health, neurodevelopmental and/or personal/family or social complexities in their lives, including adverse experiences and trauma. The relationship between these factors and gender-related distress was not always clear.
- The Multi Professional Review Group (MPRG), established to ensure that procedures for assessment and for informed consent for access to puberty blockers had been properly followed by GIDS, reported particular concerns about safeguarding shortfalls within the assessment process.
- Clinicians raised concerns about children and young people's NHS numbers being changed inconsistently, as there is no specific guidance for GPs and others as to when this should be done for this population and under what consent.



Discussion was based around two broad questions:

- 1. Based on your experience and expertise what do you see as the key risks for this cohort of children and young people?
- 2. How could/should these risks be mitigated?

Key points raised in the discussion

- There was a lack of understanding about the difference between safeguarding and child protection – people often conflated the two and therefore feared safeguarding intervention but they were not the same.
- Safeguarding needed to run alongside clinical practice throughout the pathway as with any other paediatric pathway, with consideration given to adverse childhood experiences and trauma informed practice.
- It was important to ensure that the voice of the child was heard throughout the clinical pathway, there needed to be space for clinicians to speak with the child, without the parent/carer present.
- There were cases where families and/or clinicians were concerned about disclosing family history because of concerns that if safeguarding concerns were raised, their child's treatment would not be progressed/continued [specific case studies were shared].
- Clinicians were worried about raising safeguarding concerns due to stigma and history of being deemed transphobic. Space needed to be provided for professionals involved to discuss what this meant in their



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practice. Supervision for staff should be integral to the work.

- Community services and schools were important in contributing towards support for families and assessment – this included health visitors, school nurses, and educational psychologists.
- Multi-disciplinary working should lead to multi-disciplinary guidance and training.
- There was a risk that, in trying to avoid the problems that arose in the previous GIDS service, there would be an overcorrection in the new services.
- Consideration of safeguarding was not differentiated practise for this patient group; however, safeguarding was a basic principle of safe working paediatrics. There needed to be work with children and young people and families/carers to explain why this information was needed.



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Roundtable: Supporting the wider workforce

This roundtable, held in October 2023, sought to build on learning from previous engagement with clinicians and associated professionals. The clinicians taking part in this previous work identified that clear professional guidance, enhanced training, dedicated clinical time and different pathway options would help to build confidence, competence, and capacity among the wider workforces.

Participants in this roundtable included representatives of Royal Colleges and professional bodies, Health Education England, GIDS and clinicians from the developing regional services.

This roundtable explored the practicalities of and responsibilities for delivering the required support to the workforce.

Discussion was focused on the following key questions:

- 1. What appetite is there among your members to take a greater role in supporting this cohort?
- 2. How can colleges and professional bodies support workforce training and development in this area?
- 3. Are there opportunities to collaborate on professional guidance?
- 4. General thoughts on the proposed future service model is it a viable model?



Key points raised in the discussion

- There were different models in primary care that could be effective in providing early support for these children and young people. Models suggested included GPs with Special Interest and one-stop-shop services that worked with young people across a range of issues, staffed by a multidisciplinary team.
- It is important to have a relationship between primary and secondary care. Those pathways and relationships are important to support primary care and therefore patients.
- There was a need to recognise the difficulty in staffing existing services, in particular, CAMHS services were struggling to recruit.
- Clinicians have spoken about a lack of confidence to work in this area. Being part of a multidisciplinary team could help feel confident and safe.
- Clinicians needed reassurance that they were not expected to solve every problem the child/young person was presenting with by themselves. They should focus on areas within their competence, apply their expertise confidently, and seek support for remaining issues.
- While e-learning could support training, it was not a comprehensive solution on its own. Effective training would require a structured system that involved monitoring learning progress, supervision etc. E-learning could provide knowledge and potentially some skill development, but there needed to be application in practice – under supervision and with support.

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- To ensure consistency and economies of scale, the ideal would be to make training available to the wider workforce, including social workers, therapists, educational psychologists etc. This would generally empower professionals to deal with the complex issues involved.
- There were notable gaps in individual clinician's ability to engage in discussions with children and young people on sensitive topics, including gender-related matters.
 Paediatricians would benefit from more specific guidance to reduce ambiguity in their approach.
- Significant resource would be required to keep training upto-date and relevant. Training needed to be embedded into undergraduate programmes, to avoid having to constantly retrospectively upskill the workforce in this area.
- There was a willingness for colleges and professional bodies to work collaboratively on developing and providing training as appropriate.



Royal Colleges & professional bodies

The Review held meetings with the presidents and other leads of relevant Royal Colleges and professional bodies. Representatives of these organisations were also invited to participate in various workshops and roundtables.

This included:

- Academy of Medical Royal Colleges
- Association of Occupational Therapists of Ireland
- British Association of Social Workers
- British Medical Association
- Care Quality Commission
- Children's Hospital Alliance
- General Medical Council
- General Pharmaceutical Society
- Health Education England
- Royal College of General Practitioners
- Royal College of Paediatric and Child Health
- Royal College of Physicians
- Royal College of Psychiatrists
- Royal College of Psychiatry, Wales
- School and Public Health Nurses Association

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Speaking events to clinical audiences

Dr Cass was also invited to deliver presentations and hold discussions with different professional groups at conferences, training sessions or professional association meetings. This helped raise awareness of the Review and the dilemmas around clinical care. Importantly, this created opportunities for a much wider group of clinicians to pose questions, share experiences and contribute to thinking.

Speaking events included:

- Association of Child Protection Professionals
- Association of Child Psychotherapists
- Association of Chief Children's Nurses conference
- Child Health Education and Revalidation session
- Community Child Health conference
- London School of Paediatrics Teaching
- National Network of Designated Healthcare Professionals for Children
- National Mental Health Leadership conference
- Paediatric Mental Health Association annual conference
- Royal Society of Medicine conference
- RCPCH/RCPsych adolescent health conference
- RCPCH Council
- Specialist Registrars in CAMHS



Meetings with Parliamentarians

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The Review was commissioned by NHS England and did not report to nor was it accountable to HM Government or the Department of Health and Social Care.

However, the Review was not conducted in a vacuum. There were many moving parts and a significant, often challenging public debate. A number of public policy initiatives, while outside the scope of the Review, nudged up against its work and had the potential to affect the support offered to children and young people seeking the support of NHS gender services in the future.

On occasion the Review was asked to speak to ministers, parliamentarians and teams developing such policy areas. In these instances, the Review provided evidence-based information but tried not to step beyond the clinical focus of its remit.

The Review was also approached by representatives of governments of other countries who were undertaking, or considering undertaking, similar reviews. This included the governments of the other Home Nations.

Acknowledgements

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"One of the great pleasures of the Review has been getting to meet and talk to so many interesting people. I want to thank all those who have generously given their time to share their stories, experiences and perspectives."

Dr Cass, Cass Review Final Report (2024)

The Review would like to thank everyone who supported its work by sharing their knowledge and expertise:

- All individuals who participated in a listening session, shared their personal narrative, took part in a focus group, roundtable, workshop, completed a survey, joined the professional panel or attended a meeting with the Review.
- The following organisations (with apologies to anyone missed):
- Academy of Medical Royal Colleges
- Action for Children
- Alder Hey Children's Hospital
- All Sorts Youth
- Arden & GEM Commissioning
 Support Unit
- Association for Child and Adolescent Mental Health
- Association of Child Protection
 Professionals
- Association of Child Psychotherapists

- Association of Clinical Psychologists UK
- Association of Chief Children's Nurses
- Association of Occupational Therapists of Ireland
- Barnardo's
- Bayswater Parental Support
 Group
- Beewell
- British Association of
 Community Child Health
- British Association of Social Workers

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- British Medical Association
- Care Quality Commission
- Child Safeguarding Practice
 Review Panel
- The Office of the Children's Commissioner
- Children's Hospital Alliance
- Children's Society
- Clinical Advisory Network on Sex and Gender
- Department of Education
- Department of Health and Social Care
- Department of Women and Equalities
- Equality and Human Rights Commission
- Evelina London Children's Hospital
- Gender Identity Development Service (GIDS)
- Gender Identity Research & Education Society
- Gendered Intelligence
- General Medical Council
- General Pharmaceutical Society
- Government Equality Office

- Great Ormond Street Children's
 Hospital
- Guys and St Thomas' NHS Foundation Trust: Clinical Ethics Advisory Group
- Health Education England
- Indigo gender services
- Infected Blood Inquiry team
- International Association of Therapists for Desisters and Detransitioners,
- James Lind Alliance
- LGB Alliance
- LGBT Foundation
- London School of Paediatrics
- Manchester Children's Hospital
- Mermaids
- MindEd
- MPRG (Multi Professional Review Group)
- National Children's Bureau
- National Clinical Directors -NHS England
- National Data Guardian
- National Gender Identity Healthcare reference group (Scotland)

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- National Network of Designated Healthcare Professionals for Children
- National Network of Designated Healthcare Professionals for Children
- National Research
 Collaboration Programme
- National Safeguarding Review
 Panel
- NHS Digital
- NHS England
- Nifty Fox
- Norwegian patient organisation for Gender Incongruence
- NSPCC
- Nuffield Council on bioethics
- Office of the Chief Scientific Officer - NHS England
- Office of the Chief Pharmaceutical Officer - NHS England
- Our Duty
- Paediatric Mental Health Association
- Parliamentary Office of Science and Technology

- Royal College of GPs
- Royal College of Paediatric and Child Health (RCPCH)
- RCPCH Ethics & The Law Advisory Committee
- Royal College of Physicians
- Royal College of Psychiatrists
- RCPsych Wales
- Royal Pharmaceutical Society
- Royal Society of Medicine
- School And Public Health Nurses Association
- Scottish Government
- Sex Matters
- South London and Maudsley NHS Trust
- Steph's Place
- Stonewall
- Tavistock and Portman NHS Foundation Trust
- The Kite Trust
- The Proud Trust
- The Rock Clinic
- Thoughtful Therapists
- TransActual
- Trans Learning Partnership
- Trans Safety Network



- Transgender Trend
- Traverse
- University of York
- University College London Hospitals NHS Foundation Trust
- West of England Specialist Gender Identity Clinic
- Women and Children First group
- Yellow Door