

Independent review of gender identity services for children and young people

Term		Description
Epidemiology		Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems. ⁸⁷
Exploratory approaches		Therapeutic approaches that acknowledge the young person's subjective gender experience, whilst also engaging in an open, curious, non-directive exploration of the meaning of a range of experiences that may connect to gender and broader self-identity. ^{88,89,90,91}
Feminising and masculinising hormones (also known as cross-sex hormones, and gender affirming hormones).		Hormones given as part of a medical transition for gender dysphoric individuals, where sex hormones (testosterone for transgender males and oestrogen for transgender females).
Gender dysphoria		Diagnostic term used in DSM-5. ⁹² Gender dysphoria describes "a marked incongruence between one's experienced/expressed gender and assigned gender of at least 6 months duration" which must be manifested by a number of criterion – see Appendix 3 for further detail.
Gender fluid		An experience of gender that is not fixed, but changes between two or more identities.
Gender identity		This term is used to describe an individual's internal sense of being male or female or something else.
Gender identity development		The developmental experience of a child or young person in seeking to understand their gender identity over time.
Gender Identity Development Service	GIDS	The service that NHS England commissions for children and adolescents with gender dysphoria.

⁸⁷ Centers for Disease Control and Prevention (2012). [Principles of Epidemiology in Public Health Practice: An introduction to Applied Epidemiology and Biostatistics, 3rd ed.](#)

⁸⁸ Di Ceglie D (2009). [Engaging young people with atypical gender identity development in therapeutic work: A developmental approach.](#) J Child Psychother 35(1): 3–12. DOI: 10.1080/00754170902764868.

⁸⁹ Spiliadis A (2019). [Towards a gender exploratory model: Slowing things down, opening things up and exploring identity development.](#) Metalogos Systemic Ther J 35: 1–9.

⁹⁰ Churcher Clarke A, Spiliadis A (2019). ['Taking the lid off the box': The value of extended clinical assessment for adolescents presenting with gender identity difficulties.](#) Clin Child Psychol Psychiatry 24(2): 338–52. DOI:10.1177/1359104518825288.

⁹¹ Bonfatto M, Crasnow E (2018). [Gender/ed identities: an overview of our current work as child psychotherapists in the Gender Identity Development Service.](#) J Child Psychother 44(1): 29–46. DOI:10.1080/0075417X.2018.1443150.

⁹² American Psychiatric Association (2013). [Diagnostic and Statistical Manual of Mental Health Disorders: DSM-5™, 5th ed.](#)

Term		Description
Gender incongruence		Diagnostic term used in ICD-11. ⁹³ Gender incongruence is characterised by “a marked and persistent incongruence between an individual’s experienced gender and the assigned sex”. See Appendix 3 for further detail.
Gender-questioning		A broader term that might describe children and young people who are in a process of working out how they want to present in relation to their gender.
Gender-related distress		A way of describing distress that may arise from a broad range of experiences connected to a child or young person’s gender identity development. Often used for young people whereby any formal diagnosis of gender dysphoria has not yet been made.
Gillick competence/ Fraser guidelines		A term derived from <i>Gillick v West Norfolk And Wisbech AHA</i> , 1984 that is used to decide whether a child or young person up to the age of 16 years is able to consent to their own medical treatment, without the need for parental permission or knowledge. A child or young person will be ‘Gillick competent’ for that decision if they have the necessary maturity and understanding to make the decision.
Gonadotropin-releasing hormone analogues (also known as the hormone blocker/s and puberty blocker/s)	GnRH	GnRH analogues competitively block GnRH receptors to prevent the spontaneous release of two gonadotropin hormones, Follicular Stimulating Hormone (FSH) and Luteinising Hormone (LH) from the pituitary gland. This arrests the progress of puberty.
General Practitioner	GP	GPs deal with a whole range of health problems and manage the care of their patients, referring onto specialists as appropriate. ⁹⁴
High Court		The third highest court in the UK. It deals with all high value and high importance civil law (non-criminal) cases and appeals of decisions made in lower courts. When the High Court sits with more than one judge, as required for certain kinds of cases, it is called the Divisional Court.
International Classification of Diseases, Version 11	ICD-11	ICD-11 ⁹⁵ is the World Health Organization (WHO) mandated health data standard used for medical diagnosis.

⁹³ World Health Organization (2022). [International Classification of Diseases Eleventh Revision](#).

⁹⁴ NHS. [GP services](#).

⁹⁵ World Health Organization (2022). [International Classification of Diseases Eleventh Revision](#).

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Term		Description
Looked after children		Children who are in the care of their Local Authority who may be living with foster parents or in a residential care setting.
Multi-disciplinary-team	MDT	The identified group of professional staff who provide a clinical service.
Neurodiverse		Displaying or characterised by autistic or other neurologically atypical patterns of thought or behaviour; not neurotypical.
Non-binary		A gender identity that does not fit into the traditional gender binary of male and female. ⁹⁶
Paediatrics		The branch of medicine dealing with children and their medical conditions.
Pass/passing		A person's gender being seen and read in the way they identify.
Precocious puberty		This is when a child's body begins changing into that of an adult (puberty) too soon – before age 8 in girls and before age 9 in boys.
Primary care		Primary care includes general practice, community pharmacy, dental and optometry (eye health) services. This tends to be the first point of access to healthcare.
Psychological formulation		A structured approach to understanding the factors underlying distressing states in a way that informs the changes needed and the therapeutic intervention for these changes to occur.
Psychosocial		Describes the psychological and social factors that encompass broader wellbeing.
Puberty blockers		See gonadotropin-releasing hormone above.
Secondary care		Hospital and community health care services that do not provide specialist care and are usually relatively close to the patient. For children this will include Child and Adolescent Mental Health Services (CAMHS), child development and general paediatric services.
Tanner Stage		Classification of puberty by stage of development. This ranges from Stage 1, before physical signs of puberty appear, to Stage 5 at full maturity.

⁹⁶ Twist J, de Graaf NM (2019). [Gender diversity and non-binary presentations in young people attending the United Kingdom's National Gender Identity Development Service](#). Clin Child Psychol Psychiatry 24(2): 277–90. DOI: 10.1177/1359104518804311.

Term		Description
Tertiary care		Tertiary care is the specialist end of the NHS. These services relate to complex or rare conditions. Services are usually delivered in a number of hospitals/centres.
Transgender	trans	This is an umbrella term that includes a range of people whose gender identity is different from the sex they were registered at birth.
Transition		These are the steps a person may take to live in the gender in which they identify. This may involve different things, such as changing elements of social presentation and role and/or medical intervention for some.

Appendix 1

Terms of reference



TERMS OF REFERENCE FOR REVIEW OF GENDER IDENTITY DEVELOPMENT SERVICE FOR CHILDREN AND ADOLESCENTS

INTRODUCTION

1. NHS England is the responsible commissioner for specialised gender identity services for children and adolescents. The Gender Identity Development Service for children and adolescents is currently managed by the Tavistock and Portman NHS Foundation Trust.
2. In recent years there has been a significant increase in the number of referrals to the Gender Identity Development Service, and this has occurred at a time when the service has moved from a psychosocial and psychotherapeutic model to one that also prescribes medical interventions by way of hormone drugs. This has contributed to growing interest in how the NHS should most appropriately assess, diagnose and care for children and young people who present with gender incongruence and gender identity issues.
3. It is in this context that NHS England and NHS Improvement's Quality and Innovation Committee has asked Dr Hilary Cass to chair an independent review, and to make recommendations on how to improve services for children and young people experiencing issues with their gender identity or gender incongruence, and ensure that the best model/s for safe and effective services are commissioned.

REVIEW SCOPE

The independent review, led by Dr Cass, will be wide ranging in scope and will conduct extensive engagement with all interested stakeholders. The review is expected to set out findings and make recommendations in relation to:

- i. Pathways of care into local services, including clinical management approaches for individuals with less complex expressions of gender incongruence who do not need specialist gender identity services;
- ii. Pathways of care into specialist gender identity services, including referral criteria into a specialist gender identity service; and referral criteria into other appropriate specialist services;
- iii. Clinical models and clinical management approaches at each point of the specialised pathway of care from assessment to discharge, including a description of objectives, expected benefits and expected outcomes for each clinical intervention in the pathway;
- iv. Best clinical approach for individuals with other complex presentations.
- v. The use of gonadotropin-releasing hormone analogues and gender affirming drugs, supported by a review of the available evidence by the National Institute for Health and Care Excellence; any treatment recommendations will include a description of treatment objectives, expected benefits and expected outcomes, and potential risks, harms and effects to the individual;
- vi. Ongoing clinical audit, long term follow-up, data reporting and future research priorities;
- vii. Current and future workforce requirements;
- viii. Exploration of the reasons for the increase in referrals and why the increase has disproportionately been of natal females, and the implications of these matters; and,

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- ix. Any other relevant matters that arise during the course of the review

- 4. In addition, and with support from the Royal College of Paediatrics and Child Health and other relevant professional associations, the Chair will review current clinical practice concerning individuals referred to the specialist endocrine service. It is expected that findings and any recommendations on this aspect of the review will be reported early in 2021 with the review's wider findings and recommendations delivered later in 2021.

- 5. The review will not immediately consider issues around informed consent as these are the subject of an ongoing judicial review. However, any implications that might arise from the legal ruling could be considered by the review if appropriate or necessary.

Appendix 2

Letter to NHS England from
Dr Cass – May 2021



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Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Review of GIDS for Children and Young People

John Stewart
National Director
Specialised Commissioning
NHS England and NHS Improvement

Sent by email

10 May 2021

Dear John

INDEPENDENT REVIEW INTO GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE

I am writing to update you on my current approach to the work of the independent review into gender identity services for children and young people. However, the most pressing issue is how we augment the immediate support for children and young people currently needing assessment and treatment, some of whom have already been waiting for an extended period for an appointment. I will therefore also make some suggestions about interim arrangements and ways in which the review team could help to support and strengthen these.

Commissioned research programme

As you know, a key principle of the review is that it should be evidence-based, and that final conclusions will be developed through a consensus development process contingent on the synthesised evidence.

I am pleased to see that the National Institute for Health and Care Excellence (NICE) evidence reviews of gonadotrophin releasing hormone analogues and gender affirming hormones for children and adolescents with gender dysphoria have now been published. Although this is a helpful starting point, despite following a standard and robust process the NICE review findings are not conclusive enough to inform policy decisions. As part of my review, I am therefore exploring other methodologies to give increased confidence and clarity about the optimal treatment approaches.

My team is commissioning a broader literature review of the existing evidence base on the epidemiology, management and outcomes of children with gender dysphoria. We are also commissioning qualitative and quantitative research, including considering other approaches which might be employed to understand the intermediate and longer-term outcomes of children with gender dysphoria. We intend to include a review of international models and data in this programme of work.

Addressing the immediate situation

Recognising that the outcome of the review is going to take some time, I have been reflecting on the recent court rulings on puberty blockers and consent and the Care Quality Commission (CQC) report on the Gender Identity Development Service (GIDS) run by the Tavistock and Portman NHS Foundation Trust. These significant developments have changed the context in which the review is taking place, and further added to the service pressures.

I note the proposal to establish an independent multidisciplinary professional review group to confirm decision-making has followed a robust process, which seems an appropriate interim measure pending further clarification of the legal situation.

I know that everyone concerned with the delivery of services – both commissioners and providers – are worried about the increasing number of children on the waiting list for assessment by the GIDS service and the resulting distress for the children and young people and their families. The difficulty in managing risk for those on the waiting list is exacerbated by the staff vacancies at GIDS, the increasing volume of new referrals, and the fact that the support and engagement from local services is highly variable and, in some cases, very limited.

Having a single provider may have been a logical position when the GIDS service was first set up, given that this is a highly specialised service that was seeing a relatively small number of cases each year. As the epidemiology has changed and there has been an exponential increase in numbers of children with gender incongruence or dysphoria, concentration of expertise within a single service has become unsustainable. At the same time, local services have not developed the skills and competencies to provide support for children on the waiting list and those with lesser degrees of gender incongruence who may not wish to pursue specialist medical intervention, and / or to provide help for children with additional complex needs.

I know from discussions we have had that your team is working hard to find some practical alternative arrangements, and that you have been in discussion with relevant professional bodies to come up with creative interim solutions while awaiting the outcome of my review.

The review team has also been in discussion with CQC, with the Tavistock and Portman NHS Foundation Trust and with colleagues within and external to NHS England and NHS Improvement to consider which aspects of this situation we can help with in the short to medium term, whilst keeping our focus on the longer-term questions of the appropriate clinical management and whole care pathway for these children and young people. In the past months I have also met with many groups and individuals with expertise and lived experience relevant to the review, including charities and support groups, Royal Colleges and healthcare professionals.

Recommendations to NHS England and NHS Improvement

I would encourage you to consider the following when developing an interim pathway for children and young people experiencing gender dysphoria:

- **Access and referral:** Children and young people need ready access to services. However, it is unusual for a specialist service to take direct referrals. The risk of having a national service as the first point of access is that assessment and treatment of children and young people who have the greatest need for specialist care is delayed because of the lack of differentiation of those on the waiting list. In addition, many children and

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young people have complex needs, but once they are identified as having gender dysphoria, other important healthcare issues which would normally be managed by local services can sometimes be overlooked.

- **Assessment and management:** All children and young people who are referred to specialist services should have a competent local multi-disciplinary assessment and should remain under active holistic local management until they are seen at a specialist centre.

I recognise that developing capacity and capability outside of the existing GIDS service to provide such initial assessment and support will be difficult to achieve at speed and will be incremental. This means that there will likely be a range of different models and options around the country, dependent on local resources, with some of the work being delivered through existing secondary service teams, and some being delivered at regional level. The support of wider services is vital.

- **Data:** The lack of systematic data collection is a significant issue. Therefore, when employing interim measures, I would suggest that particular attention is paid to the gathering of good quality data, which can then be used to inform the evidence base and future model of provision.

Actions for the review team

I would like to suggest how the review team might help with the challenging problem of growing an infrastructure outside of GIDS. From my conversations to date, I believe there are three barriers to the involvement of local services:

- **Capacity** – the staff most appropriately trained to be involved in initial assessment are those who are already most stretched within Child and Adolescent Mental Health Services (CAMHS) and paediatric services, and this situation has been significantly worsened through the impact of the Covid-19 pandemic on children’s mental health. However, I know that there is substantial investment in CAMHS services, so close engagement with the relevant national policy teams at NHS England and NHS Improvement and at Health Education England (HEE) will be crucial.
- **Capability and confidence** – clinical teams outside of GIDS do not feel confident in initial assessment and support of children and young people with gender incongruence and dysphoria, in large part because they have not had the necessary training and experience, but also because of the societal polarisation and tensions surrounding the management of this group.
- **Lack of an explicit assessment framework** – currently expertise in assessment of children and young people presenting to GIDS is held in a small body of clinicians and their assessment processes have not been made explicit. The CQC report drew attention to the lack of structured assessment in the GIDS notes, and this is something that the Tavistock and Portman NHS Foundation Trust is already working to address internally. However, it is equally important to develop an initial assessment approach that can be used by first contact professionals, not just those working in the specialist service.

In the first instance, it is important that we test these assumptions with a range of clinical staff and ascertain whether there are other barriers that are preventing local engagement in this work. Then we would plan to prioritise a series of workshops, in collaboration with relevant professional groups, service users and close engagement with HEE. The purpose of these workshops would be to address identified barriers and develop:

- A framework for initial assessment of children and young people presenting with gender dysphoria.
- An approach to training for professionals at local and regional level.
- Some preliminary workforce recommendations, which will be particularly important in meeting the timelines of the three-year Comprehensive Spending Review.

These workshops will serve multiple purposes – firstly to support NHS England and NHS Improvement in the establishment of local and / or regional teams; secondly as an essential component of the work needed to inform the questions that the review is tackling; and thirdly to form the professional networks that will be needed to underpin future service and research networks.

Timelines

As you will recognise, setting up a complex national review is difficult and time consuming at the best of times. It requires a team to support the work and mechanisms for stakeholders to engage safely and with confidence. Starting a review in the midst of a pandemic is even more challenging.

I have committed to a review approach which is participative, consensus-based, evidence-based, transparent, and informed by lived and professional experience. This requires extensive engagement. Pending the appointment of our research team, the review has now launched its website and I have been proactively engaging with the stakeholder community.

It is critical that we get the approach right, particularly the engagement, the evidence review and the quantitative research given the gaps in the evidence highlighted through the NICE review, and this will take time.

My intention is that an interim report will be delivered in the summer, with a report next year setting out my final recommendations.

Yours sincerely



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

Cc: Care Quality Commission
Health Education England
Tavistock and Portman NHS Foundation Trust

Appendix 3

Diagnostic criteria for gender dysphoria



DSM–5 diagnostic criteria for gender dysphoria

Gender Dysphoria in Children

A. A marked incongruence between one’s experienced/expressed gender and assigned gender, of at least 6 months’ duration, as manifested by at least six of the following (one of which must be Criterion A1):

1. A strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one’s assigned gender).
2. In boys (assigned gender), a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical feminine clothing.
3. A strong preference for cross-gender roles in make-believe play or fantasy play.
4. A strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender.
5. A strong preference for playmates of the other gender.
6. In boys (assigned gender), a strong rejection of typically masculine toys, games, and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender), a strong rejection of typically feminine toys, games, and activities.

7. A strong dislike of one’s sexual anatomy.
8. A strong desire for the primary and/or secondary sex characteristics that match one’s experienced gender.

B. The condition is associated with clinically significant distress or impairment in social, school, or other important areas of functioning.

Specify if:

With a disorder of sex development (e.g., a congenital adrenogenital disorder such as congenital adrenal hyperplasia or androgen insensitivity syndrome).

Gender Dysphoria in Adolescents and Adults

A. A marked incongruence between one’s experienced/expressed gender and assigned gender, of at least 6 months’ duration, as manifested by at least two of the following:

1. A marked incongruence between one’s experienced/expressed gender and primary and/or secondary sex characteristics (or in young adolescents, the anticipated secondary sex characteristics).
2. A strong desire to be rid of one’s primary and/or secondary sex characteristics because of a marked incongruence with one’s experienced/expressed gender (or in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics).

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3. A strong desire for the primary and/or secondary sex characteristics of the other gender.
4. A strong desire to be of the other gender (or some alternative gender different from one's assigned gender).
5. A strong desire to be treated as the other gender (or some alternative gender different from one's assigned gender).
6. A strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender).

B. The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if:

With a disorder of sex development (e.g., a congenital adrenogenital disorder such as congenital adrenal hyperplasia or androgen insensitivity syndrome).

Specify if:

Post transition: the individual has transitioned to full-time living in the desired gender (with or without legalization of gender change) and has undergone (or is preparing to have) at least one cross-

sex medical procedure or treatment regimen – namely, regular cross-sex hormone treatment or gender reassignment surgery confirming the desired gender (e.g., penectomy, vaginoplasty in a natal male; mastectomy or phalloplasty in a natal female).

ICD-11: HA60 Gender incongruence of adolescence or adulthood

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 the onset of puberty. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis.

Exclusions:

Paraphilic disorders.

ICD-11: HA61 Gender incongruence of childhood

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 2 years. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis.

Exclusions:

Paraphilic disorders.

Appendix 4

The standard approach to
clinical service development



The standard approach to clinical service development

The three examples below illustrate the usual process of developing a clinical service: Covid-19 is included because this is a new condition that everyone is familiar with; childhood epilepsy because it is a complex condition with physical manifestations; and autism because it is a condition with neuro-behavioural manifestations.

By comparing these examples of clinical service development, it is possible to demonstrate some of the challenges in developing services for children and young people with gender incongruence or dysphoria, and to identify where there are gaps and questions that need to be addressed for this population, in order to ensure any future service model delivers the highest possible standards of care.

The stages below may proceed in a different sequence for different conditions, but each stage is important in the development of evidence based care.

Stage	Covid-19	Childhood Epilepsy	Autism
<p>New condition is observed This often begins with a few case reports and then clinicians begin to recognise a recurring pattern and key clinical features, and to develop fuller descriptions of the condition.</p>	<p>Covid-19 is an example of a recent new condition that we all recognise, and this started with a few unusual cases of respiratory illness being described in Wuhan.</p>	<p>Childhood epilepsy has been recognised for centuries, but over the last century there has been growing understanding of the many different subtypes.</p>	<p>Individuals with autism have probably also existed for an indefinite period, but it wasn't until 1943 and 1944 that Leo Kanner and Hans Asperger wrote the first scientific accounts about the condition.</p>

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Stage	Covid-19	Childhood Epilepsy	Autism
<p>Aetiology Clinicians and scientists try to work out the cause of the condition or the underlying physical or biological basis. Sometimes the answers to this are never found.</p>	<p>The cause of Covid-19 was identified at a very early stage as being due to a novel coronavirus, although it remains unclear where and how this originated.</p>	<p>It is now known that there are numerous different types of epilepsy, with many different causes – for example, epilepsy can be caused by specific epilepsy genes, by birth trauma, by metabolic conditions, by brain tumours and many other mechanisms. Epilepsies due to a change in the brain structure which occur after birth are called ‘symptomatic’ – they are a symptom of something else. Epilepsies for which there is no identified cause are called ‘idiopathic’.</p>	<p>The first theory about the aetiology of autism was that it was caused by so called ‘refrigerator parents’. This was inaccurate and damaging. It has subsequently been shown that there are many complex genetic and physical or chemical brain changes underpinning this condition.</p>
<p>Natural history and prognosis It is important to understand how a condition usually evolves over time, with or without treatment. The latter is important if treatment has limited efficacy and the condition is ‘self-limiting’ (that is, it resolves without treatment), because otherwise there is a risk that treatments create more difficulties than the condition itself.</p>	<p>Covid-19 is an example of a condition where there are quite polarised views about management based on its prognosis and natural history. A relatively small proportion of people are seriously affected and need treatment, and for the majority the natural history is that it will get better by itself. This has led some people to question the need for lockdowns, vaccinations and other measures which they see as impacting personal freedoms.</p>	<p>In epilepsy the natural history is very important. Some epilepsies get better through puberty and into adulthood, and some can get worse with hormonal changes. This is important to know when monitoring and reviewing drug treatment.</p>	

Appendix 4

Stage	Covid-19	Childhood Epilepsy	Autism
<p>Epidemiology Epidemiologists collect data to find out how common a condition is, who is most likely to be affected, what the age distribution is and so on. This allows health service planners to work out how many services are needed, where they should be established, and what staff are needed. They also report on changes in who is most affected, which may mean that either the disease is changing, or the susceptibility of the population is changing.</p>	<p>Epidemiologists have been crucial in supporting the management of Covid-19 because they have extracted and analysed the data on which patients are at greater risk from the virus. This has been fundamental to planning a vaccination strategy and other protective measures.</p>		<p>The epidemiology of autism has changed considerably, with a dramatic increase in the numbers of children diagnosed over the last 20 years. This has had major implications for service provision. There is ongoing debate about the cause of the increase – whether it is because of greater awareness and better diagnosis, or because there are more children with autism. Current opinion favours the first option.</p>

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Stage	Covid-19	Childhood Epilepsy	Autism
<p>Assessment and diagnosis</p> <p>Clinicians will usually take a history from (that is, of their symptoms) and examine the patient (that is, for signs and symptoms), and where appropriate undertake a series of investigations or tests, to help them reach an accurate diagnosis.</p> <p>Sometimes the whole process of making a diagnosis through talking to the patient and asking them to complete formal questionnaires, examining them and/or undertaking investigations is called 'clinical assessment'.</p> <p>As well as diagnosing and ruling out a particular condition, clinicians often need to consider and exclude other, sometimes more serious, conditions that present in a similar way but may need quite different treatment – this process is called 'differential diagnosis'.</p>	<p>PCR has been used as a 'gold standard' test for diagnosis of Covid-19 since the beginning of the pandemic. Lateral flow testing was developed to provide a quicker and cheaper option, but it demonstrates the limitations of testing; it is 99.68% specific, which is a very high specificity. This means there are only a tiny number of false positives. It has lower sensitivity at 76.8%, which means it will miss about a quarter of all cases, so giving many more false negatives, BUT it will only miss 5% of cases with high viral load.</p>	<p>Epilepsy can only be definitively diagnosed by either getting a really clear description of the events from a parent or carer, or seeing the child or young person having a seizure on a video. An EEG (brain wave tracing) and other tests can provide information about the type of epilepsy, but unless a seizure happens during the recording, it does not demonstrate that they actually have seizures – only that they may be susceptible to seizures.</p>	<p>In autism there are no blood tests or X-rays to make the diagnosis. It is a 'clinical' diagnosis, which means it is dependent on taking a standardised history from the parents, and performing standardised assessments on the child or young person to distinguish between autism and other possible diagnoses (for example, language disorder, social anxiety). In the early days, these standardised measures did not exist; the diagnosis was very dependent on experts who were used to diagnosing autism by making a clinical judgement about each child. This made it difficult to teach new people how to do this without a long apprenticeship, and also made it difficult to know whether two different experts would come to the same conclusion about the same child or young person. Standardisation of the questions and process made diagnosis more reliable and consistent, as did an improved evidence base.</p> <p>At the same time, because children with autism all present differently, the assessment had to be flexible enough to accommodate, for example, non-verbal children with severe learning disability, as well as high-functioning children with strong verbal skills.</p>

Appendix 4

Stage	Covid-19	Childhood Epilepsy	Autism
<p>Differential diagnosis As well as making a positive diagnosis, clinicians often need to exclude other, sometimes more serious conditions that present in a similar way, but may need quite different treatment.</p>		<p>There are conditions that can be mistaken for epilepsy, so it is important to accurately diagnose whether seizures are happening and exclude other conditions (differential diagnoses) by carrying out relevant tests.</p>	<p>There are many conditions that may be mistaken for autism – for example, children who have language disorders, learning disability, severe social anxiety for other reasons, or ADHD can all appear to have autism. It is important to exclude these other conditions as well as making a positive diagnosis of autism. Sometimes these conditions can exist alongside autism, and management must then be planned to address all the child’s difficulties.</p>

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Stage	Covid-19	Childhood Epilepsy	Autism
<p>Developing and implementing new treatments</p> <p>Clinicians and scientists work on developing treatments. This involves clinical trials and, where there are new treatments, comparing them to any existing treatments. Questions include: What are the intended outcomes or benefits of treatment? What are the complications or side effects? What are the costs? To initiate a new treatment, it must be both safe and effective. Questions of affordability can sometimes become controversial.</p> <p>The best type of single study is considered to be the randomised controlled trial (RCT), but sometimes this is not feasible. Even where RCTs are not available, it is usual to at least have data on the outcomes of sufficient cases or cohorts to understand the risk/benefit of the treatment under consideration. As demonstrated in Fig. 3, the highest level of evidence is when the results of several different studies are pooled, but this is only useful if the individual studies themselves are of high quality.</p>	<p>Developing treatments for Covid-19 has been possible at speed because of the large numbers of patients, and the fact that outcomes can be observed on each patient within a matter of days to weeks. Because Covid-19 was a new condition, clinicians also started in a position of 'equipoise' which means that they did not have reason to believe any one treatment might be more effective than another; this made it ethical to have one group having a treatment and another group having a different treatment or a placebo.</p> <p>There are also really clear outcome measures, such as whether or not patients survive or need hospitalisation. This has facilitated a high level of evidence through randomised controlled trials (see diagram below).</p>	<p>Similar considerations apply to the treatment of epilepsy in that there are 'hard' outcome measures (for example, frequency of seizures), but it can take several months to determine whether a new drug is better than an existing one for any one patient, and some side effects may be longer-term, so trials can take several years. In addition, children with epilepsy may have very different conditions causing their seizures which can also make trials more challenging.</p> <p>In the most severe cases of epilepsy, surgery may be the best option for controlling seizures. This can be very radical in certain cases and have lifelong implications for how they function. These options, which have a cost as well as a benefit to the child, will only be offered after a multi-disciplinary team meeting, including the paediatricians, therapists, neuropsychologists, radiologists, neurophysiologists and neurosurgeons have all discussed whether the benefits will outweigh the costs.</p>	<p>Evaluating interventions for autism is the most difficult of these three examples. This is because it can take many years to see developmental outcomes; it is hard to get uniform groups of children; outcomes are extremely sensitive to the social (and historical) response of others; and many other things happen in children's lives (such as changes of school, other medications, new diets). Isolating the effect of the target treatment is therefore challenging.</p>

Appendix 4

Stage	Covid-19	Childhood Epilepsy	Autism
<p>In many instances, evidence is not perfect and difficult decisions have to be made. Where treatments are innovative or life-changing, the whole multi-disciplinary team will usually meet to consider the available options, and how to advise the child or young person and family so that a shared decision can be made. Sometimes an ethics committee is involved. This is one of the most challenging areas of medicine and is underpinned by GMC guidance.^{97, 98}</p>	<p>The UK has been internationally recognised for its Recovery Trial, led by Oxford University. This has recruited over 46,000 participants, and resulted in several treatments being approved. A key factor in this success was the willingness of patients to participate in these studies – with over 46,000 being recruited and consented.</p>		

⁹⁷ General Medical Council (2020). [Decision making and consent](#).

⁹⁸ National Institute for Health and Care Excellence (2021). [Shared decision making](#).

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Stage	Covid-19	Childhood Epilepsy	Autism
<p>Service development and service improvement</p> <p>Central to any service improvement is the systematic and consistent collection of data on outcomes of treatment. There is a process of continuous service improvement as new presentations or variations on the original condition are recognised, diagnosis or screening improves and/or trials on new treatments or variations on existing treatments are ongoing.</p> <p>There should be consistent treatment protocols or guidelines in place, in order to make sense of variations in outcomes. Where possible, these should be compared between and across multiple different centres.</p> <p>As time passes, services need to be changed or extended based on patient need, and on what resources are needed to deliver the available treatments. They need to be accessible where the prevalence of the condition is highest. The relevant workforce to deliver the service needs to be recruited and trained, contingent on the type of treatments or therapy that is required.</p>	<p>Service development to manage Covid-19 has been on a scale unlike any normal new service development ever experienced. It has also demonstrated how other non-Covid services have had to evolve alongside, including the need for isolation, and/or PCR testing prior to routine clinical appointments, use of remote consultation and an array of other changes across the NHS. Continuous audit and monitoring of outcomes has resulted in major improvements in survival – for example, changing ventilation approach to include ‘proning’ (putting patients on their front while on the ventilator) and delaying fully intubated ventilation by giving mask ventilation for as long as possible.</p>	<p>Paediatric epilepsy is a good example of how a national approach can be taken to service improvement through the Epilepsy12 programme.⁹⁹ This is a nationally co-ordinated audit which collects a standardised dataset, incorporating NICE standards, and is used to drive up standards of care for children and young people with epilepsy.</p>	<p>Improvement in autism services has been driven by the changing epidemiology, NICE standards, extensive training of the workforce and attempts to improve public understanding. Where previously diagnosis was undertaken in a few specialist centres, the rising waiting times and NICE standards on access, assessment and appropriate multi-professional provision have led to almost every community child development service having an autism assessment clinic or team. Services are able to self-assess against national standards to inform local improvement strategies.</p>

⁹⁹ Royal College of Paediatrics and Child Health (2021). [Epilepsy 12 – national organisational audit and clinical audit.](#)

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Clinical Guidelines & Training for Providers, Professionals, and Trainees

This section serves as a database for resources and education opportunities for professionals working with LGBTQ youth and their families. Resources are split into sections for providers delivering direct patient care and training resources for students and trainees.



Clinical Guidelines & Training for Providers, Professionals, and Trainees Topics

--- Choose One ---



A. Standards Of Care and Evidence-Based Clinical Guidelines

The following are evidence-based guidelines and standards of care that are the most up to date resources for providers across different disciplines serving youth with gender dysphoria. The two most widely known guidelines are published by the Endocrine Society and the World Professional Association of Transgender Health (WPATH).

American Academy of Pediatrics – Supporting & Caring for Transgender Children

This guideline is designed for pediatricians and mental health professionals working with transgender and gender diverse youths and provides specific information for managing social and medical transitions with patients and families. This document is a collaboration between the American Academy of Pediatrics, the American College of Osteopathic Pediatricians, and the Human Rights Campaign

American Psychiatric Association - A Guide for Working with Transgender and Gender Non-conforming Patients (requires APA log-in)

The American Psychiatric Association publishes this guide for clinical work with transgender and gender non-conforming patients.

American Psychological Association – Guidelines for Psychological Practice with Transgender and Gender Nonconforming People

The American Psychological Association provides these guidelines to assist psychologists in providing “culturally competent, developmentally appropriate, and trans-affirmative psychological practice with TGNC people.”

Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society Clinical Practice Guideline

The Endocrine Society provides this guideline on treating gender dysphoria from a interdisciplinary perspective.

The World Professional Association for Transgender Health (WPATH) - Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People

The Standards of Care document is the international gold standard outlining the guidelines for the clinical treatment of gender dysphoria.

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B. Notable Texts on Delivery of Clinical Care

The following are key academic texts that provide clinical guidelines for providers working with gender diverse youth.

Janssen, A., & Liebowitz, S. (2018). *Affirmative Mental Health Care for Transgender and Gender Diverse Youth: A Clinical Guide*. Cham, Switzerland: Springer International Publishing.

This book provides practical, evidence-based information for providers working with transgender and gender diverse youth and their families. It covers complex topics such as assessment, social transitions, non-binary identities, and psychiatric comorbidities.

Keo-Meier, C., & Ehrensaft, D. (2018). *The gender affirmative model: An interdisciplinary approach to supporting transgender and gender expansive children*. Washington, DC: American Psychological Association.

This book serves as a guide to the gender affirmative model for gender diverse youth and their families. It explores strategies for building resilience in culturally-informed contexts.

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C. Additional Resources for Patient Care

AACAP Practice Parameter on Gay, Lesbian, or Bisexual Sexual Orientation, Gender Nonconformity, and Gender Discordance in Children and Adolescents (2012)

AACAP provides guidelines intended to assist clinicians in psychiatric decision making and associated discussion. These guides are endorsed by AACAP and its Sexual Orientation and Gender Identity Issues Committee.

AACAP Statement Responding to Efforts to ban Evidence-Based Care for Transgender and Gender Diverse Youth (2019)

AACAP provides guidelines on evidence-based treatment for transgender and gender diverse youth.

American Academy of Pediatrics - Office-Based Care for LGBTQ Youth

The American Academy of Pediatrics policy statement on outpatient care including terminology, sexual health, and recommendations.

American Psychological Association – LGBT Resources and Publications

The American Psychological Association's list of LGBTQ resources on topics ranging from addressing bias/discrimination and education to marriage/families and policy/advocacy.

Association of American Medical Colleges (AAMC) - Speaking with Patients About Sexuality and Gender

A two-part video from the Association of American Medical Colleges of a moderated panel discussion between professional health educators. Part one provides an overview on terminology and guidance in creating a welcoming environment for patients to enhance understanding, doctor-patient relationships, and clinical care. Part two discusses communication skills including how to teach trainees, strategies for improvement, and most impactful lessons learned.

- Speaking with Patients about Sexuality and Gender - Part 1
- Speaking with Patients about Sexuality and Gender - Part 2

Brill, S.A., & Kenney, L. (2016). *The Transgender Teen: A Handbook for Parents and Professionals Supporting Transgender and Non-binary Teens*. Jersey City, NJ: Cleis Press.

This book provides accessible, practical information for families with gender diverse teenagers, covering topics such as communication, transitions, and school.

Brill, S., & Pepper, R. (2008). *The Transgender Child: A Handbook for Families and Professionals*. San Francisco, CA: Cleis Press.

This book provides accessible, practical information for families with gender diverse children, covering topics such as gender development and school advocacy.

Gay and Lesbian Medical Association (GLMA) – Cultural Competency webinars

This free webinar series explores cultural competence and the health concerns and healthcare of LGBT people and is geared toward clinicians, administrators, researchers, and academics.

Gender Spectrum – Medical

Gender Spectrum provides a useful list of clinical resources targeting physicians and nurses who care for gender-expansive youth.

Substance Abuse and Mental Health Administration. (2014). *A Practitioner's Resource Guide: Helping Families to Support Their LGBT Children*. HHS Publication No (PEP14-LGBTKIDS)

SAMHSA's Practitioner's Resource Guide provides information and practical guidelines for providers working with families of LGBTQ youth using data from family research studies.

SAMHSA – Practice Brief: Providing Services and Supports for Youth Who are LGBTQ

SAMHSA provides resource for providers, administrators, and policymakers to develop culturally and linguistically competent programs, including a system level approach to help youth and families and a checklist of recommendations and strategies.

SAMHSA - Top Health Issues for LGBT Populations: Information & Resource Kit

SAMHSA provides this free guide on health issues affecting diverse LGBT populations.

UCSF Center of Excellence for Transgender Health

The website for UCSF's Center of Excellence for Transgender Health includes information about trans health care access and policy, routine care, HIV prevention, cultural competency, and mental health.