Initial FOI request

Dear NHS England
I'm writing under the Freedom of Information Act to request information on training carried out by your trust on the care of trans children and young people. In a response to an FOI request to Great Ormond Street Hospital NHS Foundation Trust, I was informed that training in this area had been commissioned by NHS England.

I would like to know:

1. What training has been carried out in the last 12 months by NHS England, on NHS England premises or otherwise commissioned by NHS England in relation to any of:
    a. Treatment of patients seen at the new NHS Children and Young People's Gender Services
    b. Trans children and young people
    c. Children or young people with any of gender dysphoria, gender incongruence, gender distress or gender related distress
2. What internal or external providers were involved in the provision of any such training as defined in (1)?
3. What training materials were used in any such training as defined in (1)? Please provide copies of all such materials.

Yours Sincerely,
[Volunteer name redacted]

NHS England response

Dear [volunteer name redacted],
We refer to your email of 21May 2024 in which you requested information under the FOI Act from NHS England. We apologise for the delay in providing you with a response.

Your request

You made the following request:

[text of original request]

NHS England holds the information you have requested and has decided to release all of the information that it holds.

1. What training has been carried out in the last 12 months by NHS England, on NHS England premises or otherwise commissioned by NHS England in relation to any of:
2. Treatment of patients seen at the new NHS Children and Young People's Gender Services
3. Trans children and young people
4. Children or young people with any of gender dysphoria, gender incongruence, gender distress or gender related distress

NHS England has not carried out any such training.

In December 2023, NHS England commissioned the Academy of Medical Royal Colleges (AoMRC) to develop and deliver training to all clinicians in the new Children and Young

People’s Gender Services which aligned to the ‘Interim report of the independent review of gender identity services for children and young people, (the ‘Cass Review’), (February 2022).

- The training was delivered by a team of clinicians that was established by the AoMRC. This comprised training videos which clinicians at the new services have been given access to, and via a one-day face to face facilitated training session. Training days have taken place in February, March, April and June 2024.What internal or external providers were involved in the provision of any such training as defined in (1)?
- The Academy of Medical Royal Colleges.What training materials were used in any such training as defined in (1)? Please provide copies of all such materials.

There are seven training videos that were developed by the AoMRC. You can find the slides with accompanying transcripts attached.

Session 1

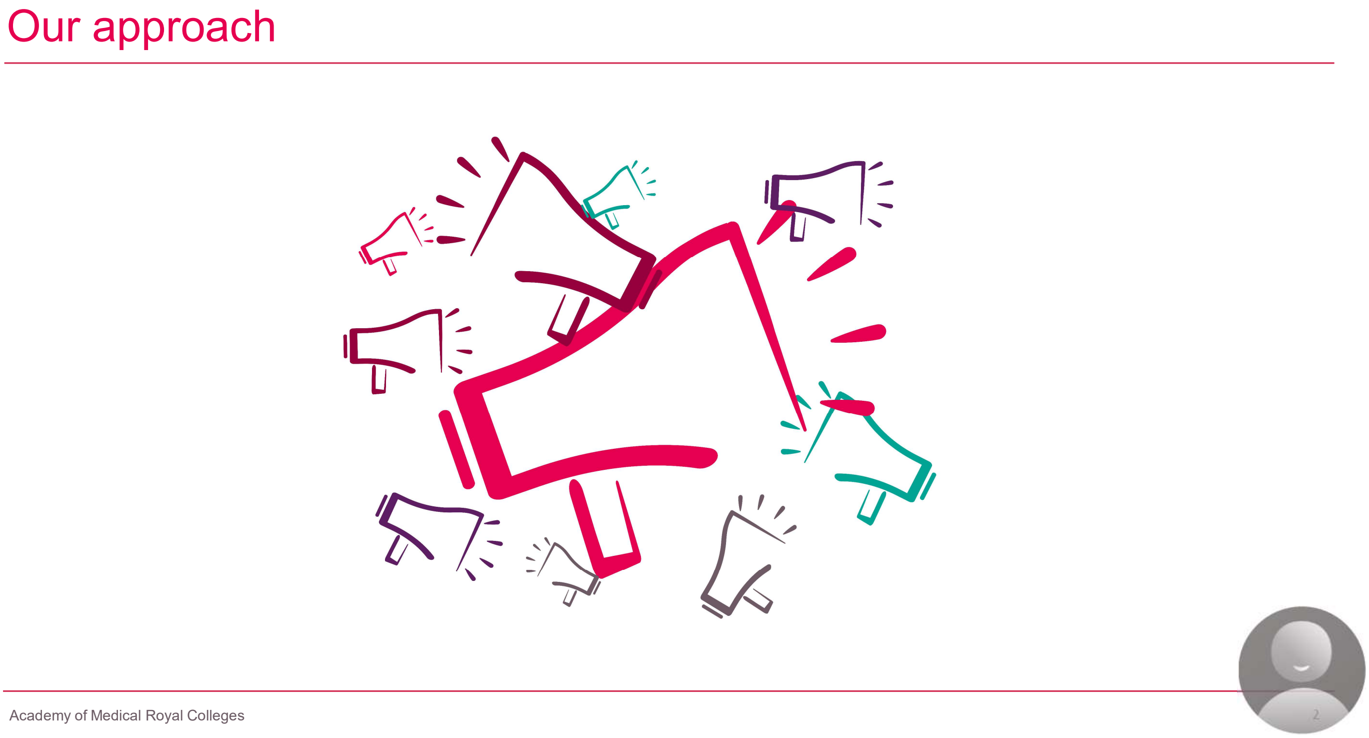
Academy of Medical Royal Colleges

Understanding the range and complexity of the children and young people presenting to GIS Good Medical Practice and our approach

Academy of Medical Royal Colleges' induction to the children and young people's gender service

February 2024

Hello and welcome to the first in a series of short sessions designed to help clinicians and other professionals deliver the NHS's new children and young person's gender service.



Our approach

It almost goes without saying this is a complex and continually evolving area of healthcare, and because there are some strongly held views, it is rarely out of the public eye.

For this reason, we cannot pretend these online sessions will train everyone for every eventuality. They are designed to equip you with an introductory understanding of the issues around gender from a clinical perspective, and importantly, to build your knowledge and confidence in this sometimes-challenging area. And don’t forget you almost certainly already have many, if not all the skills you'll need.

These online sessions have been put together by leading clinicians and senior medical professionals, drawn from a range of disciplines and medical specialties. They are designed to help you deliver the best possible and most clinically appropriate care, in line with the GMC's Good Medical Practice and other professional guidance.

Context

- History
- Rising numbers of referrals
- Changing epidemiology
- ASC and children and young people's mental health

I'll return to that best practice guidance in a moment, but first, it's worth outlining some of the context to the new service and what will be covered in the later sessions.

There is one thing almost everyone, patients, parents, carers and clinicians agree on. The Children and Young Person's Gender Identity Development Service (GIDS), based at London's Tavistock and Portman NHS Foundation Trust, has been overwhelmed in the last few years by the demand on its service provision.

Set up in 1989 as a clinic specialising in children and young people presenting with difficulties relating to their gender development, in 2009 it treated no more than 50 patients a year with that figure remaining more or less stable until 2014. But by October 2020 GIDS was receiving around two and a half thousand referrals a year with four and a half thousand on the waiting list and a waiting time of typically more than two years.

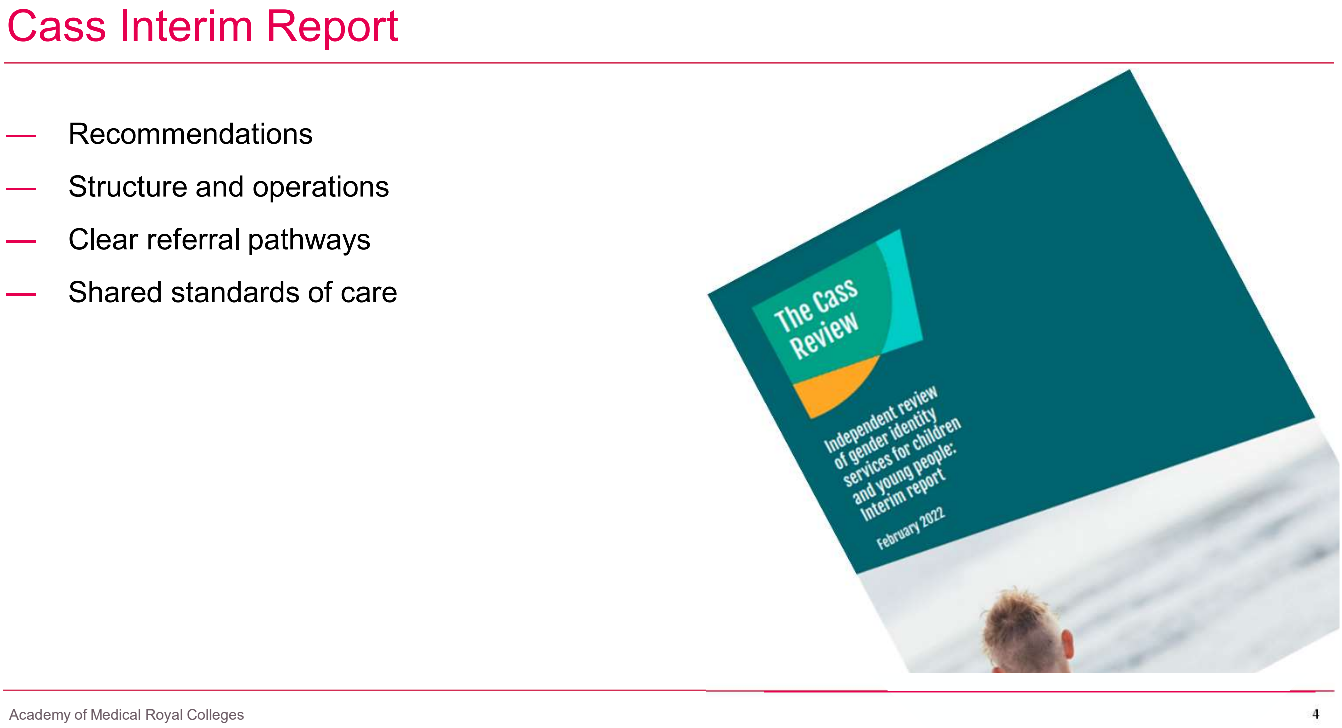
It wasn't just the number of patients seeking treatment, there were also rapid changes in the epidemiology and a significantly more complex case mix emerging. There has also been a recognition that children with a diagnosis of autistic spectrum condition or attention deficit hyperactivity disorder had become overrepresented in referrals to the clinic by this time, as well as an over representation (compared to the national average) of looked after children.

Where previously there had been majority birth-registered males presenting with gender incongruence from an early age, referrals changed to predominantly birth-registered females presenting with gender incongruence in adolescence. There has also been clinical recognition that young people who are gender questioning or experiencing gender related distress also have high rates of mental health difficulties and can be vulnerable to risk and safeguarding issues. These additional needs, and the heterogeneity of the children and young people, means that individualised care based on careful holistic assessment and formulation is essential to providing appropriate care. The links with autistic spectrum condition and children and young people's mental health more broadly will be covered in greater detail in the upcoming sessions.

In 2020 Dr Hilary Cass, a former president of the Royal College of Paediatrics and Child health was commissioned by NHS England to make recommendations about the services provided by the NHS to children and young people who are questioning their gender identity or experiencing gender incongruence.

Her interim report, published in February 2022, recognised that a single national provider was just unable to meet both the increase in overall numbers as well as the growing complexity of presentations. It also recognised that at a local level, service provision and support for patients was patchy at best and in some cases simply non-existent.

The report is also designed to set a path for what everyone hopes is a lasting and sustainable recovery.



Cass Interim Report

- Recommendations
- Structure and operations
- Clear referral pathways
- Shared standards of care

Her main recommendations being:

- The closure of one centralised centre and development of regional centres or hubs which would provide the service directly

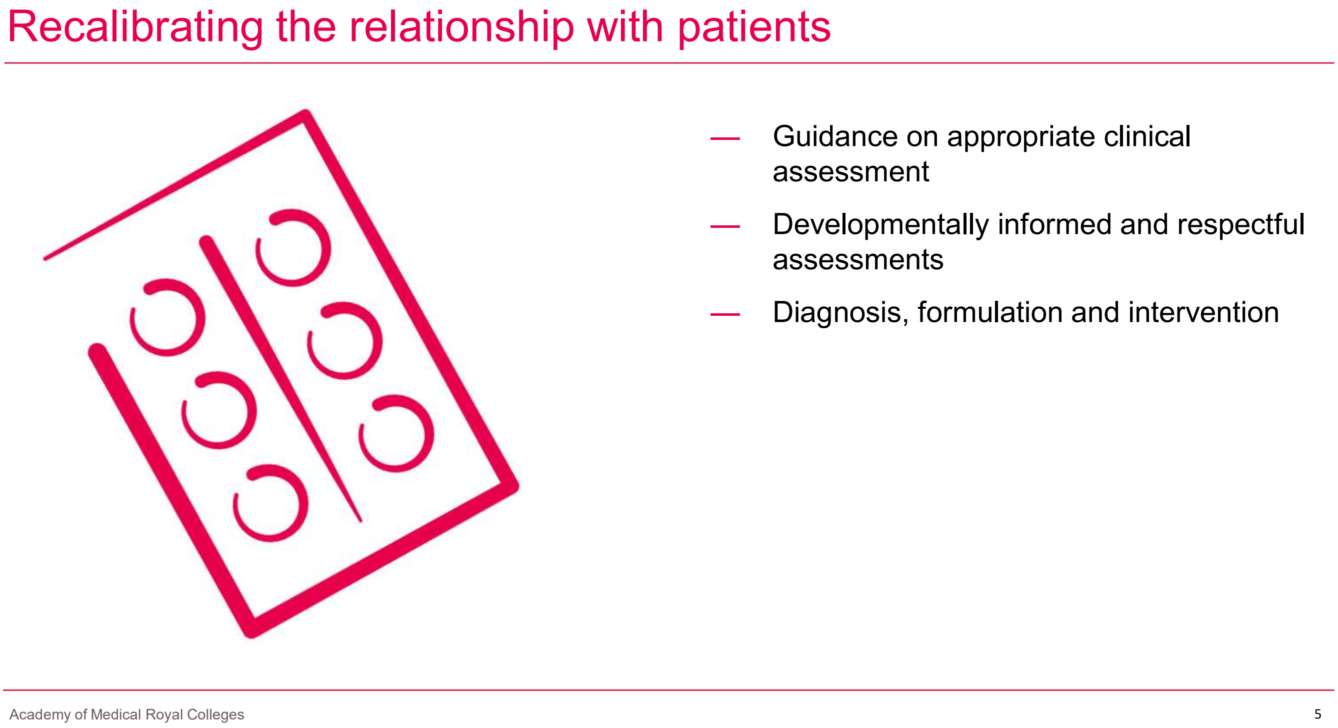
- Ensuring clear referral pathways from primary to tertiary care so that gender questioning children and young people receive equitable access to NHS services and care wherever they live and whatever their circumstances

- Access to high-level training for clinical practitioners at all levels. With appropriate competency frameworks developed alongside professional organisations in due course.

- Shared standards of care and the standardised collection of data and regular audits to provide insight into the epidemiology, assessment and treatment of this group of patients.

- The children and young people who receive hormone treatment should be part of a continuous research programme to track outcomes and improve the evidence base

- Close adherence to the General Medical Council's Good Practice in Prescribing and Managing Medicines and Devices - with standards for decision making regarding endocrine treatment being in line with international best practice.



Recalibrating the relationship with patients

- Guidance on appropriate clinical assessment
- Developmentally informed and respectful assessments
- Diagnosis, formulation and intervention

As well as focussing on the structure and operational side of the service, the recommendations made clear the relationship with the patients should be recalibrated:

- Children and young people with gender incongruence or dysphoria must receive the same standards of clinical care, assessment and treatment as every other child or young person accessing health services.

- There needs to be agreement and guidance about the appropriate clinical assessment processes that should take place at primary, secondary and tertiary level.

- Assessments should be respectful of the experience of the child or young person and be developmentally informed. Clinicians should remain open and explore the patient’s experience and the range of support and treatment options that may best address their needs, including any specific needs of neurodiverse children and young people.

And crucially, recommendation ten of twelve suggested 'any child or young person being considered for hormone treatment should have a formal diagnosis and formulation, which addresses the full range of factors affecting their physical, mental, developmental and psychosocial wellbeing. This formulation should then inform what options for support and intervention might be helpful for that child or young person.'

It's this recommendation that these sessions are designed to support.

Turning point

- Comprehensive biopsychosocial assessment
- Multi-disciplinary and patient centred approach
- Partnership working

By any measure this is a turning point in relation to the delivery of gender services for children and young people. Once operational, doctors and other clinical professionals will be able to:

- Ensure that all patients are offered a comprehensive biopsychosocial assessment to ascertain their mental and physical health needs. But where there may be multiple or complex treatment needs, a thorough assessment and formulation should precede any intervention, ensuring that the intervention is appropriate for that individual at the time.

- Accommodate a multi-disciplinary approach, delivering patient centred care based on the best available evidence.

- And allow for partnership working so that patients' views - even if they are very young - are listened to, alongside the views of their parents or carers.

In short, it's about providing a gender identity service for children and young people which is in line with other paediatric and children and young person’s mental health care pathway, utilising skills and competencies that you already have.

Language

And finally - it's worth making a note of the language used in these sessions. The words we have chosen have been carefully considered. But we know there is sometimes no consensus on the best language to use relating to this subject. The language surrounding this area has also changed rapidly and young people have developed varied ways of describing their experiences using different terms and constructs that are relevant to them.

These sessions try as far as possible to use language and terms that are respectful and acknowledge diversity, but that also accurately illustrate the complexity of what we are trying to describe and articulate.

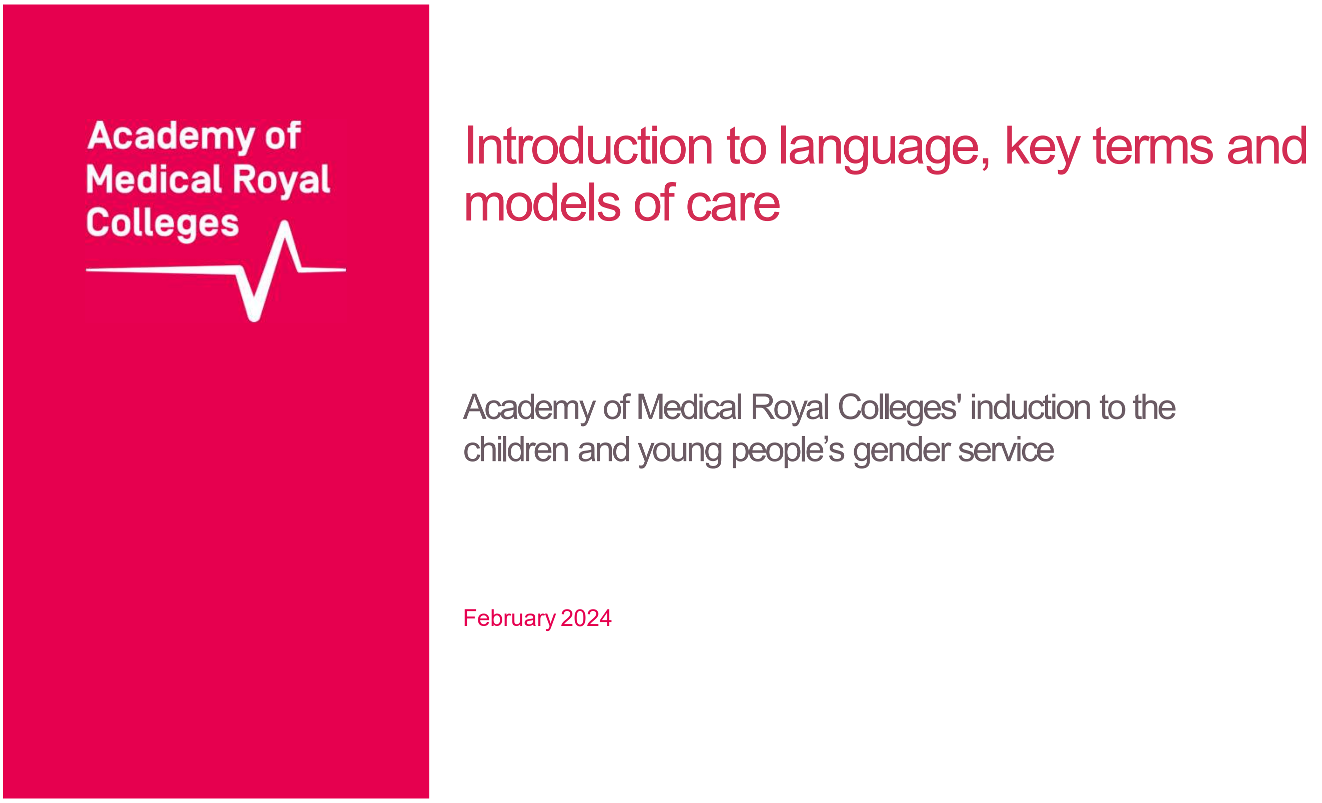
And as with all clinical professional guidance and in line with Good Medical Practice - you can practise in accordance with your own beliefs provided they are in accordance with the relevant legislation and

- do not treat patients unfairly
- do not deny patients access to appropriate interventions or services
- do not cause patients undue distress.

1. **Understanding the range and complexity of the children and young people presenting to GIS Good Medical Practice and our approach**
2. An introduction to language, key terms and models of care
3. Key skills in children and young people’s mental health care gender services
4. Child and adolescent development and puberty
5. Recognising and understanding body dysmorphic disorder (or BDD)
6. Recognising and understanding neurodiversity in children and young people
7. Safeguarding

thanks

Session 2



Academy of Medical Royal Colleges

Introduction to language, key terms and models of care

Academy of Medical Royal Colleges' induction to the children and young people’s gender service

February 2024

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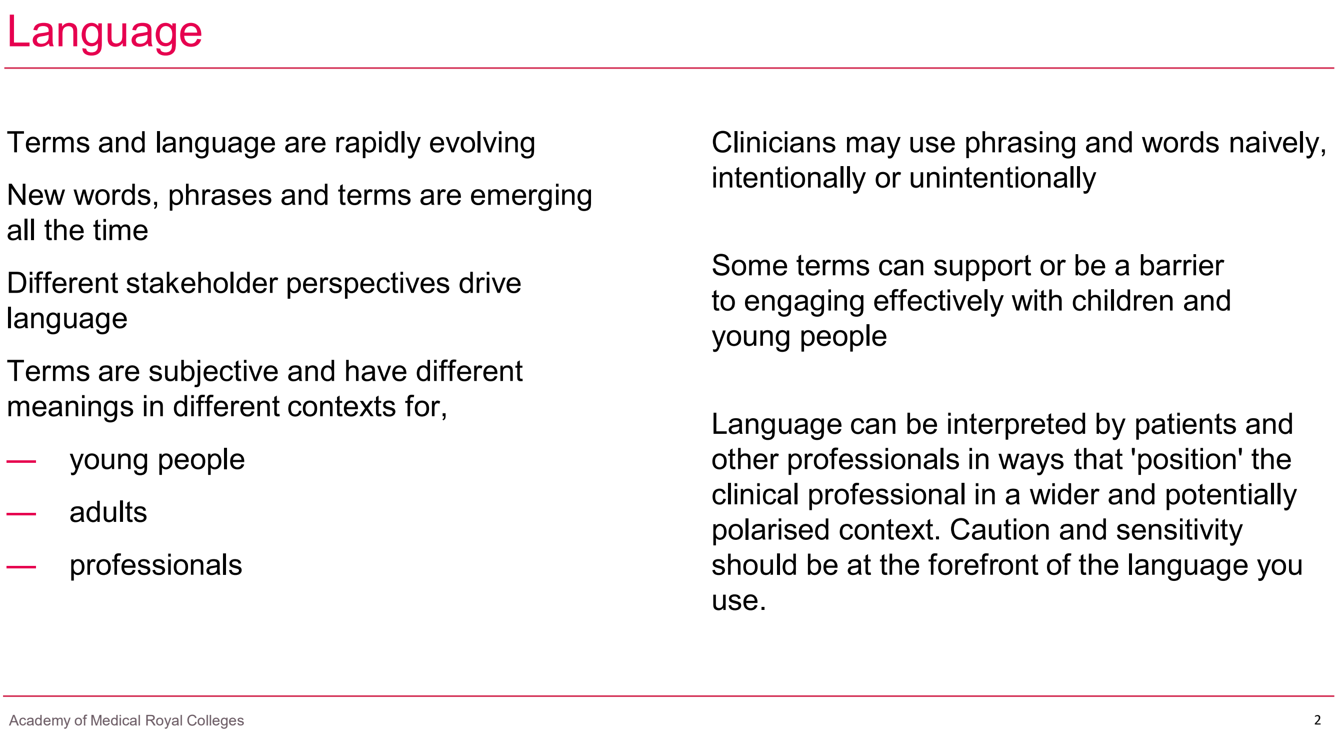


Language

Terms and language are rapidly evolving

New words, phrases and terms are emerging all the time

Different stakeholder perspectives drive language

Terms are subjective and have different meanings in different contexts for,

- young people
- adults
- professionals

Clinicians may use phrasing and words naively, intentionally or unintentionally

Some terms can support or be a barrier to engaging effectively with children and young people

Language can be interpreted by patients and other professionals in ways that 'position' the clinical professional in a wider and potentially polarised context. Caution and sensitivity should be at the forefront of the language you use.

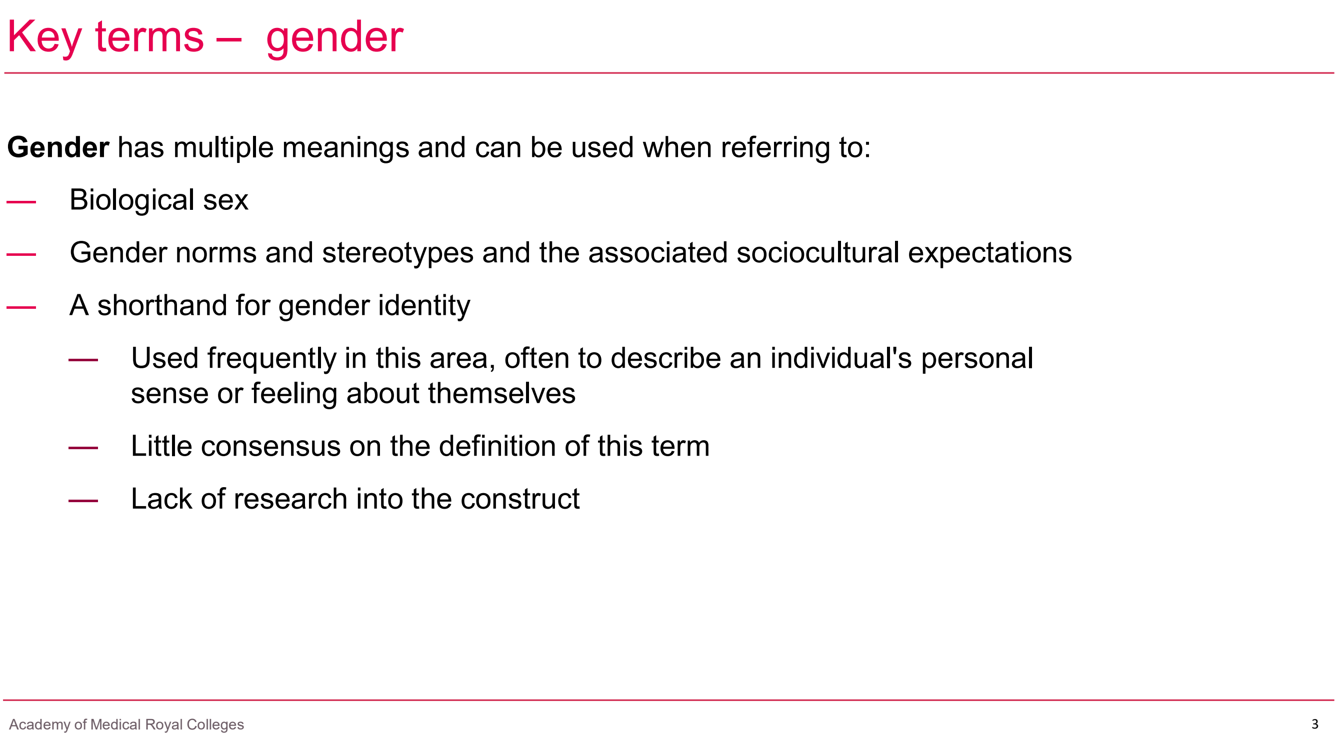
Terms and language in this area of clinical activity have changed rapidly and language continues to evolve. There are multiple influences on language for example, diagnostic nosology, social and cultural changes, stakeholder terms and priorities

New words are emerging almost all the time – and this can make it feel like it's hard for clinicians to feel informed. It is important for both patient and the clinical professional to establish a shared understanding of what words mean from the outset. Where clinical or technical terms are used, clinicians should ensure their meaning is understood by the patient and vice versa.

Remember, many key terms and constructs are subjective and have different meanings in different contexts and when used by young people, adults and professionals

Some language and terms might support engagement for some young people and parents or carers and conversely might be a barrier for others.

The language that NHS clinicians use, both intentionally and unintentionally, can help or hinder their clinical work and working relationships. So caution and sensitivity should be at the forefront of the language you use.



Key terms – gender

Gender has multiple meanings and can be used when referring to:

- Biological sex
- Gender norms and stereotypes and the associated sociocultural expectations
- A shorthand for gender identity
  - Used frequently in this area, often to describe an individual's personal sense or feeling about themselves
  - Little consensus on the definition of this term
  - Lack of research into the construct

The word gender when used in common language can have multiple meanings and so it can be helpful for clinicians to be clear on what is being described or discussed.

Gender can be used when talking about:

1- **Biological sex** – this refers to the characteristics that determine males and females, such as chromosomes, hormones and reproductive organs. These characteristics are used to classify most people as male or female.

2- **Gender norms** are the social and cultural expectations that connect to being male and female and children learn these norms as they grow up. Gender norms have an impact on the way in which people understand what it means to be a (stereotypical) boy/man or girl/woman. Norms and cultural expectations vary across contexts and communities.

3 – Gender can be used as short hand to refer to **gender identity.**

This is a concept that is used to describe an individual's personal sense or feeling about themselves. Some people feel their gender identity does not match the sex they were registered at birth with and feel that they identify as male, female, non-binary or that their gender identity changes over time.

There has been an increase in people using the term gender identity to describe their feelings and experiences. This term is being thought about and discussed. For example, what is the best way to study the concept, as well as understand its meaning for different people.

Many people feel very connected to the term gender identity and use it to describe their experiences whereas others do not feel they have a gender identity.

Key terms continued

Gender non-conforming is used to describe people who may not fit with gender norms

Transgender is an umbrella term used by a range of people who feel their gender identity does not match the sex they were registered with at birth

Non-binary is a term used to describe people who may identify as an intermediate or separate third gender, or identify with more than one gender, have no gender, or have a fluctuating gender identity.

Gender non-conforming is a broad term used to describe children who may not fit with gender norms. They may have preferences, interests and ways of being that do not fit with the perceived rules and stereotypes set within groups and communities. Some children, who are working out what they like, how they want to present and how they feel most comfortable, may be described as gender non-conforming.

Not fitting with gender norms is a part of development for many children and should not necessarily be seen as a sign of later gender-related distress or the presence of gender identity questions. Research suggests that, for most children, gender nonconformity is a part of growing up and the literature indicates can be associated with sexual orientation.

This is very important for professionals and parents and carers to hold in mind as it forms a key aspect in how we understand children's behaviour and needs from a developmental perspective. Supporting children and young people to explore the impact of negative and sometimes regressive norms and stereotypes is a key area of this work. Gender norms and stereotypes are ingrained in how children learn about many aspects of life and there are impactful cultural expectations around what it might mean to be a 'proper girl' or a 'proper boy'.

Transgender is the broad umbrella term that is used by a range of people who feel that their gender identity does not match the sex they were registered at birth. This can include terms like trans man/boy, trans woman/girl, non-binary and gender-fluid to give just some examples.

Non binary is a term used to describe people who may identify as an intermediate or separate third gender, or identify with more than one gender, have no gender, or have a fluctuating gender identity.

Influences on language

- Language in the area is being formed and constructed from a wide range of influences
- Social media platforms can be highly influential
- Cultural context including social transition
- Social transition as a research term is not well defined and there is limited research consensus

2014 saw Facebook adopt list of 58 gender identities, this is often cited as a key point that captures a shift in how gender was being talked about among young people.

Understanding both the benefits and possible harms of the internet in this area will be an important area of your clinical development.

Online groups and connections can be a rapid way of sharing information. But young people may struggle to understand or be developmentally ready for it. For example, content relating to social transition steps as well as medical transition pathways. This can expose children and young people to information that may not be safe, accurate or appropriate. Different countries have different healthcare provision and processes which can also influence how young people understand different pathways of care.

Social transition describes the process of changing name, pronouns, clothing and/or appearance to fit more closely with their felt gender identity. Changes can be varied with some children and young people making slight shifts over time. Others may make more significant changes both socially, and in relation to more formal documentation, such as changing their legal name. The process of social transition requires the child’s family, school, peer group and wider social network to also make these changes. Some children are being supported to make social transitions in early childhood and are therefore living for several years in a different gender role before puberty has commenced.

Some children and young people seek to keep the sex they were registered at birth private after making a social transition and this is sometimes described as being in 'stealth’.

Referrals of young people to gender clinics indicates that there has been an increase in children and young people making social transitions with almost 60% of those having already made this step at the point they are referred.

Social transition as a research term is not well defined and there is limited research consensus. There is also a wide spectrum of experience that it can encapsulate. Clinical consensus as to the impact in terms of wellbeing and later outcomes is limited. Robust research on the outcomes of social transition is scarce and often low in quality. This makes it difficult to predict and therefore advise on the psychological and social impact of making this step in childhood.

Diagnostic terms

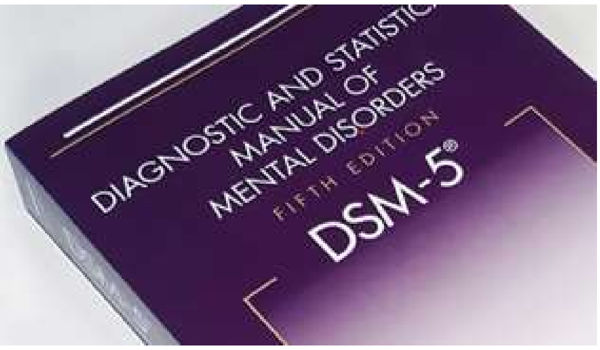
1910 – Hirschfeld/Benjamin – understanding sexuality and gender, used ‘transvestites’ and ‘transexual’ in 1923

1970’s – The term transgender emerged

1980 – DSM 111 – ‘Transexualism’ – adults and ‘Gender Identity Disorder of Childhood (GIDC)’

2013 – DSM IV – ‘Gender dysphoria’ in children and adolescents. Renamed to destigmatise ‘disorder’.

2022 – ICD11 – ‘Gender Incongruence’ – within sexual health



Since the early part of the 19th century different diagnostic categories have existed and have changed over time in response to the shifting clinical and cultural context. These constructs have also influenced the language used in this area.

Gender dysphoria was used by gender specialists and other health staff to categorise children and adolescents who experience gender difficulties (for at least 6 months) and who experienced significant distress that impacts on functioning.

Gender incongruence has been most recently outlined in the International Classification Diseases and is defined as a marked and persistent incongruence between an individual's experienced gender and the sex they were registered at birth. ‘Gender Incongruence’ has been included within the sexual health section. The emphasis on distress and impact on functioning has been removed to include much wider group.

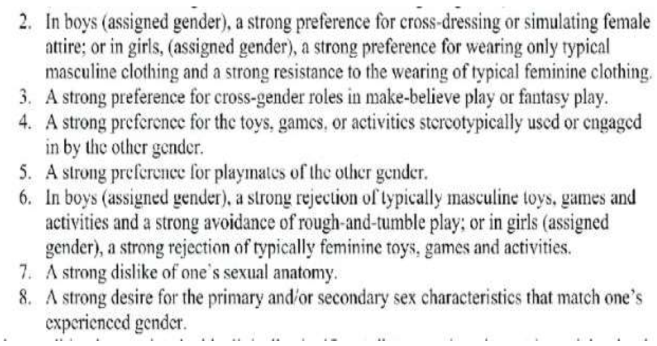
The term 'dysphoria’ can be used by young people in day-to-day speech as a way to describe a range of gender-related experiences that cause distress. This is another example of how language has been taken from diagnostic categories and incorporated into the language used by some young people to capture their experiences.

The impact of diagnostic language

Gender norms and expectations vary over time and context, culture and social class

Historical concerns in relation to pathologizing variation in children's behaviours

Tensions between risk of pathologising variation in children's behaviour, vs diagnosis and access to publicly funded or insurance-covered health care



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.

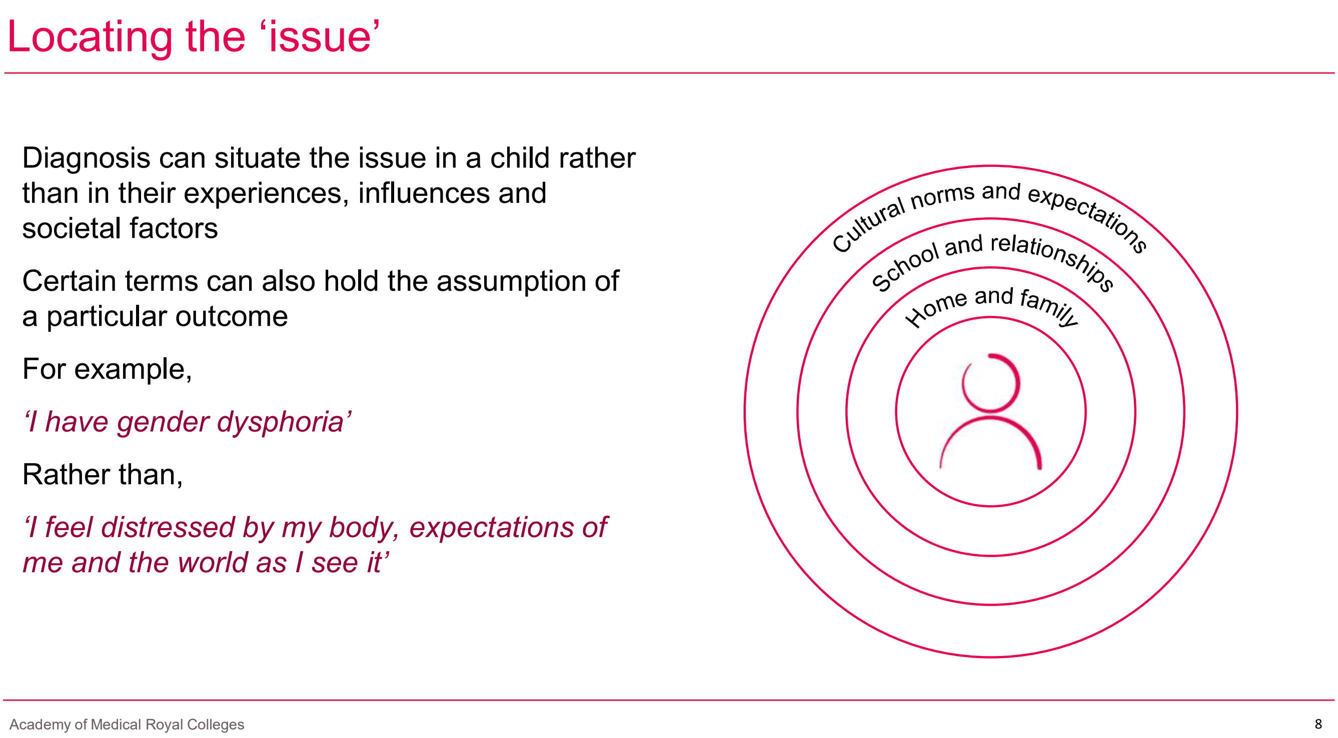
Source: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)

The criteria included within the diagnostic categories have been criticised and many argue that for children particularly the listed criteria pathologizes variation in children's preferences, play and interests.

The criteria has also drawn heavily on time and context specific ideas about gender norms.

Many stakeholders and clinicians have argued, as was the case of homosexuality in the 1970s, that it is wrong to label expressions of gender difference as symptoms of a mental disorder and that diagnostic constructs in this area have the potential to stigmatise and children and young people.

However other advocates expressed concern that removing gender differences entirely from classification manuals would lead to issues around access to medical care for those who may need it, with reference to countries that have insurance-covered health care systems



Locating the ‘issue’

Diagnosis can situate the issue in a child rather than in their experiences, influences and societal factors

Certain terms can also hold the assumption of a particular outcome

For example,

‘I have gender dysphoria’

Rather than,

‘I feel distressed by my body, expectations of me and the world as I see it’

Diagnosis can situate the issue in a child rather than in their experiences, influences and societal factors.
Certain terms can also hold the assumption of a particular outcome.

There is emerging understanding of the many paths and outcomes for children who experience a period of gender questioning or gender-related distress (Therefore, use terms carefully so as not to assume a particular outcome for anyone seeking help from services).

Gender related distress or gender questioning are non-diagnostic terms that can be used to capture the experience of distress or the questions that can arise for children and young people. This term encapsulates a broad range of factors that can potentially connect to a child or young person's gender identity feelings as well as broader aspects of development.

Different clinical approaches

Across different countries and healthcare systems there are different approaches to paediatric gender care including:

- Differences on the approach to assessment and clinical guidelines used
- Variation in emphasis and access to social and psychological support
- Variation in emphasis and access to hormone interventions

Changes in the case mix, demographics and complexity of referred population over time have also prompted several European countries to review protocols

Across different countries and healthcare systems there are different approaches to paediatric gender care including:

Differences on the approach to assessment and clinical guidelines used

Variation in emphasis and access to social and psychological support

Variation in emphasis and access to hormone interventions

Changes in the case mix, demographics and complexity of referred population over time have also prompted several European countries to review protocols

Different clinical approaches continued

Three such approaches are:

- Dutch approach
- Affirmative approaches
- Developmental approach

Professionals highlight concern about the lack of consensus and the limited evidence base on how best to support this group of children with complex needs. Over time and across countries different approaches of care have emerged.

Dutch approach

- From late 1990’s and into 2000’s a team in the Netherlands began to develop a pathway which they called a staged model of care. This involved ‘watchful waiting’ of children prior to the onset of puberty. If gender dysphoria increased, then puberty blockers would be given followed by cross sex hormones at 16 years plus. This became commonly known as the Dutch approach and was adopted by other clinics over time.
- The original Dutch approach has clear inclusion criteria for the medical pathway which included; a diagnosis of gender dysphoria, gender dysphoria from childhood, a supportive home environment, and no serious co-morbidities.
- Over time the staged care was adopted by other clinics but with less rigour around inclusion criteria so was broadened out to provide medical intervention to a much more heterogeneous and more complex group

Affirmative approach

- This is an approach that originated in the USA and recommends affirming a child or young person's felt gender identity and following the Child’s request

- Affirmation typically includes actively supporting with steps around social transition
- Affirmative care also advocates for access to hormone intervention at the appropriate age if the child continues to express gender incongruence. This is referred to as 'gender affirming hormones'
- There is limited emphasis on the requirement for assessment or criteria for inclusion or exclusion

- *'The gender affirmative model is defined as a method of therapeutic care that includes allowing children to speak for themselves about their self-experienced gender identity and expressions and providing support for them to evolve into their authentic gender selves, no matter at what age. Interventions include social transition from one gender to another and/or evolving gender nonconforming expressions and presentations, as well as later gender-affirming medical interventions (puberty blockers, cross-sex hormones, surgeries)'*

Developmental approach

- Advocates for supportive observation of how gender questions and any distress develops over time, before making changes. It advocates for assessments to seek to understand if any additional unmet needs might be adding to challenges growing up or contributing to distress and functioning
- It suggests that there can be many experiences that can lead to gender-related distress, as well as a range of ways to reduce any distress; not limited to, but including parental, broader social support and psychological therapies
- And it highlights that childhood and adolescence are crucial periods of development in which many aspects of self and identity are explored

Attributes of NHS children and young people's gender services

- Consistent process and approach to assessment
- Seek to understand each child and family's unique set of needs
- Developmentally informed
- Address co-occurring complexity
- Use recognised principles of safeguarding and risk management
- No assumption of pathway or outcome
- Collaborate with parents/carers in accordance with best practice guidelines
- Collaborate with the child or young person's wider professional and care networks
- Engage the broadest range of people seeking help

The Cass review has highlighted that NHS gender services should maintain a consistent process and approach to the assessment of this group of children and young people. Those seeking help need to feel confident that clinicians will seek to understand each child and family's unique set of needs, experiences, hopes and priorities.

The following principles have been identified to guide the approach taken:

- Assessments should be respectful of the experience of the child or young person and clinicians should seek to understand each family's experiences and the range of support and intervention options that may best address their needs.
- Assessments should be developmentally informed and seek to build a comprehensive understanding of each child/young person's strengths, needs and any areas of vulnerability and risk.
- Psychosocial support should be provided as a first line intervention. This should aim to address co-occurring complexity and improve children's well-being and functioning as appropriate to their age and stage of development.
- Services and clinicians should adhere to recognised principles of safeguarding and risk management that apply to children/young people and their parents/carers.
- Services and clinicians should not assume a particular pathway or outcome for children/young people who seek support from NHS gender

services.

- Professionals should work collaboratively with children/young people, their parents/carers and their wider professional networks to support the child or young person with the most appropriate support pathway for them as an individual.
- Clinicians should work collaboratively with parents/carers in accordance with best practice guidelines and to support better outcomes.
- Clinicians should work collaboratively with the child/young person’s wider professional and care networks to support better outcomes.
- Services need to support the engagement of the broadest range of people seeking help from NHS gender services.

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And here is a list of references in relation to the previous slides and may help you if you want to do any further reading or study

1. Understanding the range and complexity of the children and young people presenting to GIS Good Medical Practice and our approach
2. **An introduction to language, key terms and models of care**
3. Key skills in children and young people’s mental health care gender services
4. Child and adolescent development and puberty
5. Recognising and understanding body dysmorphic disorder (or BDD)
6. Recognising and understanding neurodiversity in children and young people
7. Safeguarding

And that’s the end of the second session in this series.

Session 3

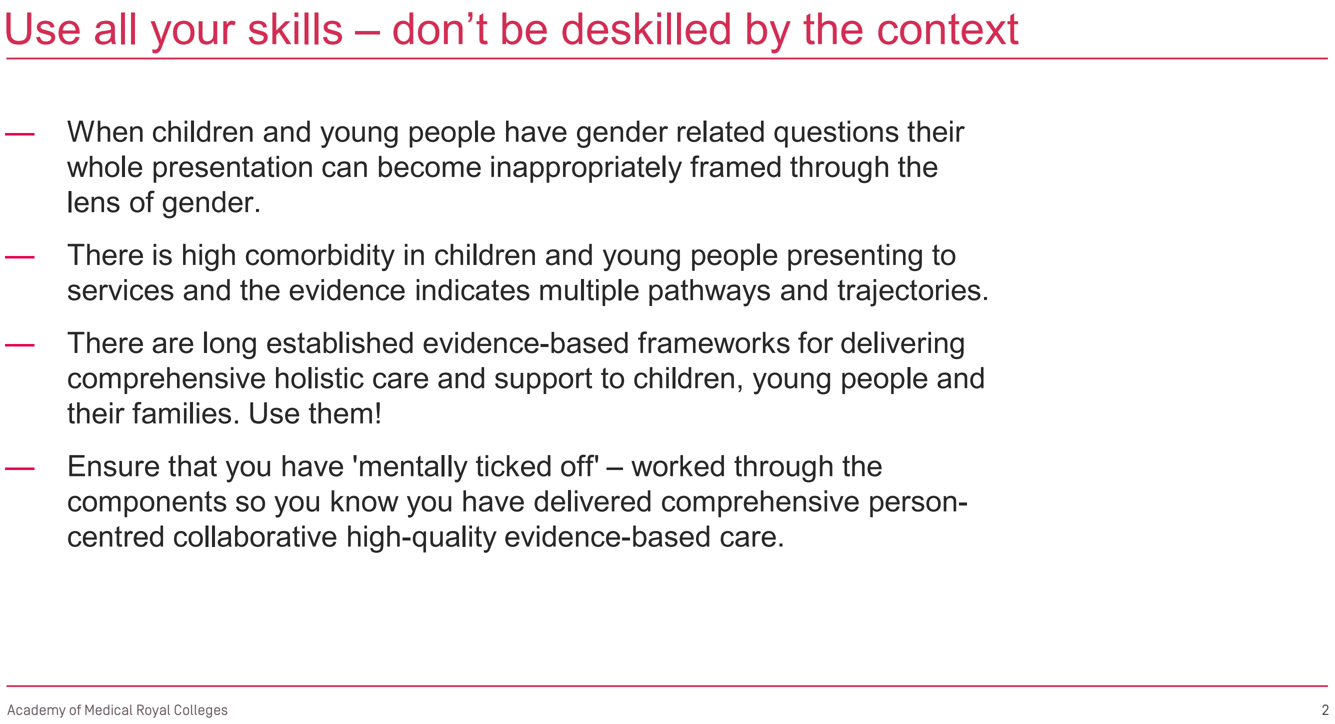
Academy of
Medical Royal
Colleges

Key skills in children and young people's mental health care gender services

Academy of Medical Royal Colleges' induction to the children and young people's gender service

February 2024

I'm here today to talk to you about your key skills in working with children and young people with mental health issues within the new gender services.



Use all your skills – don't be deskilled by the context

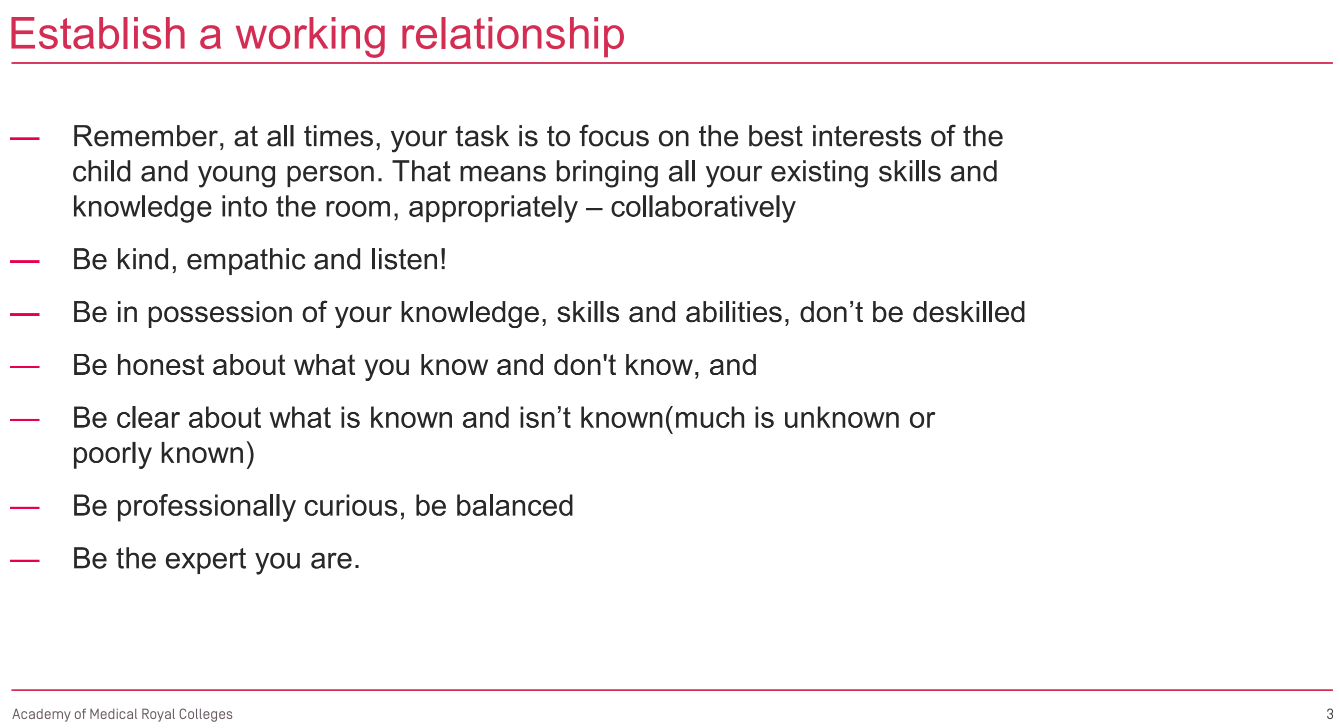
- When children and young people have gender related questions their whole presentation can become inappropriately framed through the lens of gender.
- There is high comorbidity in children and young people presenting to services and the evidence indicates multiple pathways and trajectories.
- There are long established evidence-based frameworks for delivering comprehensive holistic care and support to children, young people and their families. Use them!
- Ensure that you have 'mentally ticked off' – worked through the components so you know you have delivered comprehensive person-centred collaborative high-quality evidence-based care.

So first of all what we want you to be thinking about is all the skills and knowledge that you have from working with children's mental health and child health settings and bring those skills and bring that knowledge into the new context of the new gender services.

When children have problems related to their gender, the whole presentation can become inappropriately framed only through the lens of gender. And the concern here is that young people and children with gender related issues presenting to our services do have high rates of comorbidity, they have high rates of co-occurring life stresses and problems. We know that there is not one single pathway, one single route that such young people take through their development. Seeing everything through the lens of gender, can be doing a considerable disservice to those young people, if we're not addressing their co-occurring comorbidities.

And we do know that there are long established evidence based frameworks for delivering comprehensive and holistic care to children and young people. And so we want you to use all the evidence and all the treatments that we have, and all the care that we normally apply to other young people presenting with complex presentations to this group also.
Through this presentation, I want to be giving you key stone things that you kind of touch on to remember to ensure that you're mentally working through, ticking off all the components of a comprehensive biopsychosocial developmental approach, which is both person centred and collaborative and delivers the best

evidence based approach for each of all the children or young people that you are seeing.



Establish a working relationship

- Remember, at all times, your task is to focus on the best interests of the child and young person. That means bringing all your existing skills and knowledge into the room, appropriately – collaboratively
- Be kind, empathic and listen!
- Be in possession of your knowledge, skills and abilities, don’t be deskilled
- Be honest about what you know and don't know, and
- Be clear about what is known and isn’t known(much is unknown or poorly known)
- Be professionally curious, be balanced
- Be the expert you are.

The first touch point is to consider the working relationship. And of course, that's essential and without it you don’t get past basecamp.

You need to establish this working relationship carefully.

- At all times, keeping your focus on the best interests of the child. Bring your expertise into the room appropriately, collaboratively,
- Be empathic, be kind, and listen. Listening is a real skill, But sometimes it gets a bit lost inside all the multiple questions and the complexities that we work with. Be in possession of your knowledge and your skills. Don't allow yourself to be deskilled.
- Be honest about what you know and what you don't know.
- And be clear about what is known and what isn't. And the truth is, in relation to gender identity and gender dysphoria, there is a great deal that we don't know. And there's only relatively little that we can say with any certainty.
- Be professionally curious and to be balanced in how you work and how you approach these young people.

Four principles of evidence-based practice


Best Research Evidence
What the Literature says

Clinical Experience
What the Clinician knows

Evidence based practise

Patient Values
What the patient wants

Context
Environment and Organisation

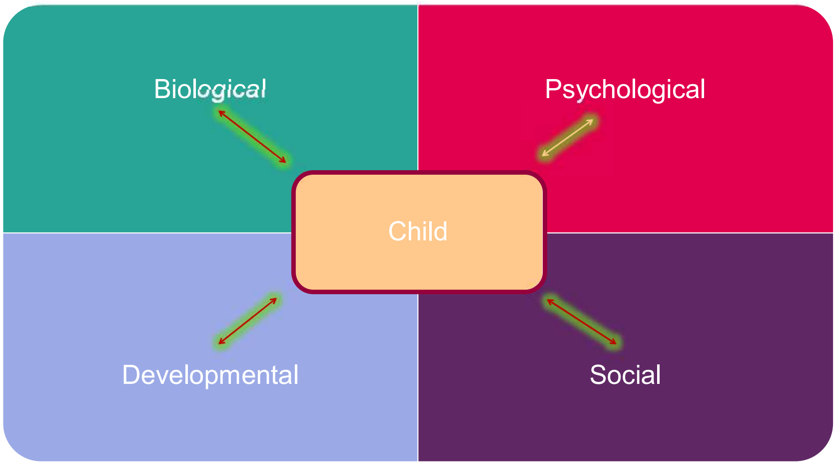
Remember that while patient's wishes are of course important, you have a duty to also consider the best research evidence, national guidance, and your expertise in arriving at a formulation and clinical decisions, in the best interests of the children and young people

As you approach working with these young people and children, we want you to be delivering evidence based practice. But you need to remind yourself what we mean when we say evidence based practice. Remember that whilst your patient's wishes are, of course important, you have a duty to also consider the best research evidence, the best NICE and national guidance, and bring your expertise, into the context, into the room, so that you can arrive at a formulation and subsequent clinical decisions in the best interests of the children and young people.

Bring together all the components and what we call evidence based practice so you don't get inappropriately focused on one single component.

Deliver your assessment and interventions

- Work across the 4 domains of bio-psycho-social and development
- Establish and take account of risk, risk factors, resilience and mental state in each domain



We want you to think and we want you to work comprehensively in a biopsychosocial and developmental framework. This graphic is there to remind you of that.

Deliver your assessment and care and interventions, taking account of the mental state, the risks that you perceive and find for the young person, any related safeguarding issues.
Pulling in the understanding of risk factors and protective factors and how you may build resilience through better understanding of how the young person feels and thinks about things and their passions and their interests.
All the things that you find out about through a good understanding and a comprehensive assessment and engagement of the young person that you're seeing.

Build understanding through collaborative-person centred formulation

This should drive your care – a form of what, why, what next?

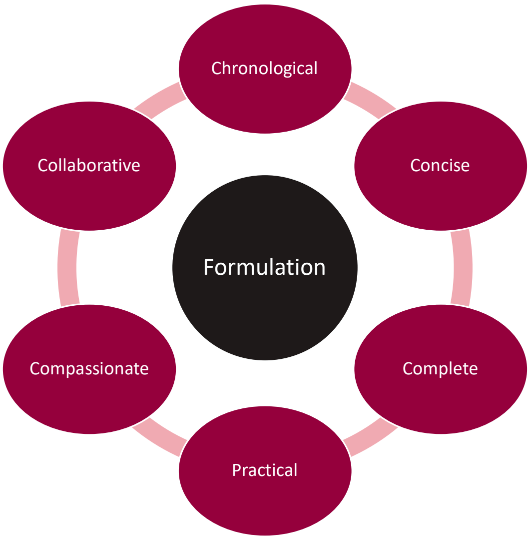
The problem-diagnosis in life history order

Assess safety and safeguarding

Risk, vulnerability, protective factors & resilience
(predisposing, precipitating, perpetuating and protective factors)

A comprehensive approach

Options for intervention and review



Formulation

Chronological

Concise

Complete

Practical

Compassionate

Collaborative

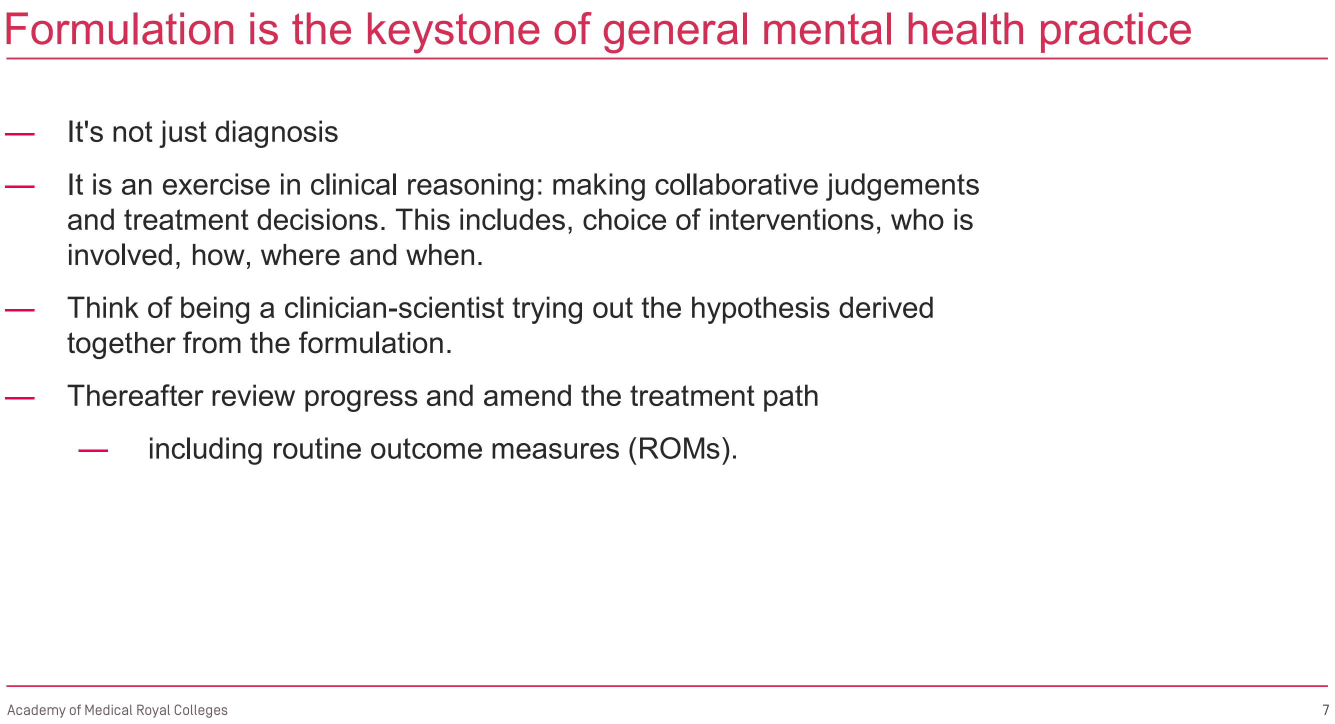
As you build your understanding. And as you as you gather your data and your information, pull it into a formulation.

Because we do see too often that people only bring a single component into what they term a formulation. And as a result, the understanding of what is the problem? Why is it occurring? And what should we do next, using our evidence based frameworks becomes weakened or undermined by the lack of the comprehensive formulation. For example, some people may end up thinking a formulation is a statement of the diagnosis. That's part one of the formulation, but it's only part one. Other people may focus on the safety and the risks and feel that they've formulated when they said that "so and so is at risk because of so and so". And that too is an important part of formulation. But it's not it. Ditto safeguarding. Ditto if we identify certain risk and vulnerability factors and protective factors.

All of these are components on the left hand side are part of a formulation. They should be knitted together into a comprehensive approach that we call a biopsychosocial developmental formulation.

What is the diagnosis? What is the safety and safeguarding issues? What are the risk factors? What are the vulnerabilities? Are there any protective factors that we can see or maybe build on going forward into the future? All of that into a comprehensive approach with then thinking and decisions and ideas for what you're going to do next, for the intervention and for review.

Record all of that you want to capture in the thinking for formulation. And therefore on the right, lays out what we mean by doing a formulation well. It should be chronological. It should be concise enough, it should be complete as possible. It should be practical in terms of what's doable and what's possible for this young person within their family, within their school within their life context within the context of what you can offer. At all times you should be compassionate and you should be collaborative. Working with warmth and kindness, and also clarity about what we know and what we don’t know

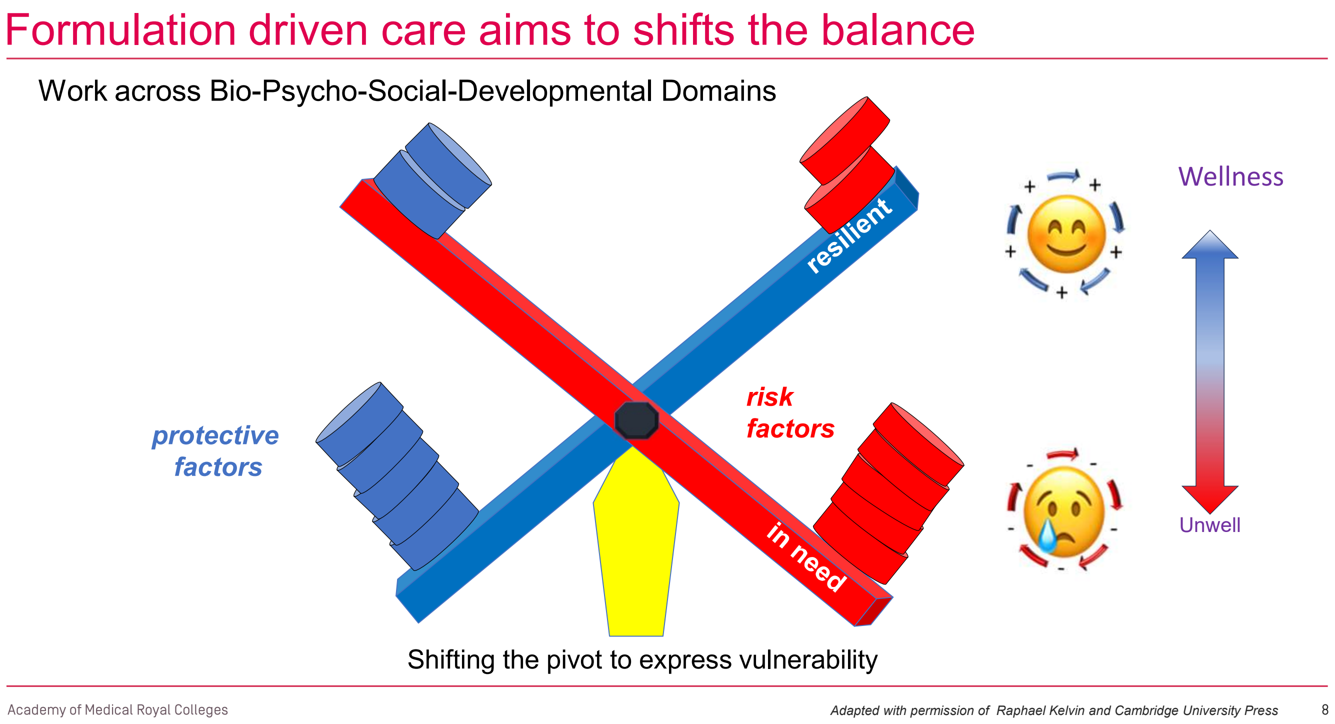


Formulation is the keystone of general mental health practice

- It's not just diagnosis
- It is an exercise in clinical reasoning: making collaborative judgements and treatment decisions. This includes, choice of interventions, who is involved, how, where and when.
- Think of being a clinician-scientist trying out the hypothesis derived together from the formulation.
- Thereafter review progress and amend the treatment path
  - including routine outcome measures (ROMs).

The formulation is the keystone of good general mental health practice and care. It's not just diagnosis. But if there are diagnoses to be made, they should be made. That is important. Because all of that helps in the comprehensive formulation. In delivering and developing your full understanding with the young person, and those around them, you're behaving as a clinician scientist, so that you use formulation as an exercise in clinical reasoning. How do you make collaborative judgements and treatments to get decisions together? How do you choose interventions together, so that you can decide who's going to do what, how they're going to do it, where and when the care is going to be delivered.

So using your expertise, listening to the person, listening to their family and their parents and potentially their school and other important informants, you're developing hypothesis or hypotheses about that young person and the difficulties and challenges that they have. And you're then going to test out your hypothesis of what you think is going to be the solution or solutions or what will make a difference going forwards. Review that progress on a regular basis as you do in good practice. Amend the treatment path according to the outcomes of the treatment that you see using outcome measures, ROMS and so forth. And feeding that back into an ongoing evolving and developing formulation.



Formulation driven care aims to shifts the balance

Work across Bio-Psycho-Social-Developmental Domains

Shifting the pivot to express vulnerability

Adapted with permission of Raphael Kelvin and Cambridge University Press

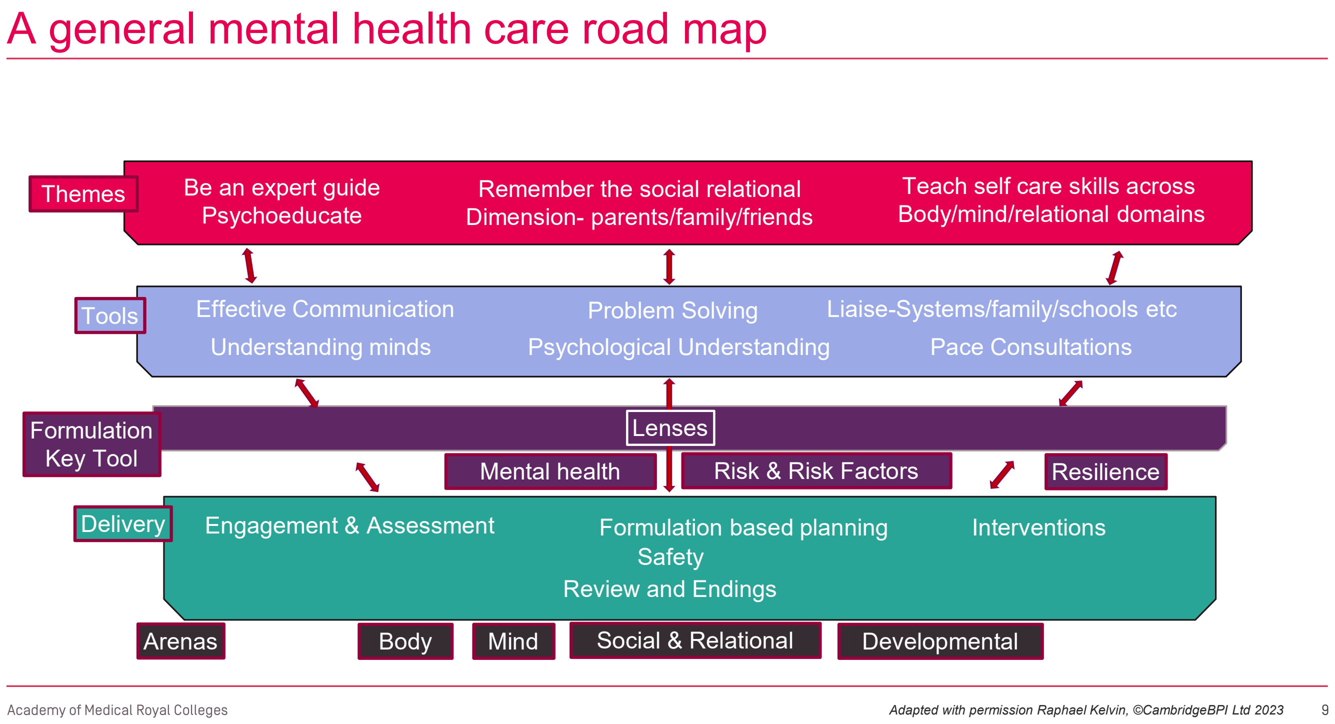
So your evolving formulation is the thing that will drive the care. In driving the care, we're aiming to shift the balance and here we can see the balance, see-saw moves on the far right hand side, from feeling poorly and not well, having mental disorder and disturbance through to feeling better through feeling well, and good mental health and well being.

So the graphic is really an illustration of the balance that we can see in the mind of our patients and the young people. And that we can help them to understand about themselves.

It's only an illustration, but it's potentially a useful one for framing this component, and this important structure of formulation.

So you see a seesaw, and you can see it on the one side, you have the red components, which are the risk factors, those factors and those things that pushed the young person towards mental disorder and mental illness. And on the other side, you see the blue components, which are protective factors, which are the young person's mind in the opposite direction towards health and towards wellness. And in the middle, you have a pivot, which expresses the vulnerability of a young person to the problems that you're seeing in front of you.

Vulnerability may be more or less for any one young person and therefore the pivot may move to the left or right for their particular seesaw. For some young people they may be more vulnerable to let's say, OCD or depression, or trauma in the context of their current life, than other young people, their pivot will be moving to the left. And what we want to do through our biopsychosocial developmental approach, driven through formulation is to move the seesaw towards wellness, towards building resilience. And therefore we need to have strategies in our formulation to diminish risk factors, and ideally to build protective factors and to help modify mind and mental state. So the whole seesaw is moving towards wellness away from illness.



A general mental health care road map

Themes

Be an expert guide
Psychoeducate

Remember the social relational
Dimension- parents/family/friends

Teach self care skills across
Body/mind/relational domains

Tools

Effective Communication
Understanding minds

Problem Solving
Psychological Understanding

Liaise-Systems/family/schools etc
Pace Consultations

Formulation Key Tool

Lenses

Mental health

Risk & Risk Factors

Resilience

Delivery

Engagement & Assessment

Formulation based planning
Safety
Review and Endings

Interventions

Arenas

Body

Mind

Social & Relational

Developmental

Academy of Medical Royal Colleges

Adapted with permission Raphael Kelvin, ©CambridgeBPI Ltd 2023

Been painting for you is a general mental Healthcare Roadmap, captured here

At the top, you can see broad themes in general mental health care engagement.

In the middle is the tools that we use, including, of course, the key one formulation. But of course, that formulation won't work without the components above it being delivered for care.

At the bottom, you can see delivery, which is the outcomes and the processes that will follow from your engagement, your assessment and your formulation.

Key themes are:

We are expert guides, to our children, young people, patients, and to their parents, and families and schools and so forth. And in being expert guides, we do so through a collaborative, a person centered approach. But don't lose sight of the expertise that you bring to the table. That's why the young person parents have sought you out and come to get help, they need help, in addition to what they've tried to do for themselves already.

We may provide psychological education, help them think about their social relational life, their parents and family and siblings and friends relationships. How they think about their own self and their identity and mind. And we may teach them skills across their care of themselves, how they care for their body, their mind, their relationships.

So you are the expert guide, providing this education and the support and this engagement. And you do that through your effective engagement and communication skills, make sure the consultation is manageable for each young person in their family. Pace it carefully. You are focusing on their mental state on their minds so that they are being understood and feel understood. And you can start to make a difference through that understanding. And you're solving issues and problems that you identify and that you capture inside the biopsychosocial formulation framework.

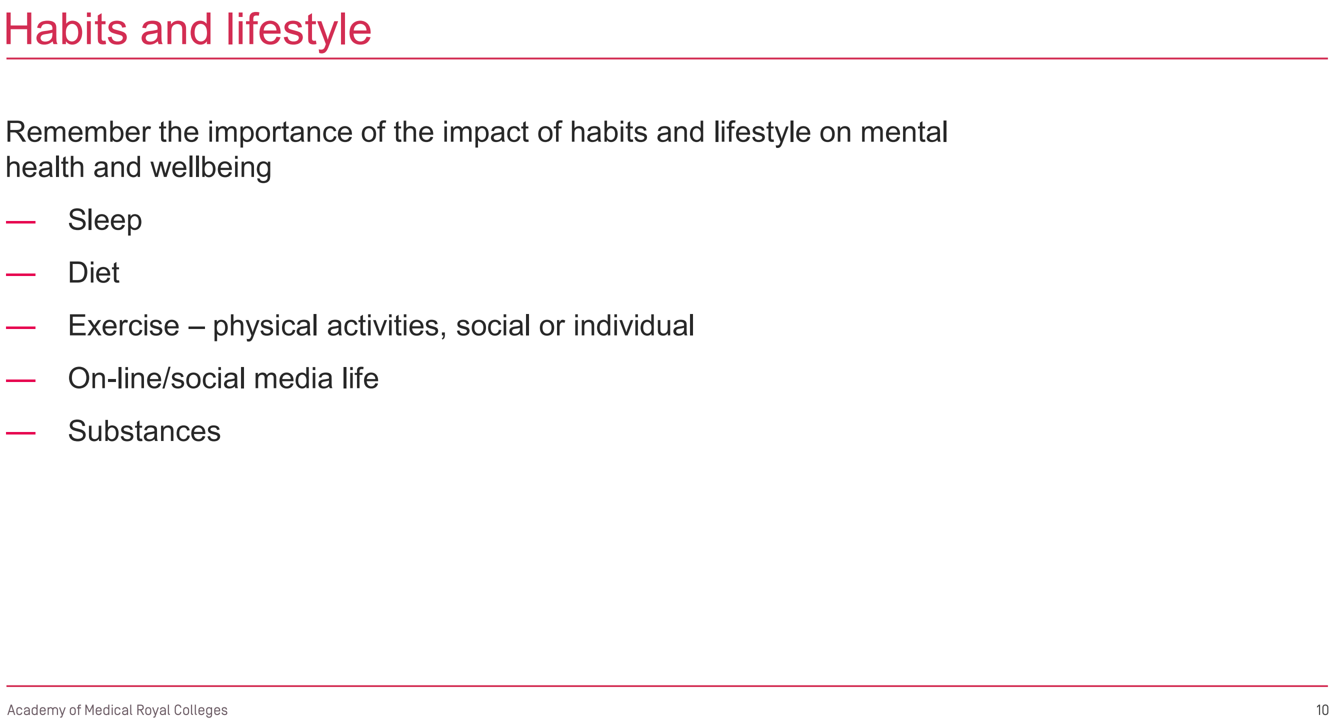
And you may then speak and liaise with important components of the child's life, obviously their family most immediately. But also with school and education and maybe social care and other community settings or even peers in certain circumstances. Obviously, with the appropriate agreements and consents and thinking through.

You do all this using your formulation as your driving key tool fed by all of this data and understanding and information. So the lenses of the formulation worked through the understanding of mind, mental state and mental health, through gathering in and understanding the risk factors and the risks and the safeguarding issues. Thinking all while about 'Who is this young person, what are their wishes and their hopes and their ambitions and their loves and their passions? Therefore, how can we build stepping stones towards resilience building.

And so that formulation leads to your delivery. Your delivery is supported through ongoing engagement and your assessment skills which carries on throughout any process of working with young people in mental health. That is then part of and leading to, the interventions that you've decided and agreed with the with the young person and or parents or carers, what you're going to be doing on how you're going to do that as safely as possible. Also how you're then going to review and bring things to a close.

All while you're thinking body, mind social, relational and developmental.

Developmental is very important for all young people of course, but for this group, we know that there is a high cooccurrence of example, autistic spectrum and ADHD.



Habits and lifestyle

Remember the importance of the impact of habits and lifestyle on mental health and wellbeing

- Sleep
- Diet
- Exercise – physical activities, social or individual
- On-line/social media life
- Substances

In your engagement and work with the young person, we want to remind you of some other key touch points here.

This is NOT every component of everything that you should be asking the young person during an assessment and engagement treatment package. Because of course, in a short slide set like this it is not possible, this is just reminding you of some, some key touchstones.

Remember the importance of habits and lifestyles and their impact on mental state.

- Sleep,
- diet,
- movement and exercise,
- online social media life
- substances.

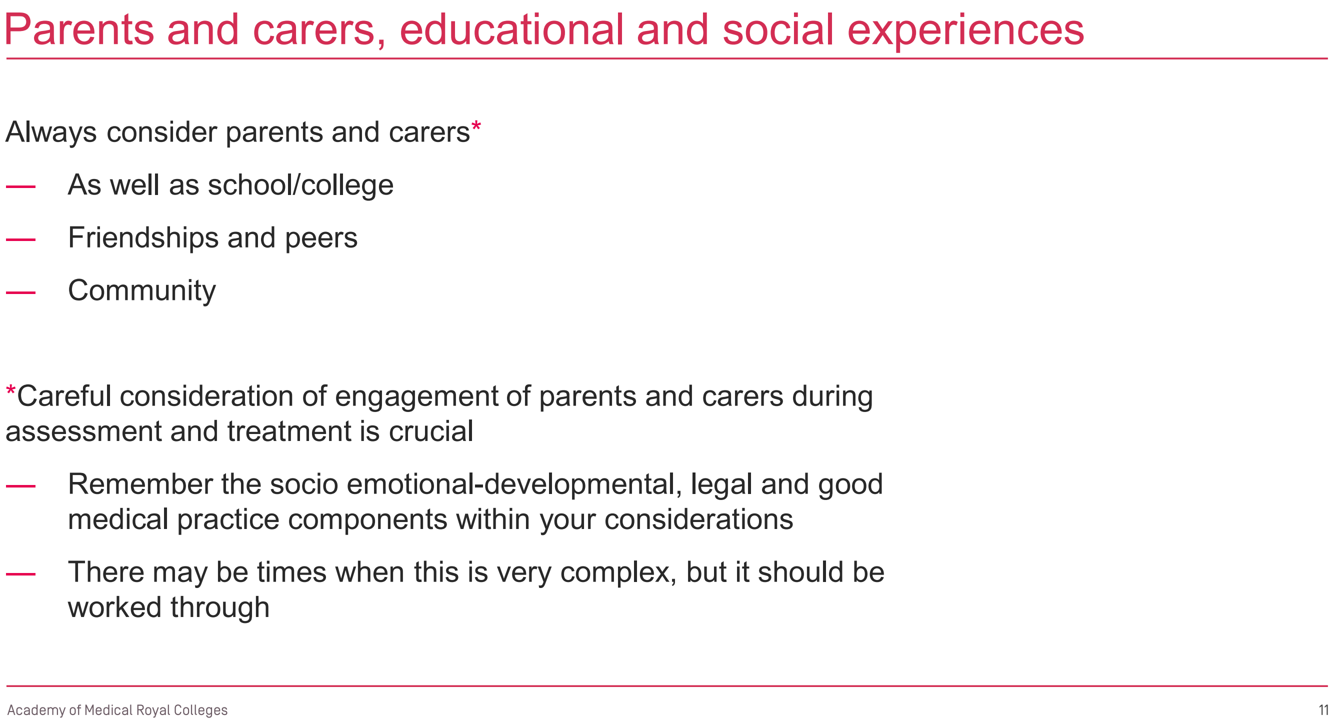
For a young person who's not sleeping or having dysregulated sleep - it's going to have impacts on mood and their mental state. Talk about it with the young person.

Same with diet. There is increasing evidence of the subtle impacts of different foodstuffs and different components of foods that impact for better and for worse, you should be thinking about that. But also the impact of eating habits, whether the young person has disordered eating, which can be relevant for a significant number of young people. And again, in this population disordered eating and eating disorders are somewhat more common.

Think about movement and exercise. There's increasing evidence of the importance of movement and exercise on the body on the mind, on inflammatory processes, which can have impacts on mental state on mood. But also, with exercise, think about the social and relational context and possibilities and how that may be important to make a difference for the young person. Maybe part of their passions or part of their interests to rekindle.

The online social media life of young person is of course important. It should be part of every good assessment. But with this group of young people, that may be even more important, given the evidence of impacts and influences, influencers and all sorts of other things that people can find online on and on social media. Of course, there are benefits, but there are risks too. Safeguarding issues can come to the fore as well. So this needs to be understood and needs to be engaged with.

Similarly, substances in another way. Obviously, substances can perturb and change mental states temporarily or even longer term. And you should have an understanding of what a young person is doing and how that may be impacting on what we see with the young person.



Parents and carers, educational and social experiences

Always consider parents and carers*

- As well as school/college
- Friendships and peers
- Community

*Careful consideration of engagement of parents and carers during assessment and treatment is crucial

- Remember the socio emotional-developmental, legal and good medical practice components within your considerations
- There may be times when this is very complex, but it should be worked through

Working with parents and carers working with education, settings, like schools and college, understanding and knowing and potentially even working with peer related relationships and friendships, understanding the young person in their community, is all standard and core components of good quality, mental health care that you will be thinking about for other young people.

Always consider this when you're working with young people in the new gender services.

Of course, in some situations, or some young people, this is more straightforward.

For others, it's a little bit tricky, and for some, it's very tricky. And of course, it depends who you're talking to within the social context of the young person, and who you want to communicate with.

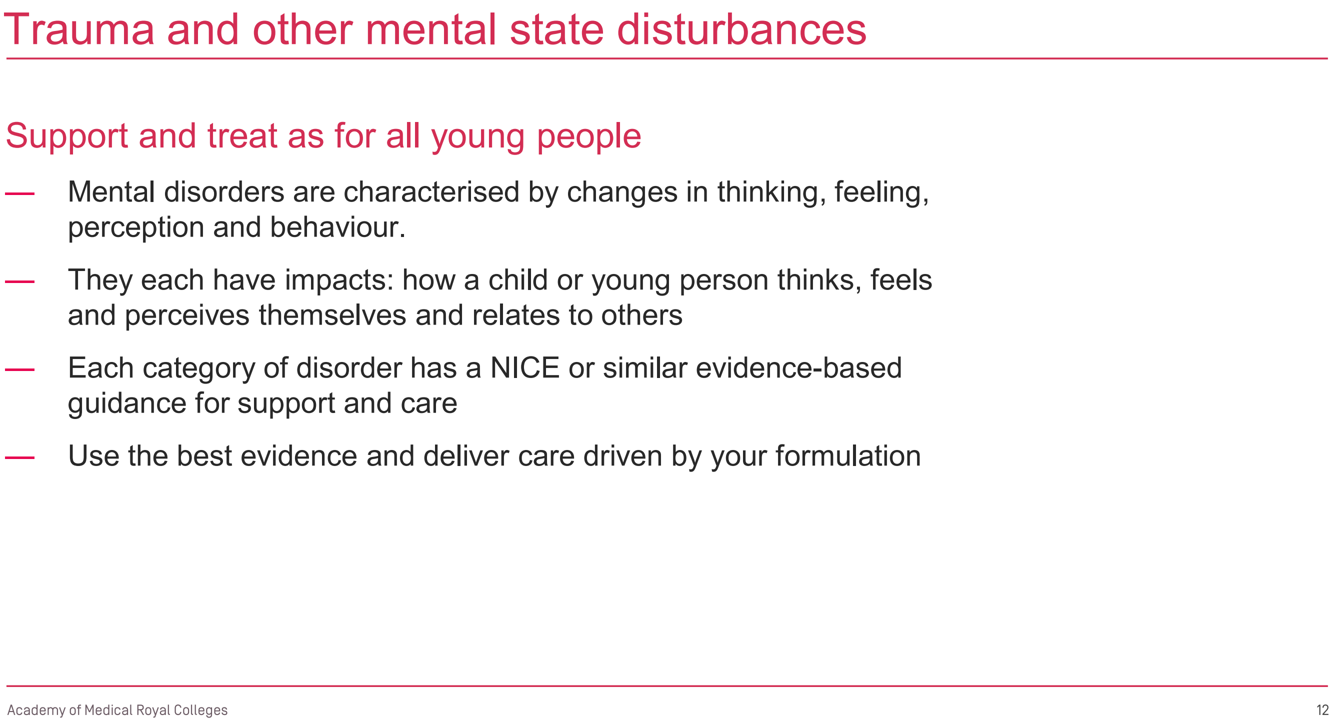
Very carefully and systematically work through the relationship between the young person and their parents. And ideally, whenever possible, have a collaborative working relationship with the parents and carers together with the young person in the processes and work that you're undertaking, so that you hear all of their opinions, hear all of their views, and where appropriate, you can share the processes of what you're doing through the formulation into the care going forwards.

With parents and carers specifically, this is of course crucial. We don't want you to be arbitrarily falling into the trap of excluding parents and carers from the care of the young person. Most of the time, it will be possible to work in this collaborative way. But sometimes, there are significant tensions and difficulties that you'll come up against. And in those contexts, still consider how you're going to be working with the young person and thinking about their family and their parents, given the importance, social, emotional, developmental context of a young person inside their family.

Work inside the boundaries of appropriate consents and confidentiality for the young person. Understand and be aware of the legal aspects of parental involvement and parental responsibility for their child. And all of that, obviously, will then fit inside good medical practice, and working with the young person, and important people who have responsibility in relation to them, their parents and or carers.

As this becomes increasingly complex or increasingly difficult, you need to take a steady and thoughtful approach to such work, and be guided by conversations with a senior colleagues and peers and supervision.

Always stop and pause and think - what is in the best interests of the child or the young person in front of you? How is talking to important others feeding into those best interests? And how can you enact that in the best interest of the child, bearing in mind what it is the child is willing to do with you, is willing to have shared, and how it is possible to share such information appropriately and safely.



Trauma and other mental state disturbances

Support and treat as for all young people

- Mental disorders are characterised by changes in thinking, feeling, perception and behaviour.
- They each have impacts: how a child or young person thinks, feels and perceives themselves and relates to others
- Each category of disorder has a NICE or similar evidence-based guidance for support and care
- Use the best evidence and deliver care driven by your formulation

Trauma and other mental state disturbances.

This is to highlight the high co-occurrence of other mental disturbances and disorders of young people presenting with gender identity issues. This should all be part of your broad formulation. And you should be considering how you can support and treat these mental disorders as appropriate to the evidence based guidance that exists for each of these different conditions.
There is extensive guidance now in NICE and similar evidence practice guidelines. The mental disorders that we're talking about like trauma, like autistic spectrum disorder like ADHD, depression, anxiety and eating problems co-occur quite frequently with young people presenting.
They all affect thinking or feeling and or perception and behaviour.
All of that is part of how the young person is in themselves in the clinic at this time. What is the direction of the relationship between these mental disorders and their impacts on mind and body and thinking and perception?

This is a complex area that we clearly need to understand better. But to make the assumption, that the person or parents or someone else may be pushing you towards, that all of their problems, all of the comorbidities all of the issues are best framed as being the consequence of gender identity queries is an inappropriate conclusion, given the poor state the knowledge that we have in relation to these co-occurrences.
You will be able to unpick this much better if you've done a chronological life course, informed by a psychosocial developmental formulation.

Begin to see where disorders and difficulties are arising, how they're impacting and where they're impacting. It is important to provide support and treatment for those co-occurring disorders, alongside anything else that you will be aiming to do with relation to the gender distress this young person has. And it may be for some young people, the outcome is that the treatment of the other disorders leads to changes in their sense of questioning and curiosity about their gender. For other young people, that may not be the case. And that is all part of a journey that will need to be taken for the variety of young people coming through the services.

Summary

- This short slide set should feel like very familiar territory
- This is the foundation of care
- Key components of this care are (too often) missing, or relegated from focus, yet being of considerable value and importance to future mental health and wellbeing
- The key message is to remember to deliver all components of good clinical care when working with children and young people and gender related questions and or distress

In summary, you have a short slide here, which should feel like very familiar territory. Providing and reminding you about foundations of good mental health care for young people.

To remind yourself that unfortunately, we see that more often than we want the key components of such good care, get missed, get relegated from focus or missed out in some way or another. And they can turn out to have been considerably important and valuable for the future of the young person. And therefore, we're then missing out those components and miss out on good care.

So deliver all the components of good care. All the things that you've been trained to do when working with children and young people with mental health related issues. Don't lose them, when you're now working with somebody with gender related distress.

References and links

NHS England MindEd eLearning: multiple modules at www.MindEd.org.uk covering:

- Formulation
- Managing common mental disorders including trauma and complex trauma, eating disorders and psychosis children and young people
- Attachment
- Child development
- Supporting Children and Young People With Gender-related Questions Or Distress And Their Sexual Orientation https://www.minded.org.uk/Component/Details/819516
  All 7 sessions cover topics most relevant to situations where a child or young person is relatively early in the care pathway, for example questioning and curious, or in earlier stages of gender identity distress and related care. They will nevertheless also be of interest to both professionals and parents and carers engaged in very specialised gender identity services and related care.

Ian Goodyer & Raphael Kelvin (2023). *The BPI Book. Brief Psychosocial Intervention for Adolescents: Keep it Simple; Do it Well.* Cambridge University Press https://doi.org/10.1017/9781108989442

Session 4

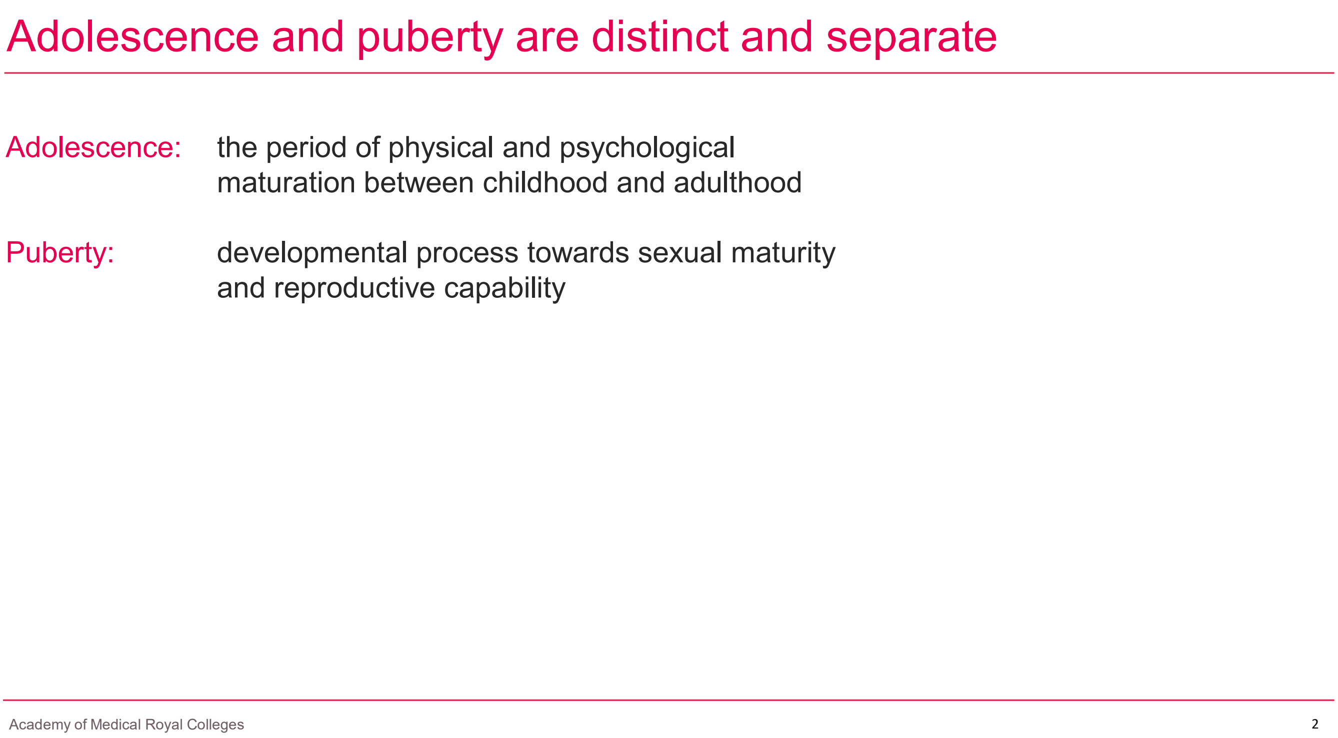
Academy of Medical Royal Colleges

Child and adolescent development and puberty

Academy of Medical Royal Colleges' induction to the children and young people's gender service

February 2024

Hello and welcome to another session as part of the induction programme to the children and young people's gender service



Adolescence and puberty are distinct and separate

Adolescence:	the period of physical and psychological maturation between childhood and adulthood
Puberty:	developmental process towards sexual maturity and reproductive capability

Adolescence and puberty have distinct meanings and can not be used interchangeably.

…

Adolescence - is the period of physical and psychological maturation between childhood and adulthood, extending to the mid twenties and expected to be complete by the age of twenty five

Puberty – is the process of gaining sexual function, capability and for most, fertility.

The age and timing of onset and completion of puberty is quite variable between sexes and within the same sex.

In birth registered girls the onset of puberty, as marked by breast budding (Breast stage two), occurs between the age of eight and thirteen years old.

Periods - or menarche - typically occur between the ages of ten and fifteen years old.

In birth registered boys the onset of puberty , marked by a testicular volume of 4mls or above, occurs between the ages of nine and fourteen years old

These definitions are helpful for clinical practice to decide if puberty is too early or late and for staging pubertal development.

precocious puberty is defined in birth registered girls as Breast stage two or breast budding starting before the age of eight years; and in birth registered boys, testicular volume ≥ 4mls before the age of nine years

delayed puberty is defined as breast stage two or breast budding after thirteen years in a birth registered girl or a testicular volume of less than 4mls after fourteen years in a birth registered boy

Physiology of puberty

Hypothalamus prompted to release GnRH

↓

GnRH stimulates pituitary gland to produce hormone FSH and LH

↓

These signal the gonads to release sex hormones (testosterone or oestrogen)

Actions of sex hormones

Growth Spurt

Optimisation of peak bone mass

Development of secondary sexual characteristics

Reproductive maturation

Hormonal environment for neurodevelopment

Kisspeptin is a neuropeptide synthesised in the hypothalamus and has a key role in the initiation of puberty.

Kisspeptin stimulates hypothalamic neurones to release Gonadotropin releasing hormone, this is known as GnRH.

GnRH stimulates the pituitary gland to produce follicle stimulating hormone and luteinising hormone, to enable gonadal function and the release of sex hormones, androgen and oestrogen.

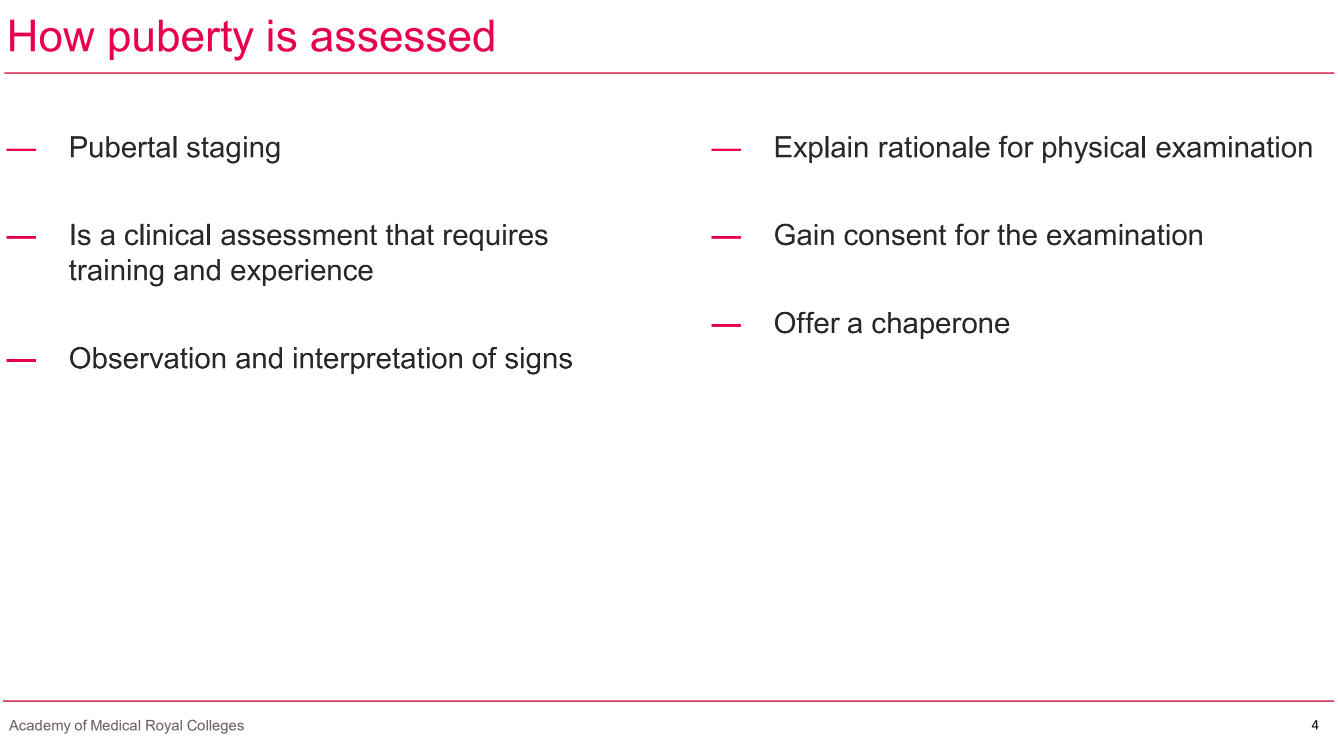
The gonads are ovaries in birth registered females, and testes in birth registered males.

Differences in sex development (sometimes called intersex) or variations in sex characteristics can also occur and prompt rare variations in sex development pathways.

Sex hormones promote growth and bone mass, physical sexual and reproductive maturity and fertility, and the development of secondary sex characteristics. These are defined as related to or derived from biological sex but may not directly be part of its reproductive system.

In humans, these characteristics typically start to appear during puberty and include breast development, voice changes, under-arm and pubertal hair, and facial hair.

Puberty also produces the hormonal environment for brain maturation and neurocognitive development .



How puberty is assessed

- Pubertal staging
- Is a clinical assessment that requires training and experience
- Observation and interpretation of signs
- Explain rationale for physical examination
- Gain consent for the examination
- Offer a chaperone

Assessment of puberty is a clinical assessment that requires training and experience.

Before the examination, the child must understand the reasons for the examination, this includes why and how the information gained will inform the consultation and/or their care.

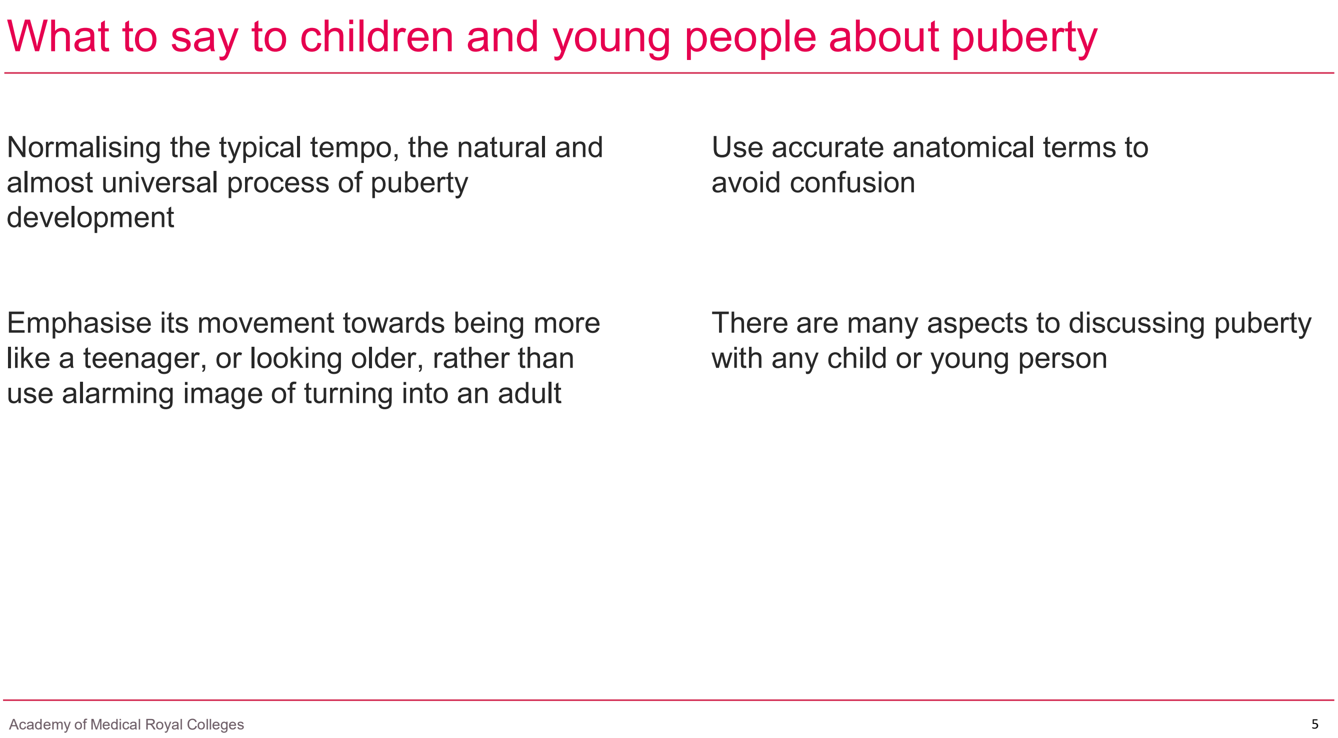
The patient must consent to examination after this information is given - and they must be offered a chaperone, this and the name of the chaperone must be documented in the notes.

It’s possible for secondary sex characteristics such as breast development and pubertal hair growth to develop at different rates making staging an interpretive process.

Some conditions or their treatment can affect the tempo of puberty or the typical sequencing of events.

While self reporting can be useful or an interesting consideration of how a child is understood within the family, pubertal staging should not be made on self or parental reporting alone, as patient expectation and vocabulary limitations can result in misleading conclusions about the child’s pubertal development.

When discussing or undertaking pubertal staging pubertal staging the use of correct anatomical labels such as penis, scrotum, clitoris, labia, breasts, and pubic hair should be used, to avoid miscommunication about body changes. Pictures with labels can sometimes help avoid misunderstandings.



What to say to children and young people about puberty

Normalising the typical tempo, the natural and almost universal process of puberty development

Emphasise its movement towards being more like a teenager, or looking older, rather than use alarming image of turning into an adult

Use accurate anatomical terms to avoid confusion

There are many aspects to discussing puberty with any child or young person

Puberty is driven by sex hormones, with girls and boys having both oestrogen and testosterone. In discussing pubertal changes, anticipated or current, clinicians should use accurate anatomical terms to avoid confusion. If a patient negotiates preferred terms for the conversation, periodically refer back to their actual meaning.

Talking to young people about puberty and sexual development can be challenging. Clinicians who work with children and young people will develop different ways of approaching this. One example is the HEEADSSS vulnerability screening tool which is widely used by paediatricians working with twelve to twenty five year olds.

We can therefore expect clinicians in paediatric and children and young people’s mental health settings to develop skills in talking to children and young people about their emerging developing sexuality, and any sexual experiences they may have had.

Emotional Aspects of puberty:
Puberty involves emotional and social changes. Some people experience strong feelings, often described colloquially as ‘mood swings’. Self-care, self-soothing and other coping strategies can be helpful for managing emotions.

Privacy during puberty:

Personal boundaries and the importance of respecting others’ boundaries.

Normalise differences in puberty and the tempo of puberty:
Puberty is an expected part of human development with varying timing.

Highlight Body Positivity:
Everyone's body is unique and develops at its own pace in different people. Self-acceptance and appreciation for one's own body is a task for everyone.

Discussions about Puberty should start early:
Discuss the human body, and the concept of growth and development at an early age. This normalising foundational work might occur in families and in school lessons about personal, social and health issues. Language will need to be suitable for the child's age and comprehension level. Use simple, accurate language to explain the basic concepts.

Encourage the child’s reflection and discussion:
It's okay to talk about feelings and concerns.

Be Accurate:
Avoid exaggeration or minimising the experiences associated with puberty.

Resources:
If advising parents and carers to use age-appropriate books, diagrams, or videos only recommend examples that reinforce the accurate information given in the service. Check all links before recommending websites or on line resources.

Identity development

Self-concept formation

Early childhood: basic sense of ‘me’

Middle childhood: me, others, groups

Further socialisation and influence of others

Family

Peers

Cultural and ethnic Identity

Background: Significantly contribute to identity formation

Cultural socialisation: Traditions, language, and practices

Digital identity

Can be less restrained, yet become integrated into one’s identity

Identity development is lifelong and there are key changes during puberty that influence identity.

Identity development involves the formation of a sense of self, including one's values, beliefs, interests, and personal characteristics.

Here are key factors influencing identity development in children and adolescents:

In Early Childhood - a child will start to have a basic sense of self, which will be influenced by interactions with caregivers, family members, and peers. They typically start to recognize their own abilities, preferences, and physical characteristics including sex and gender.

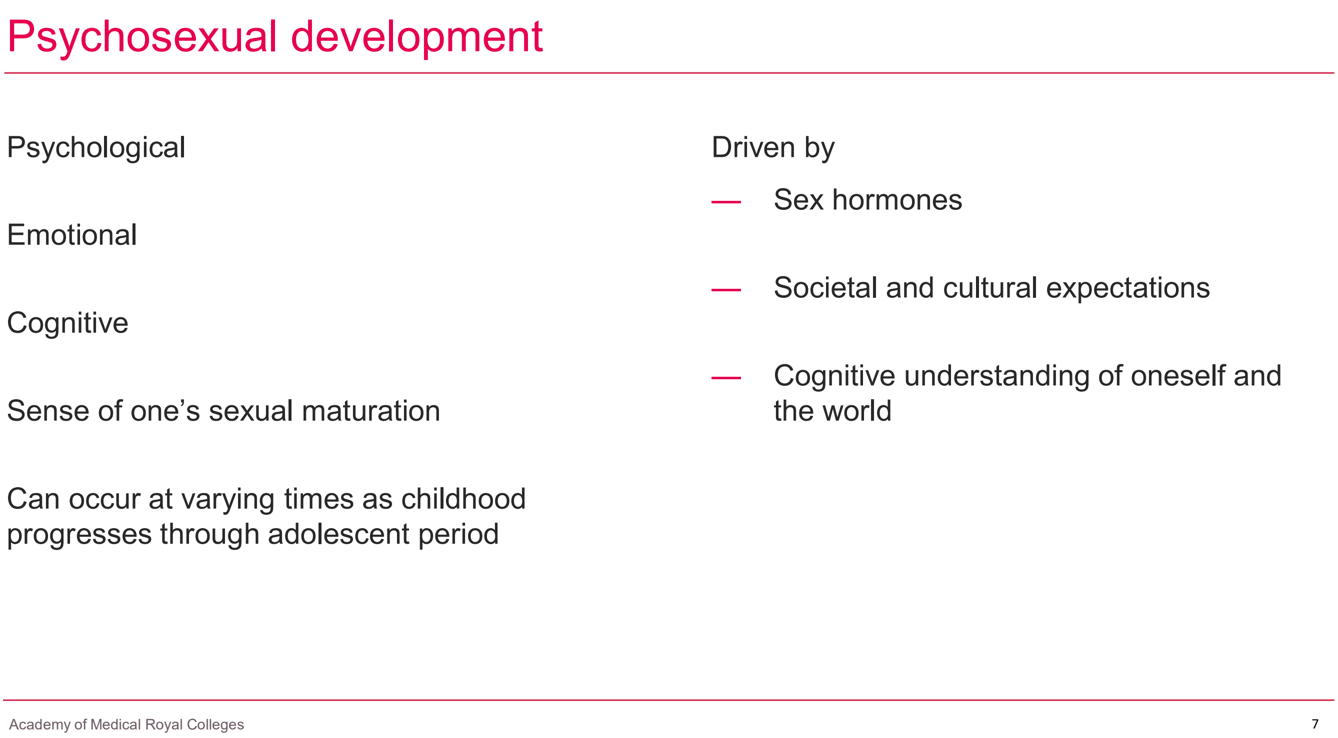
In Middle Childhood - they make more comparisons of themselves to others, I can do that , she can’t, she’s better than me….and can identify with certain social groups or roles, such as, ‘we do this at my school’.

Socialisation is Influenced by others:

Family influence can come via values, beliefs, and cultural norms. Whereas, at adolescence, peers relationships can *especially* impact identity through shared interests, values, and experiences.
This includes Cultural and Ethnic Identity socialisation and identity formation

Cultural influences significantly contribute to identity formation. Children and adolescents explore and develop a sense of belonging to a particular cultural or ethnic group via exposure to cultural traditions, language, and practices shapes cultural identity

Online expression can be a significant part of life for a person of any age. A digital identity or identities can develop amidst greater freedom of expression and experimentation. This can allow people to develop a sense of themselves that could be an enhanced or extreme versions of themselves, these can sometimes be incorporated into their core sense of who they are and influence their broader identity.



Psychosexual development

Psychological

Emotional

Cognitive

Sense of one’s sexual maturation

Can occur at varying times as childhood progresses through adolescent period

Driven by

- Sex hormones
- Societal and cultural expectations
- Cognitive understanding of oneself and the world

An aspect of development that keenly links child and adolescent development, puberty and identity formation is the development of self-knowledge regarding ones emerging developing or shifting sexuality.

Psychosexual development refers to the psychological and emotional aspects of sexual maturation and identity formation.

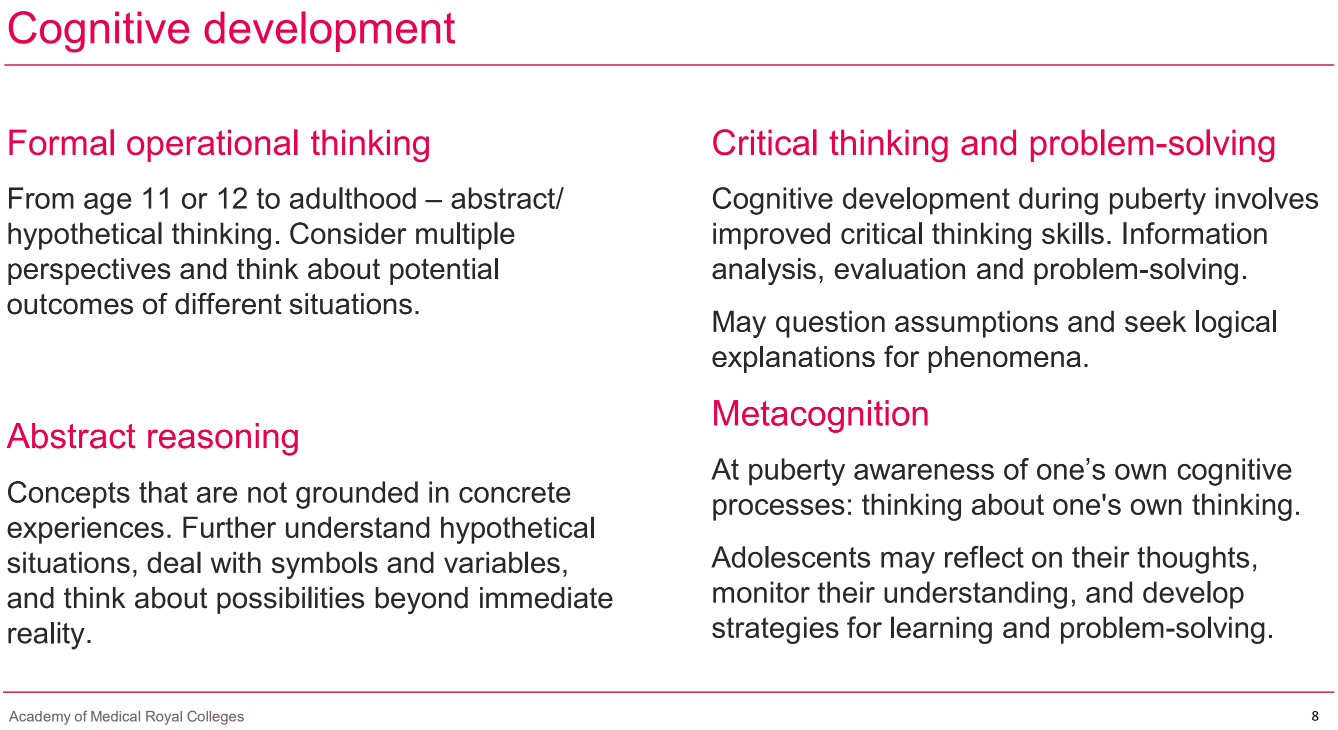
Developmentalists have tried to characterise and explain the varying trajectories of a young person moving from a latency where relationships desire may be based on a pull towards close physical proximity or emotional intimacy, to those which can involve sexual thoughts, expression or reciprocity.

The tempo of this process varies greatly.

Although sexual latency is the expected state of sexual development for children, they still need knowledge to help make sense of the world.

A socio-cultural trend for labelling the sexual identity of young people may be confusing for a child, or be experienced as stressful pressure.

A romantic fondness and desire for closeness with an intimate confidante may be an early expression of future sexuality, but labelling this as sexual partner-preference or asexuality (briefly put, being without a sexuality) can be problematic and may close down a child’s thinking.



Cognitive development

Formal operational thinking

From age 11 or 12 to adulthood – abstract/ hypothetical thinking. Consider multiple perspectives and think about potential outcomes of different situations.

Abstract reasoning

Concepts that are not grounded in concrete experiences. Further understand hypothetical situations, deal with symbols and variables, and think about possibilities beyond immediate reality.

Critical thinking and problem-solving

Cognitive development during puberty involves improved critical thinking skills. Information analysis, evaluation and problem-solving.

May question assumptions and seek logical explanations for phenomena.

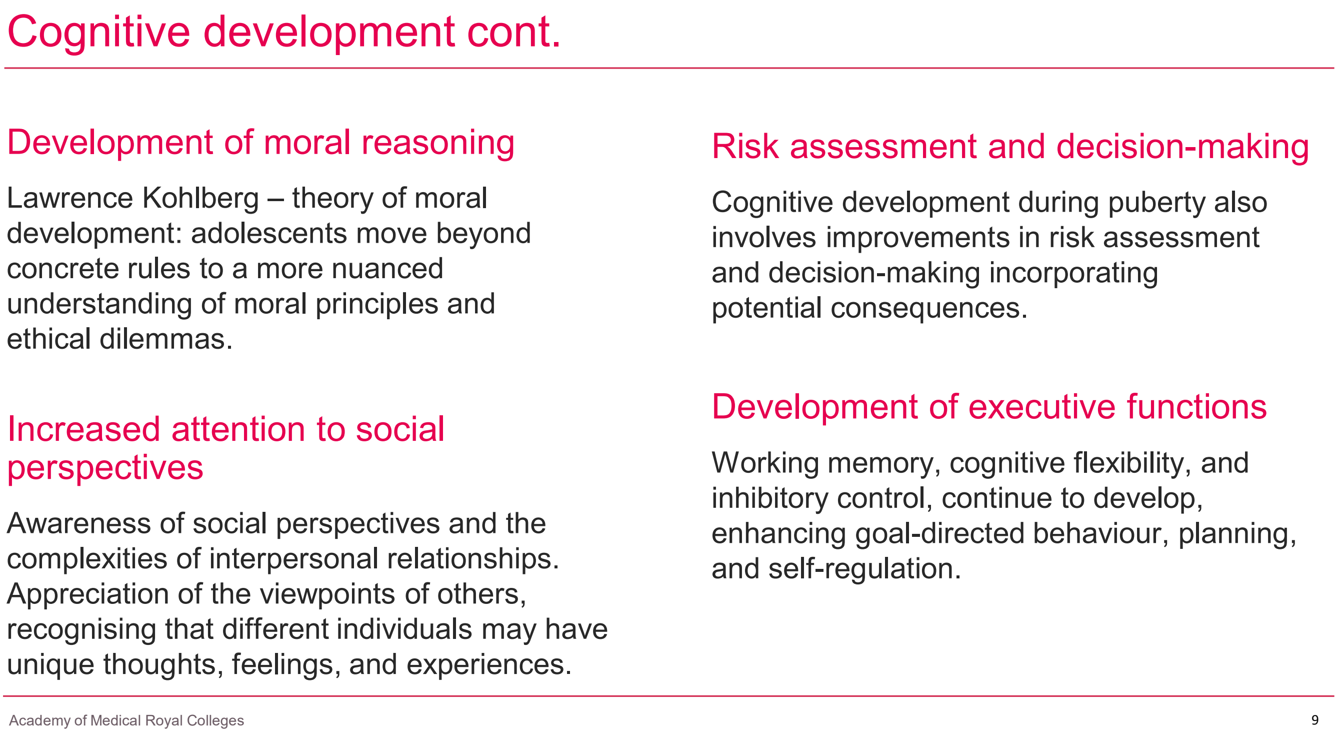
Metacognition

At puberty awareness of one’s own cognitive processes: thinking about one's own thinking.

Adolescents may reflect on their thoughts, monitor their understanding, and develop strategies for learning and problem-solving.

Cognitive development is a crucial process throughout childhood and adolescence. For completeness we have included the wide-ranging cognitive development that can occur during adolescence. Which will be covered in more detail in other sessions.

The important message here, is that children and young people are undergoing processes of development with a varying pace.



Cognitive development cont.

Development of moral reasoning

Lawrence Kohlberg – theory of moral development: adolescents move beyond concrete rules to a more nuanced understanding of moral principles and ethical dilemmas.

Increased attention to social perspectives

Awareness of social perspectives and the complexities of interpersonal relationships. Appreciation of the viewpoints of others, recognising that different individuals may have unique thoughts, feelings, and experiences.

Risk assessment and decision-making

Cognitive development during puberty also involves improvements in risk assessment and decision-making incorporating potential consequences.

Development of executive functions

Working memory, cognitive flexibility, and inhibitory control, continue to develop, enhancing goal-directed behaviour, planning, and self-regulation.

Children and young people can not be assumed to be wholly competent thinkers or decision makers beyond the capacity of their cognitive development.

Some children and young people have greater self awareness, self knowledge and thinking capabilities than others. These factors may be influenced by trauma, personal growth or environmental exposure to relevant knowledge or experiences.

Neurocognitive development

Behavioural and cognitive executive functions

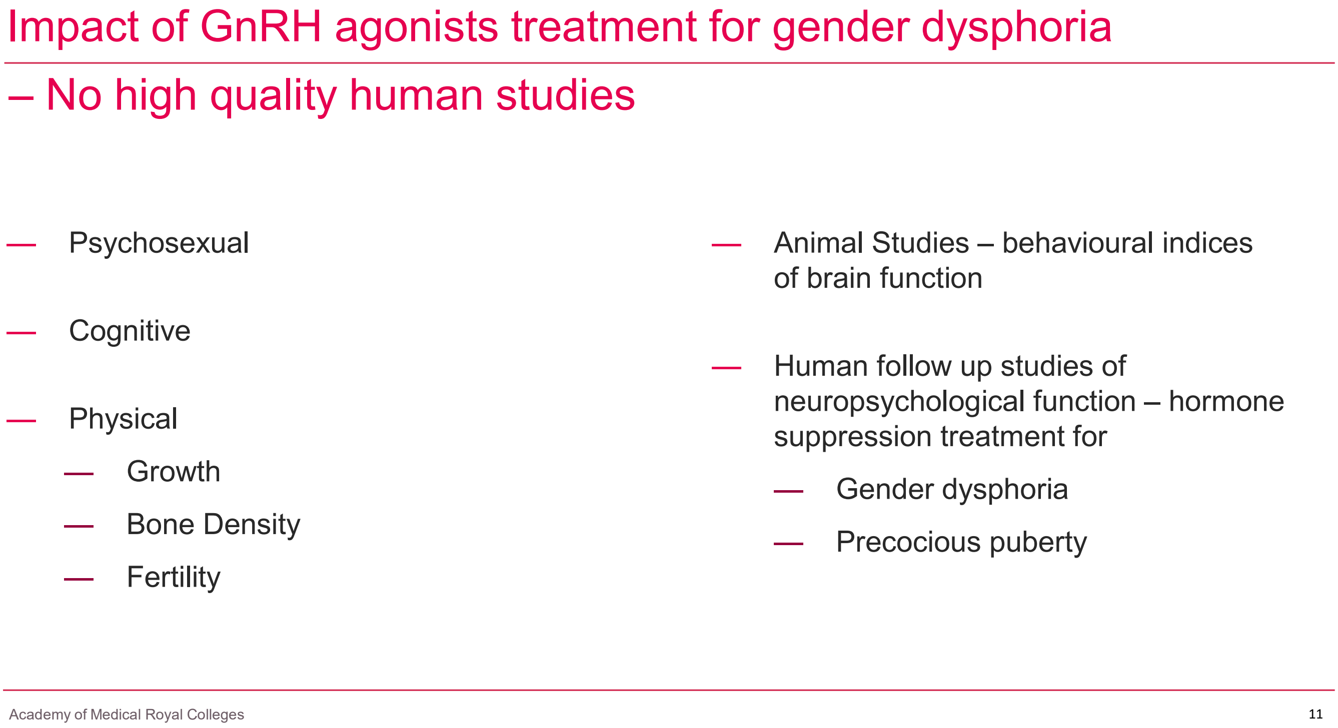
Social cognition

The brain requires a specific input to allow for the optimal development of a particular function

Internal	e.g. hormonal or nutritional state
External	e.g. exposure to language or visual stimuli

Neurocognitive development is an aspect of cognitive development that is particularity pertinent due to the vast development during the adolescent period and the suggested involvement of puberty. Periods or windows of plasticity for neurodevelopment occur throughout development .

Sensory pathways (vision, hearing) are prioritised in infancy, followed by motor and language functions in early childhood and executive functions (behavioural and cognitive) and social cognition in adolescence. Changes to the amygdala occur due to an extensive period of pruning that is thought to be driven by both internal and external environments including puberty, trauma and interaction with the world.



Impact of GnRH agonists treatment for gender dysphoria – No high quality human studies

- Psychosexual
- Cognitive
- Physical
    - Growth
    - Bone Density
    - Fertility
- Animal Studies – behavioural indices of brain function
- Human follow up studies of neuropsychological function – hormone suppression treatment for
    - Gender dysphoria
    - Precocious puberty

TREATMENT WITH Gonadotropin releasing hormone (GnRH) agonists cause inhibition of oestrogen and androgen synthesis of sex hormone secretion.

This puts on hold the biological and psychosocial development that is driven by sex hormones. This inhibits the developmental processes described previously, as these would ordinarily be driven by sex hormones during puberty and beyond.

Acknowledging that some cognitive and psychosexual development is externally driven, we do not know the extent to which an *absence* of sex hormones halts "brain maturity" and in doing so impacts cognition including social cognition and neurodevelopment.

Animal studies and human follow up studies have made early attempts to study this. Animal studies including birth multiples have reported impacts of pharmacological puberty suppression on indicators of behavioural function. Results indicate that treatment with GnRHa has a detrimental impact on learning and the development of social behaviours and responses to stress in mammals. In male sheep, impairments in spatial memory associated with the treatment were not fully reversed following discontinuation of treatment and reductions in brain volume were seen.

Human studies that have reported neuropsychological function following the administration of medications to suppress puberty young people. Two studies reported the impact of treatment with GnHRa in young people with precocious puberty, and four reported neuropsychological test performance in people treated for gender dysphoria. One of these studies was a single case study that detailed a loss in IQ and working memory. In a group study of birth registered girls treated for early puberty statistically significant loss was seen in both performance IQ and full scale IQ,.

There are no high-quality studies assessing puberty suppression USING GnRHa in adolescents experiencing gender dysphoria/incongruence. Although there are a few moderate-quality studies using an appropriate study design, no conclusions can currently be drawn about the impact on mental and psychosocial health, gender dysphoria, or cognitive development. Without this we do not know the extent to which absence of sex hormones at a critical period of brain development might affect cognitive function.

Studies do indicate that bone health and height may be compromised during treatment.

Key points

- Adolescence and puberty are distinct and separate
- Pubertal assessment/staging is by a trained and experienced clinician
- Sex hormones promote growth and bone mass, physical sexual and reproductive maturity and fertility
- Identity forms via interaction between individual and environment, with puberty being a key factor
- The role of sex hormones in the crucial period of neuroplasticity that occurs in adolescence is not known
- There are no high-quality studies assessing puberty suppression in adolescents experiencing gender dysphoria/incongruence.

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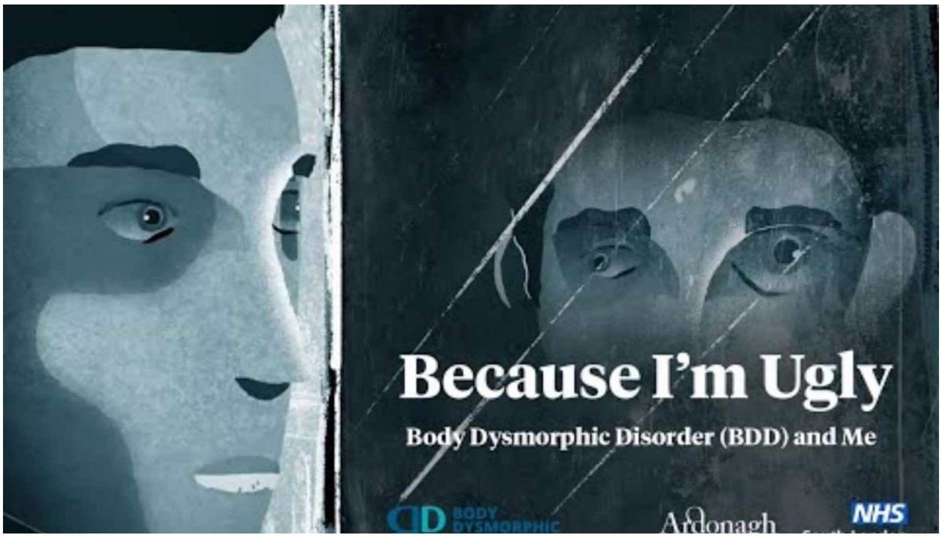
Session 5

Recognising and understanding Body Dysmorphic Disorder (BDD)

Academy of Medical Royal Colleges' induction to the children and young people's gender service

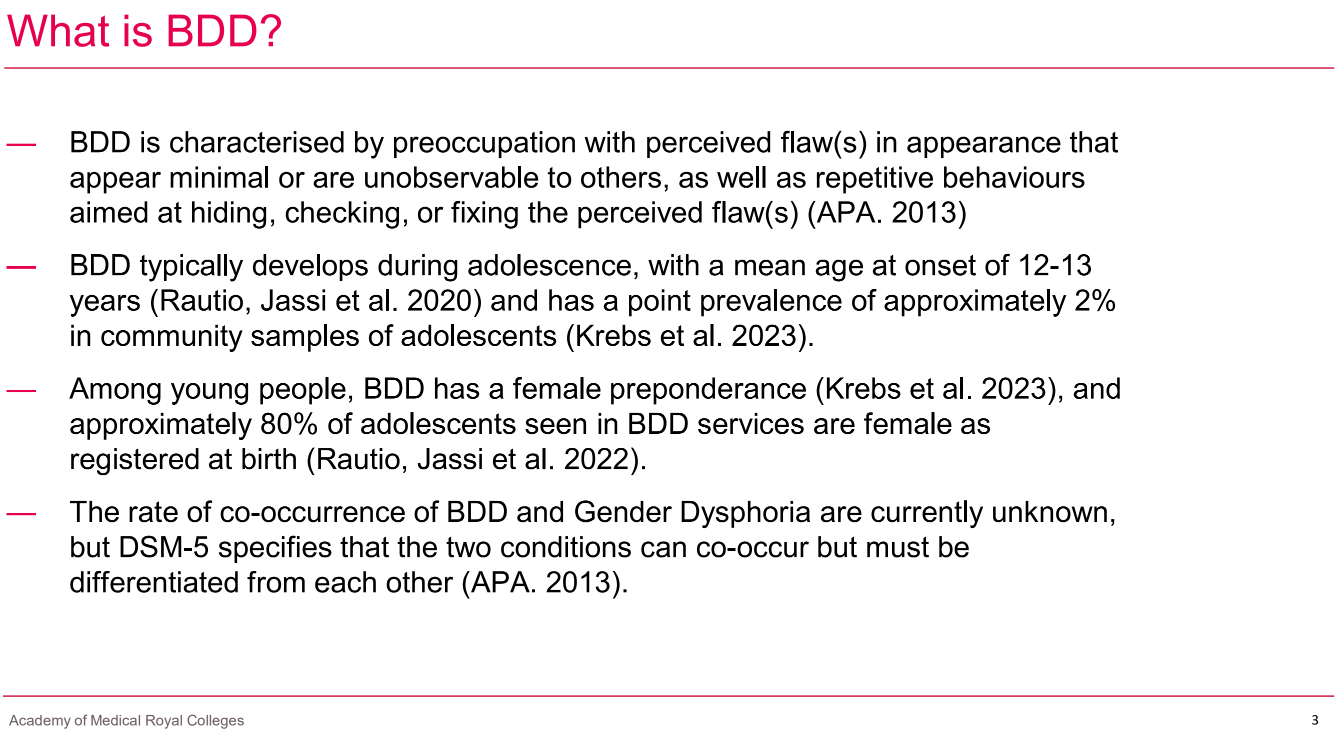
February 2024

What is Body Dysmorphic Disorder (BDD)?



Source: 'Because I'm Ugly: Body Dysmorphic Disorder (BDD) and me.' The BDD Foundation

Watch video



What is BDD?

- BDD is characterised by preoccupation with perceived flaw(s) in appearance that appear minimal or are unobservable to others, as well as repetitive behaviours aimed at hiding, checking, or fixing the perceived flaw(s) (APA. 2013)
- BDD typically develops during adolescence, with a mean age at onset of 12-13 years (Rautio, Jassi et al. 2020) and has a point prevalence of approximately 2% in community samples of adolescents (Krebs et al. 2023).
- Among young people, BDD has a female preponderance (Krebs et al. 2023), and approximately 80% of adolescents seen in BDD services are female as registered at birth (Rautio, Jassi et al. 2022).
- The rate of co-occurrence of BDD and Gender Dysphoria are currently unknown, but DSM-5 specifies that the two conditions can co-occur but must be differentiated from each other (APA. 2013).

BDD is a condition where sufferers perceive there is one or more flaw in their physical appearance, which to others appears slight or non-existent. They are preoccupied by this appearance concern.

This leads to engagement in a range of repetitive behaviours aimed at hiding or fixing the perceived flaw e.g. checking, camouflaging parts of body e.g. by wearing garments to cover or make-up, seeking cosmetic procedures to fix the flaws.

The combination of the preoccupation and repetitive behaviours must cause distress and interference to reach diagnostic threshold.

The age on onset is typically in adolescence, with a naturalistic study of 172 young people reporting an age of onset of 12-13 years old

In the UK’s largest epidemiological study to date, the point prevalence was confirmed at 2%

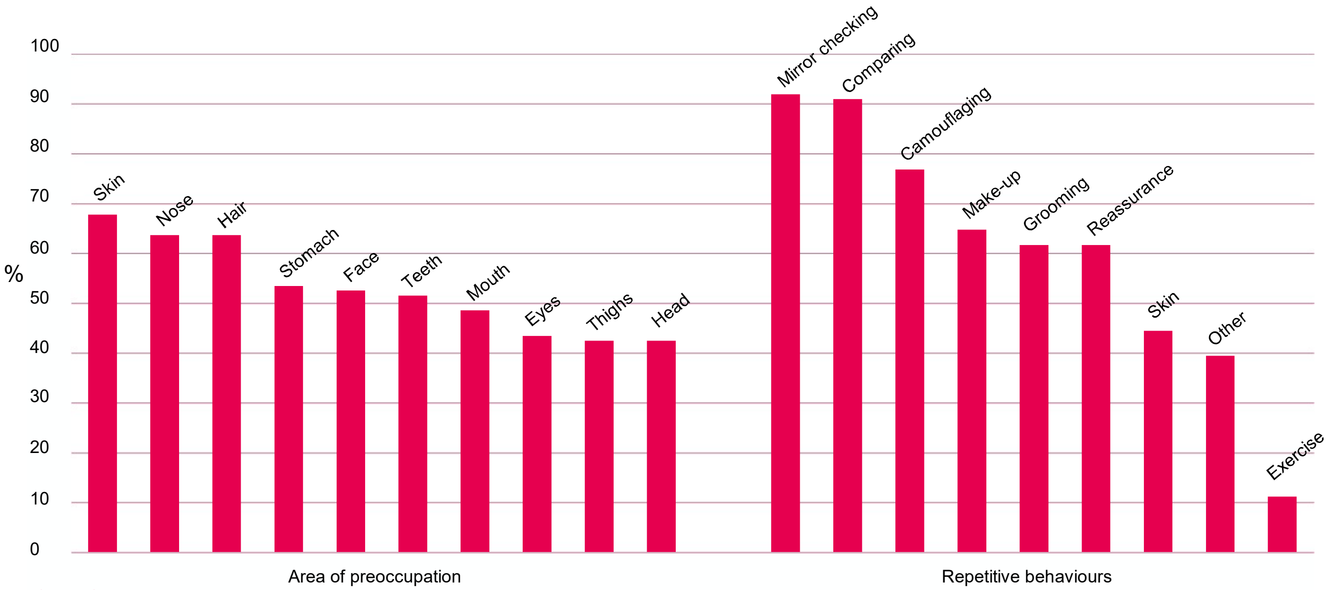
The rates of cooccurrence of BDD and Gender Dysphoria are unknown

There tends to a female as registered at birth preponderance in adolescence, but this tends to balance out in adulthood with the balance being more evenly split between males registered at birth and females registered at birth.

Of note, with BDD, it is rare for (young people) to present to mental health services querying if they have BDD. As it is a condition where they believe there is something wrong with their physical appearance, they will often be presenting to services where this can be changed e.g. GP, cosmetic settings. Just over half have poor or absent insight into their condition. Sometimes appearance worries dismissed in adolescents as normal. There are multiple reasons they may come to mental health services attention, including:

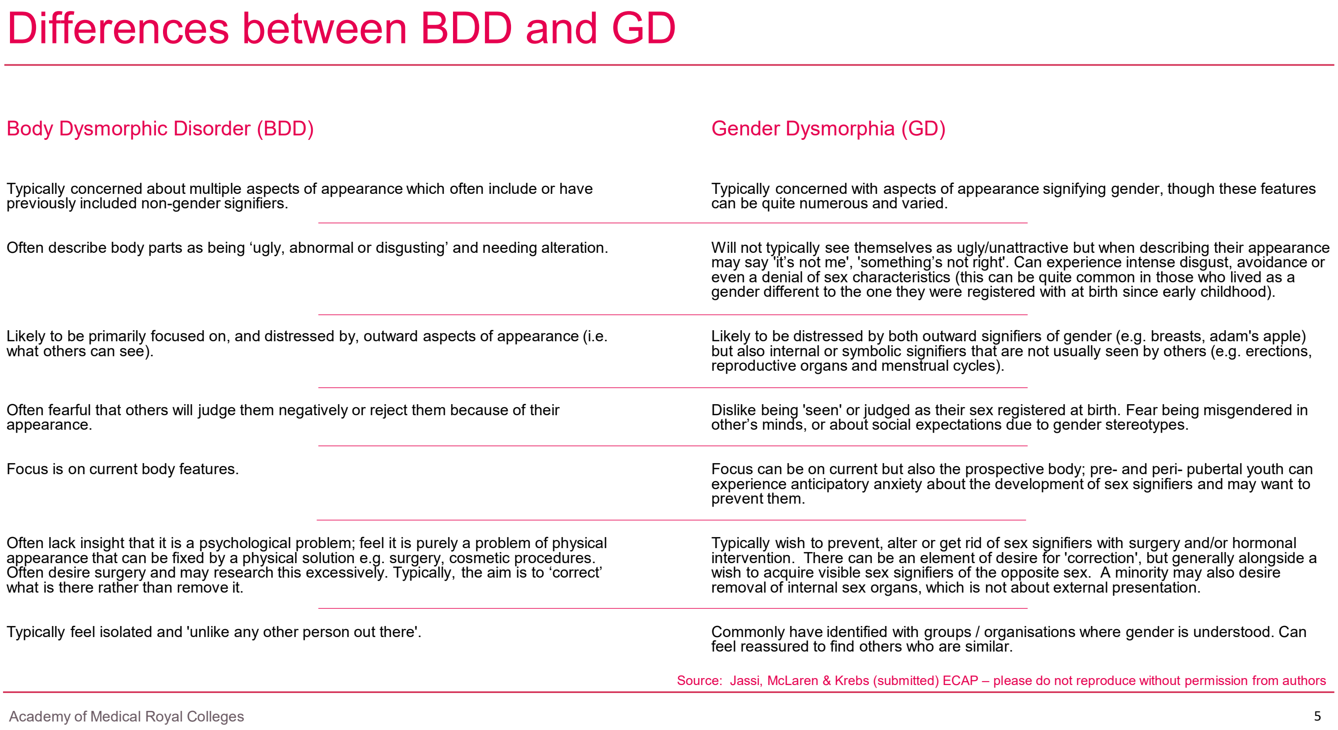
- Risk (59% past/current suicidal ideation, 1 in 10 in our clinic make attempt on life)
- Not attending school (third not attending school at all)
- Treated for social anxiety, depression etc and not got better
- Attempted self surgery

Appearance concerns and behaviours in young people with BDD



(N=99)

Source: Rautio, Jassi, Krebs et al., 2020, Euro Child and Adole Psychia.



Differences between BDD and GD

Body Dysmorphic Disorder (BDD)	Gender Dysmorphia (GD)
Typically concerned about multiple aspects of appearance which often include or have previously included non-gender signifiers.	Typically concerned with aspects of appearance signifying gender, though these features can be quite numerous and varied.
Often describe body parts as being ‘ugly, abnormal or disgusting’ and needing alteration.	Will not typically see themselves as ugly/unattractive but when describing their appearance may say 'it’s not me', 'something’s not right'. Can experience intense disgust, avoidance or even a denial of sex characteristics (this can be quite common in those who lived as a gender different to the one they were registered with at birth since early childhood).
Likely to be primarily focused on, and distressed by, outward aspects of appearance (i.e. what others can see).	Likely to be distressed by both outward signifiers of gender (e.g. breasts, adam's apple) but also internal or symbolic signifiers that are not usually seen by others (e.g. erections, reproductive organs and menstrual cycles).
Often fearful that others will judge them negatively or reject them because of their appearance.	Dislike being 'seen' or judged as their sex registered at birth. Fear being misgendered in other’s minds, or about social expectations due to gender stereotypes.
Focus is on current body features.	Focus can be on current but also the prospective body; pre- and peri- pubertal youth can experience anticipatory anxiety about the development of sex signifiers and may want to prevent them.
Often lack insight that it is a psychological problem; feel it is purely a problem of physical appearance that can be fixed by a physical solution e.g. surgery, cosmetic procedures. Often desire surgery and may research this excessively. Typically, the aim is to ‘correct’ what is there rather than remove it.	Typically wish to prevent, alter or get rid of sex signifiers with surgery and/or hormonal intervention. There can be an element of desire for 'correction', but generally alongside a wish to acquire visible sex signifiers of the opposite sex. A minority may also desire removal of internal sex organs, which is not about external presentation.
Typically feel isolated and 'unlike any other person out there'.	Commonly have identified with groups / organisations where gender is understood. Can feel reassured to find others who are similar.

Source: Jassi, McLaren & Krebs (submitted) ECAP – please do not reproduce without permission from authors

Body dysmorphic disorder (BDD) and gender dysphoria (GD) share body dissatisfaction as a core feature and are often associated with a strong desire to alter body features through cosmetic and medical procedures (Kohls & Roessner, 2003).

Read through content of slide and expand points

Treatment for BDD

NICE National Institute for Health and Care Excellence

- Cognitive behavioural therapy (CBT) including exposure with response prevention.
- SSRI medications
- Good evidence to date – naturalistic study with multimodal treatment (CBT with/out medication), 79% responded to treatment and 59% were in remission. 12 month follow-up – 82% response rate and 64% remission (Rautio. Gumpert, Jassi et al. 2022)
- Cosmetic treatment is not recommended (Bowyer et al. 2016)
- If BDD and GD co-occur, be guided by formulation in terms of priorities for treatment

CBT with or without SSRI medication is recommended by NICE

CBT should include exposure with response prevention (explain what that is along with other phases of treatment)

Bowyer et al., (2016): Critical review of the literature discussing outcomes of cosmetic treatment for individuals with BDD

There is a literature on co-occurrence of BDD and Gender Dysmorphia and guidance on what should be prioritised for treatment. It is important to develop a shared formulation with the young person about these two areas and how the overlap differ and consider how they each, or in combination cause distress and interference. You can then consider with the young person, once the treatments have been explained, what should be the first course of action. It may be what is most impairing/distressing, it may be that one course of treatment is easier to start with to get traction or it may be they need to be done alongside each other. As a specialist in BDD, if CBT is being conducted it is important it is weekly with a focus on exposure and that this happens to have an impact and not use sessions to focus on other things as the momentum has to build in treatment.

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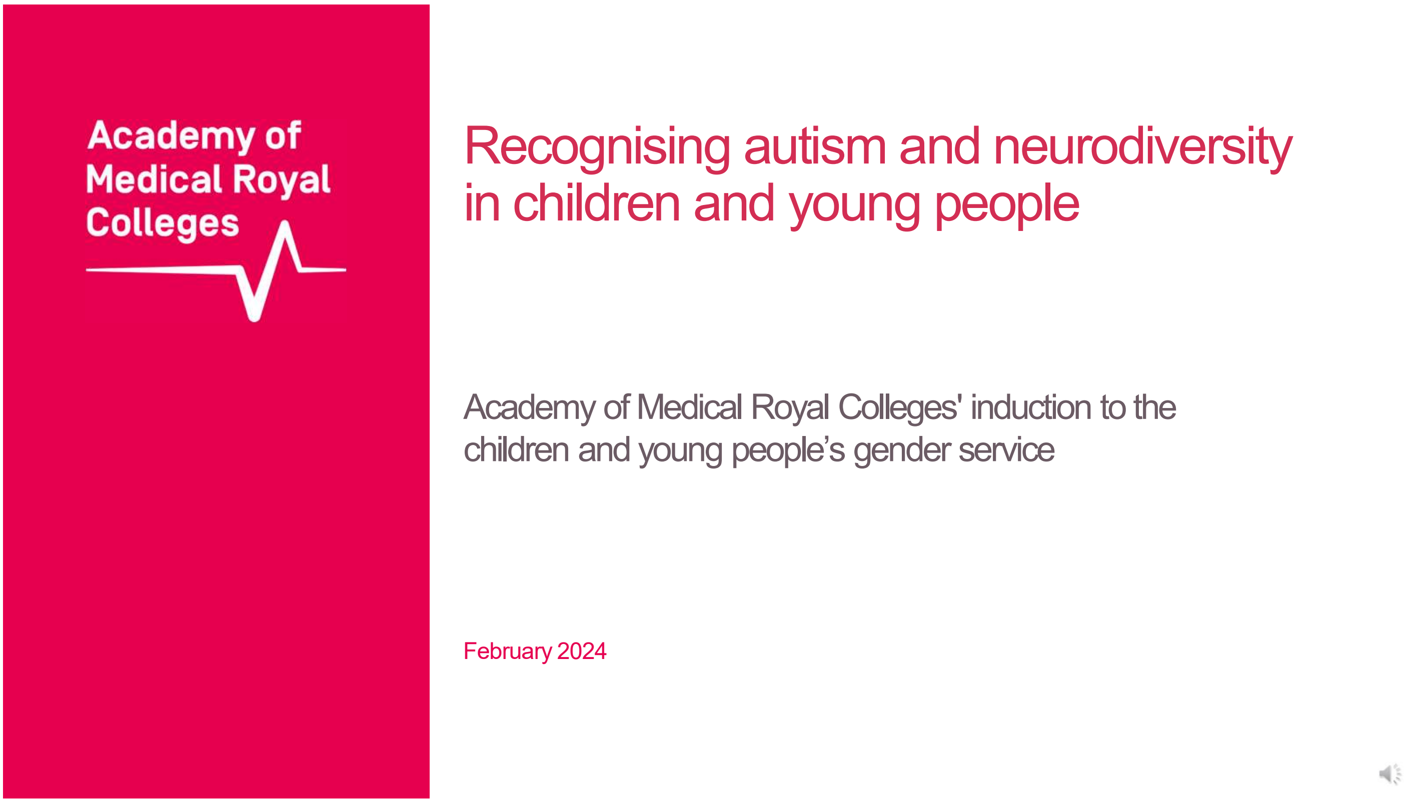
1. Understanding the range and complexity of the children and young people presenting to GIS Good Medical Practice and our approach
2. An introduction to language, key terms and models of care
3. Key skills in children and young people's mental health care gender services
4. Child and adolescent development and puberty
5. **Recognising and understanding body dysmorphic disorder (or BDD)**
6. Recognising and understanding neurodiversity in children and young people
7. Safeguarding

Session 6



Academy of
Medical Royal
Colleges

Recognising autism and neurodiversity in children and young people

Academy of Medical Royal Colleges' induction to the children and young people's gender service

February 2024

This session gives a brief overview on recognising autism and neurodiversity in children and young people, with a particular focus on the intersectionality with gender dysphoria.

Introduction – Prevalence

THE LANCET
Child & Adolescent Health

Submit Article

Log in

Social determinants, inequality, and autism

Michael Absoud

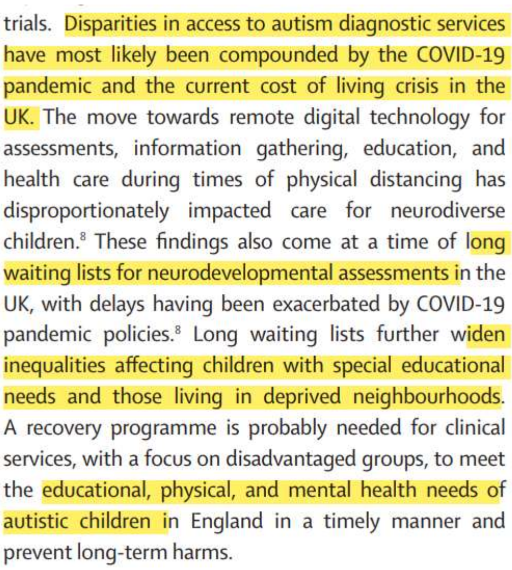
Published: October 24, 2022 • DOI: https://doi.org/10.1016/S2352-4642(22)00273-5 • Check fo

References

Article info

Linked Articles

Understanding the possible social and demographic determinants of inequities in receiving an autism diagnosis is essential for planning access to health, educational, and social service interventions. Autism spectrum disorder is a common, heterogenous neurodevelopmental condition, with a prevalence of around one in 57 children in England, and is characterised by differences in social interaction and communication and repetitive sensorimotor behaviours. Learning disability, mental health, and physical comorbidities are common in autistic people.[1, 2] Timely evidence-based assessments and personalised interventions are hence important to improve quality of life for autistic children. In *The*



trials. Disparities in access to autism diagnostic services have most likely been compounded by the COVID-19 pandemic and the current cost of living crisis in the UK. The move towards remote digital technology for assessments, information gathering, education, and health care during times of physical distancing has disproportionately impacted care for neurodiverse children.[8] These findings also come at a time of long waiting lists for neurodevelopmental assessments in the UK, with delays having been exacerbated by COVID-19 pandemic policies.[8] Long waiting lists further widen inequalities affecting children with special educational needs and those living in deprived neighbourhoods. A recovery programme is probably needed for clinical services, with a focus on disadvantaged groups, to meet the educational, physical, and mental health needs of autistic children in England in a timely manner and prevent long-term harms.

Autism is a heterogeneous neurodevelopmental condition characterised by a dyad of firstly, a domain consisting of atypical social communication and social interaction, and secondly, a domain of restricted repetitive patterns of behaviours, interests and activities.

It begins in early childhood with lifelong manifestations. It has a prevalence of around one in 57 Children in England. It's important that we acknowledge the context which clinicians like us operate in and children currently live in, with widening inequalities and the cost of living crisis, and increasing waiting lists for all neurodevelopmental assessments.

This also presents challenges for schools and social care systems. Those with neuro divergence are ultimately differentially impacted the most. Resulting in delays in diagnosis and reduced access to resources. Autistic people value social connections, but without reasonable adjustments and adaptations, there are risks of adverse social impacts. About 30 to 40% of autistic people also have a learning disability. People with a learning disability and who are autistic experience very significant health inequalities.

Autism Spectrum Disorder (in ICD-11)

Essential (required) features

Persistent difficulties in initiating and sustaining social communication and reciprocal social interactions:

- Understanding of, interest in, or inappropriate responses to the verbal or non-verbal social communications of others.
- Integration of spoken language with typical complimentary non- verbal cues, such as eye contact, gestures, facial expressions and body language
- Understanding and use of language in social contexts and ability to initiate and sustain reciprocal social conversations.
- Social awareness, leading to behaviour that is not appropriately modulated according to the social context.
- Ability to imagine and respond to the feelings, emotional states, and attitudes of others.
- Mutual sharing of interests.
- Ability to make and sustain typical peer relationships.

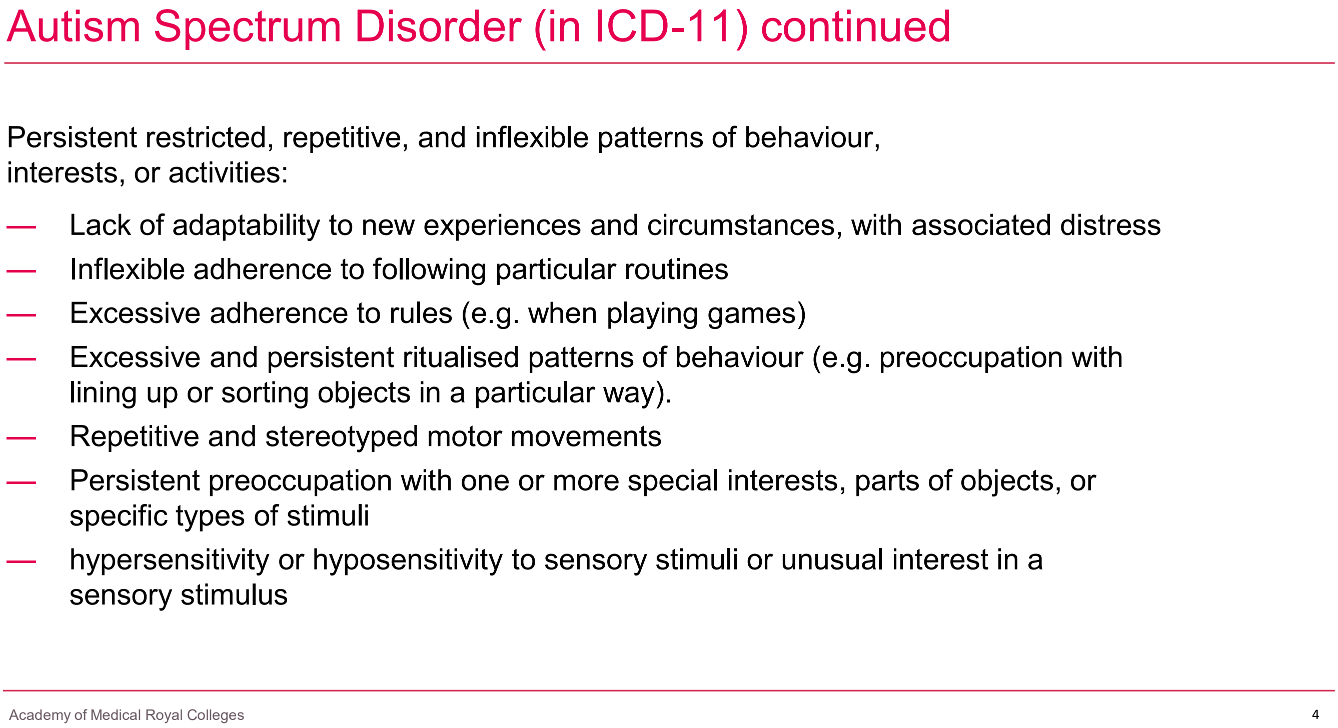
So classification systems are helpful. Ideally, classification systems have validity and clinical utility. Diagnostic guidelines are intended to provide clinicians with guidance on making a diagnosis and should focus on the essential features of the conditions ie those that are required for diagnosis and differentiated from other conditions.

So, here I present the International Classification of Diseases 11th criteria for autism. And as I said, this is a dyad with the very first domain containing essential required features of persistent difficulties in initiating and sustaining social communication and reciprocal social interactions. And these difficulties outside the expected range of typical functioning given the individual's age and level of intellectual development.

Specific manifestations of these difficulties vary according to chronological age, verbal ability, intellectual ability, and condition severity.

Manifestations may include limitations in the following:

- Understanding of interesting or inappropriate responses to the verbal or nonverbal, social communications of others.
- Integration of spoken language with typical complimentary nonverbal cues such as eye contact gestures, facial expressions, and body language,
- Understanding and use of language and social contexts and ability to initiate and sustain reciprocal social conversations.
- Social awareness leading to behaviors that may not appropriately be modulated according to the social context,
- Ability to imagine or respond to the feelings, emotional states and attitudes of others
- Mutual sharing of interests
- Ability to make and sustain relationships.



Autism Spectrum Disorder (in ICD-11) continued

Persistent restricted, repetitive, and inflexible patterns of behaviour,
interests, or activities:

- Lack of adaptability to new experiences and circumstances, with associated distress
- Inflexible adherence to following particular routines
- Excessive adherence to rules (e.g. when playing games)
- Excessive and persistent ritualised patterns of behaviour (e.g. preoccupation with lining up or sorting objects in a particular way).
- Repetitive and stereotyped motor movements
- Persistent preoccupation with one or more special interests, parts of objects, or specific types of stimuli
- hypersensitivity or hyposensitivity to sensory stimuli or unusual interest in a sensory stimulus

So the second part of the dyad is the presence of persistent, restricted, repetitive and inflexible patterns of behaviour, interests or activities. These are clearly atypical or excessive for the individual's age, gender and socio-cultural context. They may include:

- Lack of adaptability to new experiences and circumstances with associated distress
- Inflexible adherence to following particular routines
- Excessive adherence to rules for example, when playing games
- Excessive and persistent, ritualised patterns of behaviour, for example, preoccupation with lining up or sorting objects in a particular way
- Repetitive or stereotyped motor movements, persistent preoccupation with one or more special interests, parts of objects or specific types of stimuli
- Hypersensitivity or hypo sensitivity to sensory stimuli or an unusual interest in a sensory stimulus.

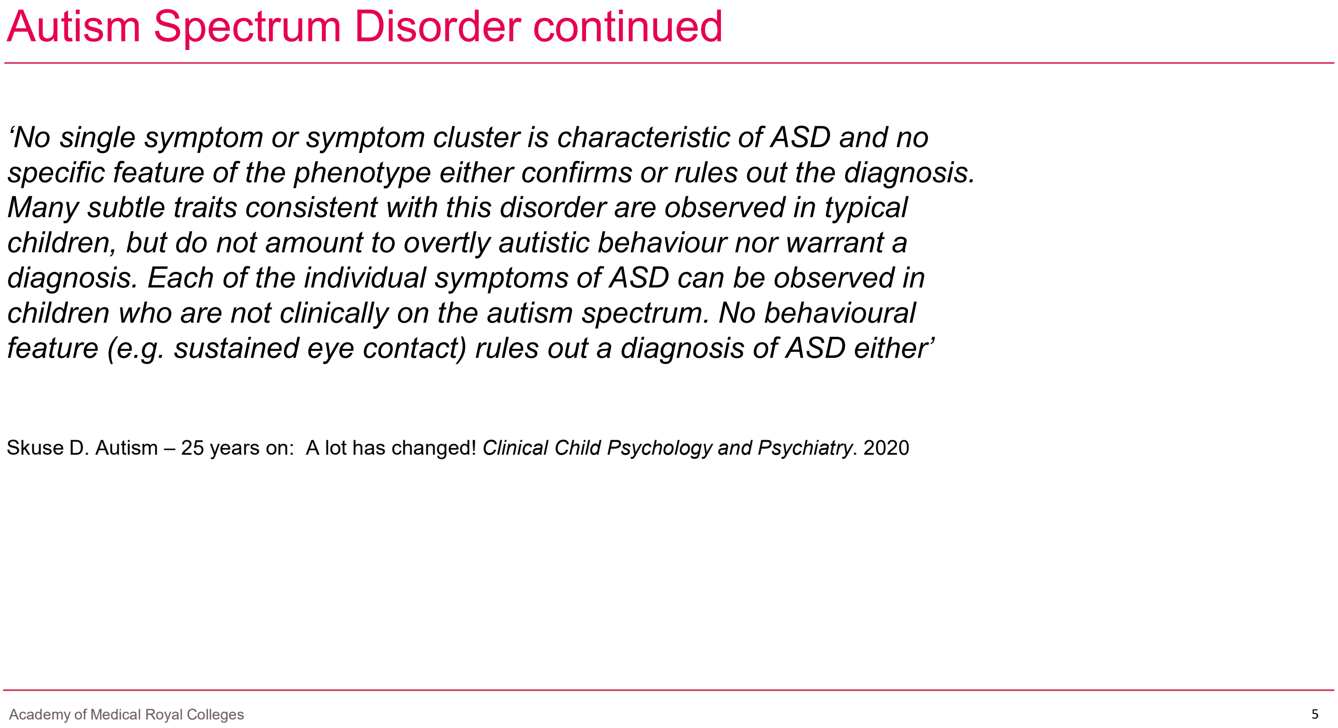
It's important to keep the following issues in mind.

So first of all, operationalisation of these criteria are beyond the scope of this presentation. So it's beyond the scope to discuss specific screening or diagnostic tools. But the overarching purpose of an assessment is to provide a formulation that increases understanding of the reasons for a patient's difficulties, highlights his strengths as well as impairments and makes recommendations for their management. So to achieve this, a comprehensive evaluation extending beyond just the use of autism diagnostic measures, issues is required, and, and has many more practical benefits and potentially more positive outcomes for the young person and family than one focused solely on the determination of an autism diagnosis.

So this includes history taking, interview observation, use of a multidisciplinary team, observations of the child and frequently collateral information from the school, family members or other sources.

The in person assessments will also typically include observation of interaction between the young person and close family members or carers were the young person is living in supported accommodation, for example. These provide important background information and contexts and observations regarding social communication.

Finally, consistent with NICE guidance, there's no single instrument for example, the ADOS-2 which is an absolutely essential component for all diagnostic autism assessments. Clinicians should determine whether information obtained from direct observations provide sufficient information for an accurate diagnostic determination.



Autism Spectrum Disorder continued

'No single symptom or symptom cluster is characteristic of ASD and no specific feature of the phenotype either confirms or rules out the diagnosis. Many subtle traits consistent with this disorder are observed in typical children, but do not amount to overtly autistic behaviour nor warrant a diagnosis. Each of the individual symptoms of ASD can be observed in children who are not clinically on the autism spectrum. No behavioural feature (e.g. sustained eye contact) rules out a diagnosis of ASD either'

Skuse D. Autism – 25 years on: A lot has changed! *Clinical Child Psychology and Psychiatry*. 2020

This is a nice commentary which helps illustrate this point.

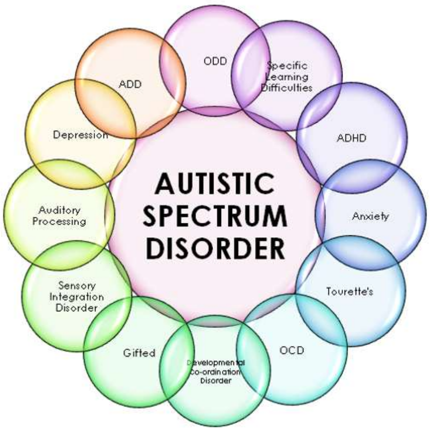
No single symptom or symptom cluster which is characteristic of autism. And no specific feature of the phenotype either confirms or rules out the diagnosis. Many subtle traits consistent with this condition are observed in typical children, but do not amount to overtly autistic behaviour nor warrant a diagnosis. Each of the individual symptoms of autism can be observed in children who are not clinically on the autism spectrum. No behavioural features (for example, sustained eye contact) rules out a diagnosis of autism either.

So overall, as a community, it's important to recognise the dimensionality to autism, and indeed, other neurodevelopmental conditions. Also important to consider that co-occurring conditions are now are the norm. The heterogeneity of individual symptoms and shared factors across other neurodevelopmental conditions. It's important to consider ethnicity, gender and cultural differences, differential diagnosis. And also the concept of diagnostic overshadowing is important - where the symptoms attributed to one condition may result that other conditions are not considered or ascertained.

Differential and multiple long term conditions

(1) Co-occurring conditions

(2) Embracing Complexity



Neurodevelopmental conditions

- Intellectual disability
- ASD
- Developmental Coordination Disorder
- Communication disorders
- Specific learning disorders
- ADHD
- Tics and Tourette syndrome
- Stereotyped Movement Disorder

So I mentioned co-occurant conditions and the importance of considering them with a developmental perspective. And other neurodevelopmental conditions include, for example, intellectual disability, or this is termed disorder of intellectual development in ICD 11, Developmental Coordination Disorder, communication disorders, specific learning disorders, or dyslexia, ADHD, Attention Deficit Hyperactivity Disorder. And like other developmental conditions, ADHD has other additional features associated with it not just hyperactivity, impulsivity, and inattention. So for example, additional co-occurring features often include emotional dysregulation, neurocognitive deficits, and working memory for example, that's holding information in mind, planning and organisation - so executive function difficulties, other neurodevelopmental conditions, such as tics and tourettes, and stereotype movement disorder also commonly co-occur with autism.

So, as well as the recognition of co-occurring developmental conditions, it's important to embrace the complexity.

About 40% of autistic people have a diagnosable mental health problem, there is a higher co-occurrence of physical health problems such as epilepsy. And this complexity can present limitations in everyday life functioning, independence and adaptive functioning, and hence barriers to accessing support.

There are still substantial gaps in the evidence for interventions in these groups as research practices classically hinder development of more inclusive evidence and multidisciplinary working.

Key terms – Neurodivergent

This is a blanket term describing any person/people who are not neurotypical - generally it is preferable to use the specific term (autistic, ADHD, dyslexic, dyspraxic, etc.) being discussed unless multiple terms apply and are relevant.

Note:

There are still disagreements within the autism community, often between autistic adults and parents/carers of autistic people with high support needs, about the meaning, usage, and relevance of this term.

When interacting with an individual, use terminology preferred by the individual.

Another key term to include, and increasingly used by the community and in the research literature, is neurodivergence. This is a blanket term describing any person or people who are not neurotypical. Generally, it is preferable to use a specific term such as autistic or ADHD or dyslexia being discussed unless multiple terms apply and are relevant. It's important to note that there are still disagreements within the autism community, often between autistic adults and parents/carers of autistic young people with high support needs about the meaning, usage and relevance of this term.

The advice is when interacting with an individual to use terminology preferred by the individual. So in general, multiple studies in the past have shown that autistic people prefer identity first language. So for example, being autistic, and then default to this unless referring to an individual who has stated a specific preference otherwise.

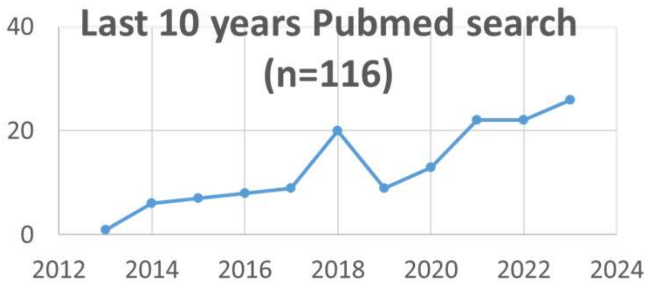
The vast majority of autistic people need some form of support at some point, and this can vary between people and across a person’s life. Stating this idea is not offensive. On the other hand, ‘high/low functioning’ is first a fixed and global state: once labelled as such, that label is perceived to apply across all aspects of life in perpetuity , regardless of circumstances. Second, it is often inaccurate:

some autistic people have persistently high support needs in an area of their life, e.g. communication, but are extremely independent when those structures are put in place effectively. Still others may vary between high and low support needs over the course of years, months, or even over the course of their day.

Strengths-based terminology asks people involved in autistic support, research, and advocacy to lead with the strengths of autistic people. Strengths-based approaches have been used in other academic spheres to support positive outcomes among marginalised groups to great success - in the field of biomedical research, they can be a way to approach and formulate questions about autism and autistic people's outcomes without bringing ableist ideas of 'curing autistic traits' into the picture. Strengths-based approaches take the agency and humanity of autistic people as a given, rather than looking at autism as, at its core, a deficit to be remedied.

Key terms – Gender Dysphoria and Autism

- The co-existence of gender dysphoria and neurodivergence is increasingly recognised
- Recent meta-analysis ~ 11% with gender dysphoria are autistic (may be underestimate)
- Often experience anxiety, depression, disordered eating and suicidality
- Increase stigmatization, executive function and social difficulties
- Highlight the needs of tailored care and personalized mental health support



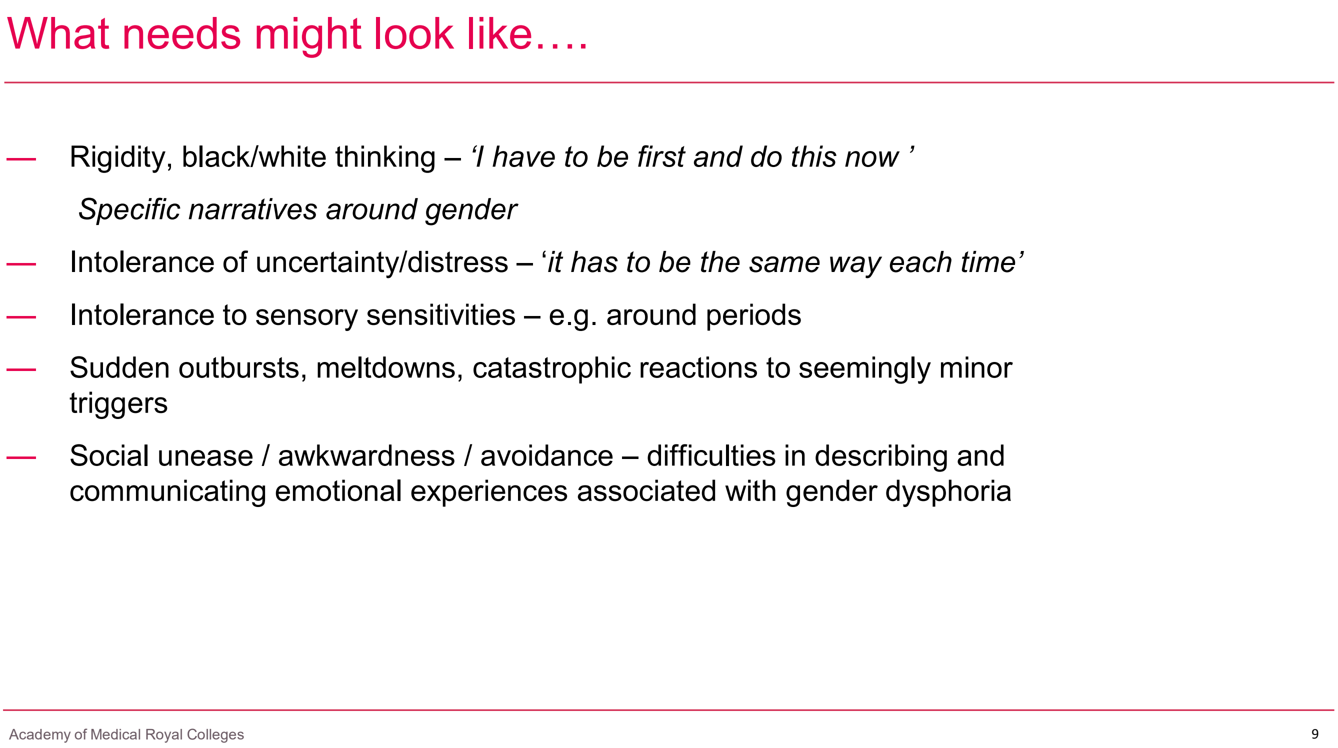
Last 10 years of papers published.

So in the last 10 years, there's been an increase in publications on the intersectionality of autism and gender dysphoria. So for example, through an interaction between body dysphoria and sensory sensitivities. However, there's still a paucity of evidence and more understanding is needed between that intersectionality. But definitely, the coexistence of gender dysphoria and neurodivergence is now increasingly recognised.

So existing evidence shows that autism and gender dysphoria commonly co-occur. But there's limited evidence available about the ways in which the features of autism and gender dysphoria relate to one another. A recent meta-analysis showed approximately 11% with gender dysphoria are autistic and this indeed may be an underestimate.

Individuals with autism and gender dysphoria often experience anxiety, depression, disordered eating, there's a higher incidence of suicidality. There's also increased stigmatization, executive functioning and social difficulties. This highlights the need of tailored care and personalised mental health support. There is, however, limited evidence based clinical guidance to support autistic people experiencing gender dysphoria, who also seek health care. So it's important for us to recognize these inequalities and be proactive.

Views of young people and parents are also more focused on the intersection rather than causal relationships between the two, and hence between features of autism and gender dysphoria.



What needs might look like….

- Rigidity, black/white thinking – *‘I have to be first and do this now ’*

  Specific narratives around gender
- Intolerance of uncertainty/distress – ‘*it has to be the same way each time’*
- Intolerance to sensory sensitivities – e.g. around periods
- Sudden outbursts, meltdowns, catastrophic reactions to seemingly minor triggers
- Social unease / awkwardness / avoidance – difficulties in describing and communicating emotional experiences associated with gender dysphoria

So studies are finding interactions between gender dysphoria and autistic traits, including, for example, sensory sensitivities, resistance to change, rigid thinking and social differences.

Findings include significant convergence in the views on the ways in which being autistic may compound gender dysphoria through the interaction of features of both conditions. So with regards, for example, rigidity, or black and white thinking there's evidence that autistic children / young people report more certainty of their gender identities and the need to meet their gender related needs, which is sometimes questioned by others, particularly their parents who want to focus more on their autism related needs.

Autistic young people also describe distress due to the interaction of sensory sensitivities, and gender dysphoria for example, when experiencing periods and menstruation. There's also difficulties describing and communicating their emotional experiences associated with their gender dysphoria. And hence, this highlights the importance of the family context when young people are seeking support for gender dysphoria.

Autistic people can attempt to hide or camouflage their differences linked to autism and hence, it's important to explore that. Autism adaptations are also needed in gender clinic settings. Also, it's important to consider interventions to support a positive sense of identity in autistic people more broadly. For example, providing post-diagnostic support groups, which can help young people make sense of their diagnoses and their neurodivergence. Such groups could also encourage a more balanced perspective on their autism and help young people to make sense of negative social experiences that they may be experiencing at school, such as bullying, supporting tackling stigma, as well as separately accessing more gender focused support to support the gender dysphoria.

There's increasing evidence that the length of time since autism diagnosis is associated with a more positive well being, so it's possible that over time with early autism diagnosis can be assimilated to oneself leading to more positive outcomes.

Factors to consider: Psychoeducation and link with school

Motivation and interests

Independence skills

Organising and planning

Attention and executive functioning

"Camouflaging"

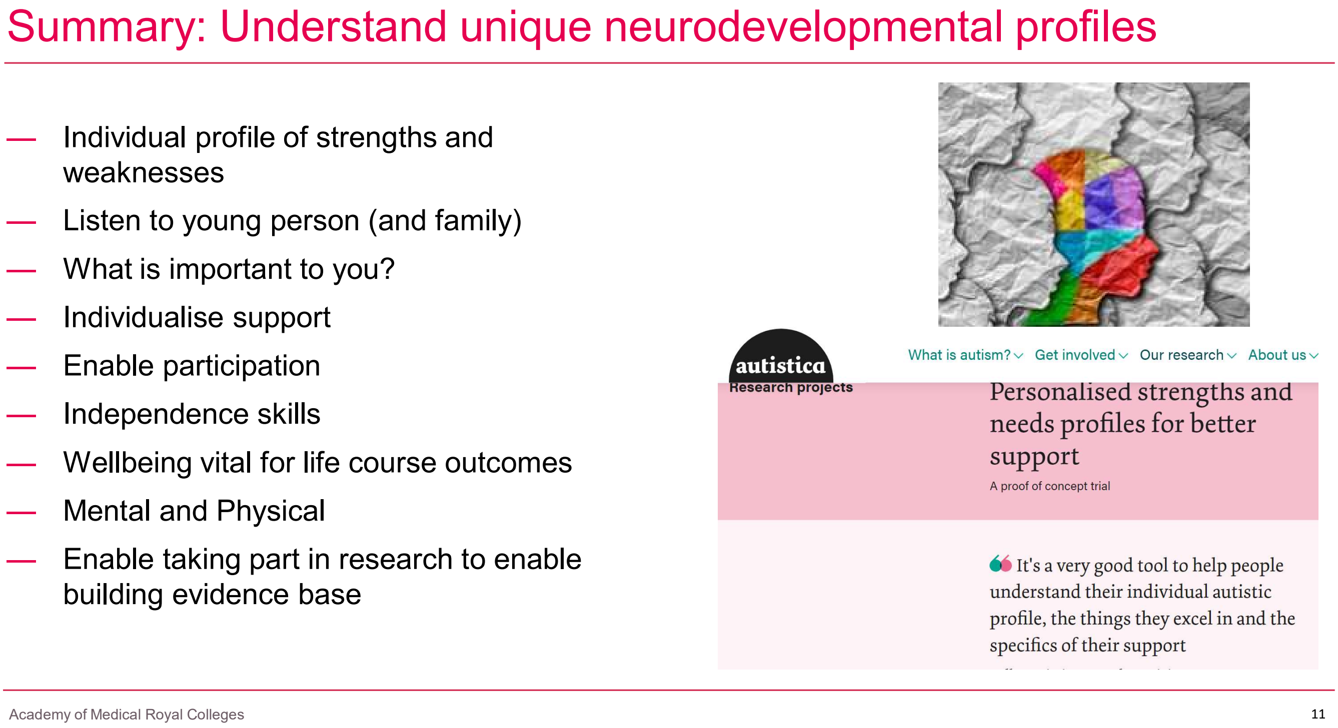
Internalising symptoms

Enable and empower young people to live their best lives

It's important to consider factors, particularly around multidisciplinary working, and also multi-agency working, so education, linking with schools, with the aim being to support various domains and aspects - such as focusing on young person's motivation and interests, independent skills, organization planning, attention, executive functioning, camouflaging, enabling, and empowering people to live their best lives, and internalizing symptoms such as anxiety.

There are challenges in detecting and managing mental illness because the signs and symptoms of particular mental illness and developmental conditions may be atypical. So working as a multidisciplinary team, and reaching out to local services, keeping in mind colleagues such as:

- occupational therapy, who focus on independent skills,
- psychological therapies,
- colleagues, such as speech language therapists who focus on communication difficulties, which could make it difficult for children to express their thoughts and feelings.
- Important to consider innovations such as telehealth services and digital tools for tracking progress,
- Enabling access to health care investigations and treatments.



Summary: Understand unique neurodevelopmental profiles

- Individual profile of strengths and weaknesses
- Listen to young person (and family)
- What is important to you?
- Individualise support
- Enable participation
- Independence skills
- Wellbeing vital for life course outcomes
- Mental and Physical
- Enable taking part in research to enable building evidence base

Personalised strengths and needs profiles for better support

A proof of concept trial

It's a very good tool to help people understand their individual autistic profile, the things they excel in and the specifics of their support

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So in summary, it's important to understand the unique neurodevelopmental profiles and include a multidisciplinary team in doing so. And that is to:

- Characterise the individual profiles strengths and weaknesses of young person.
- Listen to their family context
- Listen to the young person, ask them what is important to them.
- Individualising the support
- Enabling participation with a focus on Independence skills
- Well-being is vital for life course outcomes. So it's important to consider mental and physical health aspects. And keep in mind the inequalities in this population.
- And ultimately to enable young people take part in research to enable the community to build the evidence base.

I mentioned briefly the Autisica personalised strengths and needs for a better profile support tool. This tool is being piloted, not ready for use yet. It's an example of considering a strengths-based approach. It's based on the International classification of functioning disability and health. So the ICF core sets for autism and ADHD. The aim is to enable supporting profiles for individuals who may be neurodivergent, their strengths and support needs and personal environmental factors that help or limit everyday functioning, consider wellbeing and participation in society.

So hence, hopefully, there'll be a societal system shift towards holistic understanding of the divergent individuals, their unique world that will guide better communication support and solutions. Ultimately, to enable adjustments in education supporting children in the classroom and education settings. And ultimately into employment, supporting neurodivergent staff to identify adjustments and support needs needed.

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Skuse D. Autism – 25 years on: A lot has changed! Clinical Child Psychology and Psychiatry. 2020;25(3):721-725. doi:10.1177/1359104520929729

Thompson L, Sarovic D, Wilson P, Sämfjord A, Gillberg C. A PRISMA systematic review of adolescent gender dysphoria literature: 2) mental health. PLOS Glob Public Health. 2022 May 4;2(5):e0000426. doi: 10.1371/journal.pgph.0000426. PMID: 36962230; PMCID: PMC10021389.

1. Understanding the range and complexity of the children and young people presenting to GIS Good Medical Practice and our approach
2. An introduction to language, key terms and models of care
3. Key skills in children and young people’s mental health care gender services
4. Child and adolescent development and puberty
5. Recognising and understanding body dysmorphic disorder (or BDD)
6. **Recognising and understanding neurodiversity in children and young people**
7. Safeguarding

Session 7

Academy of
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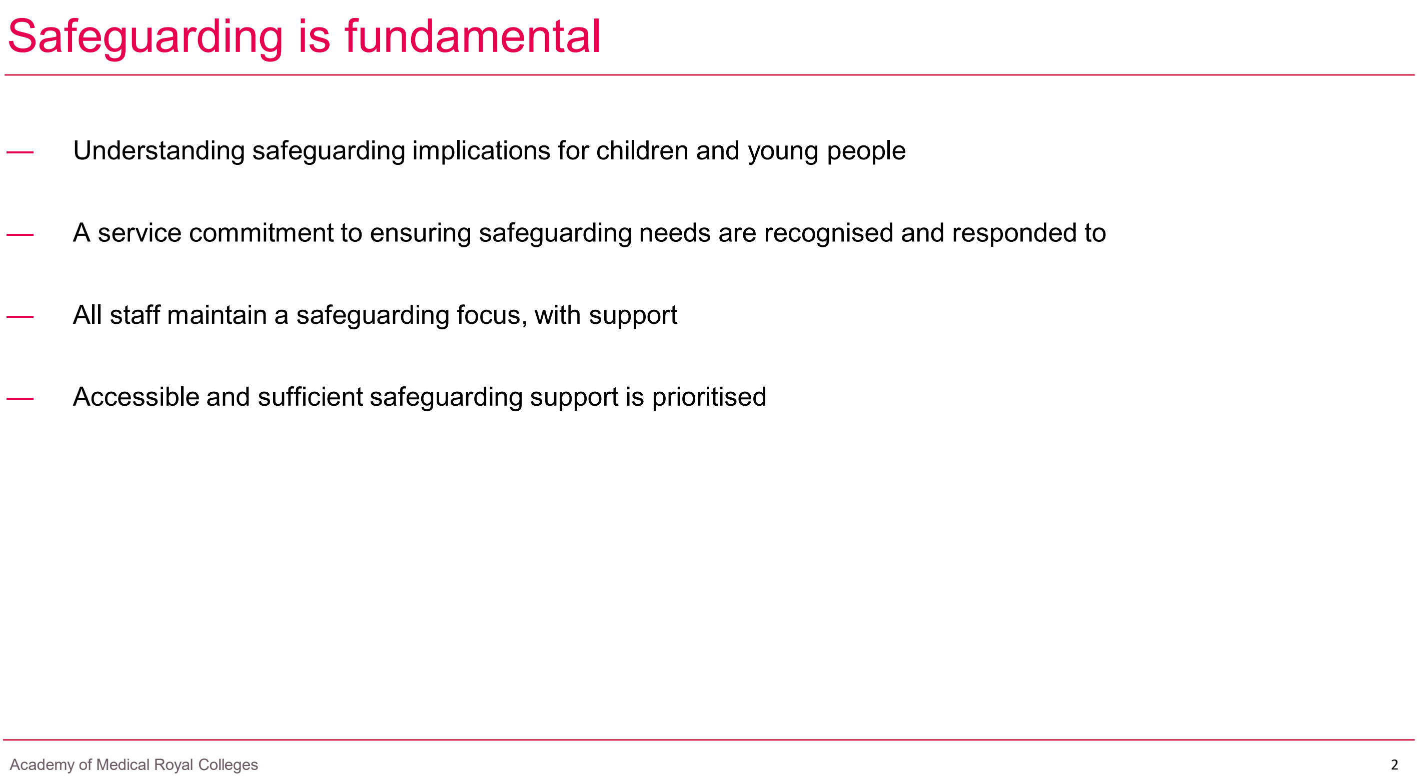
Colleges

Safeguarding

Academy of Medical Royal Colleges' induction to the children and young people's gender service

February 2024

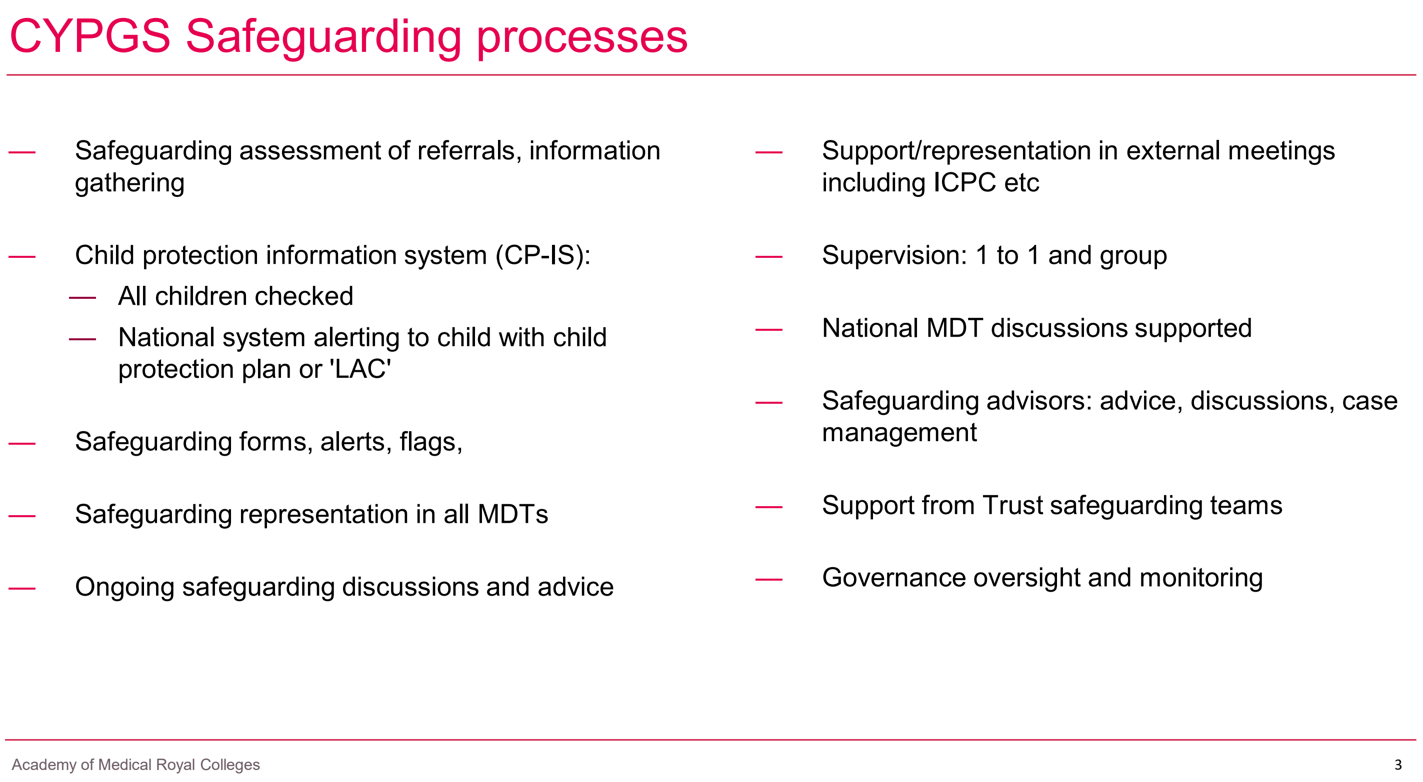
Welcome to the 7th and final lecture
This session will orientate you to the centrality of safeguarding within the new gender services, the rationale for this focus, and the extent of the support you can expect.



Safeguarding is fundamental

- Understanding safeguarding implications for children and young people
- A service commitment to ensuring safeguarding needs are recognised and responded to
- All staff maintain a safeguarding focus, with support
- Accessible and sufficient safeguarding support is prioritised

Safeguarding is an important factor of any children's healthcare service. Understanding the impact of events that can lead to safeguarding needs for children and young people living with gender related distressis. This is a crucial issue for the new gender services. The services will each develop a strong safeguarding approach. For example, the Children and Young Peoples Gender Service London, (the South Hubb) will build an integral safeguarding team. Other Hubs may elect to work closely with their local safeguarding support services, and establish robust relationships and mechanisms to support clinicians to understand and maintain full awareness of the safeguarding risks pertinent to children with gender incongruence. It is required that the gender services will have sufficient safeguarding support to fully contribute to all necessary safeguarding processes.



CYPGS Safeguarding processes

- Safeguarding assessment of referrals, information gathering
- Child protection information system (CP-IS):
    - All children checked
    - National system alerting to child with child protection plan or 'LAC'
- Safeguarding forms, alerts, flags,
- Safeguarding representation in all MDTs
- Ongoing safeguarding discussions and advice
- Support/representation in external meetings including ICPC etc
- Supervision: 1 to 1 and group
- National MDT discussions supported
- Safeguarding advisors: advice, discussions, case management
- Support from Trust safeguarding teams
- Governance oversight and monitoring

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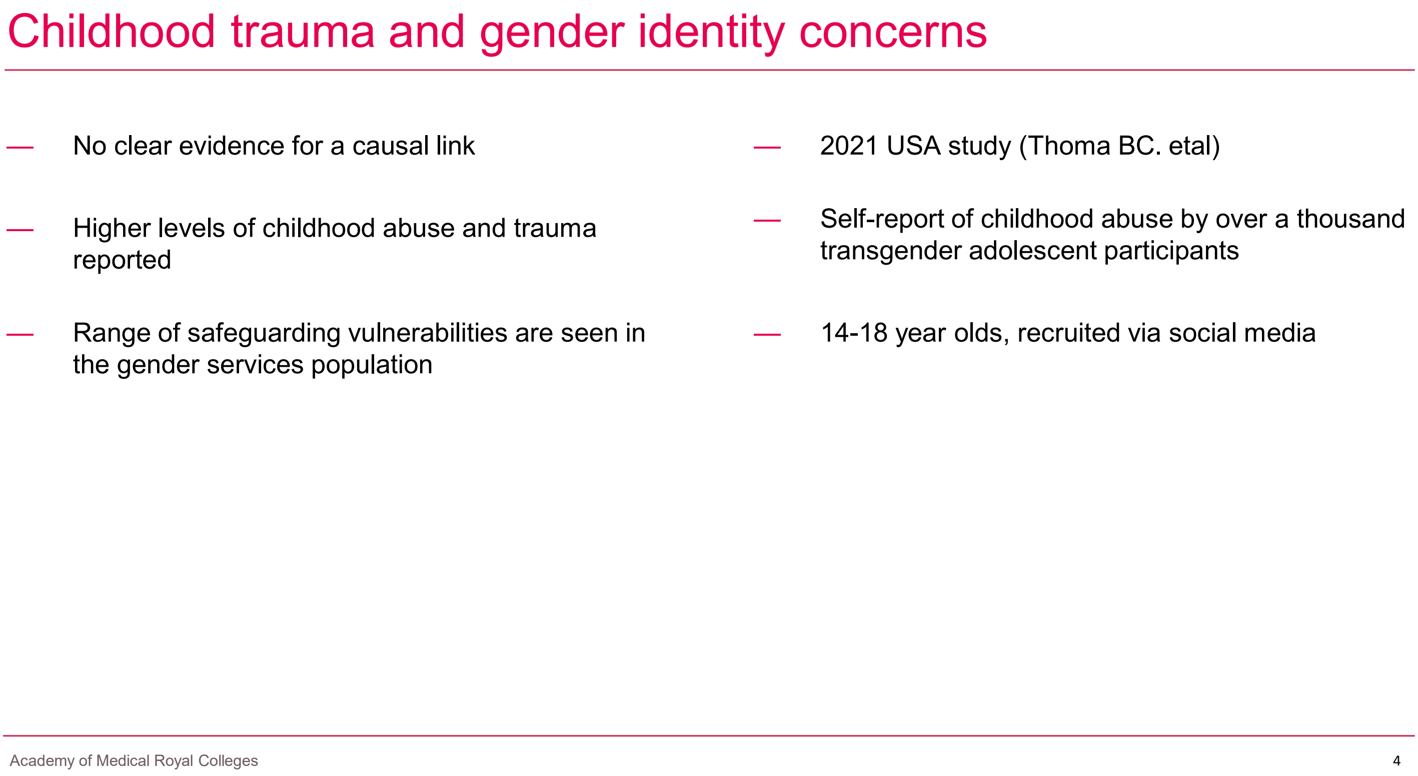
The assessment of historical abuse, vulnerability to risk of harm and the possible need for safeguarding measures will be part of a holistic assessment from receipt of referral. Routine requests information via the national digital child protection information system will form part of the assessment. All necessary safeguarding assessment, reporting, monitoring and review will be adequately provided by or for the service, including safeguarding supervision for CYP Gender Services staff. Governance, oversight and monitoring of safeguarding data will be led by the safeguarding team, or the responsible professional in the service. Safeguarding leads will also contribute to the Service submissions to the National Multidisciplinary Team for Gender Services.



Childhood trauma and gender identity concerns

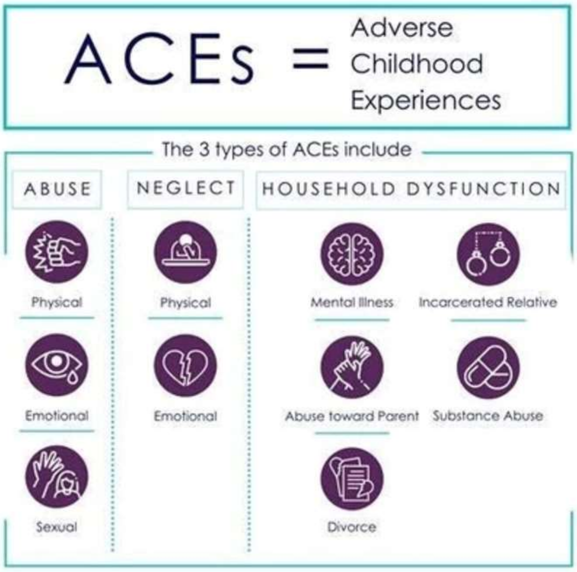
- No clear evidence for a causal link
- Higher levels of childhood abuse and trauma reported
- Range of safeguarding vulnerabilities are seen in the gender services population

- 2021 USA study (Thoma BC. etal)
- Self-report of childhood abuse by over a thousand transgender adolescent participants
- 14-18 year olds, recruited via social media

Although there is no clear evidence for a causal link between childhood abuse and gender identity concerns, some studies do suggest that childhood abuse and trauma is reported more frequently by people experiencing gender related distress . We know that children presenting to clinical services can experience a wide range of vulnerabilities , meaning that safeguarding is a core consideration. A 2021 USA study recommended that paediatric medical and mental health professionals always assess for possibility of child abuse. The study found that adolescents identifying as transgender were more likely to report childhood abuse, with birth registered females in this sample, having the greatest level of risk of psychological abuse.

Thoma BC, Rezeppa TL, Choukas-Bradley S, Salk RH, Marshal MP. Disparities in Childhood Abuse Between Transgender and Cisgender Adolescents. Pediatrics. 2021 Aug;148(2):e2020016907. doi: 10.1542/peds.2020-016907. Epub 2021 Jul 5. PMID: 34226247; PMCID: PMC8344346.

Vulnerabilities, Abuse and Trauma

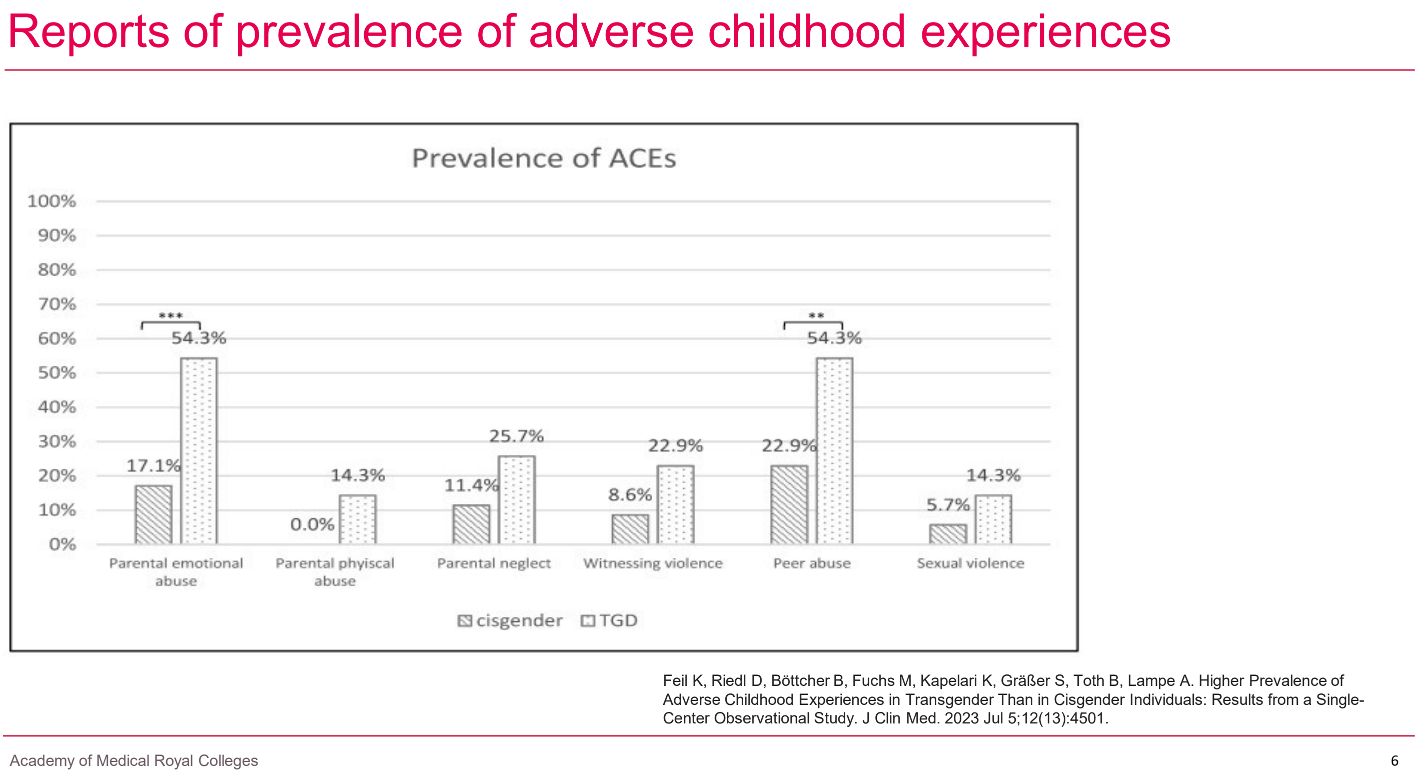


- Gender questioning children may have Adverse Childhood Experiences
- Within family, emotional, physical and sexual abuse
- 'Contextual abuse' from the wider community e.g. school bullying, sex or drug related grooming or exploitation
- The impact of abuse on gender perception is variable and not clearly understood

A history of adverse child experiences or ACES is known to have a negative impact on a wide range of health and developmental outcomes in adolescence and adulthood.

Children referred to gender services may have a range of adverse childhood experiences such as personal abuse or exposure harmful domestic or community environments.

The direct impact of these experiences on gender perception is not well understood. However,



Reports of prevalence of adverse childhood experiences

Feil K, Riedl D, Böttcher B, Fuchs M, Kapelari K, Gräßer S, Toth B, Lampe A. Higher Prevalence of Adverse Childhood Experiences in Transgender Than in Cisgender Individuals: Results from a Single-Center Observational Study. J Clin Med. 2023 Jul 5;12(13):4501.

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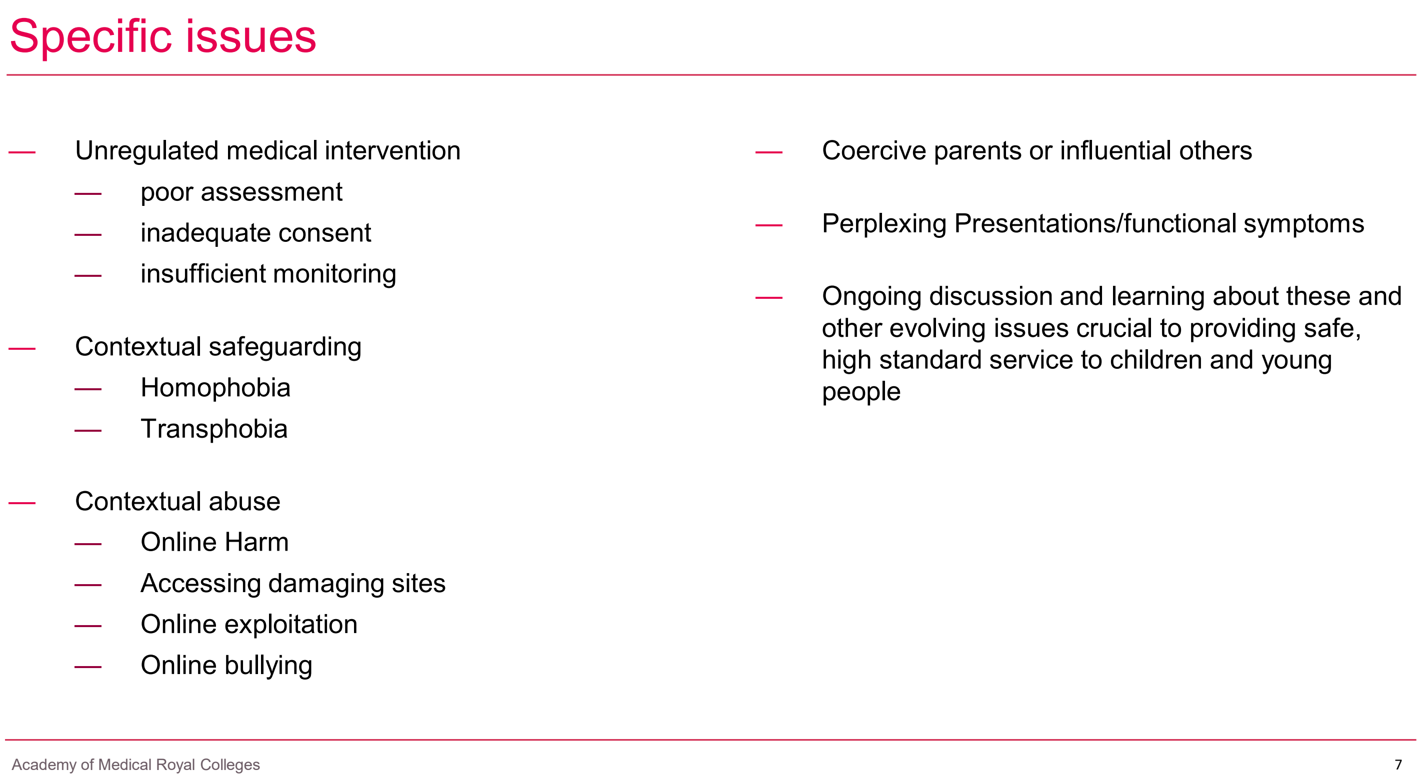
A 2023 American study of 35 trans gender adults with a mean of age 29, used standardised self-report measures to survey the childhood experience of maltreatment abuse, adversity and trauma.

The study found no significantly greater prevalence of sexual abuse reporting when the study group was compared with a matched sample of non-psychiatric hospital patients and a control group. However, the transgender and gender diverse adults reported an increased prevalence of depression, post trauma symptoms and anxiety. Just under 6% of the control group reported 4 or more adverse childhood experiences, while of the transgender and gender diverse group, approximately 30% reported for our more adverse childhood experiences. The most common of these were parental abuse and peer abuse.

Another study from an Australian paediatric gender service reports that the developmental stories told by the children and their families highlighted high rates of adverse childhood experiences, with family conflict (65%), parental mental illness (63%), loss of important figures via separation (59%), and bullying (54%) being most common. A history of maltreatment was also common (39.2%).

Kozlowska K, McClure G, Chudleigh C et al. Australian children and adolescents with gender dysphoria: Clinical presentations and challenges experienced by a multidisciplinary team and gender service. Human

Systems 2021;1(1):70-95.



Specific issues

- Unregulated medical intervention
  - poor assessment
  - inadequate consent
  - insufficient monitoring
- Contextual safeguarding
  - Homophobia
  - Transphobia
- Contextual abuse
  - Online Harm
  - Accessing damaging sites
  - Online exploitation
  - Online bullying
- Coercive parents or influential others
- Perplexing Presentations/functional symptoms
- Ongoing discussion and learning about these and other evolving issues crucial to providing safe, high standard service to children and young people

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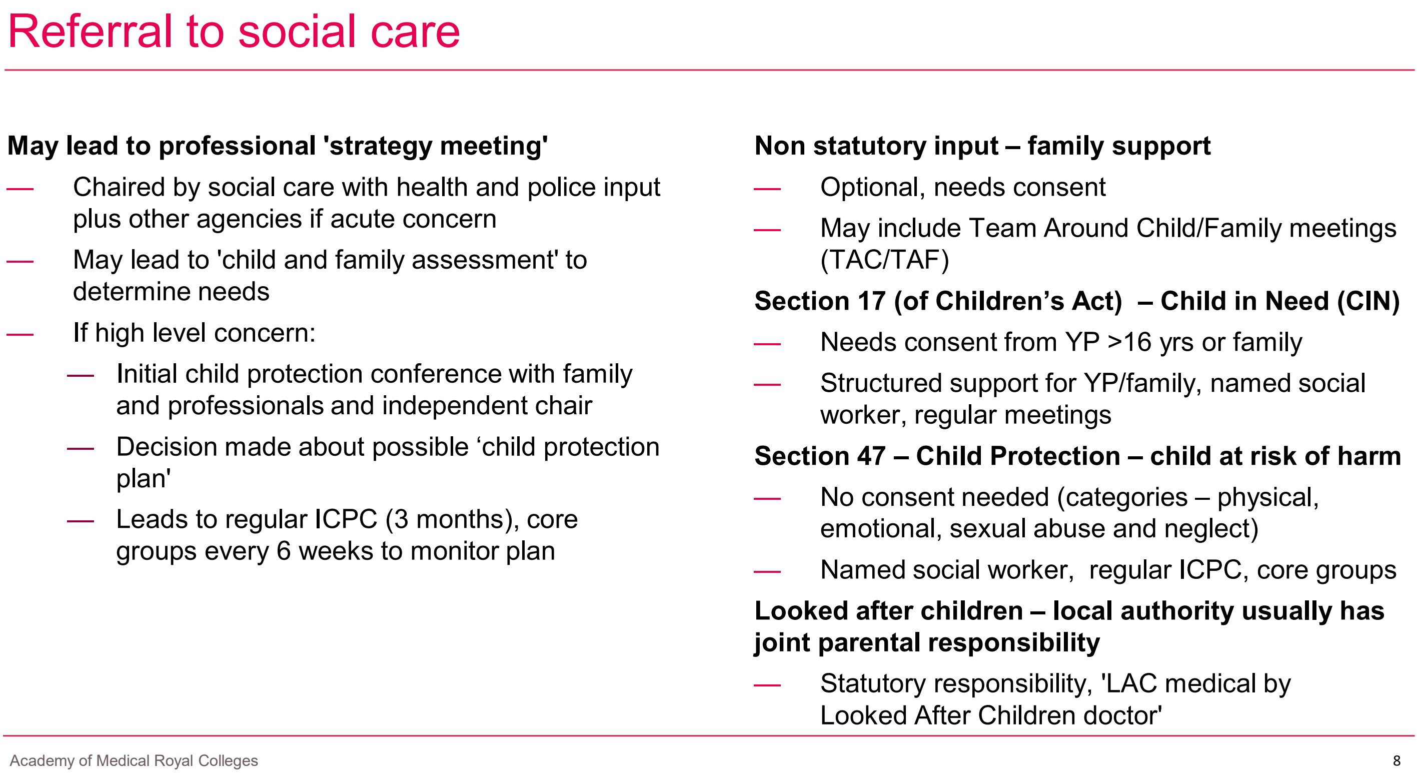
This population is also subject to some more specific potential safeguarding concerns. For example, there is a market for medical interventions that may be met by providers that may be unregulated or subject to less stringent care standards than NHS services. These pose a risk of harm due to the unregulated medicines or products. These may include the use of counterfeit chemicals, unsafe or unknown ancillary ingredients, and have a variability of potency. Children may present to our services yet they or their parents or carer may disregard professional advice such that the MDT conclude that the child or young person is at increased risk. Discussion with the safeguarding lead regarding appropriate action can be helpful at an early stage, to help promote open discussion with the family.

Existing services for young people with gender incongruence have identified a number safeguarding concerns and themes that can either be known at the point of referral or can emerge during assessment.

These can include
- Coercion from parents and career or the potential for secondary gains that can shape a child's gender understanding and expression. Parents or carers may have become heavily invested in one outcome and can drive a child’s social or medical transition.
- The use of medication that is procured outside of regulated healthcare services or that is administered without adequate professional assessment and monitoring.

- The impact of a childhood environment involving criticism, hostility or other physical or emotional abuse related to same-sex attraction or gender expression.
- Peer abuse, bullying or social isolation.
- Online harms, grooming and exploitation, under direction from others or self-driven.
- Perplexing presentations such as functional disorders or fictitious or fabricated illness. These are amongst the most challenging clinical presentations that can occur alongside presentations for professional support with gender incongruence.



Referral to social care

May lead to professional 'strategy meeting'

- Chaired by social care with health and police input plus other agencies if acute concern
- May lead to 'child and family assessment' to determine needs
- If high level concern:
    - Initial child protection conference with family and professionals and independent chair
    - Decision made about possible ‘child protection plan'
    - Leads to regular ICPC (3 months), core groups every 6 weeks to monitor plan

Non statutory input – family support

- Optional, needs consent
- May include Team Around Child/Family meetings (TAC/TAF)

Section 17 (of Children’s Act) – Child in Need (CIN)

- Needs consent from YP >16 yrs or family
- Structured support for YP/family, named social worker, regular meetings

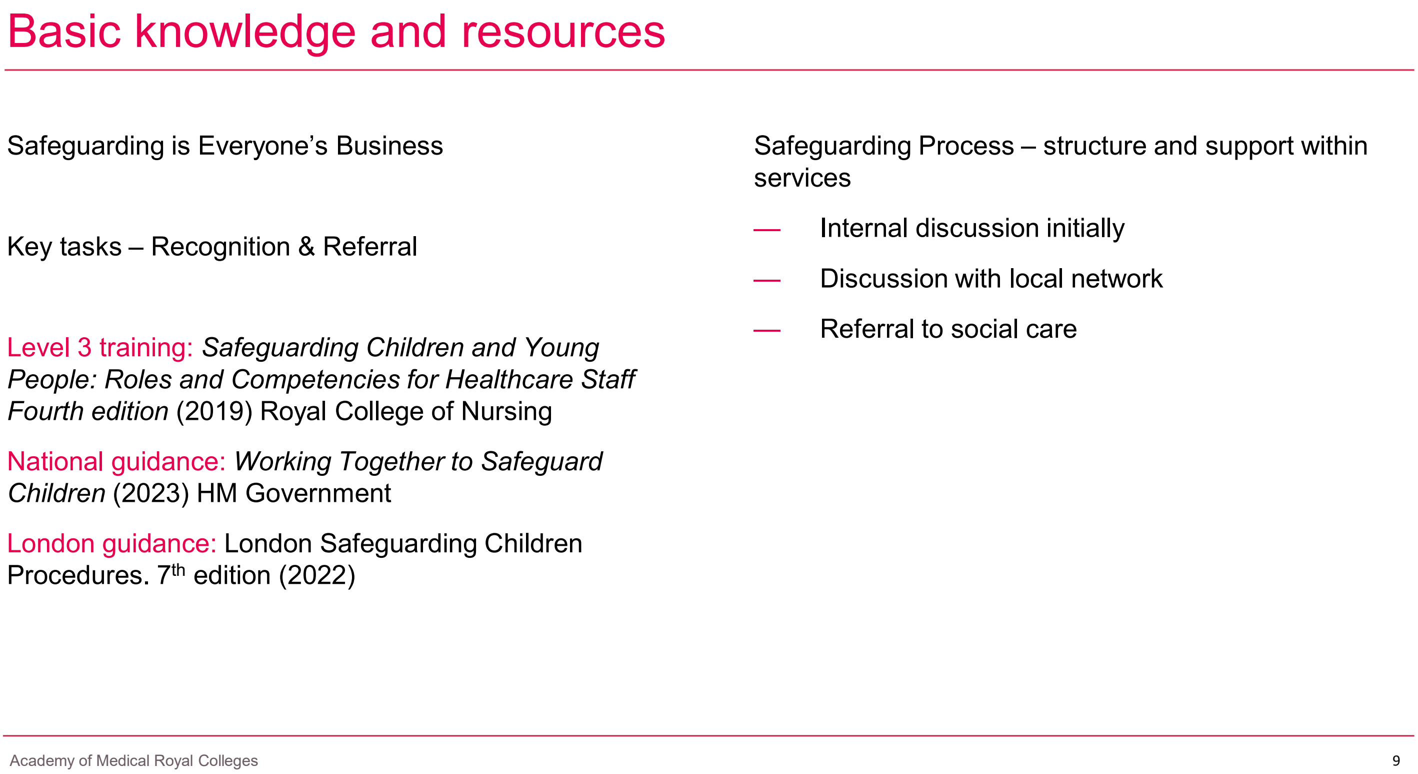
Section 47 – Child Protection – child at risk of harm

- No consent needed (categories – physical, emotional, sexual abuse and neglect)
- Named social worker, regular ICPC, core groups

Looked after children – local authority usually has joint parental responsibility

- Statutory responsibility, 'LAC medical by Looked After Children doctor'

Should a referral to social care be required, safeguarding staff within or allied to the service, should have the necessary resource to be appropriately involved in safeguarding procedures including attending strategy meetings and the creation of necessary intervention plans in partnership with statutory services.



Basic knowledge and resources

Safeguarding is Everyone's Business

Key tasks – Recognition & Referral

Level 3 training: *Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff Fourth edition* (2019) Royal College of Nursing

National guidance: *Working Together to Safeguard Children* (2023) HM Government

London guidance: London Safeguarding Children Procedures. 7th edition (2022)

Safeguarding Process – structure and support within services

- Internal discussion initially
- Discussion with local network
- Referral to social care

Finally, it is well recognised that safeguarding patients, clients or service users is the responsibility of all professionals involved in healthcare. All professional and clinical staff withing children and young people's gender services will be required to maintain safeguarding training level 3 specialist, with all patient facing staff maintaining the appropriate level of training for their role. A key skill is knowing when and where to seek help to think through or act upon safeguarding concerns. The safeguarding team or safeguarding leads within the service or the Trust will provide a clear pathway for support that is well understood and easy to utilise by all CYP Gender Service staff.

References

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1. Understanding the range and complexity of the children and young people presenting to GS Good Medical Practice and our approach
2. An introduction to language, key terms and models of care
3. Key skills in children and young people’s mental health care gender services
4. Child and adolescent development and puberty
5. Recognising and understanding body dysmorphic disorder (or BDD)
6. Recognising and understanding neurodiversity in children and young people
7. **Safeguarding**

And that’s the end of the second session in this series.