

ACAMH National Conference
14 June 2019

Ethical issues arising in the provision of medical interventions for gender diverse children and adolescents

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Steps towards accessing medical intervention at GIDS

- to build a shared understanding, between child, parents/carers and clinical team of the course of the gender identity development
- to consider the strength, stability and configuration of that identification
- to assess for current and past difficulties – including experiences of depression, anxiety, bullying, victimisation and trauma - and to try to make sense of any association with the gender feelings and the wish for bodily change
- to support understanding of what is hoped for from medical treatments and to explore the motivations for seeking them
- to provide a reflective space to consider the meaning of sexual intimacy and fertility in the developing life of the young person, now and in future



Steps towards accessing medical intervention at GIDS

- to communicate at all stages the known and unknown benefits and drawbacks of the proposed interventions and the limits of our knowledge
- to assess the young person for capacity, and/or to be assured that the parents/carers are able to give valid consent
- to ensure that any consent is well-informed, through age-appropriate scaffolding of discussions, with account taken of the many sources of influence that may be influencing the young person's and family's views
- overall, to feel confident, although not necessarily certain, as a responsible multi-disciplinary clinical team, that the intervention is in the young person's best interests.



The socio-political context: children as decision-makers

- In the UK, as elsewhere, we have increasingly come to think that enabling young people to experience some forms of autonomy is a social good (Alderson 2017).
- There is increasing acceptance of the need to consult the wishes of children about major decisions that affect their lives, considered in the light of their age and understanding (UK Children Act, 1989; UNCRC 1989).
- The idea is linked with the thesis that a measure of authentic self-knowledge, and knowledge of their best interests, can be achieved by children and adolescents.



The socio-political context: the autonomy of the patient

- In many health care systems service-users' views are increasingly sought and play a significant part in steering treatment approaches.
- There is greater acceptance of medical treatment in the service of wellbeing, including interventions into an ostensibly well body for medical purposes (e.g. in vitro fertilisation, abortion, some kinds of body modification and reconstruction), rather than as a response that is titrated against pathology.
- Modern medical practice widely provides for interventions that are w offered for needs associated with identity and self-fulfilment rather than for biological dysfunction. (e.g. contraception, Viagra,)



Competence and Capacity – UK law

- Young people aged 16 to 18 are assumed to be capable of deciding on their own medical treatment, unless there is significant evidence to suggest otherwise. (2005 Mental Capacity Act)
- Under the age of 16, young people can consent to medical treatment without the need for parental permission or knowledge if they are believed to fully appreciate what is involved ('Gillick competence').
- **There is no fixed lower age limit for Gillick competence**
- **The assessment of capacity and competence is function-based, not age-based.**
- **Judgments of capacity and competence are decision-specific.** A young person who can consent to a straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences.



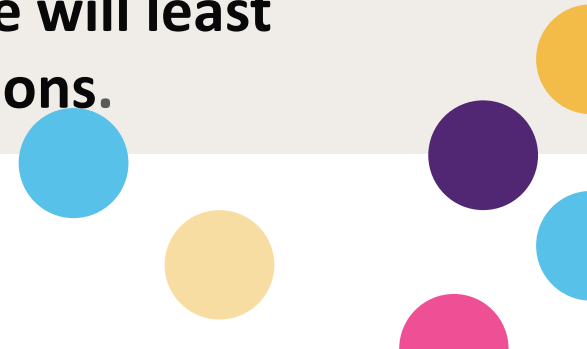
Parents/carers giving consent

Parents cannot consent on behalf of their 16/17-year-old if the young person has capacity. Neither can they override consent or refusal from a 16/17-year-old with capacity.

Where younger children are concerned, or if a child is held not to be competent, **parents or carers must make treatment decisions, with thought for:**

- ***the child's future autonomy*** - what they might wish for themselves in later life
- ***and the child's developing autonomy*** - having some meaningful sense now of what their emergent wishes look like, and doing one's best to nurture their expression.

There is an obligation to consider which choice will least restrict the child or young person's future options.



Informed Consent

To secure informed consent requires three elements:

- (a) the ***provision of adequate information*** about the nature and purpose of the proposed treatment
- (b) to a patient assessed as having ***the 'capacity' to understand*** that information,
- (c) who then ***freely, without any coercion, agrees*** to receive the treatment.

Properly valid consent requires *a balanced and interactive discussion* of benefits and risks, of alternatives, and of what could happen if the patient elects to have no treatment. Such exchanges take time.

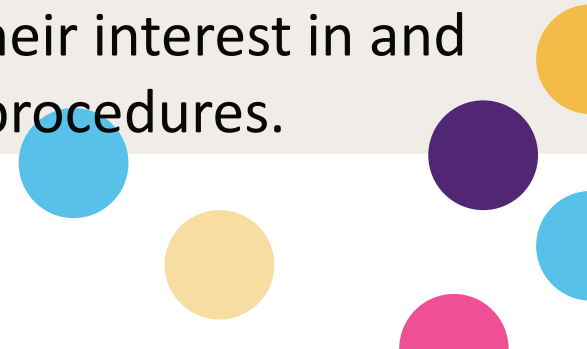


Informed Consent

A core feature of autonomous choices is that they can be for things that others might not deem wise. It is essential to distinguish between a lack of competence/capacity and the making of unwise decisions.

Otherwise, if a young person differs in her decisions from her clinician's idea of what is in her best interests, she may be deemed, by that very fact, to lack the capacity to make the decision.

To be competent or have capacity requires only a sufficient, not complete, understanding, of the issues. Complete and specific consent is an illusion. Informed consent occurs as a continuing process with people who vary enormously in their interest in and capacity to absorb information about medical procedures.



Making treatment decisions at GIDS

- **The main stakeholders in the process of coming to a treatment decision are the child/young person, the parents/carers and the treating team.**
- We encourage young people to involve their parents in making important decisions, but should (usually) abide by any decision they have the capacity to make themselves.
- We also at times consider involving other members of the multi-disciplinary team, an independent advocate or a named or designated doctor for child protection if their involvement would help young people in making decisions.



Influences on the decision-making by young people

- As young people are dependant on their parents/carers (and their clinicians) to define the meaning of their situation, the quality of those relationships may influence their capacity for *autonomous* decision-making.
- The quality of information provided can also make a difference
- **Young children may view the world in concrete terms and struggle to reason about abstract or hypothetical problems.**
- **Adolescents, with new cognitive and social skills have greater maturity in reasoning about complex issues, yet may still find it difficult to restrain impulsiveness and to see a given decision in a larger temporal context.**
- Children who have personal experiences with particular kinds of challenge may show greater insight and understanding than children of comparable age who lack this experience.

No right to a particular treatment

- In the NHS, there is no right to a particular treatment.
- **Even if a young person is deemed competent or as having capacity, they cannot insist on a treatment that a clinician does not think is indicated - either because the professional disagrees with the treatment sought (or because rationing of health resources means it is not available).**
- ...although such a view might be open to challenge under the Human Rights Act.
- In such a situation, the person seeking the treatment may be able to approach another professional.

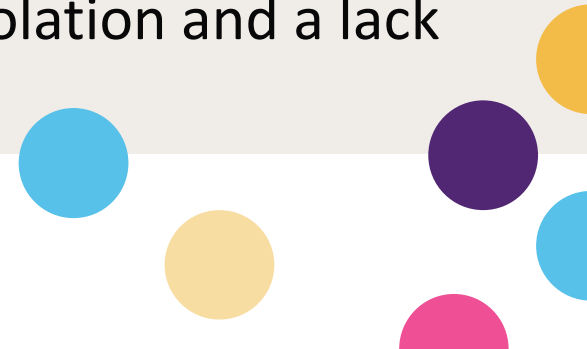


Clinicians' protection and vulnerabilities

- Securing Informed Consent is the best protection against any later challenge of harm-doing
- Clinicians also have a defence in the fact that many professional bodies now endorse the diagnosis of Gender Dysphoria and the affirmative approach to care via the *Memorandum of Understanding*. (BPC, BPS, RCGP, UKCP) See Bolam 1957
- **Montgomery ruling (2015): a patient must be properly advised about their treatment options and the risks associated with each option - reflecting the contemporary view that patients can now expect a more active and informed role in treatment decisions. The information to be provided is such as would be deemed relevant by 'a reasonable person in the patient's position', and not by**

Empirical evidence and scholarship: some knowns, unknowns, and unknown unknowns

- Young people are presenting to clinics in increasingly diverse ways – with respect to identity, presentation and self-description
- A relatively high level of mental distress and developmental atypicality is recorded for this population, chiefly depression, anxiety, trauma and self-harm.
- Autistic spectrum profiles are common - although an understanding of the interplay between gender diversity, sexuality and ASD remains limited.
- Some, but not all, of these troubles emerge as a result of the continuing social disapprobation towards gender diverse people and the impact of bullying, social isolation and a lack of effective family support.



Empirical evidence and scholarship: some knowns, unknowns, and unknown unknowns

- Studies (limited in number and quality) tracking children and teens who receive hormone treatments show a picture of the good psychosocial functioning.
- *Puberty suspension* as a routine intervention for children and young people is associated with few known medical risks but some as-yet-unknown potential impacts. e.g. the long-term effects on bone density, height, sex organ development, and body shape - or the reversibility of any changes or delays.
- Researchers are beginning to explore how early suppression might affect psychological and cognitive development, in areas such as executive functioning, or emerging sexuality.



Empirical evidence and scholarship: some knowns, unknowns, and unknown unknowns

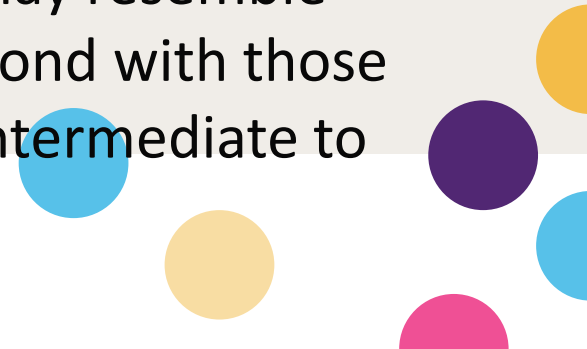
- With regard to the possible harms in the provision of *sex hormones*, these relate less to its unknown physical impacts over time, as to concerns about minors consenting to the irreversible bodily changes from these treatments, as well as from other (known) long term consequences, including on fertility.
- On the “persistence” of cross-gender identifications: studies initiated at different times over several decades are hard to interpret – with a wide range of definitions, measures and follow-up timeframes and a shift in the socio-cultural conditions in which gender diversity was experienced. More recent studies show greater persistence in identity.



Empirical evidence and scholarship: some knowns, unknowns, and unknown unknowns

Evidence regarding twin studies, brain differences and temperament, does not rule out a genetic component to gender diversity, which would align with what we know about many other human variations that appear to be the result of complex nature-nurture interactions.

- Some twin studies suggest that ‘cross-gender’ identification is approximately 60% heritable
- No evidence that genetic issues in the synthesis of steroid hormones (found in some intersex presentations) play a role
- Structural MRI studies (small and limited in scope) have found variously that the brains of trans individuals may resemble those of their birth-assigned sex, may correspond with those who share their gender identification or are intermediate to



Empirical evidence and scholarship: some knowns, unknowns, and unknown unknowns

- As in so many complex new bio-psycho-social fields of enquiry, studies are still few and limited in scope - at times contradictory or inconclusive on key questions.
- Worth looking at this evidence alongside the evidence base for interventions in CAMHS and paediatric medicine – where absence of evidence is not the same as evidence of absence
- Scientific observations are taken up and interpreted differently by groups with conflicting stakes in the matter: limited data can be read with great optimism or read, equally selectively, as providing inadequate reassurance about how to proceed without risking harm.
- In the meantime, we are faced with the need to take compassionate and reasoned decisions about how to proceed with the limited knowledge and understandings we currently

The GIDS Ethics & Law Sounding Board

Set up in 2018 to focus on issues arising at GIDS that have profound legal, ethical and political dimensions.

- To enable reflection on different clinical, legal and ethical frameworks for considering the work of GIDS
- To help us map the legal and ethical content of our work, making that dimension of our activity more visible, and opening it up to external scrutiny
- To ensure regular dialogue with people experienced in **clinical ethics**, in **professional practice** and in **the law** (equalities, consent/capacity, child protection and risk) from inside and outside the trust



Clinical Ethics Panel - for 2019-20

- To support GIDS staff in better decision-making - especially in manage uncertainty in the relative absence of evidence
- To discuss (de-identified) individual cases, rather than issues
- To produce and publish a set of ethical considerations (principles?)
- Potentially to build up categorisation of ethically 'standard' cases – and distinguish cases that are ethically more complex or unusual.
- To include psychosocial and endocrine clinicians
- To clearly acknowledge that clinicians retain responsibility for decision-making



GIDS: values-based practice

- At GIDS gender identity is seen as an adaptation, not a pathology.
- Best practice needs to be fine-tuned to developmental stage.
- While at GIDS we maintain a sense of uncertainty in relation to how gender identity may develop in any individual over time, being ethically aware cannot just mean always imposing maximum barriers and taking the maximum time to make decisions in the name of ethical prudence.
- A core ethical goal is to mitigate suffering, but we lack evidence that this is always reliably achieved through a speedy offer of medical intervention – or indeed through withholding it. Refusal of medical treatment can cause suffering.



GIDS: values-based practice

- It is not clear that it is always right to prioritise possible suffering *in the future* (if the person comes to see the physical changes made as unwanted or un-needed) over suffering *in the here and now*.
- We are respectful of non-binary and queer identities: bodies altered by hormones may not necessarily be regretted.
- There is a distinction between the respect due to the seriousness (authenticity) of a child or young person's identification, and their right to express their autonomy - and the respect due to the time and effort needed for full participation in decision making



Values-based practice – Fulford

Value conflicts are rarely resolvable by reference to guidance or rules, but rather by reference to principles of Good Process:

- Diagnose the situation in the light of values at stake and unbundle the issues (in all their pain, contradictions and conflict)
- Keep the level of distress within a tolerable range for doing the work
- Pay disciplined attention to the tractable issues, counteracting work avoidance mechanisms like denial, scapegoating, externalising the enemy, pretending the problem is technical, attacking individuals rather than issues
- Give the work back to the people with the problem – but at a rate they can stand. Don't push the problem up to authorities when the work is to be done elsewhere
- Protect those who raise hard questions (often children)

Thank you

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