# Youth should decide: the principle of subsidiarity in paediatric transgender healthcare

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#### **ABSTRACT**

Drawing on the principle of subsidiarity, this article develops a framework for allocating medical decisionmaking authority in the absence of capacity to consent and argues that decisional authority in paediatric transgender healthcare should generally lie in the patient. Regardless of patients' capacity, there is usually nobody better positioned to make medical decisions that go to the heart of a patient's identity than the patients themselves. Under the principle of subsidiarity, decisional authority should only be held by a higher level decision-maker, such as parents or judges, if lower level decision-makers are incapable of satisfactorily addressing the issue even with support and the higher level decision-maker is better positioned to satisfactorily address the issue than all lower level decision-makers. Because gender uniquely pertains to personal identity and self-realisation, parents and judges are rarely better positioned to make complex medical decisions. Instead of taking away trans youth's authority over their healthcare decisions, we should focus on supporting their ability to take the best possible decision for themselves.

## INTRODUCTION

Debates over capacity to consent and decisional authority in paediatric transgender healthcare have been brought to the fore by the English case Bell v Tavistock. In an initial ruling, the High Court declared that trans youth generally lacked the capacity to consent to puberty-blocking medication and had to seek court approval.1 The finding was considerably narrowed in a subsequent decision confirming that parents could nonetheless consent for their child without applying for court approval.<sup>2</sup> Later, the Court of Appeal overturned the High Court's ruling, stating that capacity to consent should be assessed by healthcare professionals on a case-by-case basis.<sup>3</sup> Rather than criticising the empirical and legal premises of the trial decision, which has been done elsewhere, 4-7 the present article draws on the principle of subsidiarity to argue that that decisional authority in paediatric transgender healthcare—in other words, who gets to accept or refuse an intervention offered by a healthcare professional—should generally lie in the patient even if they lack capacity to consent, at least in practice if not as a matter of law. This is so because, regardless of patients' capacity, there is typically nobody who is better positioned to make medical decisions that go to the heart of the patient's identity than the patient themself. Rather than taking away trans youth's medical authority, paediatric transgender healthcare should focus on supporting trans youth's ability to make the best possible decision in light of their values,

commitments, and cares. Throughout the article, I understand trans vouths as individuals between the ages of puberty and majority who express a gender identity that does not correspond to the gender they were assigned at birth, including those who identify otherwise than solely male or female.8

In the first section of this paper, I define the principle of subsidiarity. In the second section, I discuss the principle's application to gender-affirming care. In the third section, I set out a framework for allocating decisional authority for patients who lack full capacity to consent. In the fourth section, I briefly discuss how to better support the decision-making of youths who lack full capacity to consent.

## THE PRINCIPLE OF SUBSIDIARITY

According to the principle of subsidiarity, decisional authority should devolve to the lowest level decision-maker consistent with satisfactorily completing the task or role at hand. According to Kotalik, subsidiarity holds that 'each larger social and political group should help smaller or more local ones to accomplish their respective ends without arrogating those tasks to itself'. Higher level decision-makers should only play a subsidiary role. The principle commonly appears in law and political theory, where it serves a foundational function in the distribution of political and social authority across different levels of government and organisation. 10-12 The principle is a fundamentally liberal one, being predicated on the view that individuals should be free to organise their life according to their will except to the extent that is strictly necessary. While rarely explicitly applied in bioethical contexts, the allocation of medical decisional authority within law reflects a concern for subsidiarity—if competent, youths should make medical decisions for themselves; if they are not competent, their parents should make medical decisions; if parents are unable to or do not act in the youth's best interests, the court should make medical decisions.<sup>2</sup> 13 14 Patients are usually understood as the lowest level or most proximate decision-maker, followed by their family, and courts. As the Supreme Court of Canada expressed in AC v Manitoba, its leading decision on minors' capacity to consent, 'paternalism should always be kept to a minimum and carefully justified'. 1

The bioethical literature has tended to focus on how and which decisions should be made. By contrast, the principle of subsidiarity addresses the question of who should make the decision of accepting or refusing an intervention proposed by a healthcare professional.9 In relation to the traditional principles of bioethics of respect for

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autonomy, beneficence, non-maleficence, and justice, subsidiarity is perhaps best understood as a framework that operationalises and balances competing principles within the context of allocating decisional authority. Because it is more specific than respect for autonomy, the principle of subsidiarity can offer clearer guidance to clinicians and ethicists, curtail paternalistic tendencies, and help judges develop legal rules.

Although subsidiarity has most often been applied to the allocation of power between different levels of government, nothing in the principle precludes its application to individuals. <sup>9</sup> <sup>16</sup> For instance, Mill's discussion of subsidiarity, which he summarises as 'the greatest dissemination of power consistent with efficiency', speaks of municipal governance as bearing on those matters 'not better left to the persons directly interested'. <sup>17</sup> While the principle may find less bioethical use in relation to capable adults since they are typically free to accept or refuse care against their best interests, it is illuminating in paediatric bioethics, where protecting youth from themselves is a common justification.

Given its liberal roots and resonance with existing schemes of paediatric decision-making, the principle of subsidiarity appears well suited to paediatric transgender healthcare. In the paediatric context, the patient's best interests should serve as the guiding objective of the principle of subsidiarity. The notion of the best interests of the child lies at the heart of paediatric bioethics and is enshrined in the *Convention on the Rights of the Child*. <sup>14 18</sup> Thus, decisional authority should devolve to the lowest level decision-maker consistent with ensuring respect of the patient's best interests, understood in light of their gender subjectivity, values, cares, and commitments. Gender subjectivity refers to the totality of one's phenomenological experiences of oneself as gendered, which includes gender embodiment, and forms the basis of gender identity. <sup>19</sup>

The principle of subsidiarity in clinical bioethics can be broken down into three subprinciples:

The default subprinciple. Patients should hold decisional authority by default.

The necessity subprinciple. Higher level decision-makers should only hold decisional authority if all lower level decision-makers clearly lack the capacity to make a decision consistent with the patient's best interests, even with support.

The superiority subprinciple. Higher level decision-makers should only hold decisional authority if they are clearly better positioned to make a decision consistent with the patient's best interests than all lower level decision-makers.

As a corollary of the default subprinciple, deviations from patient autonomy are only justified if the other two subprinciples are clearly met; the corollary reduces the risk of overreach and paternalism by higher level decision-makers. The burden of justification falls on those who wish to reallocate decisional authority away from patients.

Discussions of the subsidiarity principle most often emphasise the default and necessity subprinciples, as political controversies typically involve concerns of resource allocation or collective action rather than cognitive or theoretical inability. In the context of medical care that goes to the heart of the patient's identity, however, the superiority subprinciple takes on greater importance. Pursuant to the superiority subprinciple, patients should retain decisional authority if nobody is better positioned than them to ensure respect for their best interests due to epistemic limitations. This subprinciple will most often apply where a decision is intractably complex, or where facts central to decision-making lie within the sole epistemic authority (ie,

uniquely pertains to self-knowledge) of a patient who lacks capacity.

At first glance, the subprinciples may appear contrary to the presumption of youthful incapacity embedded in law and paediatric bioethics. However, the subprinciple is a normative default rather than a procedural one. Policy may reflect the fact that the necessity and superiority subprinciples typically obtain in a class of situations, so long as exceptions are accounted for. The presumption of youth incapacity proceeds from the understanding that parents and/or courts are better positioned to make choices in the best interests of the youth. 14 15 Courts' jurisdiction over youth, known as parens patriae jurisdiction, is grounded in governments' interest in protecting the health and well-being of minors. 15 If courts were not thought better positioned to evaluate and protect the best interests of youths who lack capacity, parens patriae jurisdiction would be arbitrary, unjustified, and fail to keep paternalism to be a minimum. <sup>15</sup> A similar perspective seems implicit in the juxtaposition of article 3 of the Convention on the Rights of the Child, which sets out that 'the best interests of the child shall be a primary consideration' in law and state action, and the provision of article 12 that 'the views of the child [must be] given due weight in accordance with the age and maturity of the child'. 18 Law and paediatric bioethics agree with the principle of subsidiarity. My article departs from law and bioethics not at the level of principle but of application. I argue that in a range of medical contexts and, in particular, paediatric transgender healthcare, neither parents nor courts are clearly better positioned to make decisions consistent with youths' best interests, even when they lack capacity.

## SUBSIDIARITY IN PAEDIATRIC TRANSGENDER HEALTHCARE

If trans youth have the ethical and legal capacity to make a medical decision consistent with their best interests, they should be afforded the authority to make that decision. In jurisdictions that use the mature minor doctrine, this criterion is typically met if the minor has 'sufficient maturity and intelligence to understand the nature and implications of the proposed treatment'. Is 20 If a trans youth below the age of 16 is considered sufficiently mature and intelligent, they will be allowed to consent to gender-affirming care on their own. As a matter of law, a finding that the youth lacks the capacity to consent leads to the conclusion that parents or courts will be granted *de jure* decisional authority. Applying the subprinciple of superiority, however, decisional authority should only be reallocated if a further condition is met: are parents and/or courts better positioned to make the decision?

When applying the subprinciple of superiority, the unique nature of trans healthcare comes to the foreground. To make a decision consistent with the patient's best interests, it is necessary to have an intimate understanding of the patient's implicated values, cares, and commitments. In the case of gender-affirming care, the patient's experience of gender identity and embodiment, including gender dysphoria and gender euphoria, is central and indeed motivates them to seek out interventions in the first place. However, parents and judges rarely have an intimate understanding of what it is like to be trans or have gender dysphoria because most of them are cisgender. And even if they did—such as trans parents and judges—they would most likely not have an intimate understanding of what it's like for that child. Trans experiences are varied, and there is no one-sizefits-all description of them. Trans youths have unique knowledge of their own gender identity and embodiment.<sup>21 22</sup> Gender identity and embodiment are deeply personal, having been

called 'one of the most intimate areas of a person's private life' and going 'to the heart of an individual's identity' by courts. <sup>1 23</sup> Gender-affirming care differs from conventional medical care in the degree to which it pertains to personal identity and self-realisation<sup>24–26</sup>. Whereas higher level decision-makers are often able to make complex decisions regarding conventional care in a satisfactory, albeit imperfect, manner by relying on shared values and experiences, the same is not generally true of gender-affirming care. Accordingly, it will often fall in the 'special box' of care that does not meet the requirements of the subprinciple of superiority and makes space for decisional authority without capacity.

It is beyond the scope of my paper to define exhaustively which medical interventions fall in the 'special box' that defeats the subprinciple of superiority. Interventions like abortion, birth control, and gender-affirming care—which I have called 'definitional medical care' in other work<sup>26</sup>—do so insofar as they are closely tied to fundamental components of personal identity. However, I do not propose a rigid binary between 'conventional' and 'definitional' care. Instead, I see the boundaries as porous and open ended, more akin to a gradient than a bright line. Take, for instance, blood transfusions, which are motivated by shared desires—not wanting to bleed out and die—but can also implicate deeply personal religious beliefs. These forms of care deserve their own analyses under the principle of subsidiarity. For the purposes of my argument, it suffices to notice that the personal nature of gender identity and embodiment makes it so that higher level decision-makers will rarely be better positioned to make decisions consistent with the patient's best interests about gender-affirming care since they do not have direct access to the youth's psychological experience of gender. The subprinciple of superiority does not entail that we should never interfere with trans youths' decisional authority. However, once a medical decision pertains to the heart of the patient's identity, decisional authority should only devolve to higher level decision-makers in the rarest of cases. In the next section, I propose a framework for analysing when decisional authority should so devolve.

## **DECISION-MAKING WITHOUT CAPACITY**

I propose the following framework for allocating decisional authority in cases where trans youth are found not to have full capacity to consent. At the first step, youths must demonstrate minimal autonomy such that the resulting decision can be said to be theirs. Adapting philosopher and bioethicist Agnieszka Jaworska's work on medical autonomy to the context of gender-affirming care, we may formulate the following three criteria: (1) the patient is guided by their gender subjectivity and other values, cares, and commitments; (2) they act based on reasons prescribed by their gender subjectivity, values, cares, and commitments; (3) they are open to seeing reasons to the contrary.<sup>27</sup> These criteria are easily met, and will normally obtain in youths who have reached the age when puberty blockers are first offered. The reference to gender subjectivity is not an invitation to inquire at length into whether the person's expressed gender identity and embodiment reflect their 'true, deep-seated identity'. Rather, the criterion is meant to exclude situations where the person is unable to communicate their motivations, even in simple terms, for seeking gender-affirming care or where the expressed motivations are patently unrelated to their gender. The third criterion, openness to seeing reasons to the contrary, requires that the person be able to reflect on their choice and acknowledge reasons to the contrary as counting against their choice in the balance; nevertheless, they do not need to be open

to *accepting* these reasons, but merely *seeing* them. This third criterion primarily serves to exclude cases where the patient is so in the grip of desire as to be unable to even imagine reasons to the contrary. That reasons to the contrary are insufficient to tip the balance of choice is not, by itself, evidence that the third criterion is unmet. If these three criteria are met, the decision can be said to be properly that of the patient. If they are not met, decisional authority should not be held by the patient alone as they are unable to make medical decisions based on their gender subjectivity and other values, cares, and commitments.

Once minimal autonomy is established, the second step is to ask whether the contemplated higher level decision-makers would clearly be better positioned to make a decision that reflects the patient's best interests, understood in light of their gender subjectivity, values, cares, and commitments. I do not believe that this will often be the case in gender-affirming care. It is impossible to balance two values, cares or commitments without having intimate knowledge of both. Parents and judges rarely have an intimate appreciation of transness or gender dysphoria, and never have an intimate appreciation of the patient's gender subjectivity. Moreover, the scientific literature does not reveal any reliable predictor of regret which could inform their choice. 28-31 By contrast, patients have an intimate understanding of their own gender subjectivity and will almost always have a substantial, although limited, appreciation of countervailing considerations such as the risk of harm, infertility, etc. Indeed, research shows that trans adolescents often have a sophisticated understanding of the consequences and implications of genderaffirming care. 32 For my purposes, it suffices that they have some such understanding. Trans patients can appreciate both sides of the equation, whereas higher level decision-makers lack an intimate understanding of the reasons that lead the youth to seek out gender-affirming care in he first place.

Due to parents and judges' lack of intimate understanding of the patient's gender subjectivity, it is only possible to affirm with confidence that they are better positioned to decide if the reasons against gender-affirming care are so grave that no rational person could choose it regardless of their gender subjectivity. Imagine, for instance, that initiating puberty blockers would entail certain and immediate death in exactly 1 year. In such a case, it would be difficult to deny that refusing puberty blockers is in the best interests of the vouth—no matter how bad their gender dysphoria. In other words, higher level decisionmakers will be better positioned to decide if gender-affirming care is in the patient's best interests if the intervention poses a danger that is so great that it must be graver than any risk of denying gender-affirming care—which includes loss of self-trust, attachment difficulties, anxiety, depression, and suicide. 33 34 The bar is high.

A helpful heuristic is to ask whether trans adults in the position of the youth would agree by consensus that gender-affirming care should not be chosen. Except in rare cases of extreme medical contraindications, it is implausible that any such consensus would be reached. This heuristic does not account for trans adolescents who retransition; however, rates of regret and retransition appear sufficiently low as to have a negligible impact on hypothetical consensus. Since initiating gender-affirming care in adolescence seems reasonable to countless trans adults and medical experts, it cannot be readily assumed that higher level decision-makers are better positioned to decide in the patient's best interests. Indeed, how would we know with any certainty that the patient's decision is not in their best interests? Accordingly, only in the rarest and most extreme of cases will the subprinciple of superiority apply. In all other

cases, trans youth should be afforded decisional authority over initiating gender-affirming care.

Even when trans youth lack full capacity to consent to medical interventions, parents and judges are typically worse positioned to make decisions that go to the heart of their personal identity. Besides cases where full capacity is clearly absent, my proposed framework may be helpful in instances where capacity is disputed since it allows for decisional authority regardless of capacity. In all but the rarest and most extreme cases, only trans youth can know with whether transition-related care is in their best interests. While deferring care is sometimes framed as a non-choice, it is important to keep in mind that it has a concrete incidence for the youth's ability to live in harmony with their gender identity and embodiment, which lie at the heart of their personal identity. Deferral is neither neutral nor risk free. Rather than taking away trans youth's authority over healthcare decisions, we should focus on supporting their ability to take the best possible decision for themselves.

## SUPPORTING DECISION-MAKING

Trans youth should generally hold decisional authority over gender-affirming care even if they lack full capacity to consent. Instead of focusing on whether or not care is in the child's best interests, parents and clinicians should focus on supporting the patient in making the best possible decision according to their gender subjectivity, cares, values, and commitments. Failing to sufficiently support trans youth's decision-making is unethical and may sometimes constitute malpractice—for instance, failing to disclose physiological effects that they have reasons to believe the youth would want to know.

According to philosopher and bioethicist Quill Kukla, as adapted to gender-affirming care, the following conditions foster better decision-making<sup>39</sup>: (1) trust towards parents and clinicians, (2) the concrete ability to change one's mind at will without recrimination, shame or extended negotiation, (3) ability to effectively communicate and understand each other, (4) a broader social context that does not undermine the agency of trans youth, such as gatekeeping, transnormativity and ongoing threats to access to gender-affirming care, <sup>22 40 41</sup> (5) self-trust and a stable sense that one's gender, values, cares, and commitments are worth expressing and acting on, (6) testimonial credibility within and outside clinical, familial, and social relationships, (7) ability to obtain redress and hold others accountable when they fail in their duties, (8) being socially connected such as having a support network, a check on reality, and a community that holds people accountable. Although these considerations were proposed in relation to sexual activity under conditions of compromised autonomy, they strike me as illuminating in the context of gender-affirming care. To these, I would add (9) an opportunity for calm reflection. While decisions in trans youth care are rarely hot headed due to long waitlists and substantial social stigma, hot-headedness is nevertheless a common concern in paediatric decision-making, especially in emergency contexts, and ought to be noted.<sup>14</sup>

Some of these conditions are systemic issues and cannot be fully addressed within the immediate clinical context. The belief that trans care is one-size-fits-all or that there is a right or wrong way to be trans—known as transnormativity—can undermine youths' self-trust, gender exploration, and willingness to assert their particular needs and desires. The expectation of gate-keeping—that is, that clinicians (and now even courts) are the ones to decide whether the youth is worthy of gender-affirming care—can undermine youths' willingness to express needs,

doubts, and worries as well as create psychological barriers to gender exploration by putting them on the defensive. <sup>22</sup> <sup>42</sup> <sup>43</sup> Transnormativity and gatekeeping are socially pervasive, and long-term change is needed to better support all trans youths' decision-making. <sup>44</sup> Nevertheless, parents and clinicians can and should communicate their disagreement with transnormativity, their belief that there is nothing wrong with changing one's mind and retransitioning, and their view that it is not the clinician's role to determine the truth of the youth's gender identity and embodiment.

## CONCLUSION

The principle of subsidiarity offers an insightful approach to allocating decisional authority over trans youth care even in situations where teens may lack full capacity to consent. According to the principle, patients should hold decisional authority and only be deprived of if it is strictly necessary to protect their best interests. This, in turn, is only the case if the patient is clearly incapable of making decisions that respect their best interests and if higher level decision-makers are clearly better positioned to make such decisions. Due to trans youths' unique knowledge of their gender identity and embodiment, fundamental components of their personal identity, parents and courts should only hold decisional authority in the rarest and most extreme of cases. Although this paper focuses on gender-affirming care, this conclusion would seemingly hold for many other forms of definitional care such as abortion.

The argument presented in this paper focuses on the allocation of decisional authority once an intervention is offered by a healthcare professional. As such, I did not argue that healthcare professionals should not require psychological assessments before offering gender-affirming care, beyond identifying gate-keeping as a hindrance t decision-making. While I am of the view that such assessments are ineffective, that minimally autonomous trans individuals are better positioned than clinicians to assess whether gender-affirming care suits them, and that any proposed restriction on access bears the burden of justification, defending these claims is beyond the scope of the present paper.

An advantage of approaching decisional authority through the lens of subsidiarity is that it circumvents contentious debates about full capacity to consent and provides a framework for allocating decisional authority for youths and adults who lack full capacity to consent due to age, maturity or disability. Everyone should normally be afforded decisional authority over genderaffirming care, regardless of whether they have full capacity to consent. Courts should recognise the principle of subsidiarity and incorporate the proposed framework into the mature minor doctrine. Emphasis should be put on supporting, rather than allocating, decision-making around gender-affirming care.

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## Original research

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