Bell v Tavistock et al – Video Presentation

1. The subject of this presentation is the recent decision of the Divisional Court in the well-publicised case of Bell v Tavistock[1].

2. The presentation will be split into two parts:

    a. What is the case about?

    b. What was the Court's decision?

Part I: What is the case about?

The Claim

3. The claim was for judicial review of the practice of the Defendant NHS Trust through its Gender Identity Development Service (GIDS) of prescribing Puberty Blockers to persons under the age of 18 who experience Gender Dysphoria.

4. The question for the Court was:

    Can children and young persons under the age of 18 provide informed consent to the prescription of puberty blocking drugs and if so, in what circumstances?

Gender Dysphoria

5. Gender Dysphoria ("GD") is a condition whereby a person experiences distress because of a mismatch between their perceived identity and their natal sex (or sex at birth). Such a person has a strong desire to live according to their perceived identity rather than their natal sex.

6. GD is defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)[2] which provides for one overarching diagnosis of gender dysphoria with separate specific criteria for children and for adolescents and adults:

    "*In adolescents and adults gender dysphoria diagnosis involves a difference between one's experienced gender and assigned gender, and significant distress*

[1] Bell & Anor v The Tavistock and Portman NHS Trust [2020] EWHC 3274 (Admin)
[2] Para 12 Bell (supra);

or problems functioning. It lasts at least six months and is shown by at least two of the following:

1. A marked incongruence between one's experienced / expressed gender and primary and / or secondary sex characteristics
2. A strong desire to be rid of one's primary and / or secondary sex characteristics
3. A strong desire for the primary and / or secondary sex characteristics of the other gender
4. A strong desire to be of the other gender
5. A strong desire to be treated as the other gender
6. A strong conviction that one has the typical feelings and reactions of the other gender.

In children, gender dysphoria diagnosis involves at least six of the following and an associated significant distress or impairment in function, lasting at least six months:

1. A strong desire to be of the other gender or an insistence that one is the other gender
2. A strong preference for wearing clothes typical of the other gender
3. A strong preference for cross-gender roles in make-believe play or fantasy play
4. A strong preference for toys, games or activities stereotypically used or engaged in by the other gender
5. A strong preference for playmates of the other gender
6. A strong rejection of toys, games and activities typical of one's assigned gender
7. A strong dislike of one's sexual anatomy
8. A strong desire for the physical sex characteristics that match one's experienced gender."

7. Those with Gender Dysphoria may be referred to the Gender Identity Development Service (GIDS)[3]. GIDS may then refer them to a NHS Trust. Once referred, a clinician may then be prepared to undertake medical interventions. 3 stages of intervention are recognised:

    a. Stage 1: The administration of hormone or puberty blocking drugs (PBs). These drugs suppress the physical developments that would otherwise occur during puberty. This is clinically appropriate for children and young people who have reached Tanner Stage 2 of puberty and above (the beginning of the physical development of puberty – start of development of breasts in girls, and in boys the testicles and scrotum begin to get larger). The effects of PBs are said to be reversible.

    b. Stage 2: The administration of cross-sex hormones which can only be prescribed from around the age of 16. Cross-sex hormones are to a very significant degree not reversible.

[3] https://gids.nhs.uk

c. Stage 3: Gender reassignment which is only available via adult services to people aged over 18.

8. Stage 1 Puberty Blockers can be prescribed for Gender Dysphoria through the NHS to children as young as 10. It is the practice of GIDS to require the informed consent of a young person to whom the PBs are prescribed.

Who are the parties?

9. The **Claimants** are Keira Bell and Mrs A. Mrs A is the mother of a 15 year old girl who has ASD, and a history of mental health and behavioural problems. Mrs A is worried her daughter – who is desperate to run away from all that made her female – will be referred to GIDS and prescribed PBs. Currently, Mrs A's daughter would not meet the criteria for PBs as her parents do not support the treatment. Mrs A's involvement was thus largely theoretical.

10. **Keira Bell** was born female and describes an account of her journey to a diagnosis of Gender Dysphoria when, at 15, she was referred to GIDS. At 16, she was referred for Puberty Blockers. She says her priority was to move on to testosterone.

11. At 17, Keira Bell commenced testosterone which she was prescribed for 3 years. She says she began to doubt the process of transition. Nevertheless at the age of 20 she underwent a double mastectomy. Thereafter, she began to realise that the vision she had in her teens of being male did not fit with her reality[4]. In her early 20s she stopped taking testosterone. Keira Bell now wishes to identify as a woman. She says she feels she made a brash decision as a teenager and regrets the irreversible physical, mental and legal changes she went through.

12. The **Defendant** is the **Tavistock and Portman NHS Trust**. This is one of only a handful of NHS Trusts to whom the Gender Identity Development Service may refer a child or young person for assessment by as a clinician with a view to possible medical intervention. The Defendant asserts that Keira Bell was *Gillick* competent and was provided with the fullest information after a large number of consultations. The Defendant provided evidence from other children and young people who report to be strongly supportive of the treatment they have received[5].

What were the competing arguments?

13. The Claimants' case was that:

a. Children and young persons under 18 are not competent to give consent to the administration of puberty blocking drugs;

b. Information given to those under 18 by the Tavistock is misleading and insufficient to ensure those children and young people are able to give informed consent;

[4] Paras 80-83 Bell (supra).
[5] Paras 85-88 Bell (supra).

c. The absence of procedural safeguards, and inadequacy of the information provided results in an infringement of the rights of such children and young persons under Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms ("the Convention").

d. In the circumstances, the Court should be guided by the approach of the Court of Protection in its Practice Guidance (Court of Protection: Serious Medical Treatment) [2020] 1 WLR 641 which sets out those decisions relating to medical treatment where an application should be made to the Court of Protection.

14. The Defendant's and the Interveners' case was that:

a. The GIDS' process for taking informed consent from a child under the age of 16 was lawful, compliant as it is with *Gillick* principles;

b. In respect of 16-18 year olds, if the patient, the parents and the clinicians are agreed, then the Court has no jurisdiction;

c. The child or young person only needs to understand and consent to Puberty Blocking treatment (Stage 1);

d. Where a child or young person has Gender Dysphoria and has reached the Endocrine Clinic, there is no alternative treatment option other than PBs to alleviate the individual's distress.

How did the Court approach the issues?

15. The Court took the view that it was appropriate to consider:

a. First, whether a child under 16, or a young person between 16 and 18, can give the requisite consent; and

b. Secondly, if in principle they can do so, whether the information provided by the NHS is adequate for achieving informed consent.

What evidence did the Court receive?

16. The Court stressed that it was not deciding on the benefits or otherwise of PBs for children or young persons with GD, or expressing a judgment on the nature of GD and treatments that may or not be appropriate. It did not consider its role to judge the weight to be given to various different experts. Rather, the Court considered the evidence base relied upon by the Defendant and the Interveners in their use of PBs, in particular:

a. On the use of PBs;

b. Their impact on patients, in the short and long-term;

c. On the efficacy of their use.

17. As to the age and patient group for Puberty Blockers:

a. Age distribution – limited data. The Court noted that a research study known as the Early Intervention Study commenced in 2011 had yet to be published and peer review was outstanding. The Court did, however, receive a paper purporting to evaluate the Early Intervention Study, but noted that age distribution (ie. numbers of children within each group who had been referred) for each year since the study commenced had not been collated. The Court expressed surprise that such data had not been collated, particularly where:
   i. the age range was between 10 and 18, and where the evidence was that some children could be on PBs for a number of years, at the extreme end for 5 years from the age of 10;
   ii. the experimental nature of the treatment; and
   iii. the profound impact that it has.

b. Dramatic increase in the number of referrals to GIDS – in 2009 the number was 97 and in 2018 the number was 2519.

c. Change in gender split – in 2011 roughly 50/50 between natal girls and boys, in 2019, 76% referrals were natal females.

d. Recorded within GIDS data and the wider literature that there is a higher prevalence of autistic spectrum disorder conditions in children and young people who are presenting with GD than in the general adolescent population. And yet, as the Court noted, there was no data or analysis of the proportion of individuals referred for PBs who were considered *Gillick* competent who had ASD or a mental health diagnosis.

18. As to the process of taking consent:

a. GIDS' position is that they will only refer for PBs if they determine that that person is *Gillick*[6] competent to give consent. Clinicians within the relevant NHS Trust then conduct a reassessment of the child or young person's competence. The processes are explained in detail in the judgment[7]. The Court noted that the Defendant was unable to produce statistical material on the number, if any, of young people who had been assessed to be suitable for PBs but who were not prescribed them as either GIDS or the Trusts had considered them not to be *Gillick* competent. This provoked this observation:

"The court gained the strong impression from the evidence and from those submissions that it was extremely unusual for either GIDS or the Trusts to refuse to give PBs on the ground that the young person was not competent to give consent. The approach adopted appears to be to continue giving the child

[6] Gillick v West Norfolk and Wisbech Health Authority [1986] AC 112 https://www.bailii.org/uk/cases/UKHL/1985/7.html

[7] Paras 37-43 Bell (supra)

more information and to have more discussions until s/he is considered Gillick competent or is discharged." [8]

b. Evidence from within the field of Cognitive Neuroscience was to the effect that there are significant doubts about the ability of young people under the age of 18 to adequately weigh and appreciate the significant consequences that will result from the decision to accept hormonal treatment for GD. Professor Scott (UCL) explained the neurological development of adolescents' brains leads to teenagers making different, more risky decisions than adults. The Court highlighted Professor Scott's conclusion:

"11. ... given the risk of puberty blocking treatment, and the fact that these will have irreversible effects, that have life-long consequences, it is my view that even if the risks are well explained, that in the light of the scientific literature, that it is very possible for an adolescent to be unable to fully grasp the implications of puberty-blocking treatment. All the evidence we have suggests that the complex, emotionally charged decisions required to engage with this treatment are not yet acquired as a skill at this age, both in terms of brain maturation and in terms of behaviour."[9]

c. Parental consent: it is not the practice of GIDS to administer or to advocate for PBs to be administered without the patient's consent; whether someone with parental responsibility could consent was therefore not an issue to be considered by the Court.

19. The effect of Puberty Blockers

a. PBs are not new. They have been used for many years to stop precocious puberty. This use of PBs does not interfere with the normal development of puberty through adolescence.

b. The use of PBs for Gender Dysphoria is to halt the progression of puberty and cause the regression of some early stages of puberty.

c. There is a dispute as to the purpose of prescribing PBs for GD: one view is that the primary purpose is to give the person time to think about their gender identity; another view is that the treatment can have the effect of leading to Stage 2 – cross-sex hormone treatment, by generating persistence rather than creating space to decide.

d. There is limited evidence as to the psychological benefit of PBs.

20. The relationship between Puberty Blockers and Cross-Sex Hormones

[8] Para 44 Bell (supra)
[9] Para 46 Bell (supra)

a. The Court was concerned that whilst the Defendant argued that Stage 1 and Stage 2 treatments are separate, the evidence presented to the Court was that practically all children/young people who start PBs progress to CSH.

b. The Court expressed surprise again that the Defendant was unable to present full data as to their own figures and proportion of those on PBs who moved on to cross-sex hormones.

21. The impact of Puberty Blockers and their reversibility

a. On the available evidence, the physiological consequences of puberty blocking is reversible;

b. That said, most of the available evidence, is in respect of PBs for the treatment of precocious puberty;

c. There remain unknowns: the impact on bone density, fertility, brain development, neurological and psychological changes occurring in puberty;

d. The impact of stopping or delaying the maturing process – the normal biological, psychological and social experience through adolescence is halted and not recovered;

e. Arguably, once a young person starts on PBs they are on a very clear clinical pathway to CSH.

22. Evidence base to support the use of PBs for GD

a. There is a lack of firm evidence base for the use of PBs for GD and their effectiveness.

b. The degree to which the treatment is experimental and has an as yet unknown impact goes to the critical issue of whether a young person can have sufficient understanding of the risks and benefits to be able to lawfully consent to their treatment.

23. Persistence

a. Whether or not the use of Puberty Blockers serves to increase the likelihood of Gender Dysmorphia, and the Court declined to adjudicate thereon. But, the issue illustrates how unusual and complex the nature of the treatment is and the great difficulty there is in fully understanding its implications for the individual young person.

24. The Court's summary of the evidence gives a flavour of its view as to the lack of qualitative, longitudinal, robust, peer-reviewed research as to the wider and potentially adverse impact of PBs, their experimental nature, and the strong correlation between Stage 1 treatment (PBs) and Stage 2 treatment (cross sex hormones) (the latter being as good as irreversible).

Part II: What was the Court's decision?

25. The Court comprised of the President, Dame Victoria Sharp, a Lord Justice of Appeal, Lord Justice Lewis, and Mrs Justice Lieven.

26. Having reviewed the relevant authorities, the Divisional Court summarised the key principles:

    a. Whether a person under the age of 16 is Gillick competent to make the relevant decision, depends of the nature of the treatment proposed as well as that person's individual characteristics. The greater the significance and life-changing nature of the decision, the greater the onus to ensure the child understands and is able to weigh the information.

    b. Some lines can be drawn though – the Trusts themselves accept that a 7 year old being treated with puberty blockers for precocious puberty cannot give informed consent and his or her parents must give that consent because of the young age of the child concerned and the nature of the treatment.

    c. Clinicians should work towards helping a young person to achieve Gillick competence.

    d. Not every child under 16 can achieve Gillick competence in relation to a proposed treatment – where benefits unclear, treatment profound, long-term consequences to a material degree unknown.

    e. Bar for achieving Gillick competence should not be set too high. What is required is sufficient understanding of the salient facts.

    f. What facts are salient and what level of understanding is sufficient, requires highlighting matters which objectively a child might be concerned about in the future even though the child is currently unconcerned about them (eg fertility, sexual functioning).

27. In addressing ***the first question posed by the court[10], namely, "Whether a child under 16, or a young person aged between 16 and 18, can give the requisite consent"*** the court determined that the starting point is to consider the nature of the treatment proposed. The nature and the purpose of the medical intervention must be considered. It concluded that the clinical intervention it was concerned with is different in kind to other treatments or clinical interventions. In other cases, medical treatment is used to remedy, or alleviate the symptoms of, a diagnosed physical or mental condition, and the effects of that treatment are direct and usually apparent. The position in relation to puberty blockers would not seem to the court to reflect that description. Dame Victoria Sharp P explained that the consequences that flow from taking puberty blockers for Gender Dysphoria and which must be considered in the context of informed consent, fall into two categories, firstly those that are a direct result of taking the puberty

[10] See paragraph 15 supra

blockers themselves, and secondly those that follow on from progression to stage 2, the taking of cross-sex hormones. The Defendant and the Trusts argued that Stage 1 and Stage 2 are entirely separate; that a child can stop taking puberty blockers at any time and that Stage 1 fully reversible. On that basis they argued that the child needs only to understand the implications of taking puberty blockers alone in order to be *Gillick* competent. The Court rejected this view on the basis that in its view this did not reflect the reality and pointed to the evidence that shows that:

a. the vast majority of children who take puberty blockers move on to take cross-sex hormones;

b. Stages 1 and 2 are two stages of one clinical pathway;

c. Once a child is on that one clinical pathway it is extremely rare for a child to get off it.

28. The Court also observed that the use of puberty blockers is not a neutral process that pauses time for a child, either physically or psychologically. Puberty blockers prevent the child going through the normal biological process, which means that at least they are not undergoing the physical and consequential psychological changes which would contribute to the understanding of a person's identity. The Court noted that for some children, this may confirm the child's chosen identity at the time that they start to use puberty blockers and to that extent confirm their gender dysphoria and increase the likelihood of some children moving on to cross-sex hormones. The existence of a statistical correlation between the use of puberty blockers and cross-sex hormones in the court's view supports the case that it is appropriate to view puberty blockers as a stepping stone to cross-sex hormones.

29. The Court therefore did not accept that Stage 1 and 2 are distinct and separate processes that should be viewed independently.

The Court concluded that[11]:

" … to achieve Gillick competence the child or young person would have to understand not simply the implications of taking puberty blockers but those of progressing to cross-sex hormones. The relevant information therefore that a child would have to understand, retain and weigh up in order to have the requisite competence in relation to puberty blockers would be as follows:

(i) The immediate consequences of the treatment in physical and psychological terms;

(ii) The fact that the vast majority of patients taking puberty blockers go on to cross-sex hormones and therefore that s/he is on a pathway to much greater medical interventions;

(iii) The relationship between taking cross-sex hormones and subsequent surgery with the implications of such surgery;

[11] Paragraph 138

(iv) The fact that cross-sex hormones may well lead to a loss of fertility;

(v) The impact of cross-sex hormones on sexual function;

(vi) The impact that this step on this treatment pathway may have on future and life-long relationships;

(vii) The unknown physical consequences of taking puberty blockers; and

(viii) The fact that the evidence base for this treatment is as yet highly uncertain."

The Court concluded that it would "*obviously*" be difficult for a child under the age of 16 to understand and weigh up such information. The Court referred to:

"141. *Some of the children and young people who have been treated at GIDS* [who] *say in their witness statements that the thought of sex disgusted them, or they did not really think about fertility. These normal reactions do not detract from the difficulties surrounding consent and treatment with puberty blockers. That adolescents find it difficult to contemplate or comprehend what their life will be like as adults and that they do not always consider the longer-term consequences of their actions is perhaps a statement of the obvious.*

142. These various difficulties are compounded by the particular difficulties prevalent in the cohort of children treated at GIDS. On the defendant's case, they suffer considerable psychological distress by reason of their gender dysphoria and are highly vulnerable. In those circumstances, the consequences of taking puberty blockers on their fertility for example, or on their sexual life, may be viewed as a relatively small price to pay for what may be perceived as a solution to their immediate and real psychological distress. It would not follow however that their weighing of the risks and benefits when they might start taking puberty would prevail in the longer-term."

30. Another factor which troubled the Court is the lack of evidence as to efficacy of puberty blockers in treating gender dysphoria and the long-term outcome of taking it. The combination of lifelong and life changing treatment being given to children, with very limited knowledge of the degree to which it will or will not benefit them is one that gave the Court *"... significant grounds for concern."*[12]

31. Significantly, the Court did not consider that the answer to the case lies in giving the children more and more detailed information. The Court identified the issue in many cases to be that, however much information the child is given as to long term consequences, they will not be able to weigh up the implications of the treatment to a sufficient degree.

32. The Court deemed it appropriate to give clear guidance as to the application of the *Gillick* test to the treatment and cohort of children in question:

[12] Paragraph 143 of the judgment

"145. *… The conclusion we have reached is that it is highly unlikely that a child aged 13 or under would ever be Gillick competent to give consent to being treated with puberty blockers. In respect of children aged 14 and 15, we are also very doubtful that a child of this age could understand the long-term risks and consequences of treatment in such a way as to have sufficient understanding to give consent. However, plainly the increased maturity of the child means that there is more possibility of achieving competence at the older age."*

33. In respect of those young people aged 16 and over there is of course a presumption of capacity under section 8 of the Family Law Reform Act 1969. However that does not mean that a court cannot protect the child under its inherent jurisdiction if it considers the treatment not to be in the child's best interests. But, if the young person has mental capacity and the clinicians consider the treatment to be in their best interests, in the absence of a possible dispute with the parents then the court is unlikely to have a role.

34. That is not to say that the Court did not see a role for itself where the use of puberty blockers and cross-sex hormones is concerned. The Court no doubt recognised the impact of its decision and reasoning on treating clinicians and stated:

" 147. … *clinicians may well consider that it is not appropriate to move to treatment, such as puberty blockers or cross-sex hormones, without the involvement of the court. We consider that it would be appropriate for clinicians to involve the court in any case where there may be any doubt as to whether the long-term best interests of a 16 or 17 year old would be served by the clinical interventions at issue in this case.*

148. We express that view for these reasons. First, the clinical interventions involve significant, long-term and, in part, potentially irreversible long-term physical, and psychological consequences for young persons. The treatment involved is truly life changing, going as it does to the very heart of an individual's identity. Secondly, at present, it is right to call the treatment experimental or innovative in the sense that there are currently limited studies/evidence of the efficacy or long-term effects of the treatment."

35. The Court identified that, perhaps apart from life saving treatment, there will be no more profound medical decisions for children than whether to start on this treatment pathway. In those circumstances, it considered it appropriate that the court should determine whether it is in the child's best interests to take PBs.

36. Turning to the second question the court posed, ***the adequacy or otherwise of the information provided to children and young people by the Trusts***. The court accepted that the defendant and the Trusts have in their written information to children, young people and parents/carers tried hard to explain the consequences of taking PBs, including that of moving to cross-sex hormones and to give full information and to do so in an age appropriate way. However the court identified the problem to be not the information given, but to be the ability of the children and young people to understand and most importantly in the court's view, to be able to weigh up that information. The court expressly rejected what it identified as the Defendant's assumption that if a child is given information which is discussed with them sufficiently often, then they will be able to achieve *Gillick* competency. That assumption is incorrect.

What next?

37. The Court of Appeal has granted the Tavistock permission to appeal; the appeal is expected to be heard in June 2021. We predict that whether the Divisional Court has improperly restricted the decision in *Gillick* is likely to feature in the arguments before the Court of Appeal.

38. Although the Divisional Court's decision is stayed pending the appeal, GIDS has nevertheless effectively suspended endocrine treatment for GD in children under the age of 16 save where a Court sanctions the treatment on a best interests basis[13].

39. On 2nd February 2021, the Early Intervention Study to which the Court was referred by the Defendant was published: the study is in respect of a cohort of 44 young people between 2011 and 2014.[14] At the end of the study 98% (43) chose to progress to cross sex hormone treatment. GIDS[15] reports:

    Overall, the paper suggests that larger and longer-term prospective studies using a range of designs are needed to more fully quantify the benefits and limitations of pubertal suppression for those experiencing gender dysphoria. The study size and uncontrolled design were key limitations, meaning small changes in outcomes and causality could not be determined. This cohort will be followed up longer-term to examine physical and mental health outcomes into early adulthood.

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Deans Court Chambers
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[13] https://gids.nhs.uk/news

[14] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0243894

[15] https://gids.nhs.uk/news-events/2021-02-02/early-intervention-study-shows-puberty-blockers-are-well-received