Mermailes' Short Report "Everything feels stacked against us"

Two years on: understanding the impact of the 2020 Bell v Tavistock Case on transgender, non-binary and gender diverse children, young people and their families.

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Introduction

On 1 December 2020, Mermaids, Gendered Intelligence and LGBT Foundation, together with Dr Anna Carlile (Goldsmiths, University of London), launched an online survey in response to the Bell v Tavistock case ('*Bell*'), which asked the parents and carers of young transgender and non-binary people (shortened to 'trans' hereafter) what impact the case had on their family.

Over 230 parents/carers responded to the survey. Many of them felt their child had been let down by the ruling, and that young trans people were now left in limbo when it came to accessing gender affirming healthcare. Many felt they had little hope of knowing when it would be given again, or what the future held for them.

Two years on and this judgment continues to cast a long shadow over access to gender affirming healthcare in the UK, and *Bell* is still cited by organisations who believe young trans people should not have access to gender affirming healthcare. Despite *Bell* being permanently overturned in 2022, the repercussions of the case are still felt today.

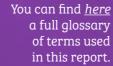
It is hoped that the findings from our survey will help support those shaping the future of healthcare, and offer recommendations for improving it for young trans people. Some key findings were:

- 1. 9 out of 10 people said the outcome of *Bell* had negatively affected their mental health,
- 2. Over a third of respondents said it was very likely they will need to look for gender-affirming hormones in less safe places, such as overseas or on the internet,
- 3. School, work and home life suffered,
- 4. Many parents felt powerless and guilty that they could not help their child more,
- 5. Transphobia in the UK was only going to get worse due to *Bell*.

Accessing gender affirming healthcare for young trans people remains challenging, and this report offers an opportunity to remember why the work Mermaids, Gendered Intelligence and LGBT Foundation do in reducing those challenges is so important. Young people deserve to be respected and they deserve to be listened to. We thank you for reading and welcome any thoughts, comments or feedback.



Kai O'Doherty Head of Policy and Research "I was unable to look him in the eye and tell him it will be ok... I am supposed to be the strong one our child can rely on."

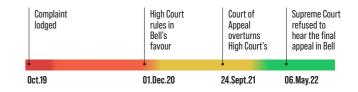


Contents

Introduction	2
What was Bell v Tavistock?	4
Methodology	5
Key Findings	6
The system is unfair and causes more harm than good	6
Impact on mental health	7
Worrying about even longer waiting times	8
The impact on accessing gender affirming hormones	9
Turning to the unknown for help	10
The impact on family, home and school life	11
Feeling powerless	12
Unfairness of denied bodily autonomy	13
Concerns for the wider trans community and the future	14
2022: Update on <i>Bell</i>	15
Conclusion	15



What was Bell v Tavistock?



In October 2019 in the UK, a judicial review (or complaint) was lodged against the Tavistock & Portman NHS Foundation Trust Gender Identity Development Service (GIDS), by 'Mrs A' and Keira Bell*.

The complaint was centred on whether people under 18 years of age could consent to puberty blockers as a matter of law. *Bell* argued that puberty blocking treatments are being unlawfully administered by GIDS to children who cannot properly consent and claimed that puberty blockers were experimental and potentially misleading. At the heart of the complaint was Keira Bell's regret at transitioning.

On 1 December 2020, the court ruled in Bell's favour. Immediately NHS England issued an amended service specification in respect of Gender Identity meaning the Tavistock couldn't accept new referrals. Access to gender affirming healthcare was immediately frozen, leaving young people who had been clinically recognised by experts as needing this healthcare in limbo.

The damage this decision did was immediate and catastrophic. The purpose of this report is to:

- Document the key concerns of parents and carers about the impact of Bell,
- Discuss the impact on families' mental health and well-being,
- Highlight the impact on the wider transgender community.

"My son felt hopeless at the ruling, that his opinions weren't valid, that he was worthless as a person."



^{*} The full citation for this case is R (on the application of) Quincy Bell and A -v-Tavistock and Portman NHS Trust and others [2020] EWHC 3274 (Admin), and the judgement text can be found <u>here</u>.

Methodology

The online survey was developed in response to the outcome of *Bell*. The survey was aimed at parents and/or carers who were responsible for a young trans person either:

- on the waiting list to be seen at the GIDS service,
- were currently receiving treatment within the GIDS service,
- or are/were considering requesting a referral to the service.

Data collection methods

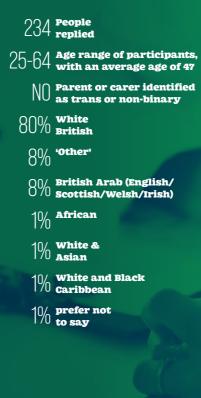
The survey was designed by Mermaids and Dr Anna Carlile. Data were collected by Mermaids via an online survey using a link to the platform Survey Monkey. All data has been anonymised and this report contains no identifiable information. The survey asked 34 open-ended questions and were a mix of tick box and free-text answers. Data were analysed by Mermaids, and used a combination of Nvivo software and manual thematic analysis.

Ethical approval was given by Goldsmiths, University of London Research and Ethics Committee.

Appropriate support was offered and made available to all participants and clearly signposted on the surveys, both at the start and at the end. You can find our support services <u>here</u>.

Participants

Participants were recruited through Mermaids, Gendered Intelligence and LGBT Foundation's secure online forums. People were encouraged to share the recruitment poster with their friends and social networks.





Key finding 1: The system is unfair and causes more harm than good

Respondents reported feeling that involving a judge and lawyers to decide about their child's access to gender affirming healthcare was unfair. Many felt access to healthcare was already stressful and challenging, and *Bell* encouraged delays and increased already long waiting times. Others felt that the matter of their child's healthcare was being decided by people who had no right (or expertise) to do so.

In fact, some parents felt involving the legal system only made matters more complicated, and increased waiting times even more. When puberty was imminent for young trans people, waiting in 'the system' had a negative impact on their own and their child's mental health. "People who are uninformed but allowed to make decisions that impact other people usually just end up doing more harm than good without realising it."

"I don't see why those with legal powers should have a say in whether a child deserves medical treatment or not. You wouldn't have a judge to decide whether a child should take anxiety medicine or not. Hormone blockers are reversible, and this will likely cause more harm than good."

"I feel like a judge shouldn't be involved in the process and if a judge were to get involved it's because there would be conflicting views on whether a child should get blockers because of their age."

"It is not anyone else's decision to make, it is purely the choice of the individual as it will affect them not the judge who has no connection to your life in any way. it is not a permanent thing therefore why should people be made to get approval from a judge?"

"There is no reason that the judicial system needs to interfere with healthcare issues when so many people and processes are already involved." "Lawyers are likely to be ill informed about the way gender dysphoria affects children and young people, and as such, may not have adequate understanding on appropriate treatments."

"Surely it should be up to educated clinicians rather than somebody trained in law. You wouldn't have to see a judge to get any other medication so why this one?"

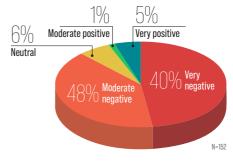
"Judges don't have enough experience of trans lives."

"Why should a judge decide on my child's medical outcomes and not a clinician?"

Key finding 2: Impact on mental health

Parents and Carers. We wanted to know the impact of *Bell* on parents and carers' own mental health. We asked them to rate this impact from very negative, to very positive.

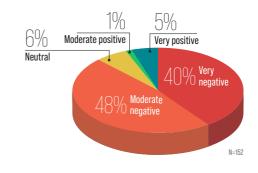
Almost 9 out of 10 people felt the outcome had a bad effect on their mental health.*



Reasons for this impact were very varied, but the one which stood out clearly was an overwhelming sense of injustice at the outcome of the case leading to negative mental health. Many felt lawyers and judges could never understand how their child really felt.

Young People. When we asked the same question to parents/carers about their child's mental health, the results were almost identical to the parents and carers. Almost 9 out of 10 people said their child's mental health had also been negatively affected.

This indicates that many parents care deeply about what the outcome of the case meant for them and their child, as well as for the rest of their family. It was clear the outcome had an impact on the whole family.



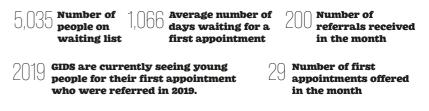
*This report appreciates that individuals' perceptions of each score is subjective, and one person's '5' is another person's '2' for example.



"The system is also vigorously thorough as it is with extremely long waiting times that are already distressing enough for a young person."

Key finding 3: Worrying about even longer waiting times

Lots of parents felt they had lost the power to help their child through an already intensely distressing time. One big cause of this distress centred on waiting times, which were already long before *Bell*. At the end of May 2022, waiting times for a first appointment at GIDS are:

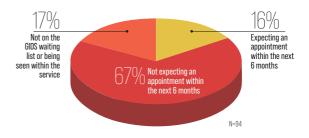


We asked parents if their child was on the waiting list to be seen by GIDS:

730/ **said yes**

Average number of months a child has been on the waiting list N=79

When we asked parents how long they are expecting to wait for an appointment, respondents answered:



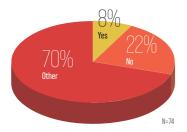
Waiting times create false hope, are distressing and make people feel unsupported and forgotten about. Participants knowing where they were on the list and more frequent communication would help improve their and their child's mental health.

"On waiting list for over two and a half years with no communication about what is happening. Very distressing for both my child and rest of the family."



Key finding 4: The impact on accessing gender affirming hormones

A big concern from respondents was how *Bell* would severely limit access to gender affirming hormones, such as puberty blockers. We asked if people had experienced any difficulty obtaining medication since 1 December 2020.



What is interesting with this result is that 70% of people were concerned about *Bells* impact. The complex reality of accessing gender affirming care highlights how listening to the lived experiences of those impacted is crucial.

No matter what each individual's circumstances were, or where their child was on their own journey, everyone was having to deal with an unknown and worrying situation, with no support or guidance. **"Our** child is with a private clinic but the effects on our family of the judgement were nonetheless significant. We have been seen by endo but they are refusing to

prescribe

binary."

blockers as

child is non-

"We have been unable

been unable to book a next appointment as we don't know if the Tavistock will prescribe/ the GP will administer."

"Last

injection was done on 1st Dec so we don't need to try and get another one yet."

"Daughter is 16 and was due to commence gender affirming hormones on 17 Dec but this has now been delayed whilst Tavistock and UCLH try to work out "new process' given the judicial verdict."

"SO far, there is no indication that this has been impacted, but I am concerned that the GP prescribing puberty blockers may withdraw care."

"We are with Gender GP, and our 16-year-old son was getting hormones from a clinic. They will no longer supply us, so we've had to get a paper prescription and find a local independent pharmacy at higher cost. This independent pharmacy has concerns about supplying us once we leave the EU. There always seems to be a hurdle, every step of the way!"

"We had already collected the Blocker from the chemist the week before the judgement and the Surgery nurse did the injection the day after the judgement. We were nervous the message might have got through to the surgery/nurse not to give the injection but nobody mentioned anything about the judgement thankfully! But it was only 24 hours since the news so I think we were lucky."

"TOO early to say as they received their most recent prescriptions and injections a week before the case,"

"We haven't yet tried/ needed to get a repeat prescription but are worried about when it becomes due." **"OUP** daughter was due to have her first blood tests this week, dexa scan in the new year. She's devastated and puberty is progressing rapidly."

"We were due to have our first endocrinology appointment in early Dec and that was cancelled immediately after the court ruling :("

"Last prescription was November, next one due in January so we have an anxious wait to find out if the prescription will be allowed."

"We have been seen by endo but they are refusing to prescribe blockers as child is non-binary."



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"The impact of paying for private counselling and care for my child and them just hating being alive has had a huge impact on my mental health."

"We made the difficult decision to see a private doctor and this put financial strain on our family, but we went private to save him."

"I have shielded him from the whole media information storm and hopefully and fortunately been able to afford to go privately for the blockers otherwise I would be very frightened of how it will impact upon his mental health."

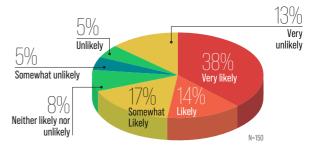
Key finding 5: **Turning to the unknown for help:** going private, the internet and overseas

The cost of going private. After *Bell*, NHSE suspended all new referrals, and no longer renewed prescriptions for puberty blockers. For those still on GIDS's already long waiting list, 11% (N=152) felt they had no solution other than to pay for private counselling.

Private care is expensive, and for the remaining 89% of respondents, this cost puts it beyond their reach. Understandably many families are unable to afford private health care and medication, or found things 'financially very difficult.' Other options included 'asking family to help with costs of private care.' This expense also had an emotional toll.

Seeking out less-secure pathways. For those who could not afford private care, their options were limited: look for help overseas or online, or in many cases, just hope for the best.

We asked if *Bell* changed the likelihood of families seeking alternative, less secure care pathways, for example 3rd party non UK based private care, or self sourcing medication from the internet?



One major outcome of *Bell* was the impossible position it put people in. Having to seriously consider finding alternative and possibly fewer safe ways to help their child caused immense stress for some. This included some people worrying their child may look online for gender affirming hormones.

"He might look to the dark web for hormones."

"It is now likely that they will try to get illegal drugs online."

Some people seriously considered going abroad to seek help.

"We have been looking at emigration or migration or private overseas treatment."

"We are now forced to consider private or international care [which means a] risk of lack of care should things go wrong medically." "Administering medication without court approval is potentially a criminal offence that threatens our right to stay in the UK...it may not be an option for us. In that case we are going to have to move abroad, or one of us parents may do, with him, so the other can stay with our other kids." "It impacts all-round on the family: having to support YET another setback."

Key finding 6: **The impact on family, home and school life**

Additional stress factors were not just felt by the parent or young person concerned, but also rippled out to other family members, and into the workplace. People talked about how *Bell* affected work, school and other family members. For example:

- Using medication to ease anxiety
- Developing insomnia
- Crying excessively
- Their child losing hope

"I am struggling to concentrate at work."

"I was sent home from work because I couldn't stop crying. Husband similar, feel like we're in a stage of grief. We've done everything we could to support our son but now feel voiceless and despairing." "On waiting list for over two and a half years with no communication about what is happening. Very distressing for both my child and rest of the family."

"It feels like I'm having a long slow-motion panic attack, like I can't get my breath properly. I feel lost and completely abandoned by the NHS, to whom we have entrusted our daughter's care."

Finding ways to cope with these feelings had a negative effect on some individual's resilience and ability to socialise, with some young people not wanting to go to school. One parent was concerned for their child's attendance at school and the ongoing bullying could trigger a 'risk of further selfharm.' "He begged me, saying 'please don't leave me [at school], I'm not safe. I might do something to myself."

"My child is miserable, she hates her body, her mental health is so bad she's not getting out of bed. She's failing all her education."

As well as worry about bullying leading to selfharm, there was also another worry regarding the loss of confidence for young people. For example, one parent's child had recently started senior school. They said:

"With the new rules, my daughter, who already tries not to speak at school as she is so concerned about her voice, really can't see a way forward and can't see how she will be able to keep going to school."

"The decision was incredibly stressful and demoralising. I'm worried about my child's mental health, physical health and loss of human rights."

Key finding 7: Feeling powerless



92% Had not reached out to their GP for support after hearing about the case* M182

Many people expressed feeling powerless. They also felt guilty they could not do more to help their child. Some parents felt they had to mask their feelings so as to not worry their child.

Respondents noted feeling overwhelmed and felt they had somehow let their child down when *Bell* was announced. Other people said even when they could find a way to help their child, they were emotionally drained. For anyone who has responsibility for looking after a child, witnessing them experiencing something upsetting and wanting to help or fix this becomes overwhelming.

*You can read our report on 'The Lottery of Primary Care' <u>here</u>

- "It has been devastating for her to have had the rug removed from under her feet and to be stuck in a 'no-man's land' of not knowing how this situation will be resolved."
- "I feel guilty that I have let my child down, very anxious about how we are going to cope and support him. Not sleeping, finding it very difficult to focus and concentrate."
- "I feel the judgement assumes we and parents like us are somehow failing in our parenting and don't have our child's best interest at heart in supporting our child's wishes and accepting that she is transgender."
- "It's a horrible realisation as a parent that I cannot support my child to follow the treatment that is right for him. To have come so far in helping him overcome issues around control and trauma to then be told by this ruling that he cannot even be granted control over his own body - it's sickening."



Key finding 8: Unfairness of denied bodily autonomy

Respondents talked about the loss (and invasion) of bodily autonomy their child was experiencing. For example one parent described their child as feeling 'trapped in a body they cannot control for even longer.'

People described their child feeling 'distraught', 'scared', 'let down', 'trapped' and 'devastated'.

"People, even children who are old enough to make their own informed decisions, should have the right to bodily autonomy and freedom of choice."



"It is unfair that a person has to wait over 2 years for treatment let alone a child. No one gives a damn about them and the impact the changes to their body has on them. My child refuses to open the curtains or go outside due to feeling a freak because of the effects of testosterone on their facial features and bodily changes."

"I feel like they often try to think of what is best for the family, which is good, but excludes the child. Ultimately, the child is the patient and should be given autonomy over their own body and treatment."

"This sort of approach can alienate young people who may have nonsupportive parents and may discourage them from seeking help until reaching full adulthood."

"My child is scared about the negative impact [*Bell*] will have on their mental health if they have to go through puberty."

"He is now being forced to go through irreversible physical changes that could negatively impact their entire life, even if this goes against the recommendation of specialist doctors, his own wishes and my judgement as a parent." "I feel our transgender community has been discriminated against. It also makes me feel my child is even more yulnerable."

Key finding 9: Concerns for the wider trans community and the future

The impact of *Bell* was felt not only by young people and their families, but rippled out into the wider trans community.

Many who support a trans child also rely on support networks to help manage their own mental health and well-being needs. These networks are especially crucial when dealing with almost constant transphobia and media hostility, which has increased since Bell.

This is what people said.

"I can only interpret this ruling as transphobic. It has emboldened antitrans campaigners. which we have seen in transphobic articles and comments all over the media and social media. Misleading information was included in the ruling and further misleading information is being spread in the media and on social media."

"It's another victory for antitrans activists." "This situation is hard enough without people waving their flag of moral outrage ripping away hope that our children will receive the treatment they so desperately need."

Leaving a vulnerable community to weather hostility without support will inevitably lead to a rise in stress and anxiety, creating a negative impact on their long-term health and wellbeing.

"Being transgender is completely misunderstood and now my son will experience more transphobia as a result, so he is feeling down and fearful."

"He has been in his room a lot more as he feels not seen or understood by society and constantly judged by people that never speak to him or have any understanding of his needs." Many parents felt their child was now left:

"Without a safety-net."

"Left in limbo."

- "Having to deal with transphobia for the rest of their life."
- "My son is an emotional time bomb and to remove hope, support and access to critical healthcare is cruel and a violation of his human rights."

"It (Bell) has reinforced the feeling that after waiting 31 months for our first appointment, we won't be getting medication on **NHS until adult** services, very frustrated that we will need to keep on paying, distressed that so many friends have been devastated by ruling and just angry that another unsupportive position taken when it didn't need to be like that."



2022: Update on *Bell*

The Bell case was never supposed to 'be about the merits or otherwise' of the treatment of trans young people or the prescription of puberty blockers. This was the point made on 24 September 2021, when the Court of Appeal told the High Court that it got **Bellwrong**. The Court of Appeal also restated that the Tavistock's policies and practices are lawful. On 6 May 2022 the Supreme Court refused to hear the final appeal in Bell, refusing the application on the basis it raised no arguable point of law.



Conclusion

This report has offered a summary of key issues faced by young people and their families as a direct result of *Bell*. It has helped to bring wider attention to some of the ways in which *Bell* highlighted grave concerns for young people's mental health and well-being. In short, *Bell* threw up unnecessary barriers to those in desperate need of gender affirming healthcare, and propped up a system which seemed stacked against them.

Our findings found that closing the pathways available, even temporarily, had a major impact on the well-being of respondents and their children. Already frustrated by long-waiting lists and a lack of gender-affirming healthcare, people felt severely frustrated, undermined and abandoned. *Bell* gave little consideration to those it would inevitably impact, or that their needs warranted being sympathetically and sensitively addressed with more care.

At the time of writing life in the UK for trans, non-binary and gender diverse children, young people and their families continues to see barriers to gender-affirming health care and a lack of focus on their well-being. The UK Government's U-turn on promising to ban conversion therapy for trans people - despite evidence from its own <u>2017 research</u> which found trans people are almost twice as likely to experience it than cisgender people - demonstrates once again that the rights of trans and non-binary people are at best overlooked, and at worst deliberately denied.

Bell has been overturned, but those responsible for improving gender affirming healthcare for those under 18 are still not listening hard enough to what young trans people and their families are saying. Mermaids hopes this research goes some way to foregrounding those voices, ensuring young trans people have access to the timely and appropriate gender affirming healthcare they are entitled to, just like everyone else. A full glossary of terms used in this report is *available here*.

Details of our helpline services are also available.

Thank you to all those who took the time to respond to the original survey. Contact our Research Team via <u>email</u> or the <u>Mermaids website</u>



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