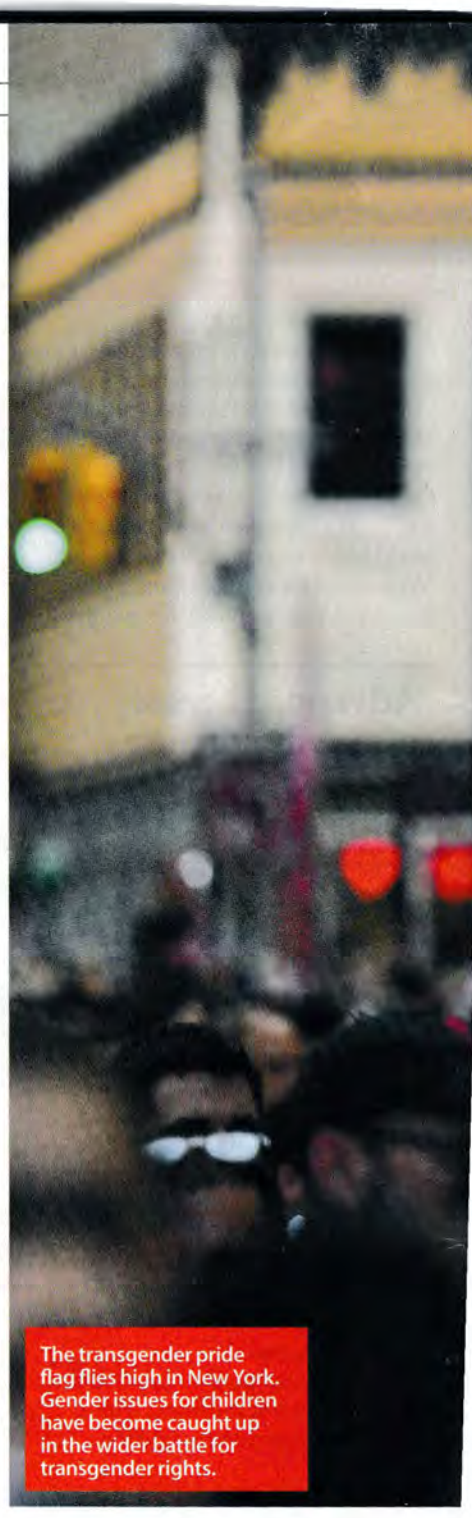
Age of uncertainty

Other countries have reviewed their use of puberty blockers for children and young people. New Zealand should too, argues CHARLOTTE PAUL.



The transgender pride flag flies high in New York. Gender issues for children have become caught up in the wider battle for transgender rights.

I am writing this article because my colleagues pleaded with me to do so. My younger colleagues, in particular, know they can't speak out because it could potentially damage their reputations.

I'm a medical epidemiologist and my relevant background is in research on sexual and reproductive health, the safety of medicines, and the ethics of research. My colleagues approached me because they're concerned about the rapid increase in the use of hormones to suppress normal puberty in children and young people who express discomfort with their biological sex. They're especially concerned that the grounds for accessing these hormones have widened greatly. How do we know this is doing more good than harm?

My colleagues are seeing in their clinics young people who have changed their minds about wanting to transition away from their biological sex and who also have serious mental health problems that have been left unaddressed. They doubt whether there is sufficient psychological assessment for children with gender dysphoria before they are prescribed puberty blockers – to help distinguish those who will remain transgender from those for whom it is a phase. They also question the capacity of children to consent to the intervention. They are worried about the lack of knowledge of long-term harms and benefits.

We all know that gender issues are highly contentious. The question has become polarised, and much commentary is written from a partisan perspective. That means there is extraordinarily little balanced information available to the public. Frank and fair discussion is surely necessary if we are to protect children and adolescents.

We should respect people who identify as trans and protect the best interests of children. How do we do this?

All trans people command our respect and deserve legal protection. Nevertheless, the widespread adoption of the idea of "gender identity", where gender (an inner sense of being male or female or non-binary) overrides biological sex, is surely both revolutionary and open to debate. Yet this notion of gender identity is the unquestioned context in which New Zealand children are now growing up, and the environment in which our doctors now practise.

CHANGED LANDSCAPE

"Gender dysphoria" is the term used where someone experiences distress because of a mismatch between perceived gender identity and birth sex. The US classification of mental disorders defines it as a difference between one's experienced gender and assigned gender.

It is only in the past decade that puberty blockers have been widely used for gender dysphoria. These hormones, gonadotropin-releasing hormone analogues, were first used in the 1980s to delay a very early puberty. The first use for gender dysphoria was reported in the Netherlands in 1998, under the "Dutch Protocol". A very small number of children who had "lifelong extreme gender dysphoria", were psychologically stable and had supportive families, were treated. The aim was

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to relieve their suffering and to improve their final physical outcomes.

This might have made sense as long as there were all the safeguards for experimental treatment in place. But the situation has got a lot more complicated since then. Originally, puberty blockers were seen as a pathway to transition. And almost all children went on to take cross-sex hormones so they could live as the other sex. Now, a huge increase in the number of children suffering gender dysphoria and a widening of the reasons to prescribe puberty blockers (to allow "a pause" for decision-making) have changed the landscape.

Since the start of the 21st century, there has been an explosion in referrals for gender dysphoria. For instance, in the Wellington region, the number of adults has increased from three per year between 1990 and 1994 to 48 per year between 2012 and 2016. In the UK, at the specialist Gender Identity Development Service (GIDS), also known as the Tavistock Centre, the number of children and young people referred increased 25-fold between 2009 and 2018.

These are huge increases, and they are continuing. Previously, it was mostly those born as boys who were accessing hormone therapy. It is now mostly those born as girls. More are apparently developing gender dysphoria only at puberty, more are on the autism spectrum, and more have underlying mental health problems. Since earlier studies show that 75-95% grow out of gender dysphoria over the time of puberty, it looks like we are in unknown territory in prescribing puberty blockers to this wider group of children. Many of those treated would not be expected to persist in their trans identity and thus not go on to cross-sex hormones.

The UK's national gender identity development service for children and adolescents is to be replaced by a regional model following damning reviews. Keira Bell, right, brought a case against the service.

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There is another major complication. In the centres where there has been some systematic follow-up, almost all children taking puberty blockers have gone on to take cross-sex hormones. This must mean either that there was careful psychological assessment so that only those expected to persist in their trans identity would be treated, or there is something about blocking puberty itself that affected young people, so they persisted.

This means that if they are being given puberty blockers, they are potentially exposed to harms with no benefits and might be put on a pathway they come to regret. So what are the potential harms of the treatment? Is it right to call this a "pause"? Can children consent in this situation?

A CASE OF REGRET

Concerns about the ability of children and young people to consent led British woman Keira Bell to bring a legal challenge against Tavistock in the UK High Court in 2020. Bell described a highly traumatic childhood in which she was gender non-conforming. From 14, she actively questioned her gender identity, and at 16 she was given puberty blockers followed by cross-sex hormones. At 21, after a double mastectomy, Bell started to have regrets. She said at the ensuing judicial review: "I started to realise that the vision I had as a teenager of becoming male was strictly a fantasy ... Transition was a very temporary superficial fix for a very complex identity issue."

Here in New Zealand, "Rachel", a 23-year-old student from the South Island, told the *Listener* last year that she had longed to be a male from the age of 10. At 14, she was put on puberty blockers; at 15, she began taking testosterone; at 16, she had a double mastectomy; and at 18, a full hysterectomy. A year later, she started to regret what she had done: "Transgender ideology stopped making sense to me and I thought, 'Wow, with time and with the right support, I could have lived perfectly happily as a masculine lesbian woman.'"

Psychological exploration could result in young people coming to a different realisation of their "embodied distress".

Am I right to worry about harms with no benefits? What do we know about harms? The Ministry of Health website describes puberty blockers as "a safe and fully reversible medicine that may be used from early puberty through to later adolescence to help ease distress and allow time to fully explore gender health options".

This was not the view of the UK High Court in the Keira Bell case. The court concluded that puberty blockers were not known to be safe, nor fully reversible. Given the complexity of the decision, the court concluded it was highly unlikely that a child of 13 or under would be competent to give consent, and doubtful that a child of 14 or 15 could understand the long-term risks and consequences.

The British Court of Appeal overturned the specific declaration of the High Court that court authorisation should be sought before minors could be given puberty blockers. It gave the evaluation of competence back to clinicians. Nevertheless, the judgment stressed the importance of recognising the "difficulties and complexities" around the issue of consent by children.

In the UK, the NHS responded to the

case by establishing a review, led by eminent paediatrician Dr Hilary Cass. In her first interim report, she described a lack of the quality controls that would typically be applied for new and innovative treatments, and a lack of routine and consistent data collection to track outcomes.

Sweden's National Board of Health and Welfare undertook a similar review. Its updated guidelines concluded that hormones should be avoided except in exceptional cases. Finland has also issued new strict guidelines. In France, the National Academy of Medicine now advises "great medical caution" in paediatric gender transition.

PSYCHOTHERAPY FIRST

In April last year, I wrote to the Minister of Health, asking whether the ministry was planning to review the use of puberty-blocking hormones for gender dysphoria. In December, I received a reply that it wasn't, and it was "a matter for discussion between a treating clinician and their patient, ensuring that patients are fully informed of their options (including any benefits, risks and alternatives) to make an informed choice and give informed consent".

The ministry provided information on the use of puberty-blocking hormones. In the 10-17 age group, there was a 66% increase between 2017 and 2020, from 305 children treated to 505. The true total will be a little lower, but assuming prescribing for early puberty has not changed over time, the increase will be in use for gender dysphoria.

We cannot be sure about the impact of stopping these hormone surges of puberty on psychosexual and gender maturation.

I also asked about psychological assessment before prescription of puberty blockers. My colleagues' concerns highlighted the importance of proper psychological assessment. Case studies showed that psychological exploration could result in young people coming to a different realisation of their "embodied distress", no longer believing they were transgender. The Royal Australian and New Zealand College of Psychiatrists' spokesperson now recommends a psychotherapy-first approach, because exploration of the patient's reasons for identifying as transgender is essential.

The reply from the ministry did not address the question, making only the same general statement about informed consent. But I found another huge complication. New Zealand's current medical guidelines are labelled as "gender affirming" and imply that the experience of being "trans" is a fixed state – and the increase in numbers is because the social environment now allows trans expression. In this case, no psychological exploration is called for.

But "trans" is not a fixed state, as childhood studies and the experience of de-transitioners show. It is a truism that puberty is a time of flux. There are also new and pervasive influences in the social environment – especially online, even in schools – which make psychological exploration particularly important.

I found few medical studies of regret and de-transition, although there are many testimonies online. The clinic in Amsterdam that pioneered the Dutch Protocol has followed up people to 2015. Reassuringly, it reported that less than 1% of its highly selected group regretted

REX FEATURES

Out there: a transgender rights demonstration in London in August 2021.

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transition if they had continued to the end of the process. But fewer than 10% of the people in their study had received puberty blockers, and most received them after 2000. Of those who had regrets, the average time lapse was 10 years. So, it provides no answers for the larger numbers of young people with different characteristics who have been prescribed puberty blockers more recently.

UNAPPROVED TREATMENT

I was surprised to discover that puberty-blocking hormones are not approved for use for gender dysphoria – not by Medsafe here, nor by the US Food and Drug Administration, nor the European Medicines Agency. It is probably because there is simply insufficient evidence available about benefits and harms. It also means that extra precautions are required.

In NZ, the Medical Council issues guidelines for unapproved medicines, or those unapproved for particular uses. Unapproved medicines must be subject to monitoring, to prior discussion with a senior colleague, and the patient must be given extra information about risks and benefits – including that the medicine was being prescribed for an unapproved indication. None of this (apart from monitoring height and bone density) is mentioned in the New Zealand guidelines for gender-affirming healthcare.

Though the Ministry of Health persists in claiming puberty blockers are "safe and fully reversible", the updated guidance from the UK NHS has moved away from this claim. It states that "little is known" about the long-term side effects. It also states that although it is a physically reversible treatment if stopped, "it is not known what the psychological effects may be". It's also not known, it says, whether hormone blockers affect the development of the teenage brain or children's bones. It notes that side effects may include hot flushes, fatigue and mood alterations.

Even the question of benefits is far from resolved. A recent systematic review concluded that, for body image, mental health and psychosocial impact, there was little change with the use of puberty blockers.

The most telling and worrying commentary on potential harms has just come from Dr Hilary Cass in the UK. In July, Cass wrote to the NHS recommending the disestablishment of the GIDS and the setting up of regional services much more closely related to existing child and adolescent mental health services.

It has since been announced that the Tavistock centre will close in the northern hemisphere spring next year, and a new model established.

Cass' letter homes in on the dangers of using these hormones to give a "pause" for decision-making when they might be actively arresting development. She says that brain maturation may be temporarily or permanently disrupted and that may have an impact on the ability to make a risk-laden decision.

The most significant knowledge gaps, said Cass, are in relation to treatment with puberty blockers, "and the lack of clarity about whether the rationale for prescription is as an initial part of a transition pathway or as a 'pause' to allow more time for decision-making". It is the latter option we have the least information about, she wrote. "We do not fully understand the role of adolescent sex hormones in driving the development of both sexuality and gender identity through the early teen years, so by extension we cannot be sure about the impact of stopping these hormone surges on psychosexual and gender maturation. We therefore have no way of knowing whether, rather than buying time to make a decision, puberty blockers may disrupt that decision-making process."

COMPLEX MORAL QUESTIONS

In New Zealand, in the face of this real uncertainty about both benefits and harms – and the lack of safeguards and monitoring – why has the Ministry of Health not commissioned a review? Was the ministry reassured by people working in the field who presented a different view of what constitutes harm?

The specialists who wrote the New Zealand gender-affirming guidelines are associated with the World Professional Association for Transgender Health (WPATH). In 2020, WPATH rejected the UK High Court judgment and expressed grave concerns about withholding puberty blockers until age 16. Children and their parents have bravely gone on TV to talk about the child's positive experience with puberty blockers. Is it too tender for clinicians to acknowledge uncertainties in the face of children they have affirmed and encouraged?

All this has led me to realise that there is more than one moral consideration here: we should respect people who identify as trans and protect the best interests of children. How do we do this? So far, there has been a conflict. The current idea, that gender identity must be affirmed as well as respected, has given no room for the possibility that adopting a trans identity – encouraged by social media – may be a passing phase or a temporary answer to a complex identity issue. Hence, I want to stress the separate moral consideration: the protection of the best interests of children.

Health authorities around the world are formally reviewing guidance in this sensitive area. It is time for New Zealand to get up to speed. ▮

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