

20 January 2025

Ministry of Health

Via email: pbconsultation@health.govt.nz

Tēnā koutou

Introduction

- Te Kāhui Tika Tangata | The Human Rights Commission ("the Commission") welcomes the
 opportunity to provide feedback as part of Manatū Hauora | Ministry of Health's ("the
 Ministry") consultation on safety measures for the use of puberty blockers in young people
 with gender-related health needs.
- 2. The Commission is New Zealand's National Human Rights Institution, with a broad mandate under section 5 of the Human Rights Act 1993 to advocate and promote in Aotearoa society respect for, and an understanding and appreciation of, human rights and the human rights dimensions of Te Tiriti o Waitangi ("Te Tiriti"). The Commission's role includes monitoring New Zealand's implementation of, and assisting New Zealand to meet, its international human rights obligations.
- 3. Children's rights are key to this issue and process. The Convention on the Rights of the Child requires that decisions affecting children are made in their best interests. The Commission urges all actors to ensure that they are working to promote children's best interests and to limit harm to children in decision-making about process and about substance.
- 4. The below feedback outlines a number of ways that the consultation process could be improved to be more aligned with a human rights-based approach; and draws the Ministry's attention to human rights standards that are particularly relevant to the consultation. We also offer some points relating to the substance of the consultation, as outlined in the Ministry's consultation documents: Impact of Puberty Blockers in Gender-Dysphoric Adolescents: An evidence brief (2024) ("the Evidence Brief"); Addendum to Impact of Puberty Blockers in Gender-Dysphoric Adolescents: An evidence brief ("the Addendum") and Position Statement on the Use of Puberty Blockers in Gender-Affirming Care ("the Position Statement").
- 5. The Commission would welcome the opportunity to meet to further discuss any of the points in the below feedback, if that would be useful to the Ministry.

¹ Article 3. See Mana Mokopuna <u>Being child-centred - Decision tool</u>.

Process

Open public consultation

- 6. Transgender children are a gender minority, estimated to be around 1% of New Zealand children.² Some of these children will experience distress due to gender incongruence. Taking a human rights-based approach, it is critical to pay particular attention to upholding the rights of minorities and marginalised groups, as they are often subject to high levels of discrimination and even violence.³ "Respect for minority rights assists in achieving stable and prosperous societies, in which human rights, development and security are achieved by all and shared by all."⁴ This means that it may be inappropriate to allow majority views to determine minority rights.⁵
- 7. These human rights principles and guidance should be carefully considered in the approach to consultation, and analysis of the information collected. As discussed below, significant weight should be placed on opinions grounded in lived experience of gender incongruence, and on medical expertise.
- 8. An open public consultation on minority rights in a field of expert knowledge risks collecting misleading or incorrect information. The Commission urges caution in publication of the responses collected, to ensure that care is taken to be clear about the quality of any information published and to consider its impact on the affected minority.

Consultation with children

- 9. Consultation with children on issues which affect their rights is required under the Children's Convention.⁶ Safe and useful consultation with children needs to be done with care and cannot be rushed.
- 10. Whilst we understand that some children will be engaged in the consultation voluntarily and via some outreach done by the Ministry, we suggest that for an issue directly affecting

² See Jeffrey O'Malley et al. <u>Sexual and gender minorities and the Sustainable Development Goals</u> United Nations Development Programme (2018) at p 27 – 30; John Fenaughty et al. <u>A Youth19 Brief: Transgender and diverse gender students</u> Youth19 Research Group, The University of Auckland and Victoria University of Wellington, New Zealand; Evidence Brief at p 6.

³ See Jeffrey O'Malley et al. Sexual and gender minorities and the Sustainable Development Goals United Nations Development Programme (2018);); New Zealand Human Rights Commission Prism: Human rights issues relating to Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) in Aotearoa New Zealand - A report with recommendations (2020) at p 16: "Multiple comprehensive reviews show that people with a diverse sexual orientation and gender identity experience a higher risk of physical and sexual violence than the general population. In most cases, the person's sexual orientation or gender identity was a factor in the perpetration of the abuse. The United Nations Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity states, "the data available show that [lesbian, gay, bisexual, trans and gender non-binary persons] face the near-certainty of suffering violence during their lives, and that as a general rule [they] live every day in the awareness and fear of it." [Citations omitted.]

⁴ United Nations *About minorities and human rights: Special Rapporteur on minority issues*

⁵ See *R v Hansen* [2007] 3 NZLR 1 at [107].

⁶ See articles 3 and 12.

marginalised children's rights there needs to be a thorough consultation process to ensure adequate representation of views and insights of affected children.

Robust and active consultation

- 11. Transgender adults will also have useful and relevant information based on their experiences accessing gender affirming healthcare as children, and how this access (or lack of it) affected them. However, discussion of such a topic can be distressing, and must be done in a way that feels safe for participants. It has been reported that there were no transgender people in the Ministry's Expert Advisory Group because their safety was not assured. We encourage the Ministry to ensure that people with lived experience as transgender people are included in the Expert Advisory Group, while ensuring their safety. As was noted by the British Medical Association, a key principle in healthcare (and human rights) is 'no decision about me without me'.
- 12. The consultation period provided is approximately two months covering Christmas and New Year when many people, including families with children, are on holiday. This limits people's ability to provide feedback and may affect the quality of information received during the consultation.
- 13. We suggest the Ministry undertake further targeted safe consultation with transgender people, including transgender children making use of Mana Mokopuna's expertise in the area for the latter.⁹
- 14. There will also be some directly affected people who do not identify (now, or have not ever identified) as transgender or non-binary. Given that the decision to receive gender-affirming hormone treatment is a separate clinical decision, 10 and not all children using puberty blockers will identify as transgender, the Ministry may also seek to hear from people who used puberty blockers and did not continue with gender-affirming treatment, or who continued with further gender-affirming treatment for a limited period of time. While the consultation focuses on the use of puberty blockers only for the purposes of gender-affirming care, the Ministry may also benefit from hearing from people prescribed puberty blockers for other reasons.

⁷ Jennifer Shields <u>Gender-affirming care affects a small minority – so why the public consultation?</u> (4 December 2024).

⁸ British Medical Association <u>BMA to undertake an evaluation of the Cass Review on gender identity</u> services for children and young people (31 July 2024). See also <u>Principle 25(E)</u> of the Yogyakarta Principles.

⁹ See also Children's Convention Monitoring <u>Group Getting It Right: Are We Listening? Children's Participation Rights in Government Policy</u> (June 2019); Save the Children <u>So you want to consult with children? A toolkit of good practice</u> (November 2003).

¹⁰ Separate from the decision to take puberty blockers.

Human rights

15. Medical decisions should be primarily grounded in scientific and medical research. However, provision of healthcare is linked to many human rights standards, meaning there are relevant human rights duties on the State.

Right to health

- 16. New Zealand, as a party to the International Covenant on Economic, Social and Cultural Rights ("ICESCR"), has agreed to recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.¹¹ The right to health is also included in a number of other treaties which New Zealand has ratified.¹²
- 17. This right is central to the creation of equitable health systems and requires an effective, responsive, integrated health system that is accessible to all. There is evidence that a human rights approach to health has positive impacts on health and health services. ¹³ Applying human rights to health policies, programmes and other interventions not only helps governments comply with their binding obligations, but also contributes to improving the health of individuals.
- 18. We agree that "young people experiencing gender incongruence or gender dysphoria should have access to comprehensive quality care... which meets their physical and mental health needs and upholds their holistic range of rights as young people". 14 It is crucial that access to gender affirming healthcare is maintained and not weakened. In Aotearoa New Zealand, trans people are still frequently subject to discrimination which violates their human rights.

Freedom from discrimination

- 19. Unlawful discrimination by government breaches both the Human Rights Act 1993 and the New Zealand Bill of Rights Act 1990.¹⁵
- 20. Sex is a prohibited ground of discrimination under the Human Rights Act. It has long been interpreted by the government and the Commission as inclusive of gender identity which includes transgender and non-binary people.¹⁶ Although more clarity in statute would be

¹¹ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Human Rights Council, 44th session, A/HRC/44/48 (15 April 2020).

¹² Elimination of All Forms of Racial Discrimination (Article 5(e) iv); International Convention on the Elimination of All Forms of Discrimination Against Women (Articles 11(1) (f), 12 and 14(2)(b)); Convention on the Rights of the Child (Article 24); Convention on the Rights of Persons with Disabilities (Article 25).

¹³ See F Bustreo and P Hunt et al. *Women's and children's health: evidence of impact of human rights* (2013) World Health Organization.

¹⁴ Position Statement at p 5.

¹⁵ NZBORA 1990, s 19; Human Rights Act 1993, s 21.

¹⁶ In 2006 a legal opinion by the acting Solicitor-General concluded that transgender people were already covered by the Human Rights Act, leading to the Human Rights (Gender Identity) Amendment Bill 2004 (225-1) being withdrawn. See Cheryl Gwyn "Crown Law opinion on transgender discrimination" (23 August 2006). The opinion by the acting Solicitor-General cited decisions by Canadian, United Kingdom, and European courts, and found that the prohibition of discrimination on the ground of sex in the Human Rights Act includes prohibition of discrimination on the ground of gender identity. See Law Commission *la*

preferable,¹⁷ interpreting our human rights law this way is in line with international human rights standards and guidance. New Zealand is held accountable for our protection and promotion of the rights of transgender and non-binary people in New Zealand through various UN mechanisms.¹⁸ The Commission receives regular complaints of alleged unlawful discrimination from transgender New Zealanders, with the highest numbers of complaints relating to the area of government activity.¹⁹

- 21. Research has consistently found that transgender New Zealanders experience high levels of discrimination and violence. This can be compounded by multiple and intersecting forms of discrimination if the person has other identities that are associated with high levels of discrimination and violence, such as sexual orientation, ethnicity, or disability. Despite these concerning statistics, knowledge and acceptance of gender diversity is increasing, as occurred with the increasing knowledge and acceptance in society of homosexuality. This has also meant that transgender people, including adolescents, likely feel more comfortable to be who they are, share this with others, and seek medical advice as needed in the same way that destigmatisation of homosexuality was/is critical in facilitating better sexual health and saving the lives of homosexual people. Any reported increase in medical intervention should be carefully scrutinised in light of these correlating social forces on the seeking of and access to healthcare.
- 22. The enquiry into the "impact of puberty blockers" has been restricted to impact on "gender-dysphoric adolescents". It is not clear in the consultation documents why the impact assessment has been restricted to this group, when (as noted in the documents) cisgender adolescents are also prescribed puberty blockers. Similarly, regulation of other medications with potential risks is not typically subject to open public consultation. This differential treatment may be assessed as unlawful discrimination by a Court.²⁴
- 23. If a restriction on access to puberty blockers was implemented, then discrimination could also arise as compared to other groups of healthcare consumers who remain able to access off-label medications that contain comparable levels of risks, or quality of research or evidence, to that of puberty blockers. It creates an inconsistency where some consumers have the ability to choose, with informed consent, and subject to professional obligations of

Tangata: A review of the protections in the Human Rights Act 1993 for people who are transgender, people who are non-binary and people with innate variations of sex characteristics (2024). The Law Commission is currently considering whether the ground should be more clearly enunciated and how.

¹⁷ As the Commission submitted to *Ia Tangata* (NZLC, IP53 2024) in 2024. Trans people have made it clear that they do not feel protected by the current position – see New Zealand Human Rights Commission *Prism: Human rights issues relating to Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) in Aotearoa New Zealand - A report with recommendations* (2020) at p 14.

¹⁸ See for example Murphy *NZ told to improve human rights of LGBTQI people* Radio New Zealand (22)

¹⁸ See for example Murphy *NZ told to improve human rights of LGBTQI people* Radio New Zealand (22 January 2019).

¹⁹New Zealand Human Rights Commission <u>Prism: Human rights issues relating to Sexual Orientation</u>, <u>Gender Identity and Expression</u>, <u>and Sex Characteristics (SOGIESC) in Aotearoa New Zealand - A report with recommendations</u> (2020) at p 15-16.

²⁰ Jaimie Veale et al. <u>Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand</u> (Transgender Health Research Lab, University of Waikato, Hamilton, 2019).

²¹ See the UN definition of <u>multiple and intersecting forms of discrimination</u>

²² https://pmc.ncbi.nlm.nih.gov/articles/PMC7966621/

²³ See Annelou L. C. de Vries et al. <u>Bell v Tavistock and Portman NHS Foundation Trust [2020] EWHC 3274:</u>
Weighing current knowledge and uncertainties in decisions about gender-related treatment for <u>transgender adolescents</u> International Journal of Transgender Health, 22(3), 217–224.

²⁴ R v Hansen [2007] NZSC 7, [2007] 3 NZLR 1.

- the prescribing clinician, to take off-label medication; whereas a particular group do not. This could be found to be unlawful discrimination by a court.
- 24. Similarly, it could also be found to be discriminatory if access to puberty blockers had to be on the basis of taking part in a clinical trial.

Children's rights

- 25. New Zealand is a signatory to the United Nations Convention on the Rights of the Child ("the Children's Convention").²⁵ It covers civil and political, as well as economic social and cultural rights for children people under the age of 18. The rights are commonly viewed as falling into:
 - <u>provision rights:</u> which include the right to an adequate standard of living, free education, adequate health resources, and legal and social services
 - <u>protection rights:</u> which include the right to be free of abuse, neglect, bullying and discrimination and the right to safety in the justice system
 - <u>participation rights:</u> which include the right to freedom of expression and to participate in public life
- 26. All of these categories of rights are potentially affected and need to be considered in the context of access to gender-affirming care for children experiencing gender incongruence. The rights that are particularly relevant to the consultation are:
 - Article 3 best interests of the child
 - Article 2 freedom from discrimination
 - Articles 7 and 8 child's right to protect and preserve their identity, meaning the government should assist them to do so
 - Articles 13 and 14 freedom of expression, thought and belief including the right to seek and receive information of all kinds
 - Article 17 right to be informed and have access to information relevant to you
 - Article 24 right to health and health services
- 27. The best interests of the child must be a primary consideration in any action affecting a child or young person, a principle which links to the other rights in the Convention.²⁶ For example the right to non-discrimination requires that proactive measures must be taken to ensure equal opportunities for children to enjoy their rights under the Convention;²⁷ and assessment of best interests must include due respect for the child's views.²⁸
- 28. A child or young person who is capable of expressing their views has the right to the opportunity to be heard, and to have their views taken into account.²⁹ As a child matures, their

²⁵ Convention on the Rights of the Child, adopted by the UN on 20 November 1989 by General Assembly resolution 44/25; ratified by New Zealand in 1993.

²⁶ Children's Convention, Article 3. For Māori tamariki and rangatahi, this includes their rights under Te Tiriti o Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples.

²⁷ Committee on the Rights of the Children <u>General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration</u> (29 May 2013) at B1.

²⁸ Ibid at B3.

²⁹ Children's Convention, Article 8.

views and wishes must be given greater weight, to respect and promote their development into adulthood.³⁰ The Committee on the Rights of the Child ("**the Committee**") has pointed out that an adult's judgement of a child's best interests cannot override the obligation to respect all of the child's rights under the Convention.³¹ The Committee further stated:³²

For individual decisions, the child's best interests must be assessed and determined in light of the specific circumstances of the particular child. For collective decisions – such as by the legislator –, the best interests of children in general must be assessed and determined in light of the circumstances of the particular group and/or children in general.

- 29. In the current context, the particular group whose best interests must be considered is children experiencing gender incongruence. This again reinforces why it is essential to hear and be informed by their views.
- 30. The World Health Organization has similarly noted:33

To grow and develop in good health, adolescents need information, including age-appropriate comprehensive sexuality education; opportunities to develop life skills; health services that are acceptable, equitable, appropriate and effective; and safe and supportive environments. They also need opportunities to meaningfully participate in the design and delivery of interventions to improve and maintain their health. Expanding such opportunities is key to responding to adolescents' specific needs and rights.

31. It is also important to consider any vulnerability, such as belonging to a minority group, when determining the best interests of the child. The Committee has noted that "Adolescents who are subject to discrimination are more vulnerable to abuse, other types of violence and exploitation, and their health and development are put at greater risk. They are therefore entitled to special attention and protection from all segments of society." This means that the state needs to ensure that adolescent healthcare services are "known and easily accessible (economically, physically and socially) to all adolescents, without discrimination". So

³⁰ Children's Convention, Article 5. See also the Gillick competency test: *Gillick v West Norfolk and Wisbech AHA* [1986] found that a child under 16 had the legal competence to consent to medical examination and treatment if they had sufficient maturity and intelligence to understand the nature and implications of that treatment. The aim of Gillick competence is to reflect the transition of a child to adulthood. This case concerned the right of a child under 16 to consent to medical examination and treatment, where a mother of girls under 16 objected to Department of Health advice that allowed doctors to give contraceptive advice and treatment to children without parental consent.

³¹ Committee on the Rights of the Children <u>General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration</u> (29 May 2013) at [4].

³² Ibid at [32].

³³ WHO <u>Adolescent health</u>.

³⁴ Committee on the Rights of the Children <u>General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration</u> (29 May 2013) at [75].

³⁵ CRC <u>General comment No. 4 on adolescent health and development in the context of the Convention on the Rights of the Child</u> (2003) at [2].

³⁶ CRC <u>General comment No. 4 on adolescent health and development in the context of the Convention on the Rights of the Child</u> (2003) at [37(b)].

32. On the right to health specifically, the Committee has said: 37

The child's right to health (art. 24) and his or her health condition are central in assessing the child's best interest. However, if there is more than one possible treatment for a health condition or if the outcome of a treatment is uncertain, the advantages of all possible treatments must be weighed against all possible risks and side effects, and the views of the child must also be given due weight based on his or her age and maturity. In this respect, children should be provided with adequate and appropriate information in order to understand the situation and all the relevant aspects in relation to their interests, and be allowed, when possible, to give their consent in an informed manner.

33. This is consistent with the right to informed consent.

Right to informed consent

- 34. Bodily autonomy is a key concept in human rights and medical ethics, reflected in sections 10-11 of the New Zealand Bill of Rights Act. The Cartwright Inquiry was a turning point in New Zealand, paving the way to a modern approach to informed consent, away from a paternalistic model to a consumer one including the creation of the Code of Health and Disability Consumers Rights.³⁸ The right to informed consent is captured in right 6 and right 7.
- 35. The UK Supreme Court case of Montgomery also captured this sea change: 39

[75] ...it has become increasingly clear that the paradigm of the doctor-patient relationship implicit in the speeches in that case has ceased to reflect the reality and complexity of the way in which healthcare services are provided, or the way in which the providers and recipients of such services view their relationship. One development which is particularly significant in the present context is that patients are now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical profession. They are also widely treated as consumers exercising choices:

...

[80] In addition to these developments in society and in medical practice, there have also been developments in the law. Under the stimulus of the Human Rights Act 1998, the courts have become increasingly conscious of the extent to which the common law reflects fundamental values. As Lord Scarman pointed out in *Sidaway's* case, these include the value of self-determination ... As well as underlying aspects of the common law, that value also underlies the right to respect for private life protected by article 8 of the European Convention on Human Rights. The resulting duty to involve the patient in decisions relating to her treatment has been recognised in judgments of the European Court of Human Rights, such as *Glass v United Kingdom* (2004) 39 EHRR 15 and *Tysiac v Poland* (2007) 45 EHRR 42, as well as in a number of decisions of courts in the United Kingdom. The same value is also reflected more specifically in other international instruments: see, in particular, article 5 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, concluded by the member states of the Council of Europe, other states and the European Community at Oviedo on 4 April 1997.

³⁷ Ibid at [77].

³⁸ Auckland Women's Health Council <u>The Cartwright Inquiry</u>; Health and Disability Commission <u>About the Act and Code</u> (4 September 2024).

³⁹ Montgomery v Lanarkshire Health Board [2015] <u>UKSC 11</u>. Montgomery has been applied in the New Zealand courts – see *Shand v Accident Compensation Corporation* [2020] NZHC 2743; [2020] 3 NZLR 507.

[81] The social and legal developments which we have mentioned point away from a model of the relationship between the doctor and the patient based upon medical paternalism. They also point away from a model based upon a view of the patient as being entirely dependent on information provided by the doctor. What they point towards is an approach to the law which, instead of treating patients as placing themselves in the hands of their doctors (and then being prone to sue their doctors in the event of a disappointing outcome), treats them so far as possible as adults who are capable of understanding that medical treatment is uncertain of success and may involve risks, accepting responsibility for the taking of risks affecting their own lives, and living with the consequences of their choices.

36. Lady Hale went on to make some additional observations:

[115] A patient is entitled to take into account her own values, her own assessment of the comparative merits of giving birth in the "natural" and traditional way and of giving birth by caesarean section, whatever medical opinion may say, alongside the medical evaluation of the risks to herself and her baby. She may place great value on giving birth in the natural way and be prepared to take the risks to herself and her baby which this entails. The medical profession must respect her choice, unless she lacks the legal capacity to decide (*St George's Healthcare NHS Trust v S* [1999] Fam 26).

- 37. The Court's comments demonstrate the reality of risk as part of providing healthcare, and the importance of allowing the healthcare consumer to be informed of that risk and to make a decision on those risks based on their own values.⁴⁰
- 38. Reflecting this, the 2018 Aotearoa guidelines for gender affirming healthcare are "based on the principle of Te Mana Whakahaere; trans people's autonomy of their own bodies, represented by healthcare provision based on informed consent". 41
- 39. The risks identified of puberty blockers should form part of the discussions with adolescents and their whānau, so that an informed decision can be made consistent with the right to informed consent. 42 But such risks should not lead to denial of access. The dignity of risk means having the right to make our own choices and self-determine, even if it could have negative consequences, in order to live an independent life. 43

Te Tiriti o Waitangi

40. Human rights in Aotearoa New Zealand are grounded on Te Tiriti o Waitangi and must reflect Te Ao Māori values. This means recognising the rights and mana motuhake of Māori as Tangata Whenua and the Te Tiriti guarantee of tino rangatiratanga.

41. Tangata Whenua and other Indigenous peoples with a range of gender identities and expressions have existed throughout history, including in the Pacific and Te Ao Māori.

⁴⁰ Examples that demonstrate this approach include the oral contraceptive pill or HRT, which have impacts on hormones and carry some risk of blood clots and breast cancer respectively. For the vast majority of people using these medications, they are critical if not life-saving, and the risks do not occur. Similarly, a lot of psychiatric medication comes with risks, requiring blood tests to monitor lipid levels etc. Those risks may be acceptable for someone who would otherwise suffer extreme levels of mental distress, which themselves can result in life threatening /life expectancy limiting behaviour.

⁴¹ J Oliphant et al. <u>Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender</u> <u>Children, Young People and Adults in Aotearoa, New Zealand</u> NZMJ 14 December 2018, Vol 131 No 1487.

⁴² As noted in the Position Statement at p 4.

⁴³ See NZLC IP52 at chapter 3 for discussion on dignity of risk.

Culturally specific terms relating to gender identity in te reo Māori include irawhiti, tangata ira tāne, and whakawahine, among others.

- 42. Pae Tū (Hauora Māori Strategy) is an interim step for the health system to uphold Te Tiriti, including equitable outcomes for Māori. The five priority areas are:⁴⁴
 - enabling M\u00e4ori leadership, decision-making and governance at all levels
 - strengthening whole-of-government commitment to Māori health
 - growing the Māori health workforce and sector to match community needs
 - enabling culturally safe, whānau-centred and preventative primary health care
 - ensuring accountability for system performance for Māori health.
- 43. This means that in order to meet its obligations under Te Tiriti,⁴⁵ and to be consistent with Pae Tū, the government must ensure active consultation with irawhiti, tangata ira tāne, and whakawahine in relation to gender affirming care; and ensure that any resulting policies and procedures are culturally safe and provide for tino rangatiratanga.

Substance

Analysis of the evidence

- 44. The literature review in the Evidence Brief focused on three major physiological outcomes: bone health, anthropometric measurements, and cardiometabolic outcomes. Its focus was not primarily on whether puberty blockers had the intended effect when used for children experiencing gender incongruence.⁴⁶
- 45. The Evidence Brief findings on physiological outcomes were:
 - No evidence of impact on renal function, liver function, onset of diabetes, or executive function.
 - Bone mineral density increased, but less than in matched controls.
 - Some studies reported a change in blood pressure, lipids, and body composition.
- 46. The review did not identify any clear and significant risks justifying immediate withdrawal of the medication to all who are prescribed it; rather, it found that the quality of evidence for the benefits or risks is low and there is "a need for high-quality longitudinal data and research to understand the specific needs of gender-dysphoric adolescents". As above, any such research needs to involve active consultation with transgender people.
- 47. Medical professionals have suggested that the Evidence Brief shows that risk of physiological harm is low and puberty blockers can continue to be prescribed, despite any ongoing

⁴⁴ Ministry of Health *Pae Tū: Hauora Māori Strategy* (2023).

⁴⁵ Waitangi Tribunal <u>Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry</u> (2023).

⁴⁶ I.e. to block hormones, in an easily reversible way, thereby pausing puberty and giving the young person time to consider their next steps, if any. Of the four studies included in the scope of the Evidence Brief, 'Pubertal suppression appeared to have been achieved in all individuals in almost all studies in which this variable was reported.' Evidence Brief at p 21.

⁴⁷ Evidence Brief at p 3.

research.⁴⁸ It is also relevant that the current Aotearoa guidelines include measures to mitigate the possible risks.⁴⁹

- 48. Like all prescriptions, puberty blockers are subject to protocols and protections in our medico-legal systems which provide protection and guidance, as noted in the Evidence Brief.⁵⁰ There is specific guidance relating to unapproved medicines in the Medicines Act, including providing adequate ethical professional care and taking responsibility for unapproved use.⁵¹ That will likely include a holistic assessment, discussion with the adolescent and their guardian, and making a decision on a case by case basis with appropriate informed consent procedures. If a dispute arises between the parties, then the courts are able to make a determination of what is in the child's best interests.⁵² Complaints can be made and investigated by the Health and Disability Commission or the Medical Council.
- 49. The review did not consider whether there was any evidence of irresponsible or concerning prescribing of puberty blockers by health practitioners, that current protocols were insufficient to guard against. The Ministry may find it useful to enquire with the Health and Disability Commission and Medical Council about whether they have received any such complaints, which may also become apparent during the consultation process.
- 50. Furthermore, the scope of the review did not include any harm to trans youth of not having access to puberty blockers, the evidence (or lack of) for any alternative treatments, or the harm (or lack of) when using these medications in other medical contexts (e.g. cisgender children's use of blockers for precocious puberty).
- 51. The Evidence Brief concluded that there is limited quality evidence for both the risks and benefits of puberty blockers for children experiencing gender incongruence.⁵³ This is unlikely to be unique to puberty blockers treatment for example studies suggest only a minority of outcomes for health care interventions are supported by high quality evidence.⁵⁴ For equal

⁴⁸ Dr Rona Carroll (Senior Lecturer, Department of Primary Health Care and General Practice, University of Otago) *NZ is consulting the public on regulations for puberty blockers – this should be a medical decision not a political one* (5 December 2024).

⁴⁹ For example the 2018 *Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa New Zealand* state: "It is advisable to encourage young people on puberty blockers to have an adequate calcium intake, provide vitamin D supplementation where needed and encourage weight bearing exercise. For those requiring a prolonged period on puberty blockers or who have other significant additional factors for reduced bone density, a Dexa scan to monitor bone densitometry should be considered."

⁵⁰ See for example Medical Council of New Zealand *Prescribing*.

⁵¹ BPAC <u>Upfront: Unapproved medicines and unapproved uses of medicines: keeping prescribers and patients safe</u> (24 February 2021): "Many of the medicines administered to children are used off-label. This is because trials have not usually been conducted in this patient group and, therefore, the company marketing the medicine has not applied for use to be approved for this age-group."

⁵² Evidence Brief at p 28.

⁵³ Position Statement at p 4.

⁵⁴ See A Conway et al *High quality of evidence is uncommon in Cochrane systematic reviews in*Anaesthesia, Critical Care and Emergency Medicine European Journal of Anaesthesiology 34(12):p 808-813 (December 2017); J Howick et al. *The quality of evidence for medical interventions does not improve or worsen: a metaepidemiological study of Cochrane reviews* Journal of Clinical Epidemiology

Vol 126, October 2020, Pages 154-159; J Howick et al. *Most healthcare interventions tested in Cochrane Reviews are not effective according to high quality evidence: a systematic review and meta-analysis*Journal of Clinical Epidemiology Vol 148, August 2022, Pages 160-169.

access to the right to health,⁵⁵ this needs to be borne in mind in the context of puberty blockers in the same way it is for other medical practices which proceed nonetheless; particularly as the nature of the effects of puberty blockers mean that it is impossible to achieve a high-quality placebo clinical trial.

52. A number of experts have raised methodology issues with the Cass Review,⁵⁶ which the Addendum refers to. A key issue raised is that it was not peer reviewed.⁵⁷ These issues should also be considered by the Ministry.

Other available evidence

- 53. A recent Australian study was not included in the review.⁵⁸ The use of puberty blockers as appropriate gender affirming care forms part of the two main international guidelines⁵⁹ and best practice recommendations from major medical bodies.⁶⁰ Local information also supports the use of puberty blockers for trans young people.⁶¹
- 54. As noted in the Ministry's Position Statement, the World Health Organization ("WHO") is developing a guideline on the health of transgender and gender diverse people. WHO issues evidence-based guidance and recommendations in the full range of health areas, meaning they have extensive expertise to draw upon. It would be beneficial to have WHO guidance before proceeding with any changes to practice in New Zealand.

Mental health considerations

- 55. Recently the United Nations High Commissioner for Human Rights stated: "Diversity is the fuel of life, and minorities are a fundamental part of the rich kaleidoscope that makes up our world. We must do more to protect them". 62
- 56. Research from both New Zealand and overseas shows concerning levels of mental distress for transgender and non-binary people, including high rates of suicidal thoughts and

⁵⁵ Elimination of All Forms of Racial Discrimination (Article 5(e) iv); International Convention on the Elimination of All Forms of Discrimination Against Women (Articles 11(1) (f), 12 and 14(2)(b)); Convention on the Rights of the Child (Article 24); Convention on the Rights of Persons with Disabilities (Article 25).

⁵⁶ Jennifer K Shields <u>New Yale Law report finds Cass Review critically flawed</u> (3 July 2024); British Medical Association <u>BMA to undertake an evaluation of the Cass Review on gender identity services for children and young people</u> (31 July 2024); Dr Ruth Pearce <u>What's wrong with the Cass Review? A round-up of commentary and evidence</u> (last updated 18 November 2024).

⁵⁷ Dr Ruth Pearce *What's wrong with the Cass Review? A round-up of commentary and evidence* (last updated 18 November 2024).

⁵⁸ Queensland Government <u>Independent evaluation finds Queensland paediatric gender services safe</u> <u>and evidence-based</u> (19 July 2024).

⁵⁹ Annelou L. C. de Vries et al. *Bell v Tavistock and Portman NHS Foundation Trust [2020] EWHC 3274:*Weighing current knowledge and uncertainties in decisions about gender-related treatment for transgender adolescents International Journal of Transgender Health, 22(3), 217–224.

⁶⁰ Including the <u>Endocrine Society</u>, the <u>Royal Australasian College of Physicians</u>, the <u>American Psychiatric Association</u> and the <u>American Psychological Association</u>.

⁶¹ Julia de Bres <u>Family Experiences with Puberty Blockers in Aotearoa</u> Project Village Aotearoa (2023).

⁶² HC Türk addresses Minority Forum: "Diversity is the fuel of life" (28 November 2024).

- attempts.⁶³ This includes findings specifically relating to the impact of restricting access to gender affirming care.⁶⁴
- 57. It is therefore critically important, from a human rights perspective, to adequately and carefully consider mental health and suicide risk in any policy relating to transgender youth.
- 58. The best interests of the child principle in art 3 of the Children's Convention is a substantive right, a fundamental interpretive legal principle, and a rule of procedure, which applies to all actions affecting the child in either the public or private sphere. It is an overarching right which other rights in the Convention should be interpreted through the lens of. Considerations to be taken into account in assessing best interests include:⁶⁵
 - the child's views
 - identity of the child (such as sex/gender, sexual orientation, national origin, religion and beliefs, culture)
 - personality
 - care, protection, and safety of the child
- 59. Whenever a decision is made that impacts a child or a group of children, there must be a thorough evaluation of all possible impacts, both negative and positive, on them. Doing so is how we procedurally and substantively give effect to obligations under the Convention.
- 60. The mental health of the child is clearly encapsulated in these considerations; and, as above, mental health is part of the right to health.
- 61. The Evidence Brief states: "Current evidence indicates a significant improvement in depression, anxiety and suicidal ideation for individuals treated with puberty blockers. However, the quality of this evidence is low with a high risk of bias". 66 It went on to conclude that:

Evidence about the impact of GnRHa on clinical and mental health and wellbeing outcomes is scarce, with available evidence largely of poor quality. While there are studies on non-medical interventions that show improvements in the mental health and wellbeing of gender-dysphoric adolescents, these generally rely on small, localised cohorts, making it difficult to extrapolate to other, larger cohorts.

62. The Commission supports efforts towards more research and information to support transgender children's access to appropriate healthcare. For the reasons discussed above and below, the current evidence supporting the positive impact on the children's mental

⁶³ Jaimie Veale et al. <u>Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand</u> (Transgender Health Research Lab, University of Waikato, Hamilton, 2019); Wilson Y. Lee et al. <u>State-level anti-transgender laws increase past-year suicide attempts among transgender and non-binary young people in the USA</u> Nature Human Behaviour (26 September 2024).

⁶⁴ Dr Natacha Kennedy <u>Children of Omelas</u>; <u>Effects of the UK Puberty Blocker Ban</u>; Annelou L. C. de Vries et al. <u>Bell v Tavistock and Portman NHS Foundation Trust [2020] EWHC 3274: Weighing current knowledge and uncertainties in decisions about gender-related treatment for transgender adolescents International Journal of Transgender Health, 22(3), 217–224.</u>

⁶⁵ See Committee on the Rights of the Children <u>General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration</u> (29 May 2013) at [52]-[79]. ⁶⁶ At p2.

health should not be discounted. The risks of not providing gender affirming care can be significant with life-long consequences.

63. One of the reasons the Evidence Brief notes that the evidence available to date on mental health is of poor quality is the risk of bias. This may be unavoidable and not unacceptable because: research on mental health necessarily includes a high level of self-report; and many mental health medications have physical impacts on the body, which make a high-quality placebo trial nigh on impossible. These same challenges do not prevent many other medications prescribed for both mental and physical health from being used responsibly. We would encourage the Ministry to consider and discuss these aspects with the medical and scientific community, to ensure that there is consistency (and hence non-discrimination) with other pharmaceuticals.

Prudence Walker

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