



Proactive Release

Submissions on the Child and Youth Wellbeing Strategy

August 2019

The Department of the Prime Minister and Cabinet has released the following submission received during its public consultation on the child and youth wellbeing strategy.

Some of the information contained within this release is considered to not be appropriate to release and, if requested, would be withheld under the Official Information Act 1982 (the Act).

- Where this is the case, the information has been withheld, and the relevant section of the Act that would apply, has been identified.
- Where information has been withheld, no public interest has been identified that would outweigh the reasons for withholding it.

Key to redaction codes and their reference to sections of the Act:

- **9(2)a** – Section 9(2)(a): to protect the privacy of natural persons, including deceased people.

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Organisation Name:	ITANZ
Organisation description: (tell us about your organisation – i.e. who do you represent? How many members do you have? Are you a local or national organisation?)	<p>ITANZ is a New Zealand registered charitable trust that provides information, education and training for organisations and professionals who provide services to intersex people and their families.</p> <p>The content of this submission is copied from the 2016 submission to the 73rd session for the convention on the rights of the child prepared by ITANZ human rights intern, Aych McArdle. It outlines the key points to consider. ITANZ would like to recognise the work of 9(2)(a) as the organisation is not effectively funded to reimburse 9(2)(a) for their commitment to this life changing work.</p>
Executive Summary: (Please provide a short summary of the key points of your Submission - 200 words)	<p>ITANZ has been involved in the consultation and development of the New Zealand Human Rights Commission (NZHRC) submission to this committee and we support their list of recommendations to the state to:</p> <p>(a) Develop and enact legislation and practice guidelines that ensure that no one is subjected to medical or surgical treatment during infancy or childhood without informed and supported decision-making that guarantees bodily integrity, autonomy and self-determination to children concerned, and provides families of intersex children with adequate counseling and support;</p> <p>(b) For this purpose, direct the Ministry of Health to support the establishment and functions of a National Multi-Sectoral Expert Advisory Group, to advise it on:</p> <p>(i) Legislative and procedural safeguards for intersex children, an ethical framework, funding and research requirements;</p> <p>(ii) Specific support services for intersex children and adults and their families, including consideration of a single, family-centred national service that ensures whole of lifelong multi- disciplinary care and support care; and</p> <p>(iii) Development of agreed definitions of intersex and DSD conditions to enable enhanced data collection, and consideration of the establishment of a national register.</p> <p>Additionally, we ask the committee to:</p>

	<ol style="list-style-type: none">1. Seek assurance from the state that they end the practice of genital normalizing surgery on intersex children through legislative protections and the implementation of a set of professional standards for the medical profession that affirm the genital autonomy of intersex children.2. Question the state on what financial commitments it will make to ensure that appropriate advocacy and social support services are made available to intersex children for the whole of their lives and their families.
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Submission Content

The full copy of the original submission from 2016

List of questions and recommended actions

ITANZ has been involved in the consultation and development of the New Zealand Human Rights Commission (NZHRC) submission to this committee and we support their list of recommendations to the state to:

(a) Develop and enact legislation and practice guidelines that ensure that no one is subjected to medical or surgical treatment during infancy or childhood without informed and supported decision-making that guarantees bodily integrity, autonomy and self-determination to children concerned, and provides families of intersex children with adequate counseling and support;

(b) For this purpose, direct the Ministry of Health to support the establishment and functions of a National Multi-Sectoral Expert Advisory Group, to advise it on:

(i) Legislative and procedural safeguards for intersex children, an ethical framework, funding and research requirements;

(ii) Specific support services for intersex children and adults and their families, including

consideration of a single, family-centred national service that ensures whole of lifelong multi-disciplinary care and support care; and

(iii) Development of agreed definitions of intersex and DSD conditions to enable enhanced data collection, and consideration of the establishment of a national register.

Additionally, we ask the committee to:

3. Seek assurance from the state that they end the practice of genital normalizing surgery on intersex children through legislative protections and the implementation of a set of professional standards for the medical profession that affirm the genital autonomy of intersex children.
4. Question the state on what financial commitments it will make to ensure that appropriate advocacy and social support services are made available to intersex children for the whole of their lives and their families.

The landscape in Aotearoa, New Zealand

As explained in the NZHRC submission to this committee under this review: “infants born in New Zealand with an intersex (condition) or Disorder of Sex Development (DSD) may undergo surgery and other medical interventions intended to make their genitalia appear more typically “male” or “female”. As such interventions take place when the child is still an infant, consent is procured from

the parents or legal guardian of the child”. We note the Special Rapporteur on Torture’s comments on the non consensual medical interventions on intersex children which were described as resulting in “permanent, irreversible infertility and causing severe mental suffering.”¹

Issues

1. The preservation of life and right to genital autonomy

The intersex community has no problem with the idea of life saving surgery. Of concern for our community are genital surgeries that are undertaken for reasons other than the preservation of life and which consequently undermine a child’s right to genital autonomy. We affirm the Helsinki Declaration of 2012² which defines the right to genital autonomy to be: a) personal control of their own genital and reproductive organs; and b) protection from medically unnecessary genital modification and other irreversible reproductive interventions. We affirm the work of Dr Milton Diamond³ who explains that surgeons should not remove any tissue that a person may want later on in life. We know that many in the medical institution in Aotearoa, New Zealand claim that the surgeries they are performing **are** medically necessary. However we counterclaim that more often surgeries are performed in the interests of aesthetics, heteronormative bias and binary constructions of gender and on this basis undermine the child’s right to genital autonomy

¹ Para 77, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, ² <https://www.genitalautonomy.org/helsinki-declaration-2012/>

³ <http://www.hawaii.edu/PCSS/>

2. Bodily integrity

We affirm the Child Rights International Network description of bodily integrity as being “the right of each human being, including children, to autonomy and self-determination over their own body”⁴ and we endorse their position that “unconsented physical intrusion as a human rights violation”⁵. Surgeries that are performed on us without our consent and/or a full understanding of the impact of these decisions, compromises our bodily integrity. We call on the state to implement effective legislative and professional standards for the medical profession to protect intersex children from surgical decisions that compromise our bodily integrity.

3. Informed consent and the role of the parents

As discussed in the NZHRC submission to this committee, in Aotearoa New Zealand consent is procured from parents or guardians of intersex infants on behalf of the child for surgical interventions on our bodies. We support the Helsinki Declaration’s position that “the only people who may consent to medically

unnecessary genital modification and other irreversible reproductive interventions is:

- • in the case of a person who is competent to give free and informed consent, being fully informed about the nature, the risks and benefits of the intervention – the person undergoing the intervention; and
- • in the case of an incompetent person including a young child – only a properly constituted public authority or tribunal appointed to balance the human rights and the best interests of the person after considering the views of family members, professionals and an independent advocate for the person.”

We call on the state to establish a public authority or tribunal that can advocate for the best interests of the child. We call on the state to fund counselling and social support services for the child, parents and family for the whole of life including parent support groups that have access to a wide variety of quality information.

4. Legal protections

In Aotearoa New Zealand there is no legal protective legislation under our Human Rights Act that specifies intersex status, gender identity and gender expression. We call on the state to immediately include intersex status, gender identity and gender expression as grounds of non discrimination in Aotearoa, New Zealand.

5. Education and professional development

ITANZ core services include education and training for professionals and students on the diversity of sex, gender and sexuality. We are currently teaching staff and students at the University of Auckland and the University of Otago Medical School about gender identity, gender formation and the diversity

⁴ <https://www.crin.org/en/home/what-we-do/policy/bodily-integrity> ⁵
<https://www.crin.org/en/home/what-we-do/policy/bodily-integrity>

of sexual orientation. Of priority in the education for medical students is to help them understand the components of care that will help a person born with a different body to grow up as a healthy, well informed, self anchored and self-loving person. Although we are contributing to this teaching, it is not mandatory for all medical students in Aotearoa New Zealand.

We call on the state to hold the medical profession to account for ongoing professional development in the areas outlined above. We call on the state to

ensure medical training institutions include compulsory learning modules on the health needs of peoples with diverse sex, gender and sexualities.

We call on the state to actively find avenues to fund research on and about the experiences of intersex people living in Aotearoa, New Zealand.

6. Whole of life approach to health care

We believe that any intersex adult seeking surgery in relation to their intersex condition should have access to life giving and life affirming surgery. In Aotearoa, New Zealand intersex children up to the age of 16 can access free surgical interventions under our public health system. After this age the waiting list is often longer than our life expectancy.

We call on the state to ensure access to safe and appropriate medical care for intersex peoples for all of their lives.

List of questions and recommended actions

As stated above, ITANZ has been involved in the consultation and development of the NZHRC submission to this committee and we support their list of recommendations.

Additionally, we ask the committee to:

- - Seek assurance from the state that they end the practice of genital normalizing surgery on intersex children through legislative protections and the implementation of a set of professional standards for the medical profession that affirm the genital autonomy of intersex children.
- - Question the state on what financial commitments it will make to ensure that appropriate advocacy and social support services are made available to intersex children for the whole of their lives and their families.

Conclusion

We conclude with a vision of hope for our country, that it might be a place where intersex children grow up without fear of discrimination and unnecessary medical procedures.

We believe New Zealand has the capacity to make these changes and afford these protections.

We welcome the opportunity to provide you with any further clarification you may require on the needs and experiences of intersex people in Aotearoa, New Zealand.

Ngā mihi nui,

Dr Geraldine Christmas, Board member, ITANZ

Tom Hamilton, Lecturer, Unitec / Counselor, OUTLINE / Treasurer, ITANZ

Mani B. Mitchell, Executive Director, ITANZ

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Dr Katrina Roen, Professor, Department of Psychology, The University of Oslo / Board member, ITANZ

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Dame Margaret Sparrow, DNZM MBE BSc MBChB DipVen FACHSHM DSc(Hon) Retired senior sexual health clinician / Board member, ITANZ

Dr Jeanie Douché, Adjunct Research Fellow, Graduate School of Nursing Midwifery & Health, Victoria University / Board member, ITANZ

This submission is also supported by:

9(2)(a)



Appendix 1: A personal story by Mani Bruce Mitchell

Kia ora Committee Members

It would have been my preference to speak to you in person.

I am grateful for the opportunity to talk to you via a submission.

My name is Mani Mitchell, born in Aotearoa New Zealand and I am an intersex person, I identify as a queer, non binary person.

For the last two decades I have been involved in and part of the international intersex movement.

I am also an educator, a critical incident stress specialist, and a counsellor. I am

the founder of ITANZ and have been involved in intersex change work, both nationally and internationally for the last two decades.

In the course of my work I have been frustrated by the fact that the medical model for treating intersex children has failed to address the concerns of the now well documented consistently narrated voice of the **intersex community**.

There are some critical points to emphasis:

Genital normalizing surgery. Like most intersex people I fully respect and value the role that the medical profession play in life saving surgery, critical diagnosis in those presentations where medical intervention is necessary. (To save life) Where the presenting situation is such that medical knowledge is needed.

Yes I had my surgery a long time ago. I live with that reality every single day. The fact that perfectly healthy, functioning tissue was removed from my body, so that I might look more like a 'normal girl'. My sexual function has been significantly damaged. I will never know what 'normal' sex might feel like. It has taken a life time to move past the crippling shame, sense of dislocation I felt toward my body – my society narrated - 'abnormal/deformed body'

I had very 'good' genital surgery, to 'reduce' my supposed large clitoris, my cosmetic result was/is exceptional. However, I wish most days I had never had that surgery.

I have friends who also were given **hormones** with their consent – all 'normalising' treatment must involve where ever possible full informed consent processes. (as consenting adults)

Consent, I have no way of knowing what my parents thought they were agreeing to – they are both deceased, so cannot answer that question. What I know is the person who owned the body, lives with it, ME, was not involved in any way with the decisions (yes made with best intentions) that changed my life for ever.

Gender my story is somewhat unusual, as I was assigned male at birth, then changed to female at age one. Neither designation was accurate. I live now as a non binary person. I understand the need for a gender designation, we live in a binary world, and there are legal requirements. However our medical intersex (DSD) model is not robust in its current understanding of gender and gender identity. The truth is that the only person who truly knows their gender identity is the person who owns the

body. We need a model that holds the fact that no one can truly know what a persons adult gender identity will be.

Further that the sense of feeling okay about our body, who we are and who we are is a much more nuanced complicated process and includes our doctors, our parents and society at large. It includes being told we are okay, not deformed, being loved, being accepted, being valued for who we are! There is an opportunity

for new narrative that helps informs a person to feel in control, informed and confident about their difference – resilient to world that poorly tolerates difference.

Parents, I feel my parents got very little support, or insight to manage the practical difficulties my birth presented for ALL our family. (Siblings and relations) As we move forward to change this model we must include funding, accurate information parents support and parents support groups as part of a new treatment pathway.

To do this we need a paradigm that shifts the focus away from pathology and disorder to one that focuses on health and wellbeing in its broadest sense.

That includes appropriate training that teaches medical specialists how to have 'difficult' all of life conversations with parents and patients around issues we in the west do not manage well – genitals, variance/difference sex/gender etc...

Listen to, learn from practitioners around the world who are already doing this work differently e.g. People such as Paediatric Surgeon, Mika Venhola, MD, PhD, Oula University Finland.

"Why operate on the child's body if the problem is in the minds of the adults?"

Peer support groups, meeting other intersex people changed my life (positively) that this did not happen until I was 40 years of age is a sadness I live with.

Focus on **bodily autonomy** and wellness... not on binary constructions of gender, and the cis privilege of heterosexuality.

Surgery that when we seek it as adults (reparative/congruence or any other reason for wellness) it should be available, and not as it currently is only funded for children.

All of life care: I have struggled as an adult to find appropriate, safe, knowledgeable medical care. Again its professional education, both in the details/awareness of those of us born with different bodies, but it is also about those of us who live outside the binary construction of gender. Wherever we locate ourselves as adults we should be treated with respect with knowledge.

Finally I invite the notion that intersex people are intelligent fabulously diverse people who as adults spread all across the gender and sexual orientation maps.

Capable and desiring to be involved in our care and our treatment. Thank you for taking the time to hear my words.

Ngā mihi maioha, Mani Bruce Mitchell

References:

Malta accord:

3rd International Intersex Forum, 29 November 1 December 2013,

<http://ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex/events/3rd-international-intersex-forum>

Astraea Foundation report:

Astraea Lesbian Foundation for Justice. (2016). We are Real: The Growing Movement Advancing thE

Human Rights of Intersex People. New York: Astraea Lesbian Foundation for Justice

Please note that your submission will become official information. This means that the Department of the Prime Minister and Cabinet may be required to release all or part of the information contained in your submission in response to a request under the Official Information Act 1982.

The Department of the Prime Minister and Cabinet may withhold all or parts of your submission if it is necessary to protect your privacy or if it has been supplied subject to an obligation of confidence.

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