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Federal pre-budget submission 2024-25:

Funding for a national intersex community-controlled healthcare service

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Summary recommendation

That the government provides **$2,100,000 in annual resourcing** to develop and sustain an intersex community-controlled healthcare service, to support the provision of biopsychosocial health and medical services for people with innate variations of sex characteristics and families, and support provision of policy advice to government. The service will be developed and run by Intersex Human Rights Australia, which currently provides advocacy and pilot psychosocial support services.

About IHRA

Intersex Human Rights Australia (IHRA) was established as OII Australia in 2010. A charitable not-for-profit company, IHRA engages in systemic advocacy to promote the health and human rights of people with innate variations of sex characteristics, and, following recruitment of a mental health practitioner in July 2023, provides psychosocial support services through the pilot InterLink program.

In promoting the health and human rights of people with innate variations of sex characteristics, IHRA advocates have been commended for our 'diligent, passionate and highly intellectual work' and Executive Director Morgan Carpenter was specifically commended for his 'tireless work' by Andrew Barr, ACT Chief Minister (1,2). Staff and directors played a key role in an Australian Human Rights Commission inquiry into the health and human rights of people born with variations of sex characteristics, reporting in 2021 (3). We have contributed to improvements to research and data collection, including through the development and implementation of national statistical standards, in the 2020 Australian Bureau of Statistics standard on sex, gender, variations of sex characteristics and sexual orientation (4).

Our work is guided by a community consensus statement, the 2017 Darlington Statement, agreed by organisations and individuals involved in advocacy and peer support across Australia and Aotearoa New Zealand (5).

We welcome the commitment by the government to develop a 10-year National LGBTIQ+ Health and Wellbeing Action Plan, and are grateful that executive director Morgan Carpenter has been appointed to the expert advisory group.

Characteristics, health needs and barriers in our population

People with innate variations of sex characteristics have innate reproductive development, genetics or hormones that do not fit medical norms for female or male bodies. There exist a wide spectrum of innate variations to genitals, hormones, chromosomes and/or reproductive organs.

Characteristics of our population include:

- A diversity of nomenclature: other umbrella terms used to describe innate variations of sex characteristics are intersex or differences/disorders of sex development ('DSD').
- There are more than 40 different innate variations, each with different typical age of diagnosis, expression, likely observed/assigned sex, and health needs. Examples include androgen insensitivity syndrome, gonadal dysgenesis, micropenis, sex chromosome variations, and congenital adrenal hyperplasia with XX or mosaic sex chromosomes.
- Variations may be determined prenatally, at birth, during puberty, when trying to conceive a child, or at other times.
- The population includes infants and children, adolescents and adults.

- Individuals old enough to freely express an identity may be LGBTQ or not.
- People with innate variations of sex characteristics have a range of different values and preferences that are poorly served by current medical pathways and dominant conceptions about identity, sexuality, sex, and gender diversity.

Key healthcare needs and barriers include:

- Significant and pervasive experiences of stigmatisation, shame, marginalisation and incomprehension. These impact on social isolation, community engagement, and family and intimate relationships.
- Common health needs include issues relating to prior medical treatment; fertility/infertility; sexual dysfunction arising from shame, stigma and prior medical treatment; psychosocial support, and diagnosis-specific biopsychosocial health needs.
- Medical practices are biased towards heteronormative identities and function, 'social and familial integration', and pre-emptive medical interventions to make bodies appear and function in ways that are felt more typically female or male.
- Paediatric surgical and endocrinological services are over-emphasised and prioritised, and many early medical interventions are understood to be human rights violations (3).
- Adult biomedical services are negligible and under-resourced, with no population-specific service.
- Psychosocial support needs for individuals and families are neglected and under-resourced; IHRA (via the InterLink pilot project) and the ACT government (via a new paediatric Variations of Sex Characteristics Psychosocial Support Unit in Canberra Hospital) deliver the first such services.
- There is often a lack of evidence supporting which medical interventions may be helpful.
- There is widespread lack of comprehension of the characteristics, needs and circumstances of the population, by institutions and service providers, in both mainstream and LGBT settings, impacting safety, disclosure, and access to treatment, leading to incoherent policy development and lack of safe and accessible services. For example, Headspace and the Australian government have wrongly framed intersex as a matter of gender diversity (6,7).
- Intersex community organisations seek to scale-up psychosocial and other health services, but these are often believed to be already delivered to adult LGBTI populations.
- Without specific resourcing, unmet healthcare needs will not be addressed.

Recommendations for service improvements

Our proposal implements previously unimplemented recommendations by the Senate Community Affairs References Committee, by UN Treaty Bodies in recommendations to Australia, by the Australian Human Rights Commission and by LGBTIQ+ Health Australia. These recommendations are summarised below.

In 2013, the Community Affairs References Committee recommended significant changes to clinical practices, including oversight to ensure that treatments occur within a human rights-affirming context. The Committee also recommended:

> *"Recommendation 12: The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases." (8)*

United Nations Treaty Bodies have made strong recommendations for reform to clinical practices in Australia, including the provision of adequate human rights-affirming support and counselling to

individuals and families. In 2019, the Committee on the Rights of the Child recommended that Australia prohibit harmful practices and improve services:

> *"31 (b) Enact legislation explicitly prohibiting coerced sterilisation or unnecessary medical or surgical treatment, guaranteeing bodily integrity and autonomy to intersex children as well as adequate support and counselling to families of intersex children." (9)*

In the same year, the Committee on the Rights of Persons with Disabilities recommended that Australia protect the integrity of the person, provide redress, and improve services:

> *"34 (b) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent … without their free and informed consent of the person concerned; also provide adequate counselling and support for the families of intersex children and redress to intersex persons having undergone such medical procedures." (10)*

In 2021, the Australian Human Rights Commission (3) recommended legislative reform to ensure oversight of medical interventions, accompanied by national guidelines to ensure adherence, plus:

> *"Recommendation 5: All people born with variations in sex characteristics should have access to comprehensive, appropriately qualified multidisciplinary care, with input from mental health and other key professionals, and other people with variations. Care should be available across their lifespan and regardless of where they live."*
>
> *"Recommendation 10: The Australian Government and state and territory governments should provide sufficient public funding for:*
> - *a) sustainable operation of advocacy and peer support organisations led by people born with variations of sex characteristics*
> - *b) comprehensive psychological and psychiatric health services, for people born with variations of sex characteristics, their parents and other family members*
> - *c) improved access to peer support and health services, including online and by telephone*
> - *d) comprehensive and up-to-date consumer resources for people born with variations in sex characteristics, their parents and other family members informed by clinical, peer support and human rights experts.*
>
> *"The Australian Government and state and territory governments should also consult on establishing and funding coordinator positions to integrate care across multiple specialties and institutions."*

In a submission on the 2023/24 federal budget, LGBTIQ+ Health Australia (LHA) noted the crucial importance of a robust community-controlled health sector in order to address LGBTIQ+ health and wellbeing disparities. LHA specifically called for core funding to establish the sustainability of IHRA and intersex-led peer support programs (11) but necessary funding levels were not specified. This submission specifies the necessary funding.

Proposal

In relation to existing capacity and resourcing in IHRA:

- Our staff team are highly skilled and qualified, including a bioethicist with completed PhD studies (Sydney), a graduate in psychology and PhD candidate (USQ), a postgraduate in biological anthropology (ANU), and a registered occupational therapist. Our board include people with expertise in health law, business law, bioethics, and public administration.
- Foreign philanthropic funding for systemic advocacy began in December 2016, with current funding due to end in July 2024. Funding for InterLink comes from a pilot DSS program addressing sexual violence, and is due to end in June 2025. Project funding from the Victorian and ACT governments has supported the employment of a staff member to develop training and patient resources, with funding available until late 2024.
- IHRA has adopted the Enterprise Agreement of Queensland Council for LGBTI Health (12), which has recently concluded; a new agreement is currently in development. Budget figures include 12% superannuation, 17.5% leave loading, professional supervision, and work cover.
- IHRA does not have physical office facilities or services.

This proposal ensures that IHRA can support the currently unmet healthcare needs of children, parents and carers, prospective parents, and adults, across the lifespan, and beyond current funding arrangements. It incidentally seeks to ensure the sustainability of IHRA as an intersex community-controlled healthcare service provider. Specifically, the proposals seek to ensure continuity of funding for current policy and psychosocial support positions, none of which are funded beyond mid 2025, and many of which have no funding beyond mid 2024.

- We seek to add additional positions, largely focusing on medical, psychosocial and allied health services, engagement with governments, and education and training.
- The policy, training and education staff team will add a new training manager position ensure the sustainability of other staff positions.
- The psychosocial service will increase from two part-time roles and casual peer support staff to add a new clinical psychologist and increase paid time from other staff who are currently paid by a time-limited pilot.
- Medical and allied health services are proposed to include a 0.6 FTE general practitioner, plus regular clinics by other medical and allied health practitioners, including a genetic counsellor, paediatric speech pathologist and endocrinologist. These are expected to occur quarterly.
- Administrative support staff include an existing bookkeeper and a proposed new operations management position.
- Provision is made in this proposal for office facilities that deploy teleconferencing services and telehealth to the maximum extent possible. We will utilise co-working spaces and deepen partnerships with other service providers (including Queensland Council for LGBTI Health, Working It Out and others) to the extent possible.

Annual budget

Costs in year 1 are as follows.

Policy, management, education and training staff Staffing: executive director, training and senior projects staff	416,200
Psychosocial support services Staffing: service manager, clinical psychologist, mental health workers	538,000
Medical and allied health services Staffing: 0.6 FTE general practitioner, plus regular clinics including a genetic counsellor, child development specialists including speech pathology, and paediatric and adult endocrinologists	633,000
Administrative support Staffing: operations manager and administrator	161,500
Office facilities and overheads Overheads and new provision for office services in Brisbane, Canberra, Hobart, Melbourne/regional Vic, regional/metropolitan NSW	351,300
Total	**2,100,000**

Costs in years 2 and 3 will be similar, accounting only for minor incremental increases in salary costs.

Notes

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10. Committee on the Rights of Persons with Disabilities. Concluding observations on the combined second and third reports of Australia. 2019 Sep. Report No.: CRPD/C/AUS/CO/2-3.
11. LGBTIQ+ Health Australia. Submission for the 2023-2024 Federal Budget [Internet]. 2022 [cited 2023 Nov 29]. Available from: https://consult.treasury.gov.au/pre-budget-submissions/2023-24/view/426
12. Fair Work Commission. Queensland AIDS Council Inc (AG2018/7277) Queensland AIDS Council Inc. Enterprise Agreement 2018. Melbourne; 2019 May. Report No.: [2019] FWCA 3357.