

Darlington Consortium

Prospectus 2019



Darlington Consortium Prospectus 2019

To discuss this prospectus, and partnering with the Darlington Consortium, please contact:

Morgan Carpenter

Co-executive director

Intersex Human Rights Australia

morgan.carpenter@ihra.org.au

Bonnie Hart

Intersex Peer Support Australia

bonnie@isupport.org.au



darlington.org.au



ihra.org.au

IPSA
Intersex Peer
Support Australia
isupport.org.au

Intersex People in Australia

Intersex people are born with sex characteristics that do not fit medical or social norms for female or male bodies. There are many different underlying traits, including at least 40 known to science. Each has different characteristics, and individuals can experience those variations in different ways. Intersex traits can be discovered prenatally, at birth, at puberty, and at other times, such as when trying to conceive a child. Some people may never realise they are intersex.

There is a lack of awareness of the specific needs and situation of intersex people in public, clinical, and policy settings in Australia. Despite a 2013 Australian Senate Committee Inquiry calling for the development of a human-rights based protocol for “normalising” surgery on intersex children, to date Australian governments have failed to adequately act. As such, a pattern of human rights abuses on infants, children, adolescents and adults born with intersex variations continues to occur across the country, without effective, independent oversight, often based on gender stereotypes, and lacking a scientific basis. These interventions are currently the subject of an inquiry by the Australian Human Rights Commission.

"There is a real lack of adequate health and social service delivery targeting the specific needs of our communities"

According to Australian sociological research on people born with atypical sex characteristics, the population experience relatively high levels of poverty and social exclusion. Our communities also suffer from on-going stigma, misconceptions and misrepresentation, and harmful clinical practices coupled with legacies of secrecy and poverty. Yet, there is a real lack of adequate health and social service delivery targeting the specific needs of our communities¹.

Typically, intersex people are aggregated with same sex attracted and gender diverse populations. This aggregation reflects some common issues (such as experiences of stigma arising from sex and gender norms), and some intersex people may be same sex attracted or gender diverse, but the issues and populations are distinct. For example, we are at risk of profound human rights violations in clinical and other institutional settings before we are old enough to freely express any sexual orientation or gender identity.

The absence of discrete funding for intersex-led institutions has led to a lack of access and knowledge of those institutions and their expertise, and the production and reproduction of inappropriate information that frames intersex as matters of sexual orientation and gender identity. The needs of our population (including children, and their parents and prospective parents) are largely not addressed by LGBTI organisations focused on matters of personal identification of gender and sexuality.

¹ Jones, Tiffany; Hart, Bonnie; Carpenter, Morgan; Ansara, Gavi; Leonard, William; Lucke, Jayne (2016). Intersex: Stories and Statistics from Australia. Cambridge, UK: Open Book Publishers. ISBN 978-1-78374-208-0.

The Darlington Consortium

Intersex Human Rights Australia (IHRA) (formerly known as OII Australia) and Intersex Peer Support Australia (IPSA) (also known as the AIS Support Group Australia or AISSGA), are national intersex-led organisations with a history of warm collaboration and effective joint work.

IHRA and IPSA played leading roles in organising the Darlington retreat in 2017 that created the [Darlington Statement](#), a world-leading community consensus statement about the needs and demands of intersex people in Australia and Aotearoa-New Zealand. We have established the Darlington Consortium as a strategic, intersex-led initiative that will work with governments, health providers, legal practitioners, intersex community members, carers, family members, allies and others, to realise the vision of the Darlington Statement.

Our work has contributed to legal and regulatory reform across Australia, including inclusion of “intersex status” in federal anti-discrimination law, and the removal of sex and gender discrimination from Medicare service item codes. Whilst our two intersex-led organisations remain almost entirely volunteer-run and volunteer-led, we have nevertheless contributed to local, national and international policy and norm development, research and provided peer support, front line suicide intervention, and community visibility, which has created a mental health safety net for our communities. Our oversight of on-going medical interventions performed on adults and children born with variations of sex characteristics drives rights-based improvements in clinical practices. Our organisations act as a ‘grass-roots’ regulator of the industry and fill the significant gaps left between services. The National LGBTI Health Alliance is providing support to the Consortium, and modelling best practice in intersex allyship and working with its members.

"We have established the Darlington Consortium as a strategic, intersex-led initiative"



IHRA engages in systemic policy work and individual advocacy, evidence-building, and capacity-building. Our systemic work includes policy, resource and strategy development, and advising on legal and regulatory reform. We are recognised for our expertise internationally, and contribute to processes and norm development internationally, nationally and at State/Territory level. Our individual advocacy work is currently limited due to resource constraints, but needs to include helping individuals access services, including health and reparative health services, and medical records. We have board expertise in law, bioethics, healthcare, and public administration.

We have two part-time staff funded by foreign philanthropy, with expertise in bioethics, technology, policy reform, and public administration.

IPSA is a national peer and family support organisation, with youth and parent support lead roles and a presence in each State and Territory delivering a national program of online and in-person support meetings and events.

Our in-hospital patient advocacy assists parents and adults to navigate medical diagnosis and decision making processes and builds relationships between the intersex community and health-care providers.

We provide policy review, education and advocacy for the meaningful inclusion, improved access to services, and the protection of the human rights of intersex people across Australia.

We support other intersex advocates in the work they do and work to develop intersex community and a culture of pride, acceptance, and respect.

"Intersex-led organisations act as a 'grass-roots' regulator of the industry and fill the significant gaps left between services."



How can the needs of intersex people in Australia be met?

Strategic advocacy by the intersex community has led to important recent legal and regulatory changes as outlined above, which has created the potential for Australia to be a world-leader in advancing the human rights, and addressing the needs, of intersex people. Yet, the rapid inclusion of intersex issues into social policy often remains based on misconceptions and lacks genuine engagement with intersex-led organisations. At present, materials produced by IHRA are widely cited, including by public and specialist institutions. However, few institutions have considered how to integrate materials giving definitions of intersex into their programs and services, and few policy-makers have considered

the implications of definitions and research on intersex people for public and institutional policy.

At the same time, greater visibility and public awareness about intersex issues is increasing the number of intersex people seeking peer support and assistance with accessing affirming health and other social services. A high proportion of inquiries that we receive are grounded in misconceptions about our populations. As with peer intersex-led organisations in other countries, the lack of discrete funding to IPSA and IHRA means that we are unable to meet demands from our communities and from the broader population. This potential to meet the needs of the intersex community in

Australia can be realised through dedicated resourcing for:

- **Intersex expert voices** to contribute to policy discussions and reform, and provide effective services to meet the needs of our population.
- **Strengthening our growing community** to ensure that service creation and delivery for intersex people is informed by our lived experience, and our contribution to program development processes are representative, meaningful, and contextualised.
- **Psychosocial support** for intersex people and families in Australia, appreciating that some individuals and their parents and carers require support in order to access public and other services.
- Promoting the creation of **accurate data and research** that meets the needs of intersex populations, and responds to our experiences and issues.
- **Communicating** effectively with the public, LGBT, disability, and public institutions, **to combat misconceptions and mythology, and promote social inclusion.**



The Role of the Darlington Consortium

The members of the Darlington Consortium have the expertise, community networks and trust and proven track record in structural and individual advocacy, community development and peer support to play a pivotal role in addressing the specific needs of the intersex community in Australia. With dedicated funding partners, over the next three years the Darlington Consortium will:

Outcome 1: Effectively advocate for a human rights-based and evidence-informed legal, regulatory and policy framework for intersex issues in Australia. We will do this by:

- Expanding our existing resources and briefing papers, and developing our evidence base (led by IHRA);
- Engaging in collaborative work to improve policies and practices to ensure that they effectively meet the needs of intersex people and our families (led by IHRA);
- Providing accurate, timely advice and representation on legal, health and human rights issues relevant to intersex people (led by IHRA).

- Providing guidance for governments, health providers and other institutions on key legal, regulatory and policy issues (led by IHRA), ensuring that relevant advice is centered on lived experience of intersex people in Australia (led by IPSA).

These issues include:

- protection from harmful practices in hospital, primary care and other health settings;
- addressing and eliminating discrimination and stigma due to intersex characteristics;
- the development of standards of care and oversight for the delivery of medical services to intersex people;
- Addressing the human rights implications of preconception screening, prenatal and postnatal screening;
- establishing redress and reparations processes for abuses experienced by intersex people in medical settings.

Outcome 2: Ensure that intersex Australians are supported to realise their individual legal and health rights. We will do this by:

- Establishing specialist legal and social work support services that will:
 - provide advice on seeking compensation for medical harm, navigating the legal system and accessing identification documents;
 - undertake systemic and individual advocacy;
 - promote accurate and useful information on legal rights for intersex people in Australia;
 - develop and implement strategies for legal reform; and
 - establish referral pathways for legal representation (led by IHRA)
- Undertaking specialist health advocacy for individuals, for example, persons seeking access to medical records and families needing support to navigate medical processes or access services such as the NDIS (joint leadership).

Outcome 3: Strengthen and expand the delivery of peer-led programs for our communities so that intersex people, their parents, partners and others feel connected and supported to access the services they need.

We will do this by:

- Establishing support and social engagement programs for youth, adults, and elders, parents and prospective parents, partners and other family members;
- Providing direct psychosocial counseling and establishing referral pathways to affirmative mental and other health services;
- Developing and formalising our peer support and case management model, which will be disseminated across the country through:
 - training intersex peer support workers to deliver appropriate services;
 - the production of kits and resources;
 - 24/7 online peer support chat rooms;
 - an annual national peer support conference (led by IPSA).

Outcome 4: Improve the capacity of the health and education systems to effectively and appropriately respond to the needs of intersex people in Australia. We will do this by:

- Developing, piloting and rolling out training for medical education institutions, doctors and other healthcare practitioners (led by IHRA);
- Establishing relationships with peak medical bodies such as the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the Royal Australian College of General Practitioners (RACGP) and others (joint leadership);
- Developing, piloting and rolling out age-appropriate educational resources and training for individuals and educational institutions, and establishing relationships with teacher federations (led by IPSA)

Outcome 5: Foster the development of a vibrant, proud, supportive and connected intersex community across Australia. We will do this by:

- Establishing new, and expanding existing, community groups for youth, parents and others, using trauma-informed models of community development;

- Organising regular community retreats for intersex people and our families, including retreats focused on advocacy and mentoring, and retreats focused on peer and family support;

- Providing training and mentoring for our staff and volunteers of all ages;
- Formalising our work as a consortium, and establishing a national network that will be led by IHRA, IPSA, and it will include the Alliance, clinical and other parties.

Outcome 6: Address stigma, discrimination and misconceptions about intersex issues amongst the public.

We will do this by:

- Implementing a communications strategy that will include the dissemination of resources that explain intersex issues and outline the lived experience of intersex people in Australia;
- Run an education and information service, that will include providing information and advice to individual institutions and the general public through our online platforms and through in-person speaking engagements and presentations.

What resources are needed?

Realising the vision of the Darlington Statement and advancing the needs and demands of intersex people in Australia will require dedicated funding that will enable the Darlington Consortium members to scale up their human resources and organizational capacity. Based on the interrelated and complementary role that each organisation will play in the Consortium, it is envisaged that within three years, the following positions would exist within the Consortium:

IHRA	IPSA
Manager	Manager
Senior Policy and Research Coordinator	Peer/family Support Lead (in each State and Territory)
Lawyer	Training, Education and Policy Officer
Policy and Research Officer	Psychologist (with specialisation in trauma and/or childhood development)
Social worker	Youth Support Lead
Communications Officer	Parent Support Lead
Administrator	Elderly/Aged-care Lead (P/T)
Finance Officer	Administration and Finance Officer

In addition to human resources, both IHRA and IPSA are seeking support to cover programmatic, infrastructure and administrative costs as both organisations grow to meet the needs outlined above.

These actions are aligned with the objectives of, and can be supported by a range of sources, including PHNs, the Commonwealth and State and Territory governments, and philanthropic funding opportunities. The Darlington Consortium is looking to establish funding partnerships that will enable us to fulfil the goals outlined in this prospectus and create real and lasting impact in the lives of intersex people and their families across Australia