



Submission

NSW Inquiry into the Human Rights Bill 2025

Introduction

Down Syndrome NSW (DSNSW) welcomes the opportunity to provide a submission to the NSW Parliamentary Inquiry into the Human Rights Bill 2025.

Down Syndrome NSW is the peak body representing people with Down syndrome and their families across New South Wales. For more than four decades, we have worked to promote inclusion, safeguard rights, and support people with Down syndrome to live full and meaningful lives as equal members of the community.

People with Down syndrome are citizens with the same inherent dignity, rights and freedoms as all other people. However, they continue to experience significant barriers in education, health care, employment, housing, justice, decision-making and participation in community life. These barriers are often created not by an individual's disability, but by systems, policies and attitudes that fail to recognise and uphold their human rights.

Down Syndrome NSW strongly supports the introduction of a Human Rights Act for New South Wales and contends that the NSW Human Rights Bill 2025 would be an important step toward ensuring that human rights are respected, protected and fulfilled for all people in the State. The Bill proposes a statutory framework containing protected rights and mechanisms for accountability and oversight. Such a framework would provide significant benefits for people with disability and contribute to a more inclusive and equitable society.

A NSW Human Rights Act Matters for People with Down Syndrome

Human rights belong to everyone. Yet for many people with Down syndrome, rights that are taken for granted by others are not consistently realised in practice.

People with Down syndrome frequently encounter discrimination and exclusion despite Australia's commitments and obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006.

The Disability Royal Commission documented widespread failures across education, health, justice, employment and service systems affecting people with disability.

Many individuals and families report negative experiences including exclusion or difficulties in accessing:

- mainstream education and community activities.
- health care and specialist services.
- employment and career progression.
- housing options and support services.
- Simultaneously, people with Down syndrome frequently report experiences of:
- restrictions on decision-making and autonomy.
- lack of meaningful participation in public decision-making processes.
- negative assumptions about capacity and competence.

A NSW Human Rights Act would require that government agencies and public authorities consider the impact of their decisions on the rights of people with disability. It would provide a framework for identifying and addressing systemic barriers before harm occurs.

A NSW Human Rights Act would give effect to the provisions and safeguards of the CRPD, which until now has relied on the awareness, knowledge and motivations of public authorities to implement rather than a deliberate stated commitment and obligation to implement.

Importantly, a NSW Human Rights Act would shift the focus from disability as a welfare issue to disability as a human rights issue.

Equality before the Law and Freedom from Discrimination

Down Syndrome NSW strongly supports the inclusion of rights relating to equality before the law and protection from discrimination.

People with Down syndrome continue to experience unequal treatment across many areas of life. While anti-discrimination legislation plays an important role, it is mostly reactive and places the burden on individuals to make complaints. Similarly, DSNSW supports the work of the NSW Ageing and Disability Commission, but again the Commission heavily relies on receiving complaints.

A NSW Human Rights Act would create a positive obligation on government and public

authorities to first consider and uphold rights in decision-making before things go wrong. This approach is particularly important for people with intellectual disability who face significant barriers to pursuing legal remedies.

The Bill must be implemented in a manner that recognises intersectionality, acknowledging that people with disability may also experience discrimination based on age, gender, cultural background, sexuality, poverty or geographic location.

Supported Decision-Making and Legal Capacity

One of the most significant human rights issues facing people with Down syndrome is the denial of legal capacity and autonomy.

People with Down syndrome have the right to make decisions about their own lives and to receive support to exercise that right where required.

Down Syndrome NSW urges the Committee to ensure that the implementation of the NSW Human Rights Bill is aligned with contemporary supported decision-making principles. Public authorities should be required to recognise that people with intellectual disability can make decisions when provided with appropriate support, information and communication assistance.

To embed supported decision-making practices across all public authorities, government agencies must receive formal training on:

- Supported decision-making.
- Accessible communication.
- Understanding and respecting will and preferences.
- Rights-based approaches to capacity.

A NSW Human Rights Act:

- must require that the will and preferences of the person are central to all decisions affecting them, and
- must use substitute decision-making arrangements only as a last resort.

Inclusive Education

Education is a fundamental human right.

Many students with Down syndrome continue to experience barriers to genuine inclusion in education settings. Families report experiences including:

- Reduced access to the full curriculum.
- Segregation from peers.
- Inadequate supports.
- Low expectations.
- Exclusion from school activities.

These experiences are in direct breach of the NSW Education Inclusive Education for Students with Disability Policy.

A NSW Human Rights Act would strengthen accountability for ensuring that all students can access quality, inclusive education on an equal basis with others. It would require public authorities to assess policies and practices through a human rights lens and promote inclusive educational environments that recognise diversity as a strength.

Stories of inclusive practice vary from school to school and region to region.

It is clear that current policies are not enough to make sure every school takes a human rights approach to enrolment.

One family shared that when they tried to enrol their child in a mainstream school, they were told that if their child left the classroom or had an incident, they would be automatically suspended each time it happened.

The school did not ask about the child's individual behaviour, strengths, needs or abilities. They also did not discuss what supports or planning could be put in place.

The family felt the aim was to discourage them from enrolling in the mainstream school and push them towards a support unit or School for Specific Purposes.

Health and Access to Health Care

People with Down syndrome often experience poorer health outcomes than the general population despite advances in medical knowledge and support.

Many families report difficulties accessing:

- Specialist services.
- Mental health supports.
- Preventative healthcare.
- Communication adjustments.
- Appropriate health information.
- Brain health clinics and dementia services
- Specialist ID health services

People with intellectual disability also experience diagnostic overshadowing, where symptoms are incorrectly attributed to disability rather than properly investigated.

The protection of the right to health within a NSW Human Rights Act would promote accessible, non-discriminatory health care services and require public authorities to address systemic barriers that contribute to health inequities for people with Down syndrome and others.

In discussions with parents, many stories have been shared about interactions with the health system, both positive and negative.

The negative stories have been alarming, including refusal to allow support staff or family members to stay with the person while receiving hospital treatment, failure of health staff to read charts and health information resulting in repeated near misses in medication errors, foods provided that do not meet allergy and intolerance requirements that are directly outlined in the persons health information, refusal to test for conditions and only treating symptoms.

Housing and Community Inclusion

Access to safe, secure and appropriate housing is essential to the wellbeing and dignity of people with Down syndrome.

Many people with intellectual disability face limited housing options, long waiting periods for supports, and a lack of genuine choice about where and with whom they live.

Recognition of housing-related rights within a human rights framework would strengthen government accountability, and support policies that promote inclusion, independence and community participation.

Access to Justice

People with intellectual disability remain significantly disadvantaged when interacting with the justice system.

Barriers include inaccessible information, communication difficulties, lack of support persons and assumptions about credibility or capacity.

A NSW Human Rights Act would require justice agencies to ensure accessibility and provide reasonable accommodations so that people with disability can effectively participate in legal processes. This could serve to strengthen equitable treatment for people with Down syndrome and others before the law.

Public Accountability

Down Syndrome NSW strongly supports provisions that require human rights considerations to be incorporated into government decision-making and legislative processes. The proposed framework, including statements of compatibility, parliamentary scrutiny and independent oversight mechanisms, has the potential to embed human rights across government thinking, services and activities.

Accordingly, DSNSW strongly supports the purpose of Human Rights legislation as set out in

section 1 of the Victorian Charter of Human Rights and Responsibilities Act 2006, which includes:

- the specific human rights that Parliament seeks to protect and promote
- all statutory provisions to be compatible with human rights
- all public authorities to act in ways that are compatible with human rights
- the preparation of Statements of Compatibility with human rights for all Bills introduced to Parliament, and that a Parliamentary Committee (the Victorian Scrutiny of Acts and Regulations Committee) reports on such compatibility
- that the Supreme Court ensures that statutory provisions are not inconsistent with human rights and that relevant Ministers must respond where there are contradictions.

The Importance of Public Authority Obligations

One of the strongest features of the Bill is the requirement for public authorities to act compatibly with human rights and to properly consider human rights in decision-making.

For people with Down syndrome, this approach is critical. Many rights violations occur not because of deliberate discrimination but because human rights are simply not considered.

As explained, Anti-Discrimination NSW and the NSW Ageing and Disability Commission rely largely on people making complaints. People with disability and families can lack the knowledge, capacity, resources and energy to make complaints, or are fearful of real or perceived retributions. A NSW Human Rights Act will give increased power to both Anti-Discrimination NSW and the NSW Ageing and Disability Commission to implement progressive improvements in the work of government agencies as well as supporting the inclusion of people with disability across NSW.

In everyday life, people with Down syndrome and other disability have to interact with several public authorities and service systems simultaneously when negotiating access, raising issues or resolving problems. Coordination between these public authorities and service systems can be variable, and problem solving can be difficult when responsibility for

an issue is shared between agencies and systems. Each authority plays a part but none accepts responsibility to act. The person with disability can experience a constant run-around.

A NSW Human Rights Act could eliminate continual transfers of responsibility between service systems and regulators as agencies, separately and together, are required to uphold the person's human rights.

Embedding human rights considerations into everyday decision-making can prevent harm before it occurs.

This cultural shift has been one of the most significant benefits of human rights legislation in other jurisdictions.

Culture Change

For people with Down syndrome, cultural change is as important as legal reform. Human rights protections are most effective when they influence everyday decisions made by public officials, educators, health care providers, justice agencies and service systems.

Recommendations

Down Syndrome NSW recommends that the Committee:

- Consult people with disability and representative organisations on the actual draft of the Human Rights Bill 2025 prior to its formal introduction to Parliament.
- Ensure that people with disability, including people with intellectual disability, are actively involved in the implementation and review of the legislation.
- Strengthen recognition of supported decision-making principles and legal capacity.
- Require public authorities to provide accessible information and communication supports.
- Ensure robust mechanisms for monitoring, complaints and remedies.
- Invest in education and training for public authorities on disability rights and human rights obligations.

- Establish processes for ongoing consultation with people with disability and representative organisations.
- Ensure that all implementation measures are consistent with Australia's obligations under the Convention on the Rights of Persons with Disabilities.

Conclusion

Down Syndrome NSW believes that a Human Rights Act represents a significant opportunity to strengthen the protection of rights, dignity and inclusion for people with Down syndrome and all people with disability in New South Wales.

Human rights should not depend on where a person lives, their disability, or their ability to advocate for themselves. A NSW Human Rights Act can help ensure that the rights of all people are recognised, respected and protected in law and in practice.

We encourage the Committee to recommend the adoption of a strong and effective Human Rights Act that promotes equality, participation, autonomy and dignity for all people in New South Wales.

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