

# **Submission: Strengthening Provider Governance in Aged Care**

**Supporting an inclusive, vibrant and diverse  
aged care system in Australia**

**November 2022**



**Down Syndrome**  
New South Wales



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## About Down Syndrome NSW

The Down Syndrome Association of NSW was established in 1980 by parents of young people with Down syndrome. As the children of the founding members grew to adolescence and adulthood, so too our services extended to all life stages. We now provide information and support, advocacy, capacity building workshops, training in schools, community participation programs, pre-natal expert advice, new parent resources and support and specialist employment preparation and connection.

We are an enthusiastic team of professionals with expertise in our relevant fields of service provision, support and advocacy. Some of us have lived experience with a family member with Down syndrome, some bring a range of expertise and industry experience. We are here to support you – all working together to help our members with Down syndrome achieve their full potential.

## Introduction

Down Syndrome NSW welcomes the opportunity to provide a submission on the *Aged Care Legislation Amendment (Governance and Reporting for Approved Providers) Principles 2022*. In responding to the legislative changes, we commend the work to date, whilst also advocating for the need for greater consumer engagement, clear continuous improvement mechanisms and clarity regarding accountability.

We support the introduction of key elements as enshrined in the proposed legislation amendments, namely:

- the establishment of quality care advisory bodies that will report to the approved provider's governing bodies,
- the provision of an annual statement by approved aged care providers to the Secretary,
- the establishment of consumer advisory bodies,
- stipulations around the records approved providers should keep on the proposed legislative provisions.

We know that we are experiencing the first generation of people with Down syndrome who will outlive their carers en masse, with the life expectancy of people with Down syndrome now over 60 years of age. For aged care, this means we will start to see people with Down syndrome in the aged care system.

Down Syndrome NSW seeks to work with the Aged Care Quality and Safety Commission to ensure that people with Down syndrome (and intellectual disability more broadly) are recognised to enable governing entities to adequately and meaningfully comply with, and hopefully exceed, not only legislative requirements, but also consumer expectations.

We are particularly interested in the requirement for providers to establish a quality care advisory body and recommendation of a consumer advisory body, viewing both as necessary to drive transformational change. The development, implementation, evaluation and mechanisms needed to support such initiatives, however, require a deep understanding of and commitment to genuine consumer engagement for people with Down syndrome. We recognise that this is a relatively new requirement of the aged care sector and one that Down Syndrome NSW seeks to support aged care providers, peaks, regulators and the government to understand and implement.

## General Commentary

### Overview of Proposed New Legislative Requirements

Down Syndrome NSW supports the aim of the new governance responsibilities, namely to:

- improve leadership and culture;
- improve transparency and accountability;
- ensure providers focus on the best interests of consumers.

We note that the Exposure Draft of the *Aged Care Legislation Amendment (Governance and Reporting for Approved Providers) Principles 2022* are open for consultation in November 2022, with a commencement date of 1 December 2022.

It should be noted that this timeframe gives providers little time to understand and implement the changes in a robust and meaningful manner, particularly for residents with Down syndrome or with intellectual disability or cognitive impairment more broadly. We also recommend that a communications strategy be implemented to ensure that consumers are aware of their rights and changes under these amendments.

Under the proposed legislative amendments, Down Syndrome NSW supports the introduction new governance responsibilities, including:

- the membership of governing bodies;
- the provider's constitution;
- advisory bodies;
- staff qualifications, skills and experience;
- the suitability of key personnel in the provider's organisation;
- providing an annual statement on the provider's operations.

We know that the provision of quality care is important for all consumers and would argue that it is imperative for consumers who may be more vulnerable, at risk or at times require support to express their wishes as is the case for people with Down syndrome.

Herein we outline our recommendations to ensure quality care is embedded in practice, in line with the intent of the legislative reforms in the exposure draft of the *Aged Care Legislation Amendment (Governance and Reporting for Approved Providers) Principles 2022*.

## General Feedback

Down Syndrome NSW welcomes measures that provide greater transparency to consumers, enhance informed choice and strengthen meaningful consumer engagement.

Down Syndrome NSW strongly supports the establishment of consumer advisory bodies and quality care advisory bodies to actively contribute to the improvement and monitoring of quality care, provided these bodies are representative and mechanisms are in place to ensure both entities have a meaningful voice and impact.

With the scale and quantum of reform underway in the aged care sector, we note the current and emerging reporting requirements placed on providers and recommend that strengthening governance is a key part of the broader accountability framework. The review of the Aged Care Quality Standards, the expansion of the quality indicator program and the introduction of star ratings are welcome reforms, though it would be useful to see an overview to ensure alignment and reporting synergies, particularly as they relate to translating this for consumers to better inform their choices.

To ensure optimal outcomes, we advocate for clear impact measurement in order to evaluate if and how such reform measures are moving the needle to improve quality care. Achieving this will require the establishment of baseline metrics, as the foundation to measuring transformational change as well as meaningful and authentic engagement of consumers to inform this.

## Detailed Response to Proposed Amended Legislation

### Part One: Governance

Down Syndrome NSW strongly supports the requirement of all approved providers to establish a quality care advisory body and the recommendation to establish a consumer advisory body. We advocate that the latter should be a requirement also, not only for the purposes of informing the governing body but the broader organisation service planning, delivery and evaluation.

We know that people with Down syndrome – and with intellectual disability and cognitive impairment more broadly – have much to contribute as active and valued recipients of care.

We strongly support the introduction of a quality care advisory body in all organisations. We agree with the remit for the six-monthly report from the quality care advisory body to the governing body to comprise:

- trends in quality of care (including quality indicators, incidents, consumer surveys, staff and consumer feedback and complaints);
- concerns about the quality of care;
- action being taken to address any concerns;
- matters/issues referred to the quality care advisory body by the governing body;

In addition, we recommend that these reports also include a profile of care recipients, including those with a diagnosis of Down syndrome, intellectual disability or cognitive impairment, and trends in this respect.

The strong focus in the proposed amended legislation on the quality care advisory body referring clear actions for the governing entity to adopt and report back to the quality care advisory body in relation to progress is commended and welcomed. Demonstrated continuous improvement and cyclical accountability is vital. It is pleasing to see this included in the new requirements for record keeping, in part.

In relation to the composition of the quality care advisory bodies, we would seek that the legislation (or supporting documentation) ensures that the member(s) representing the interests of care recipients is representative of the profile of the care recipients, including people with Down syndrome, intellectual disability or cognitive impairment where relevant with these members appropriately supported to do so.

It is pleasing to see that the annual statement to be provided to the Secretary includes a provision for mandatory reporting in relation to the diversity of the governing body of the approved provider as well as initiatives undertaken to support a diverse and inclusive environment. In establishing these important structures and processes care needs to be taken to ensure the focus is on the outcomes achieved not solely on the processes followed.

Engaging and promoting the voice of consumers is central to our work. Down Syndrome NSW strongly advocates for the establishment of consumer advisory bodies. However, the proposed amended legislation appears to be silent on Consumer Advisory Bodies, as separate from the Quality Care Advisory Body. We see a Consumer Advisory Body as an essential enabler to the Quality Care Advisory Body. Consumer Advisory Bodies are only mentioned in the proposed amended legislation in relation to record keeping.

## **Part Two: Record Keeping**

Down Syndrome NSW supports the enhanced independence of governing bodies from operational staff as well as the inclusion of clinical care expertise. We advocate that the provision to have a member on the governing body who has clinical care expertise covers all providers without excluding smaller providers or providers that are State, Territory or Local authorities. The input of clinical care experts, including nurses and personal care assistants are critical to ensuring that quality care is understood at the executive level and translated into practice. We support the requirement for governing bodies to report the names and experience of each governing body member. It would be helpful to also record the length of their role.

Down Syndrome NSW supports the detailed record keeping requirements of the quality care advisory body. We recommend that the profile of members of quality care advisory bodies matched against the profile of residents be considered, to ensure fair representation.

Notwithstanding the omission on this critical body in the first section of the proposed amended legislation to guide what the entity does, Down Syndrome NSW supports the record keeping requirement to show a copy of each written offer made to all care recipients and their representatives to provide them with the opportunity to establish a consumer advisory body. We note, however, that for people with Down syndrome, cognitive

impairment or intellectual disability, there would likely more required than a written letter to ensure active and meaningful engagement, as well as more frequent engagement.

We are pleased to see this inclusion and support the mandatory requirement for the governing body to keep records on how they have ensured that staff have the appropriate skills, experiences and qualifications and are given opportunities to develop. This, of course, needs to be matched with an understanding of the profile and needs of care recipients to aptly assess suitability.

### **General Feedback**

Given the prevalence of cognitive impairment and intellectual disability across all aged care settings and the necessity to understand this to inform service planning and have meaningful impact, we advocate for governing entities to:

- capture data on care recipients, including the number of people living with cognitive impairment and intellectual disability;
- be trained in cognitive impairment and intellectual disability.

## About Down Syndrome

Down syndrome is a genetic condition, sometimes referred to as Trisomy 21. It is the most common genetic disability. There are approximately 13,000 people in Australia with Down syndrome. The birth rate in Australia for Down syndrome is one in every 1,100 births. Evidence tells us that 9 out of 10 pregnancies in Australia are terminated if Down syndrome is detected.

Most people have 23 pairs of chromosomes, making 46 in total. People with Down syndrome have 47 chromosomes in their cells, having an extra of chromosome 21.

People with Down syndrome have:

- Areas of strengths and other areas where they need support;
- Some level of intellectual disability;
- Some characteristic physical features;
- Increased risk of some health conditions;
- Some developmental delays and learning difficulties.

Down syndrome is a genetic condition, it is not an illness or a disease. It is nobody's fault. There is no cure and it does not go away.

In the 1950's (not that long ago), the life expectancy for people with Down syndrome was as low as 15 years of age. In recent times, progress in medical and social sciences has improved the quality of life enjoyed by people with Down syndrome. In Australia today, the life expectancy of Down syndrome averages 60 years of age.

Whilst this is a milestone to be celebrated, it also presents us with the first generation of people with Down syndrome who will, in the main, outlive their parents. This creates an even greater need for representative associations like Down Syndrome NSW to provide critical services, supports and advocacy at all stages across the lifespan.

With the right supports, people with Down syndrome are able to live full and active lives in their communities. From education, to employment, to community participation, to relationships and housing options, people with Down syndrome enjoy the same needs and aspirations just like everyone else. However, achieving these goals can be harder for people with Down syndrome, with some level of support needed to help them achieve the kind of life that most people take for granted.

Down Syndrome NSW proudly works with passion to support all people with Down syndrome to live inclusive, valued and active lives.

## Our Important Work: Down Syndrome NSW

We provide services and supports currently to all people with Down syndrome in NSW, their families and carers across the full lifespan including:

- Information and support;
- Library and resources;
- Workshops and training;
- Parent support networks and regional hubs;
- Prenatal and early years resources and support;
- Inclusive education support, teacher training and behaviour management;
- Transition to school, school years and teens support and advice;
- Post school years transitions including travel training,
- Community engagement and participation for children, teens and adults;
- Accessibility support to participate in events and access infrastructure.
- Health, sexuality and ageing advice, advocacy and support;
- Guardianship and wills resources;
- Self advocacy, capacity building and mentoring;
- Individual advocacy support, advice and resources;
- Systemic advocacy, policy submissions and research.
- Policy, lobbying and proactive government relations;
- Community capacity building, awareness, inclusion and social capital.

We work to promote and represent the views of people with Down syndrome, their families and carers in all that we do. We are governed by a Board comprised of parents and family members, as well as a Down Syndrome Input Council comprised of people with Down syndrome. We hold monthly “Have Your Say” sessions with our adult cohort also to ascertain their views at frequent intervals and undertake robust consultation in a variety of forms to ensure all members have their views heard and represented.

We are enthused to work together with the Commonwealth, state and territory governments to support an inclusive, vibrant and diverse Australia where every person with disability is heard and valued.

## Conclusion

We commend the work undertaken to strengthen provider governance in response to the Royal Commission. The meaningful engagement of consumers of all abilities, including those with Down syndrome, is critical to positively shift service provision and performance and in turn, outcomes for people in aged care. People with Down syndrome, intellectual disability and cognitive impairment have the same rights as all consumers to be actively involved and supported to engage in this process.

The amended legislation provides a solid foundation to strengthen governance and leadership provides a solid foundation and represents the changing environment within which we operate, one that places the consumer firmly at the centre.

Whilst more remains to be done, Down Syndrome NSW sees this as a step in the right direction and looks forward to further collaboration to ensure that the implementation of the legislation meets (and exceeds) expectations and embeds quality care across the sector in an inclusive, equitable and meaningful way that delivers real outcomes for consumers.

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