Down Syndrome &
Intellectual Disability
Queensland

Down Syndrome and Intellectual Disability Queensland	
Submission Title	Submission on the New Program for Children and Families – Intellectual Disability Focus
Date	5th December 2025
Prepared by	

Down Syndrome & Intellectual Disability

Executive Summary

Our mission at Down Syndrome & Intellectual Disability Queensland is to support, advocate for, and empower people with intellectual disability to reach their goals and be included in their community.

Formerly known as Down Syndrome Queensland (DSQ), we officially launched our new name, Down Syndrome & Intellectual Disability Queensland (DSIDQ), on 1 July 2025. This change reaffirms who we are and what we stand for as Queensland's peak body for people with an intellectual disability since 2022. Our new name strengthens our visibility, clarity, and commitment to the communities we represent.

At DSIDQ, our team is driven by a commitment to ensure that individuals with intellectual disability, their families, their schools, and their communities feel a strong sense of connection and support throughout their lives. We strive to provide vital information, services, support, and systematic advocacy.

DSIDQ acts as a bridge, linking individuals with intellectual disability, their families, kindergartens, schools, communities, employers, and service providers to valuable resources and assistance. We empower people with intellectual disability to pursue meaningful paths in life by offering guidance, sourcing support, and equipping them with the tools they need.

DSIDQ's services include:

- Information, advice, referrals, and prenatal support
- Education services
- MyTime peer support
- Carer Gateway services
- Hear Me Out self-advocacy and debating program
- Social programs, family events, and capacity building opportunities
- Skills for Independence Program
- Continued Education Programs
- Employment support
- Music therapy for under 5s
- Training for service providers and employers

In July 2025, DSIDQ conducted a statewide engagement project involving individuals with intellectual disability, their families, carers, and supporters. Community messages emphasised **respect**, **recognition**, **safety**, and **employment**, alongside the need for *accessible information*, *place-based services*, *whole-of-family opportunities*, and the *embedding of lived experience* in system design, delivery and evaluation.

In June 2025, **20,555** Queenslanders were receiving NDIS due to having an intellectual disability. That figure represents only those who successfully navigated the NDIS eligibility process and secured a funded plan; a significant proportion of people with intellectual disability remain outside the scheme for a range of reasons.

People with intellectual disability remain over-represented in child protection, justice, and health systems and often experience poorer health outcomes (Emerson & Hatton, 2014; McConkey et al., 2015). These realities highlight the importance of early, targeted, and evidence-informed supports that enable individuals with intellectual disability and their families to thrive and participate fully in their communities.

Many individuals with intellectual disability rely on informal support networks, most commonly family members and friends, and the level of care required varies between individuals. In Queensland, more than 640,000 people identify as carers for someone with disability, a chronic illness, or age-related frailty. However, the actual number is likely higher, as many do not formally recognise themselves as carers.

Caring for a person with intellectual disability can involve complex, ongoing challenges that can have lifelong impacts for both the individual and their family. Caring responsibilities are rarely linear, and families must navigate multiple transitions and key life milestones, including early childhood, schooling, adolescence, and adulthood, often within systems that are not fully equipped to understand or respond to their unique needs. These challenges are amplified for individuals with limited or nonverbal communication skills, who may struggle to access education, healthcare, and community participation. Evidence shows that families of children with intellectual disability often experience higher levels of stress, poorer health outcomes, and increased social and financial pressures compared with other families (McConkey, Kelly & Craig, 2015; Emerson & Hatton, 2014).

Caring for a person with intellectual disability is often motivated by love, commitment, and a desire to see the individual thrive. While it may be challenging, families frequently report discovering new skills, resilience, and strengths both in themselves and the person they support. Many carers develop enhanced problem-solving abilities, patience, and creativity. At the same time, children and adults with intellectual disability often gain confidence, independence, and social skills through the care and guidance of their families and wider support networks. Recognising these positive aspects alongside the challenges highlights the importance of supports that nurture both family wellbeing and individual growth.

Summary of Recommendations

**Full recommendations can be found on page 10*

- Recognise lifelong and complex care responsibilities
- Support carers' wellbeing and family resilience
- Promote inclusion, independence, life skills, and social participation
- Deliver culturally safe, evidence-informed, and integrated services
- Embed lived experience in design, delivery, and evaluation
- Prioritise transitions across life stages
- Promote positive outcomes and skills development

By prioritising these recommendations, the program can ensure children with intellectual disability and their families receive the support they need to thrive.

Flexible, culturally safe, evidence-informed, and integrated services with lived experience at the centre of design and delivery will strengthen family wellbeing, promote inclusion and independence, and reduce reliance on formal support systems.

This approach will help families navigate the complexities of lifelong care while fostering positive outcomes, resilience, and opportunities for all members to participate in community life fully.

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Vision and Outcomes

The new vision of wellbeing, resilience, and supportive environments is a strong foundation. However, the two main outcomes, empowering parents and carers, and supporting children to grow into healthy, resilient adults, do not fully reflect the unique needs of families supporting children with intellectual disability or complex needs.

Outcome 1: Parents and Caregivers Are Empowered

Strong, supported carers are central to children's wellbeing. For families of children with intellectual disability, empowerment must include:

- Tailored supports for complex needs.
- Flexible respite services to prevent burnout.
- Training and guidance to best support people with intellectual disability.
- Ongoing flexible support, including navigation support and case management where appropriate.

Without these, carers risk remaining overwhelmed despite being "empowered."

Outcome 2: Children Grow into Healthy, Resilient Adults

For children with intellectual disability, resilience and wellbeing may differ from typical developmental benchmarks.

Outcomes should explicitly promote:

- Inclusion
- Independence.
- Education.
- Development of life skills.
- Peer support
- Social and community participation.
- Tailored support through key life transitions to prevent long-term disadvantage.

Summary

The vision should explicitly address often lifelong caring responsibilities, tailored approaches for intellectual disability, and connection to community supports to ensure outcomes are inclusive and responsive to all families' needs.

Program Structure and Funding Streams

A single national program with one overarching grant agreement provides flexibility, reduces administrative burden, and allows services to adapt to changing community needs.

For families supporting children with intellectual disability, funding must reflect the intensity, complexity, and often lifelong nature of care.

Future Priorities

- Pre and postnatal supports for families.
- Tailored support for children through key life transitions

- Peer support
- Meaningful engagement of families in design, delivery and evaluation.
- Flexible reporting capturing lived experience perspectives.
- Equitable access in rural, regional, and under-resourced communities.
- Additional services and supports for ageing carers.
- Support for sibling and young carers
- Integrated service pathways to prevent families from falling through gaps.
- Lived experience employment opportunities for people with intellectual disability and carers

This approach ensures responsive, inclusive, and sustainable support for those with the greatest needs.

Prioritising Investment

We broadly support the four priority-evidence-informed programs, prevention and early intervention, intensive family supports, and national information services.

Additional emphasis is needed on:

Lifelong and complex care: Many children require ongoing support; services must prevent potential burnout and build family resilience.

Carer wellbeing: Flexible respite models, mental health support, and community participation.

Transitions across life stages: Supporting children and families through key life transitions, with a focus on social and community participation and independence.

Equity and Accessibility: High-quality services must reach rural, regional, and underresourced communities.

Lived experience: People with intellectual disability, and families must be involved in program design and evaluation.

These enhancements make investments more **inclusive**, **responsive**, and **sustainable**.

Improving Family Wellbeing

While supporting families at risk of child protection involvement and young parents is essential, families of children with intellectual disability face unique challenges.

Children and adults with intellectual disability are over-represented in child protection, criminal justice, and health systems (Emerson & Hatton, 2014).

- Lack of tailored support and early intervention contributes to involvement with the police, child protection or criminal justice services.
- Families often experience high emotional, physical, and financial stress.

- Often, caring families have fewer opportunities to participate in further education, training or employment, due to the requirements of their caring role.

Recommendations:

- Targeted, evidence-informed programs providing intensive and informal support, flexible respite, and mental health services.
- Integrated approaches across health, education, and community sectors.
- Meaningful engagement of children with intellectual disability and their families to ensure programs are practical, inclusive, and responsive.

Connected and Coordinated Services

Beyond co-location, effective service coordination includes:

- Integrated case management, not just navigation support.
- Multi-agency partnerships and formal referral pathways.
- Cross-sector meetings and collaboration opportunities
- Ongoing staff training and commitment to personal development.
- Digital platforms for communication and shared data.

Grant applications should demonstrate:

- Community engagement and collaboration with local schools, health providers, disability services, and community groups.
- Involvement of children with intellectual disability, carers, and families in planning, delivery, and evaluation.
- Capacity to deliver culturally safe, evidence-informed, and integrated services adaptable to local needs.
- Assessment should consider responsiveness, sustainability, and quality of partnerships.
- Employment opportunities for individuals with an intellectual disability and carers.

Responding to Community Needs

Beyond locational disadvantage, funding should reflect:

- Prevalence of intellectual disability.
- Number of families with high or complex support needs.
- Socioeconomic disadvantages and cultural diversity.
- Availability of tailored services to meet individual and family needs.
- Intersectionality

Evidence should include:

- Service reach, uptake, and outcomes.

- Mapping local service gaps and how the program addresses unmet needs.
- Skills development.
- Social and economic participation.
- Collaborations and partnerships to best meet community needs

This ensures funding prioritises communities with the greatest need.

Aboriginal and Torres Strait Islander Children and Families

To support ACCOs delivering services:

- Grant processes should be accessible, culturally safe, and flexible.
- Provide plain-language guidance, capacity-building, long-term funding, and recognition of community-led approaches.
- Flexible delivery and reporting processes

Children with intellectual disability in Aboriginal and Torres Strait Islander communities face higher vulnerability and limited access to specialised services.

Program design should include:

- Culturally informed, holistic, wraparound approaches integrating health, education, and family support.
- Engagement with Elders, families, and lived experience.
- Workforce development and culturally safe training.

Measuring Outcomes

Both quantitative and qualitative data are essential:

- Child and family wellbeing.
- Carer stress and resilience.
- Skills development
- Educational engagement, social and employment participation
- Reduced crisis/system involvement.

Case studies should capture context, challenges, tailored supports, and meaningful outcomes.

Relevant DEX SCORE domains: Child Development and Family Functioning, as well as social and economic outcomes, should be measured.

Relational Contracting

Relational contracting allows long-term, collaborative partnerships focused on outcomes and flexibility. Criteria should include:

- Expertise in supporting children with intellectual disability.
- Evidence-informed practice.
- Lived-experience engagement.
- Capacity to deliver integrated, flexible services.

Selection should consider track record, community reach, and cross-sector collaboration. This approach supports sustainable, high-quality care for families.

Other Considerations

Families caring for children with intellectual disability can face:

- Lifelong caring commitments and increased safety risk.
- Increased carer burnout leading to relinquishment of care.
- Poorer health outcomes for children, carers, and families.

Conclusion

The new program must prioritise families supporting children with intellectual disability by recognising the lifelong and complex nature of caring, supporting carers' wellbeing, and promoting inclusion, independence, and social participation for children and families. Services should be flexible, culturally safe, evidence-informed, and integrated, with lived experience central to design, delivery, and evaluation. By embedding these principles, the program can improve outcomes, reduce over-reliance on formal child protection services and over-representation in criminal justice services, prevent avoidable relinquishment of care, and ensure sustainable, equitable support that enables children and families to thrive.

DSIDQ Recommendations

Recognise lifelong and complex care responsibilities

Programs must acknowledge that caring for a child with intellectual disability can be long-term, evolving, and non-linear, particularly during key transitions and for children with limited communication skills.

Support carers' wellbeing and family resilience

Provide flexible respite, mental health support, peer support, and family-centred guidance to prevent burnout and minimise avoidable relinquishment of care.

Promote inclusion, independence, life skills, and social participation

Programs should explicitly support children in accessing and fully participating in education, developing life skills, engaging in their communities, and participating in social and recreational activities, ensuring they have every opportunity to thrive.

Deliver culturally safe, evidence-informed, and integrated services

Services must be holistic, wraparound, flexible, and regionally accessible, with a focus on equitable access for rural, remote, Aboriginal and Torres Strait Islander, and Culturally and Linguistically Diverse (CALD) communities.

Embed lived experience in design, delivery, and valuation

Children, adults with intellectual disability, and their families must actively participate in all program stages, with information provided in accessible formats.

Ensure connected and coordinated service pathways.

Implement integrated case management, multi-agency collaboration, formal referral pathways, and clear communication pathways to respond to individual family needs.

Prioritise transitions across life stages

Programs must support children and families through key milestones, including schooling, adolescence, transition to adulthood, and workforce participation.

Use evidence to guide funding and program design.

Evaluation should capture child and family wellbeing, carer resilience, social and economic participation, and system involvement, using both quantitative and qualitative measures.

Promote positive outcomes and skills development

Recognise that caring responsibilities, while challenging, foster new skills, resilience, and strengths in both carers and children with intellectual disability.

References

Emerson, E., & Hatton, C. (2014). Health Inequalities and People with Intellectual Disabilities. Cambridge University Press.

McConkey, R., Kelly, F., & Craig, S. (2015). Family Experiences of Caring for Children with Intellectual Disabilities: Stress, Support, and Resilience. Journal of Applied Research in Intellectual Disabilities, 28(3), 230–243.