

# Voices That Matter: Insights from Queensland's Intellectual Disability Community



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DSIDQ COMMUNITY ENGAGEMENT  
TOWNSVILLE, GOLD COAST, TOOWOOMBA, BRISBANE SOUTH, BRISBANE  
July 2025

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*Supported by Department of Families, Seniors, Disability Services and Child Safety*



Down Syndrome &  
Intellectual Disability  
Queensland

# Contents

Contents .....	2
Executive Summary .....	3
About Down Syndrome and Intellectual Disability Queensland (DSIDQ).....	5
Meet the Team .....	6
Community Consultations .....	7
About the Survey .....	8
Survey Demographics.....	9
Survey Responses.....	10
Key Themes.....	14
Queensland All Abilities Network (QAAN) .....	15
Community Feedback .....	16
Post Event Evaluation.....	17
Community Solutions .....	18
Conclusion.....	19

## Executive Summary

Down Syndrome and Intellectual Disability Queensland (DSIDQ) is the peak body for people with intellectual disability across the state. In July 2025, DSIDQ conducted statewide consultations and survey to gain a deeper understanding of community needs, challenges, and priorities.

**Locations:** Townsville, Toowoomba, Gold Coast, Brisbane South & Brisbane, plus an online survey.

**Participation:** 118 surveys, 25% were completed by individuals with an intellectual disability.

**Approach:** Lived-experience speakers, surveys, and solution-focused discussions.

### Key Findings

**Safety & Inclusion:** Many people with intellectual disability feel welcomed in their communities, but concerns remain in public transport, hospitality venues, and shopping centres. Families and carers reported lower levels of confidence in safety and inclusion.

**Respect in Services:** While many individuals reported positive experiences, gaps exist in employment, education, and NDIS support. Families consistently reported lower perceptions of respect and inclusion.

**Access to Services:** 72% of people with intellectual disability found services accessible, compared to just 23% of families and carers. Barriers included a lack of awareness, high costs, limited regional options, inaccessible information, staff training gaps, and negative community attitudes.

### Community Priorities:

Individuals: Feel safe, build friendships, and are respected.

Families & carers: Inclusion, friendships, and quality healthcare.

### Community Challenges

Communication barriers and a lack of Easy Read resources.

Limited training for service providers.

System complexity (NDIS, healthcare, education).

Stigma, discrimination, and exclusion from mainstream opportunities.

Financial and transport.

## **Community-Driven Solutions**

**Education & Training:** Greater post-school pathways, self-advocacy training, and disability awareness for providers.

**Employment:** Employer education, stronger job support, and quotas in government contracts.

**Social & Peer Supports:** More inclusive community events, sports, and opportunities for young people and families in their communities.

**Transport:** Staff training, expanded travel programs, parking concessions.

**Information & Navigation:** Easy Read resources, one-stop hubs, and system navigators.

## **Community Opportunities**

Expand training for families, carers, support staff, and community providers.

Increase inclusive social opportunities statewide, particularly in regional and remote areas.

Embed lived experience in service design, delivery, and evaluation.

Strengthen place-based supports and pathways to further education and employment.

Improve communication through accessible and centralised information points.

Provide more support for families during key life transition points.

Ensure regular community consultations to maintain authentic representation.

## **Conclusion**

The consultation confirmed the community's desire for greater inclusion, respect, and equitable access to opportunities. By prioritising lived experience, strengthening regional supports, and addressing systemic barriers, Queensland can foster communities where people with intellectual disability are valued, connected, and supported to thrive.

## About Down Syndrome and Intellectual Disability Queensland (DSIDQ)

Down Syndrome and Intellectual Disability Queensland (DSIDQ), formerly known as Down Syndrome Queensland (DSQ) until 1 July 2025, has served as the peak body for intellectual disability in Queensland since 2022. DSIDQ is committed to improving the quality of life for people with intellectual disabilities, including those with Down syndrome.

Established in 1976 by parents seeking to support and strengthen families, DSIDQ is a registered charity that promotes positive, realistic representations of people with disabilities. Today, its dedicated and expert team delivers a wide range of services and supports across Queensland, backed by a passionate group of volunteers, including the DSIDQ Board.

DSIDQ operates with a small but impactful team, delivering high-quality, statewide services to individuals with intellectual disability and their support networks, including families, carers, and paid supports. The organisation also plays a vital role in building community capacity to understand, respect, and respond to the needs of people with intellectual disability. At the heart of this work is ensuring that community voices are included in program design, delivery, and are embedded in all advocacy initiatives.

DSIDQ collaborates with key partners and other peak bodies through the Queensland Peak and Representative Bodies Inclusion Program, and as a member of the Queensland Disability Advisory Council. This collective brings together diverse voices and expertise to influence policy and drive systemic change, working toward a society that is inclusive, accessible, and respectful of the strengths and aspirations of all Queenslanders.

Funding for DSIDQ's work is sourced through a combination of state and federal grants, sponsorships, donations, and fundraising initiatives.

### Social Media Channels:

 <https://www.facebook.com/DownSyndromeQld/>

 <https://www.instagram.com/dsidq/>

 <https://www.linkedin.com/company/18786792/admin/dashboard/>

## Meet the Team

Individuals with intellectual disabilities played a vital role in each community engagement event, generously sharing their personal stories that highlighted experiences of hope, opportunity, and challenge. The events were facilitated with the support of Sarah Bone (CEO), Georgie Greaves (Office and Programs Manager), and Michael Harrison (Community Engagement and Fundraising Manager).

All facilitators with lived experience were remunerated for their time and played a vital role in the success of each event.

During the planning and preparation of our community events, we consulted with individuals with intellectual disability and family representatives to refine the survey questions. Edits were made throughout the process, even after the online survey was launched, to improve accessibility and ease of completion. However, we recognise that next time we need to allow more time to adequately consult and prepare the questions to meet the needs of a wider audience.

We extend our sincere thanks and congratulations to the entire lived experience team for their invaluable contributions and support during each event. Nikela Carrigan (Brisbane), Sam Le Feuvre (Townsville), Sarah McRae (Brisbane South), Liv Swain & Mitch Toohey (Toowoomba), and Calum Scanlon & Taylor Anderton (Gold Coast).





## Community Consultations

We extend our sincere thanks to the Department of Families, Seniors, Disability Services, and Child Safety for providing additional funding that enabled DSIDQ to conduct statewide community consultations. This support came at a pivotal moment, as we begin a new chapter under fresh leadership and a renewed identity reflected in our new name and branding. These changes demonstrate our ongoing commitment to supporting individuals with intellectual disability and their broader support networks.

To ensure broad representation, our team identified five key regions for in-person consultation sessions: *Townsville*, *Toowoomba*, *Gold Coast*, *Brisbane North*, and *Brisbane South*. In addition to these face-to-face events, we launched an online survey to reach those unable to attend in person. This approach enabled us to hear from individuals with intellectual disability, their families, carers, and other stakeholders across Queensland. It was important to us that this opportunity be inclusive and accessible, ensuring the voices captured reflected both statewide and community-wide perspectives.

In Townsville, Gold Coast, and Toowoomba, we hosted two events in each location, one during the day and one in the evening, to accommodate those with commitments such as education, employment, training, appointments, or other competing priorities. For our Brisbane South event, we partnered with an existing playgroup to capture voices and lived experiences at a time and place that best suited the community's needs.

Our final consultation was held at our Ascot office, with an open invitation extended to all, including participants already engaged in our programs and services on the day.

During each event, attendees were invited to complete the survey independently to ensure consistency in the data collected across all consultation activities. Following this, participants were given the opportunity to contribute community-driven solutions to the key issues identified through the survey responses.

These events created valuable spaces for attendees to be heard, to learn more about our service offerings, and to connect in a relaxed and welcoming environment.

Strengthening community connections through open dialogue, shared stories, and inclusive engagement across the state.

## About the Survey

We commenced our community engagement events on July 1st, and the final event was held at our Ascot office on July 29th.

Events and surveys were promoted through our social media channels, newsletters, and emails, with support from internal and external stakeholders who shared these opportunities through their networks.

### Appendix 1 – Community Engagement Event Flyer

Our survey was launched online on **July 10th** and closed on **July 29th**.

### Appendix 2 – Survey Questions

The survey consists of seven questions; the first few questions were designed to determine whether people with intellectual disabilities feel safe, included, respected, and able to access services easily when needed. The answers will help identify areas for improvement in both social inclusion and service quality.

We then asked respondents to identify their priorities and what DSIDQ could do to better listen to, communicate with, and represent our community. This information will help guide our decision-making, identify priorities for improvement, and ensure services are tailored to meet the real needs of our community.

### Appendix 3 – Post-Event Feedback Form

Service improvement is vital to us, as this was the first time in a while that DSIDQ had undertaken community-based consultations. After each event, we asked all attendees to complete a post-event survey to gather feedback on their satisfaction with the event.





## Survey Demographics

We received **118** completed surveys. Out of these, approximately **25%** were completed by individuals with an intellectual disability.

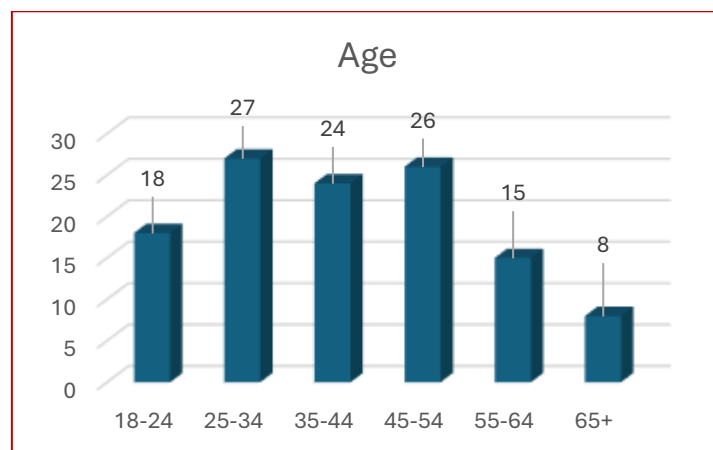
### Gender

Most of our surveys were completed by females, with **79** completed by females and **39** by males.

There were a larger number of males with an intellectual disability completed the survey than females, **15%** males and **9%** females.

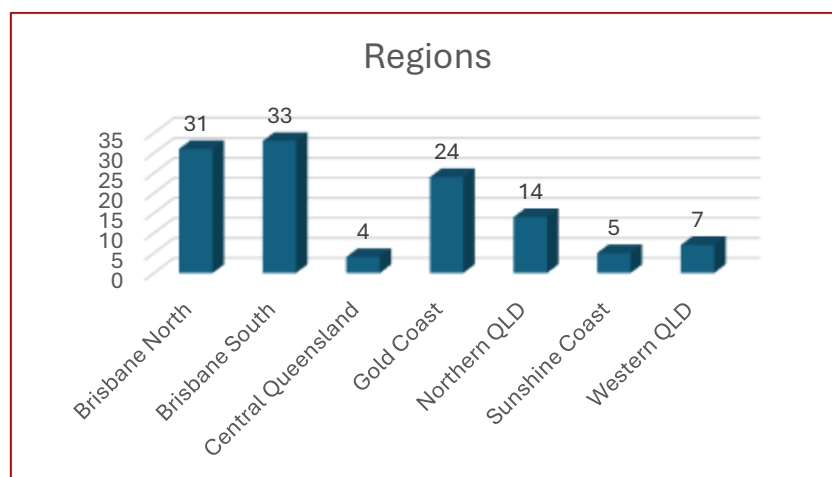
### Age

Respondents represented a diverse range of ages across all categories, with the majority falling between 25 and 54 years old.



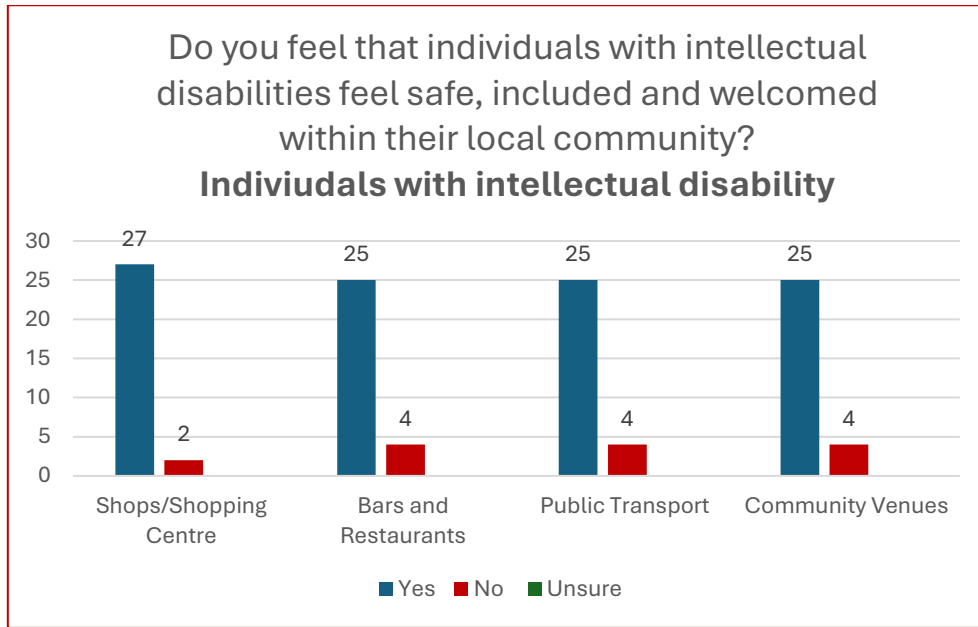
### Regions

The survey was promoted across the state, with the highest number of completions in the **Brisbane South** region, closely followed by the **Brisbane North** region. It was evident that the areas we visited generated the highest number of responses.

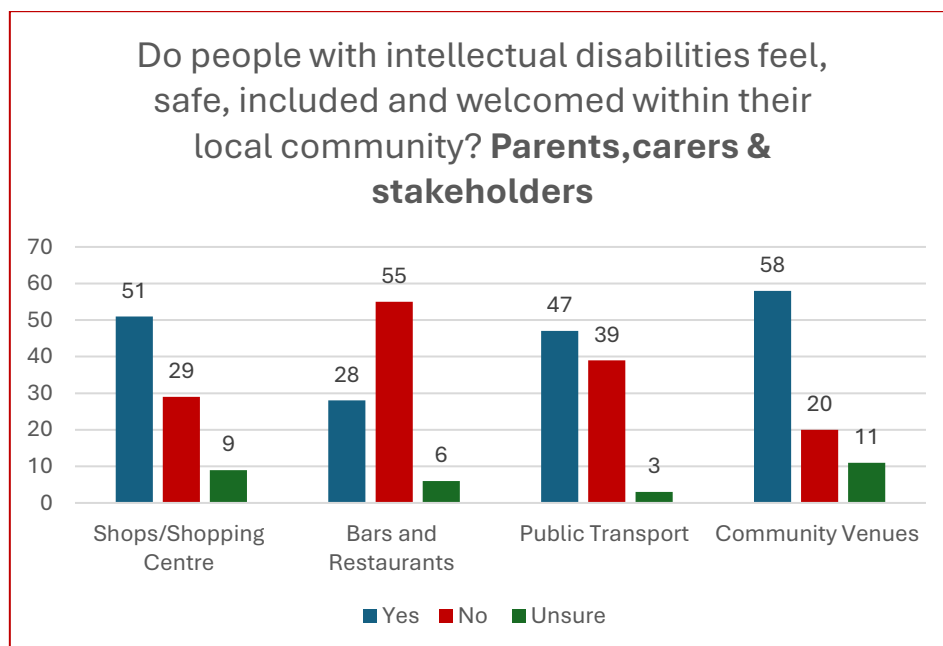


## Survey Responses

When we asked individuals with an intellectual disability if they feel safe, included and welcomed within their local community most respondents stated they felt safe, included, and welcomed in their local community; however, **14%** noted that they didn't feel safe, included, and welcomed in bars, restaurants, community venues, and public transport, and **7%** in shopping centres.

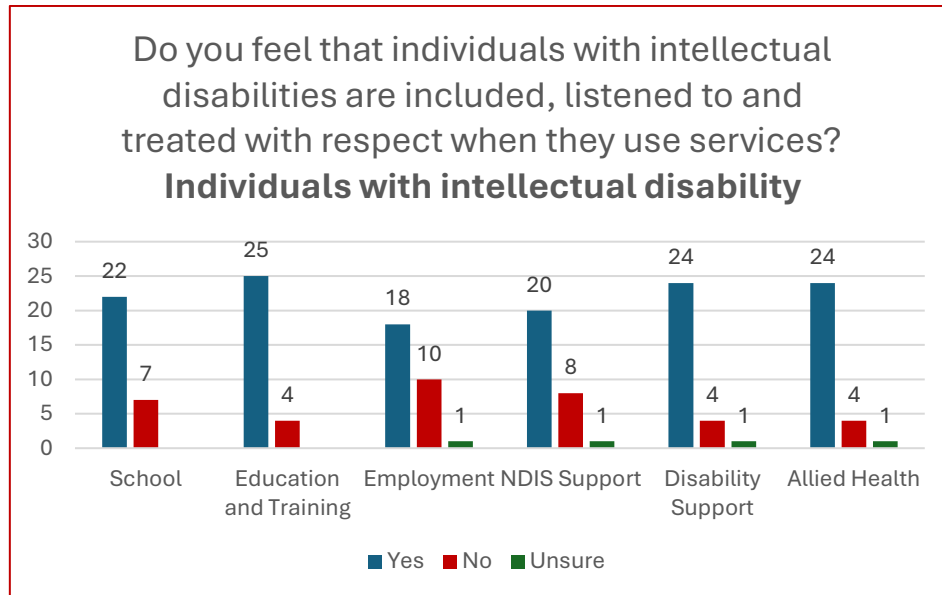


When we asked families, carers, and paid support their answers differed considerably, with many respondents noting that they didn't feel that individuals with an intellectual disability felt safe, included, and welcome within their local community, **62%** in bars and restaurants, **44%** in public transport **34%** shops and shopping centres and **22%** in community venues.

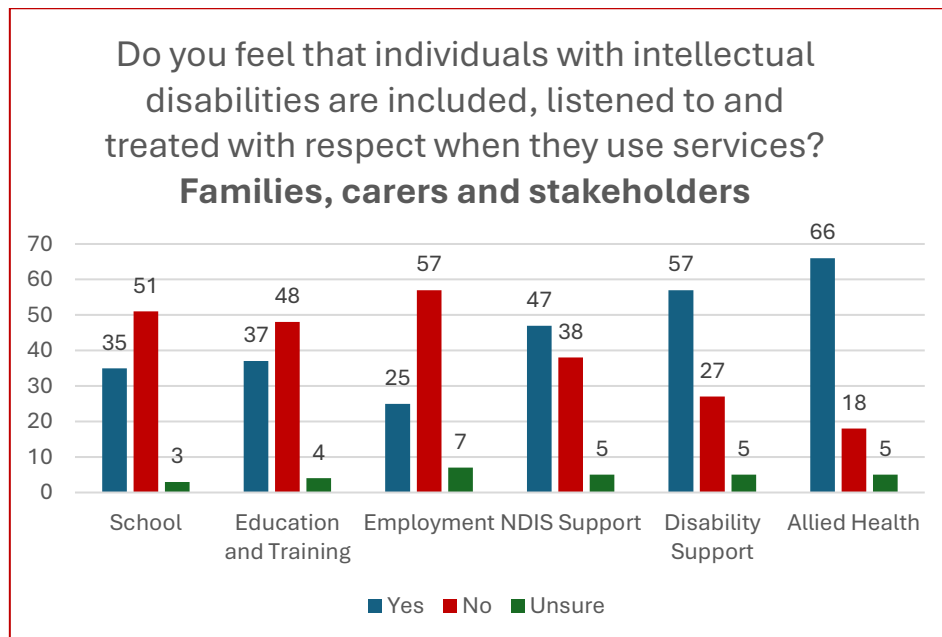


When we asked individuals with an intellectual disability if they felt included, listened to, and treated with respect when they use services the consensus was **Yes** across service settings.

However, **34%** stated they did not feel included, listened to, and respected in employment settings, **28%** whilst accessing NDIS supports, and **24%** in school.

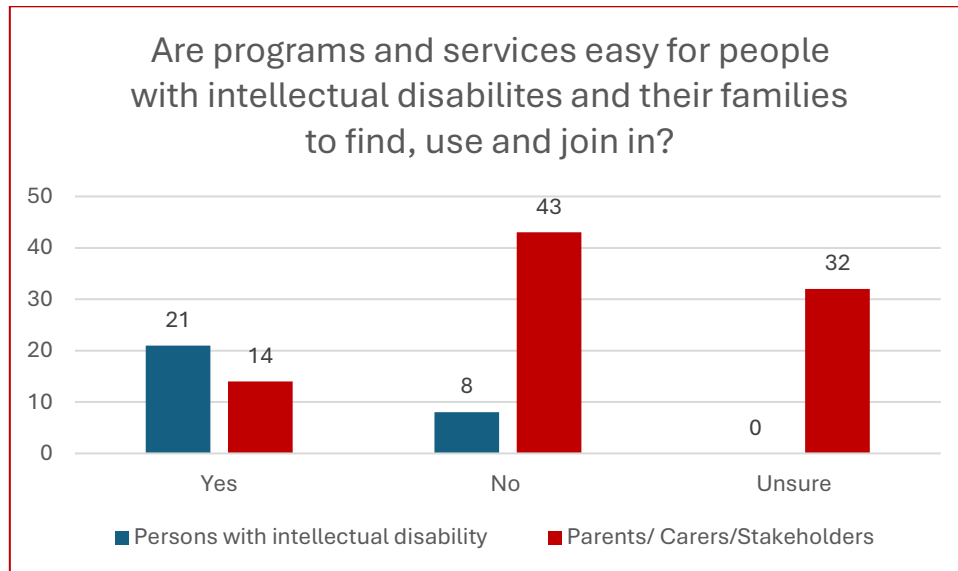


When we asked families, carers, and paid support, their answers differed considerably across three service settings: employment, education, and training, and school, where they felt that individuals were not respected and listened to, with the highest being employment at **48%**, school **43%** and education and training at **40%**.



We then explored whether the respondents found programs and services easy to find, use, and join in.

**72%** of individuals with an intellectual disability felt that programs and services were easy to find, use, and join in, compared to **16%** of parents, carers, and stakeholders.



To expand on this question, we asked what makes it hard for individuals to access services, and we received some great feedback.

Key themes identified during the consultations included **a lack of awareness of services on offer, quality options, transport, funding, community inclusion, accessibility, eligibility, and staff training**, as well as having **limited options in regional areas** and for individuals with **higher support needs**.



## **What makes it hard for people with an intellectual disability to access services**

- Don't know what's available, limited options in regional areas
- For those who are non-verbal, there are limited opportunities, and nobody takes the time to consult or hear their voices.
- Lack of inclusive opportunities for people with an intellectual disability to participate in mainstream community and sporting events.
- Insufficient user-friendly resources and information, including Easy Read
- Access to technology
- Cost implications
- Lack of goal-based opportunities, including education and employment options that have an authentic design embedded.
- Lack of disability awareness training for staff facilitating community events or working in the community.
- Lack of understanding of intellectual disabilities
- Preconceived ideas and attitudes about intellectual disability
- Health literacy

To better understand our community's priorities, we asked them to rank their top three out of ten options.

## **Appendix 2 – Survey Questions**

### **Individuals with an intellectual disability identified their top three priorities as:**

1. Feeling safe and supported in public spaces
2. Having friendships
3. Being included and respected in the community

### **Families, carers, and paid support identified their top three priorities as:**

1. Being included and respected in the community
2. Having friendships
3. Access to quality healthcare

## Key Themes

At the end of the survey, we asked the community what DSIDQ could do better to listen to, communicate with, and represent people with an intellectual disability.

- Ensure lived experience voices are integral in all that DSIDQ does
- Deliver more intellectual disability awareness training for professionals in communities.
- Continue advocating for key issues impacting the community
- Seek more funding to deliver more place-based services outside Brisbane
- Increased community consultation opportunities and provide opportunities for individuals to share their stories.
- Deliver more workshops, training opportunities, and support to families and carers.
- Increased support for individuals and families to identify, secure, and sustain open employment in their community.
- Simplify organisational communications and the website
- Offer more whole-of-family social opportunities





## Queensland All Abilities Network (QAAN)

Established in 2024, is our lived experience advisory group provide vital feedback and input into service design and delivery, as well as key advocacy issues. Members join online every month, with representatives from across the state participating.

Not all QAAN members were able to join our community engagement events; updates were provided before and after the project.

The group were also asked to provide a response to the below question:

### **1. What is one piece of advice you would give Queensland Government to better support people with intellectual disabilities?**

#### **Sam**

To provide more opportunities for people with a disability to connect and make friends in the local community.

#### **Luca**

Provide more training and information on how to keep the environment safe, including opportunities to learn about how to protect the environment in our community.

#### **Michael**

Ensure there is adequate government funding to support people with disabilities, that disability remains a government priority, and changes in government don't impact current services and supports.

#### **Eion**

More training for Support Workers, to help people with disability become independent in their community.

#### **Nikela**

Offer funding and support to help people do the things that they love.

#### **Ethan**

To provide more training to people about intellectual disability.

#### **Callum**

Give people with an intellectual disability the opportunity to do sport in their local community.

#### **Sarah**

To ensure that the voices of people with a disability are heard and they are supported to make their own decisions.

Thank you to all QAAN members for your wonderful questions and contributions.

## Community Feedback

Throughout all events, we heard many wonderful stories and received some great feedback from those in attendance. We value the positive and constructive feedback shared by those who felt comfortable and supported to do so.

### Attendee Quotes

- I still see an overwhelming tendency to address the support person or family member, with people talking about the person with intellectual disability rather than to them, even at a recent disability awareness workshop.
- My son has a dual diagnosis of Down syndrome and Autism and gets left behind in mainstream events and services offered for people with ID.
- Services and systems are too complex to navigate for many families
- Those with higher support needs often get left out as services can't accommodate them, and they are often put in the too-hard basket.
- Families often feel confused and overwhelmed
- Funding for the things I like to do is not available
- Remember, everyone isn't on social media
- Families really need a navigator to work through support systems, NDIS, My Aged Care, and Centrelink.
- My son is five and is not capable of participating in activities aimed at 5-year-olds. He is better suited to activities aimed at 3-year-olds, but is sometimes excluded due to his age and the need for parental support.
- My person with an ID is a 10-year-old child, so I have no experience with her having to negotiate access to services independently. As parents, our journey so far has been relatively easy. The services have always made contact with us and provided adequate services.
- People with intellectual disability are not seen as valuable, which is reflected in a lack of REAL inclusion, a lack of opportunities, and individual choice and control.

## Post Event Evaluation

To evaluate the effectiveness of the events and identify opportunities for improvement, attendees were asked to complete a post-event evaluation.

### Appendix 3 – Post-Event Feedback Form

#### Results

**97%** of attendees felt the event provided them with an opportunity to feel heard

**97%** of attendees learnt more about DSIDQ services

**97%** of attendees said the event helped them feel more connected to others

**87%** of attendees felt the event met their expectations

#### What did you like most about this event?

- Warm and welcoming, informative, and learned information about services I didn't know about – thank you
- Lived experience speaker
- Having my say as a person with intellectual disability
- Being listened to
- Opening and inviting approach by the team
- Standing at the front, reading the Acknowledgement
- Gaining an understanding of DSIDQ vision and hearing ideas from other parents.
- Learning more about services and supports and being able to ask questions with reliable answers.
- Honesty and willingness to own past mistakes and push forward to bright outcomes.



## Community Solutions

During the events, attendees shared their ideas on what is needed in their community for individuals with intellectual disability and their families and carers.

### Education /Training

- Provide more community-based post-school options with a focus on regional and remote areas.
- More sign language training, to better support those who are non-verbal
- Expand accessible training opportunities in life skills, relationships, and self-advocacy, ensuring programs are practical, inclusive, and available across all regions.

### Employment

- More support for families to help find suitable open employment opportunities
- More support for individuals with an intellectual disability to sustain and explore career progression opportunities when in employment.
- Ensure all employers and employees are required to complete disability awareness training.
- Government contracts that stipulate a percentage of employees with disability to be recruited.

### Social /Support

- Community peer support groups, for individuals with an intellectual disability and their families and carers, to foster friendships.
- Increased funding for whole-of-family community-based opportunities
- Provide access to more inclusive community sports

### Transport

- Fund transport training programs across Queensland
- Parking permit for all individuals with an intellectual disability who struggle with their vision.

### Communication

- Ensure all communication is accessible
- Ensure co-design processes meaningfully include people with intellectual disability, including those with diverse communication needs.
- Ensure the views and wishes of those with an intellectual disability are central to any decision-making process.

## Conclusion

People with intellectual disabilities often face multiple barriers when trying to access services. These barriers can be structural, social, communication-related, or systemic.

The consultations clearly highlighted several key challenges, including communication barriers, a lack of training and awareness among service providers, complex systems, physical and environmental obstacles, limited advocacy, and opportunities for genuine consultation. These factors often prevent individuals with intellectual disability and their families and carers from reaching their full potential.

Despite these barriers, the community has been clear and consistent about its priorities. People with intellectual disability, their families, and carers want to see greater inclusion, stronger place-based supports, meaningful opportunities for connection, and easier access to information and pathways to education and employment.

The voices captured through this consultation process provide government and service providers with some tangible, community-driven solutions. By expanding inclusive social opportunities, embedding lived experience into the design and delivery of services, and ensuring that individuals with diverse communication needs are fully included in consultations and decision-making, Queensland can foster communities where people with intellectual disabilities are valued and respected.

It was clear that many individuals and families are missing out on participating in community opportunities for many reasons, including accessibility, isolation, and financial reasons. The introduction of a program, like the 'Take a Break' initiative, would enable families to access direct funding for short breaks and inclusive community activities. This program would provide opportunities for individuals with intellectual disability, their families, and carers to connect, recharge, and participate more fully in community life. Far from being a cost, such an investment is a catalyst for better health outcomes, stronger and more resilient families, increased social connection, and a more inclusive and productive economy. <https://takeabreakscotland.org.uk/>

DSIDQ extends our sincere thanks to every individual, family member, carer, and paid support who contributed their time, energy, and experiences. Your insights have been invaluable in shaping this report and will guide our future strategic direction and advocacy priorities.

This report is not the end of the conversation; rather, it is an invitation to continue building solutions together. We welcome further opportunities to collaborate with government, community organisations, and stakeholders to ensure that the voices and needs of the intellectual disability community remain central to policy, service design, implementation, and evaluation across Queensland.



# Down Syndrome & Intellectual Disability Queensland

