Disability Reform Community Forums Summary Report May - June 2025

# The QDN logo, which is made up of the capital letters 'QDN' in navy blue font, with the following text underneath, in dark grey font: 'Queenslanders with Disability Network' A second line of text sits beneath, in light blue italicised font: 'Nothing about us without us'.Queensland GovernmentA black and white logo Description automatically generated

# Acknowledgements

Queenslanders with Disability Network (QDN) acknowledges the Traditional Owners of the lands on which we work. We pay our respects to the Elders – past, present and emerging – and acknowledge the important role Aboriginal and Torres Strait Islander people continue to play within the community.

QDN also acknowledges people with disability who have come before us and died in institutional settings, as well as those who are still trapped in institutions or silenced by institutional practices. We take on the responsibilities of being clear about the rights of all people with disability and, where necessary, speak in an informed and considered manner, for those who cannot speak for themselves.

# Background and introduction

QDN was engaged by the Department of Families, Seniors, Disability Services and Child Safety to develop the Queensland Disability Stakeholder Engagement and Co-Design Strategy (the Strategy) as a priority action of the Queensland Disability Reform Framework. The Queensland Disability Reform Framework is a framework for coordinating disability reform in Queensland in response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) and the Independent Review of the National Disability Insurance Scheme (NDIS Review). For a full overview please read the [Queensland Disability Reform Framework](https://www.dcssds.qld.gov.au/our-work/disability-services/queensland-disability-reform-framework/about-the-framework) for more information.

The Strategy establishes structures to put people with disability and stakeholders at the heart of reform processes and guide collaborative work. You can read more about the Strategy on the [QDN website](https://qldcodesignstrategy.qdn.org.au/our-work/). Initial steps in the implementation of the Strategy included engagement of a variety of diverse stakeholders via community forums that occur at different times of the year. This report summarises the participation and key outputs of the forums focused on foundational supports that occurred in May and June 2025. You can read previous reports summarising key outputs from previous forums in the [resources library](https://qldcodesignstrategy.qdn.org.au/our-work/resources/) on our website.

# About the community forums

The community forums were hosted by QDN in partnership with the Department of Families, Seniors, Disability Services and Child Safety. This was the second round of Community Forums held in 2025 and served several purposes including:

1. Connecting with people across Queensland communities
2. Sharing information about the approach to disability reform in Queensland
3. Sharing updates about the progress of the work being delivered through the Queensland Disability Stakeholder Engagement and Co-Design Strategy
4. Hearing feedback from Queensland communities about their ideas for targeted foundational supports for families with children aged under nine (9).

The community forums were held between 26 May and 13 June 2025. In total there were ten (10) community forums held across the state and online with a total of 347 registrations and 233 attendees, a 67% attendance rate. Eight (8) face-to-face forums were facilitated in Mt Isa, Longreach, Townsville, Brisbane (two held), Gympie, Hervey Bay, and Sunshine Coast. Two forums were held online.

The forums were well attended by a range of stakeholders, including people with disability and their families, carers or kin, advocacy, community and peak body organisations, disability service providers, state, local and federal government and community stakeholders. The list below breaks down the range of forum attendees by stakeholder type:

1. Person/people with disability = 25%
2. Family/carer = 18%
3. Local government = 3%
4. State government = 8%
5. Federal government = 1%
6. Service provider = 27%
7. Community organisation = 13%
8. Interested community member = 5%

During the forums, participants completed an activity focused on targeted foundational supports for children under nine (9) years old in the local community. The activity was completed in groups; at the in-person forums this was table discussions and during the online forums this was in breakout groups. The activity was split into three phases: discovery, sensemaking and prototyping.

During the discovery phase, attendees discussed the below questions:

1. In relation to Early Supports for children under 9 years old, what already works well in this community?
2. What does this look like across the four areas of assessment, family support and capacity building, early intervention supports, allied health supports?

During the sensemaking phase, attendees discussed the below questions:

1. In relation to Early Supports for children under 9 years old, what is missing?
2. What has been helpful before but now isn’t part of ecosystem of supports that should be here?

During the prototyping phase, attendees discussed the below questions:

1. For Early Supports for children under 9 years old in this community to work well – what are important things that need to be considered?
2. Who will provide services?
3. What are the key points where children/families link with other systems?
4. How will families know about it and who to talk to?

# Key themes

## High-level summary

The most common themes to emerge across all of the forum locations include:

1. Communities want wrap-around supports for the whole family unit
2. Workforce shortages and retention challenges are widespread
3. Affordability is a big barrier to accessing assessments
4. All communities are experiencing long waitlists and service gaps
5. There is a need for local navigators or places for families to go for information
6. Communities want to utilise existing infrastructure and partnerships
7. Parents and carers need support
8. There needs to be equity between NDIS and non-NDIS families
9. It is important that services are place-based and culturally safe
10. Early identification and support need to happen in natural settings

## Brisbane

### Discovery: Our strengths

In Brisbane there are areas with strong local connections, for example, where children transition into school early with support from disability service providers, community centres and schools working together. “The teachers have a plan before the year starts... the kids are a lot more comfortable than they normally would be”. Child health nurses and Neighbourhood Centres were also seen as key strengths, but forum attendees pointed out that their effectiveness depends on their funding. Many attendees reflect on how things used to work in Queensland. Roundtable approaches with allied health professionals, the Education Queensland assessment role, and family-led service models were all seen as things that worked better before the NDIS was implemented. “It worked well when families led services, had a lot more input… now we feel people are quite individualised and on their own.”

### Sensemaking: What is missing

A big issue is the loss of local connectors, with people repeatedly referring to a “one stop shop… that person would know the right person to speak to.” There is a sense that families are left to navigate the system alone, finding information from Facebook or other online forums that are not always reliable sources of information. Extremely long waiting lists for allied health, specialists and child development officers, lack of inclusive daycare, inaccessible classrooms, high out-of-pocket costs for assessments and reliance on GPs as gatekeepers were all raised as key issues. Some people are concerned that “people without NDIS funding are falling through the cracks.”

### Prototyping: What is important to our community

A very strong theme is that people want wrap-around, family-centred models of support, not just therapy-focused outcomes, but support to improve “parent stress, carer outcomes, and quality of life”. There were strong calls for ending the two-tiered system where people who are not eligible for the NDIS are not able to access the type of services as those who are. People also want to restore funding to organisations who used to provide support to the community, who are now limited to being NDIS providers only.

Ideas generated from the Brisbane forums included:

1. Funding for early assessments based on functionality, not diagnosis
2. Peer support and lived experience mentors
3. A single point of access for information and referrals
4. More teacher and GP training on disability pathways
5. Embedding allied health professionals into schools, homes and other places where families already visit – their natural settings

## Gympie

### Discovery: Our strengths

In Gympie, there are some existing early interventions and support networks that are strong and have built genuine partnerships. There are also some local efforts making a difference, specifically, Kindy Uplift funding to upskill the workforce, early intervention networks (where they exist), and employing local people who know the community. “Telehealth providers working together locally” was also seen as a positive shift.

### Sensemaking: What is missing

Gympie is experiencing some serious structural challenges, with attendees explaining that “there are areas around Gympie with no internet or phone signal”. Workforce shortages, particularly paediatricians and other specialists, long waitlists for healthcare appointments, the high cost of assessments and the lack of advocacy services were major concerns. “The cost of specialists is high - a lot of people cannot afford it, the expenses of applying for the NDIS are not covered”. Transport was flagged as a major issue, especially accessible taxis. “Adults and children are being left waiting on the side of the road”. Housing is also an important issue in Gympie; with the massive population growth the region has experienced.

### Prototyping: What is important to our community

People in Gympie want holistic, family-focused supports. Attendees explained that “having a child with a disability changes the whole family dynamic” and they want services to reflect that. The need to simplify processes, reduce waitlists and bring services closer to where families already are spending time was a strong theme. They want foundational supports to be inclusive and accessible and want children to receive early diagnoses so they are adequately supported when they are starting school. Being a regional area, travel and transport costs need to be taken into consideration.

Ideas generated from the Gympie forum included:

1. Building clear, consistent information channels
2. Community champions to spread awareness and support
3. Embedding supports in early settings like pregnancy care and kindy
4. Incentives for the workforce beyond just financial ones — purpose and satisfaction are important
5. Parent Connect-style programs to support families before they get to NDIS
6. Inclusive, local people with lived experience of disability providing support rather than online or fly in fly out services
7. Doctors, allied health, educators being educated in disability as a part of their training from the start

## Sunshine Coast

### Discovery: Our strengths

On the Sunshine Coast, health services were mentioned as a strong connection point from maternal health onwards. Some new health centres, including Aboriginal and Torres Strait Islander community controlled health organisations that are community-focused and culturally driven were highlighted as a good model for foundational supports. The example given is the new Aboriginal community health centre at Birtinya (North Coast Aboriginal Corporation for Community Health). The plan is to have a staff member at the door to greet people and ask “Why are you here? What do you need? Do you want a cup of tea? How can I help you? What services are you looking for? Do you know what you are looking for? Do you want to have a chat and talk about what you need?” with a kitchen/lounge area where people can hang out and have some space if they need it, with all allied health in the one area. Additionally, Neighbourhood Centres, when accessible, were seen as a valuable place to go for support as there are almost 200 across Queensland. Have local area coordinators (LACs) or National Disability Insurance Agency (NDIA) workers and advocates based in Neighbourhood Centres. Some attendees reflected that Home and Community Care (HACC) worked well for some people.

### Sensemaking: What is missing

There was a lot of concern about the affordability of assessments, with one attendee raising the point, “what if you have multiple children who need assessments? $2000 each is not sustainable”. Parents on the Sunshine Coast are homeschooling at an increasing rate, not out of choice but because the school system isn’t meeting their needs. “Even parents who are familiar with the system are struggling”. Capacity-building was challenged, with one attendee saying, “we need to capacity build people who work with people with disabilities”. There are also very long waitlists for supports on the Sunshine Coast, up to 18 months, and then it is very difficult to get an appointment with allied health professionals and therapists due to workforce shortages. Some parents at the forum felt the supports their children need were identified too late and should have been identified earlier at kindergarten or childcare. There was a strong emphasis on parents and carers needing support due to extreme burnout, especially parents with disability. Travel costs were also raised an issue.

### Prototyping: What is important to our community

Attendees emphasised the importance of people in support roles having lived experience of disability and being able to access them in natural settings. “We want allied health and support in places families are going to, their natural settings, like kindergarten”. They called for equity in how much funding children have and don’t want the skills and knowledge of advocates to determine funding. They want foundational supports to be part of an ecosystem that works together so children get the most out of funding. It was acknowledged that families need foundational supports, but they don’t want people removed from the NDIS before they get foundational supports.

Ideas generated at the Sunshine Coast forum included:

1. Peer support for parents
2. Family-centred approach where a family with more than one[potential] NDIS participant get their plans done together to ensure they are cohesive and meet the family’s needs
3. Embedded supports in kindy and schools so parents don’t have to make additional appointments and travel
4. Use the hub model with occupational therapists, social workers and advocates in one place
5. Vouchers or free assessments
6. Funding foundational supports before removing people from the NDIS
7. Medicare funding of assessments
8. Training for early educators to use developmental screening tools
9. Community development models.

## Hervey Bay

### Discovery: Our strengths

Hervey Bay has strong informal and community-based supports. Attendees mentioned youth and family mental health programs, service providers including specialists, allied health professionals and general practitioners with knowledge of disability and strong social networks including peer groups and family activities. Group therapies and early intervention that do not require a diagnosis were also seen as strengths. One attended noted that “there’s some good stuff here — like group mentoring programs where it’s person-centred and voluntary — not mandated.” Multiple attendees mentioned the community’s inclusive infrastructure like the All-Abilities Park and waterpark and the benefits these bring to families.

### Sensemaking: What is missing

Despite there being good specialists in Hervey Bay, families still experience delays in getting appointments and often cannot afford to pay for appointments. Others mentioned the high turnover of providers and the impact this has on families needing to re-tell their stories. Some families in Hervey Bay report feeling overwhelmed by information and feel that there is a lot of misinformation being spread. It was raised that GPs don’t always have deep knowledge of the NDIS process or what other supports are available. There’s a lot of confusion around the NDIS process and a lack of advocacy and a need for local coordinators who are well connected. Some mentioned that there is not enough support available for carers, and that they are being dismissed by professionals; “believing what the main carer said about the child is not happening”. Transport and cost-of-living issues were referenced multiple times, as well as long waitlists, gaps between the NDIS and mainstream health system.

### Prototyping: What is important to our community

People in Hervey Bay want a “one stop shop” for services and consistent, clear information and ongoing relationships. There was also a big push for supports that meet the needs of the entire family unit, not only the child and more independent advocacy. Attendees want reduced wait times, support to navigate the system and more mental health support and supports for carers. It was emphasised that parents bring knowledge, and services need to be built with families, not just delivered *to* them.

Ideas generated at the Harvey Bay forum included:

1. A family navigator role for families with children aged 0–9
2. Reducing wait times and supporting the workforce to reduce turnover
3. More fee-free training and professional development for the existing workforce
4. Bringing back what was working — like pre-NDIS financial support for assessments
5. Mentoring and community capacity building to reduce burnout
6. More funding for independent advocacy to address long waitlists

## Longreach

### Discovery: Our strengths

The Longreach community notes that there have been some positive changes, including better access to allied health services and programs like Lady Gowrie and Outback Futures filling some gaps. Telehealth is working in some cases and there’s a new Ed-LinQ coordinator linking kids to paediatric and psychology support. Larger organisations were seen as better at governance and sharing information, and playgroups and mainstream service options were acknowledged as valuable early supports. Forum attendees felt there was a strong local interest and willingness to improve services. Some people noted good turnaround times with Assessment and Referral Team (ART) and plan access.

### Sensemaking: What is missing

A major concern was the fly-in-fly out nature of services in the region, where there is a high turnover of providers which is creating instability for families. Workforce issues was a reoccurring theme, with a range of unfilled roles such as guidance officers in schools. Health services in remote Aboriginal communities in the region have declined considerably. Long wait times for paediatric assessments and limited early intervention programs were highlighted, along with gaps in school-based supports and difficulties in retaining experienced support workers. Funding limitations, particularly where travel is not covered by the NDIS or Patient Travel Subsidy Service (PTSS) and the high cost of assessments, were noted as key barriers to service uptake and effectiveness. People are concerned that children not connected to schools or childcare risk missing crucial early intervention.

### Prototyping: What is important to our community

People in Longreach need better recruitment, retention and training of support workers. The challenge of providing equitable funding for rural areas, where travel costs are unavoidable but not covered under current models such as the NDIS, was repeatedly raised. Telehealth’s limitations for child-focused services and long wait times for specialist assessments were also key themes. Suggestions included multidisciplinary assessment models and incentives to attract and retain a qualified regional workforce from the point of training through to employment.

Ideas generated at the Longreach forum included:

1. Travel-inclusive funding models
2. Local, mobile, multidisciplinary teams to help reduce waitlists
3. Incentives and pipelines to build a rural workforce
4. Recognition of carers as an untapped workforce (e.g. recognition of prior learning)
5. Coordinated roles that cut across health, education and disability
6. Improved communication between health, education, and disability services
7. Local navigation or key worker roles to streamline service access

## Mt Isa

### Discovery: Our strengths

The Mt Isa community report that there are a variety of NDIS services available, and they value local programs like Bush Kids and services through Gidgee Healing, North West Remote Health (NWRH) and North West Hospital and Health Service (NWHHS). Partnerships and warm referral pathways are helping. People spoke positively about allied health professionals working directly with schools. The Rural Immersion Placement Program Allied Health (RIPPAH) student placement program was highlighted, attendees mentioned it helps to attract professionals.

### Sensemaking: What is missing

A strong theme to come through during the Mt Isa forum was the severe workforce shortages. People explicitly said that there is “no workforce”, not enough incentives and the services that are available are siloed and don’t collaborate well with each other. This has meant families have to re-tell their stories repeatedly. In Mt Isa there are long waitlists, not enough GPs, not enough support for parents and financial barriers. Attendees felt there is no point of contact for services or people to access information. Some mentioned that telehealth is not an option for everyone in the community due to internet access issues. Lack of transport and difficulties with home modifications was also raised as an issue.

### Prototyping: What is important to our community

The Mt Isa community want cost-effective local responses and to leverage what is working already. There were calls for investment in the workforce and mentioned mentorship models and incentivisation. Parents need support at the time of and after diagnosis to help families understand what supports are available to them. Some attendees suggested expanding on Project 1000 from kindy to Year 2 and to use kindy settings as opportunities for early assessment and support.

Ideas generated at the Mt Isa forum included:

1. A central information hub for coordination, referrals and updates
2. Investment in mentoring and HECS waivers for remote work
3. Family-focused support post-diagnosis
4. Cultural awareness in materials and support roles
5. Incentives to keep good staff — accommodation, bonuses, flight subsidies

## Townsville

### Discovery: Our strengths

The Townsville community acknowledged that there is a lot of allied health services in the area, and programs like Connected Beginnings, Community for Children Networks, youth hubs and Local Level Alliance meetings are helpful for families. Some schools have allied health professionals coming onsite, and free playgroups were mentioned as a good entry point.

### Sensemaking: What is missing

Despite the number of service available, people talked about a lack of integration and mentioned that services are siloed and do not collaborate, for example, NDIS, GPs and allied health. Some mentioned that there is a lack of understanding about services and that a lot of families in childcare do not access inclusion supports that exist already. There are gaps for children who do not access daycare and supports are limited to children who have NDIS funding. There are long waitlists and workforce shortages, particularly therapists, and financial barriers where people cannot afford to pay fees. Some mentioned cultural beliefs of disability including fear, stigmatism and trauma from institutionalisation, and a lack if culturally safe services.

### Prototyping: What is important to our community

Families in Townsville want choice and control over who they work with and how they engage with services. Forum attendees called for flexible, participant-driven support rather than one-size-fits-all. Support coordinators and liaison roles are seen as critical and people want a more holistic, team-based approach to assessments, and they want assessments to happen in places families visit, like their child’s primary school.

Ideas generated at the Townsville forum included:

1. Flexibility in how goals and budgets work
2. More transparency and simplicity in assessment processes
3. Liaison roles for navigating supports and managing budgets
4. Training and upskilling across allied health and family supports
5. Mainstream roles like social workers and support coordinators embedded across settings
6. Recognition that some parents may also have undiagnosed disability
7. A person-centred approach rather than the medical model

## Online

### Discovery: Our strengths

The online forums brought together people from areas all across Queensland, rather than from one place, meaning the themes to emerge below came from people from a range of communities and contexts.

Strengths of communities included:

1. Lots of different cross-sectoral services and supports have emerged over time through innovations and flexibility
2. Gathering places for young people and families
3. Supports that consider the entire family as well as afterhours services
4. Early identification mitigating long-term costs
5. There are a lot of good service providers doing the right thing
6. Informal supports, including extended family, friends and peers are paramount
7. The Carer Gateway is helpful
8. The NDIS is good in that it is clear what you can apply for
9. Local governments that have good physical spaces, libraries and free programs
10. Education Queensland’s Autism Hub
11. Therapists (when they can be accessed)
12. Communities that have services embedded, rather than fly-in-fly-out is working well and supporting continuity
13. Some therapists are rebuilding their skills
14. Telehealth service has proved to be useful for assessing behaviour problems
15. Inclusive, person-centred services that are strengths-focused rather than deficit-focused
16. Early diagnosis works well when identified and easily accessed
17. Allied health professionals using social media to stay connected and problem solve

### Sensemaking: What is missing

What is missing from communities included:

1. Early identification missing and children are waiting too long
2. Education system can’t include kids with minor challenges
3. Funding for non-government organisations used to exist in past (for supports)
4. Understanding of the interaction of co-morbidities and how they are managed because
5. A ‘whole of life’ view
6. Supports for parents
7. Greater social intervention when couples separate or divorce
8. Allied health professionals and therapists in school
9. Quick diagnosis – it takes too long and is too costly at the moment
10. Gaps not covered by Medicare (reports for diagnosis)
11. Training for teachers and teacher aides
12. Time to read reports written by specialists
13. Supports for the whole family unit
14. Education for providers and parents (ableism, disability rights, accessibility and inclusion)
15. Navigator of supports to ensure everyone in child’s life is working in sync
16. Support for transport costs
17. A system to deliver foundational supports (health and education systems under strain)
18. Access to early assessments for invisible disabilities
19. Remedial programs in schools
20. Parents are not being heard
21. Transdisciplinary approaches where a range of qualified specialists work together
22. The need for formal diagnosis is a major constraint

### Prototyping: What is important to our community

What is important to community’s included:

1. Long term, wrap around supports for the whole family, not only the children
2. Peer-led family groups, embedded roles in schools and early childhood settings
3. Shared equipment banks, lending libraries and recycled supports to stretch budgets
4. Real transdisciplinary approaches
5. Navigators or coordinators who ensure all parts of the system are talking to each other
6. Stronger community connectors and safe, inclusive physical spaces (especially for neurodivergent and immunocompromised kids)
7. Let families find the natural points of connection with the system rather than compelling them to use a specific point of entry
8. Outreach provided by non-government organisations
9. Non-government organisations providing outreach under flexible funding
10. Supports needs to be specialised based on diagnosis and level of need
11. Fast response – otherwise people will go to online forums for answers
12. Online hub where people can have discussions that are monitored, you could speak with an allied health clinician, NDIS employee, or advocates
13. Schools to clearly outline the suite of supports available to help parents understand what is available to support their child
14. Therapists and allied health professionals in schools
15. Place based local community connection - building those natural touch points
16. Identified Aboriginal and Torres Strait Islander workforce is vital to deliver education appropriately
17. Play based and place based to address the overmedicalisation of therapies
18. Specialised educators to provide remedial services outside of schools, funded by foundational supports

## Conclusion and Next steps

This document provides an overview of the strengths, challenges and ideas discussed as part of an activity focused on targeted foundational supports for children under nine (9) years old for communities in Mt Isa, Longreach, Townsville, Brisbane, Gympie, Hervey Bay and Sunshine Coast. Across these communities, several consistent themes emerged, including the need for wrap-around supports for the whole family, not only the child, local and place-based services embedded in natural settings like schools and daycare, and access to a local navigator who families can contact for information, advice and referrals. Communities expressed the importance of services being inclusive, accessible and culturally safe as well as lived experience. We also heard about the barriers people are facing in accessing Early Supports for children, including long waitlists, workforce shortages and services working in silos, rather than collaboratively. Communities made it clear that they want to build on the good work that is already happening in their communities, or previous programs and services that worked well for them.

We acknowledge and thank all the communities across Queensland for hosting our forums and for sharing their insights and feedback. We value the time you spent participating in the forums, both online and in-person. Keep up to date with disability reform and co-design by regularly checking the QDN website [here](https://qldcodesignstrategy.qdn.org.au/our-work/resources/). We encourage you to participate in our quarterly co-design Community of Practice, you can find out more [here](https://qldcodesignstrategy.qdn.org.au/get-involved/). For more information, please contact QDN’s policy team on 1300 363 783 or [admin@qdn.org.au](mailto:admin@qdn.org.au).