

# Your Supports, Your Way – *Join the Conversation*

Engagement with autistic people and their  
communities to contribute to the  
**NDIS Independent Review**



July – August 2023



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# ACKNOWLEDGEMENT OF COUNTRY

Autism Queensland acknowledges the importance and value of the reconciliation journey with Traditional Custodians and Owners of all the lands and waters on which we live and work.

We acknowledge the wisdom of Elders past and extend our respect for the valuable contributions of Elders present and those emerging leaders who willingly share cultural knowledge.

Our teams recognise the significance of connections between country and culture for Aboriginal and Torres Strait Islander peoples as we walk together toward participation, opportunity, and choice.



**Artist:** Yvonne O'Neill

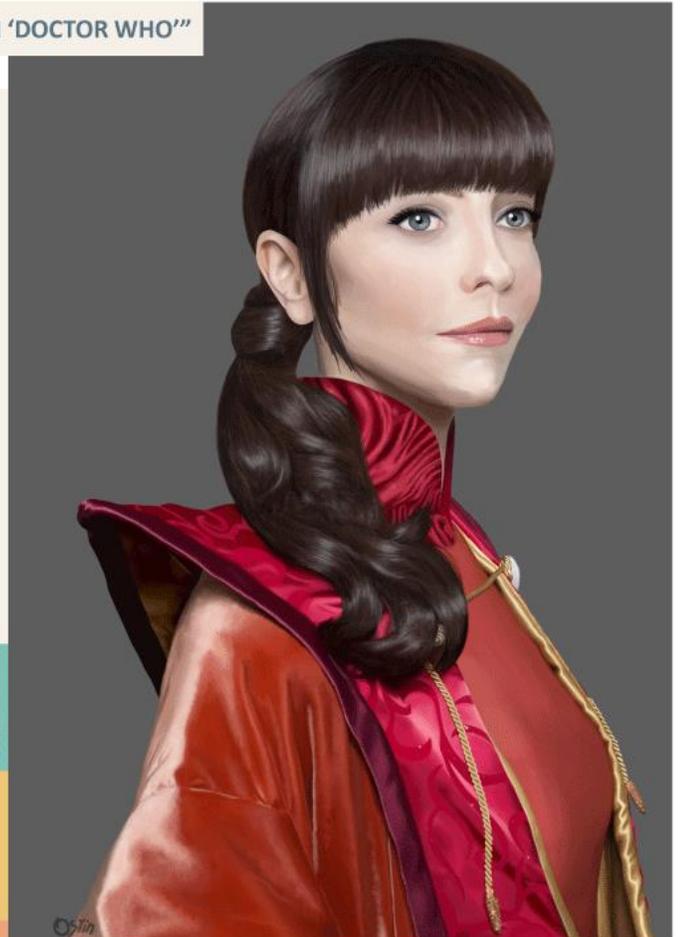
This artwork represents the way cultural conversations interact between Autism Queensland and the wider Australian community.

“ROMANADVORATRELUNDAR III FROM ‘DOCTOR WHO’”

“The NDIS has provided me with several services however the one I feel has helped me the most has been Teen Tech Shed and Studio G.

...Mentors have helped me improve my art skills greatly, something I have a huge passion for and that has helped me in my journey to hopefully have a [career] in art and animation.”

- Polly, 15-18 years old. QLD.



# 1. PROJECT OVERVIEW

This project involved the coordination and facilitation of engagement sessions (*through surveys, individual and group engagements, and creative submissions*) with **autistic people and the autism communities**, with the aim to develop a deeper understanding of their experiences and interactions with the **National Disability Insurance Scheme (NDIS)**, to help inform the **NDIS Independent Review**.

**The project aimed to include a minimum of 100 autistic people, fifteen years and older, and families/carers of autistic adults. The project aimed to capture a diverse range of Australian autistic people and their families, including:**

- Culturally and Linguistically Diverse (CALD)
- Individuals from regional and remote areas of Australia
- Aboriginal and Torres Strait Islander
- Complex support needs (Communication, Social, Co-occurring conditions).
- Families experiencing high levels of stress.
- Intersectionality of minority groups (LGBTQIA+)
- Complex care arrangement (Child Safety, public guardianship, ageing carers, carers with disability)
- NDIS participants, as well as non-NDIS participants.



## 1.1. Use Of Language

*Definitions of terms used in this report are consistent with those published on the NDIS website.*

### Terms:

- Themes:** The themes or categories represent people’s perceptions, feelings, values and experiences.
- NDIS Participant:** A person who meets access requirements to be a participant in the NDIS.
- Informant:** The term informant demonstrates the important role that a diverse range of people contributed throughout the project, to help inform a deep understanding of the topic.
- Respondent:** People (or informants) who responded and participated in the project.
- Experience gathering:** We purposefully chose not to use the term ‘data’, to acknowledge and respect the experiences shared by people. The aim was to ensure that the person’s voice remained central to all discussions.

### Abbreviations:

- ADHD:** Attention Deficit Hyperactivity Disorder
- AQ:** Autism Queensland
- ASD:** Autism Spectrum Disorder
- AT:** Assistive Technology
- ATSI:** Aboriginal & Torres Strait Islander
- AHRC:** Australian Human Rights Commission
- CALD:** Culturally and linguistically diverse
- ILO:** Independent Living Options
- LAC:** Local Area Coordinator
- LGBTQIA+:** Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, A-sexual, plus
- NDIA:** National Disability Insurance Agency
- NDIS:** National Disability Insurance Scheme
- NDS:** National Disability Strategy
- NESB:** Non-English Speaking Background
- SIL:** Supported Independent Living
- SDA:** Specialist Disability Accommodation
- STA:** Short-Term Accommodation (Respite)
- SLES:** School Leaver Employment Supports
- TAFE:** Technical And Further Education



## 2. INFORMANT DEMOGRAPHICS

THIS PROJECT INCLUDED THE VOICES OF **170** INFORMANTS

EXPERIENCES WERE GATHERED THROUGH FOUR MAIN METHODS:

### 1. ONLINE SURVEYS

77 INFORMANTS

Surveys were distributed to respondents via FormAssembly

Thematic and qualitative analysis  
Online Survey



### 2. INDIVIDUAL AND GROUP ENGAGEMENTS



61 INFORMANTS

Each session was tailored to meet the preferences of each respondent

Thematic analysis  
Online and face-to-face

### 3. CREATIVE SUBMISSIONS

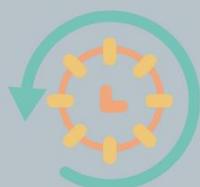
12 INFORMANTS

Creative submissions of various mediums were accepted

Semiotic analysis and qualitative analysis  
8 out of 12 were visual submissions i.e., drawings  
3 out of 12 were video submissions



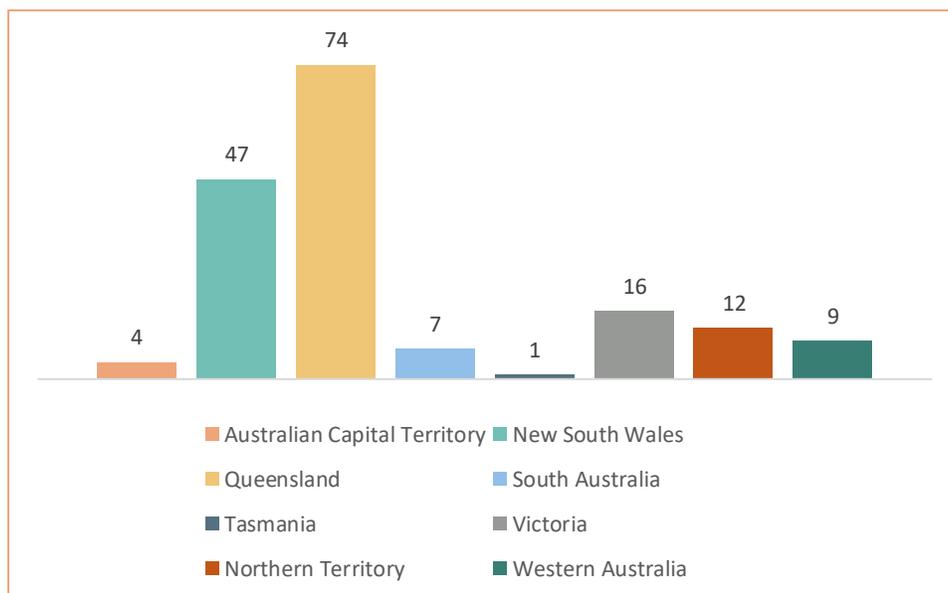
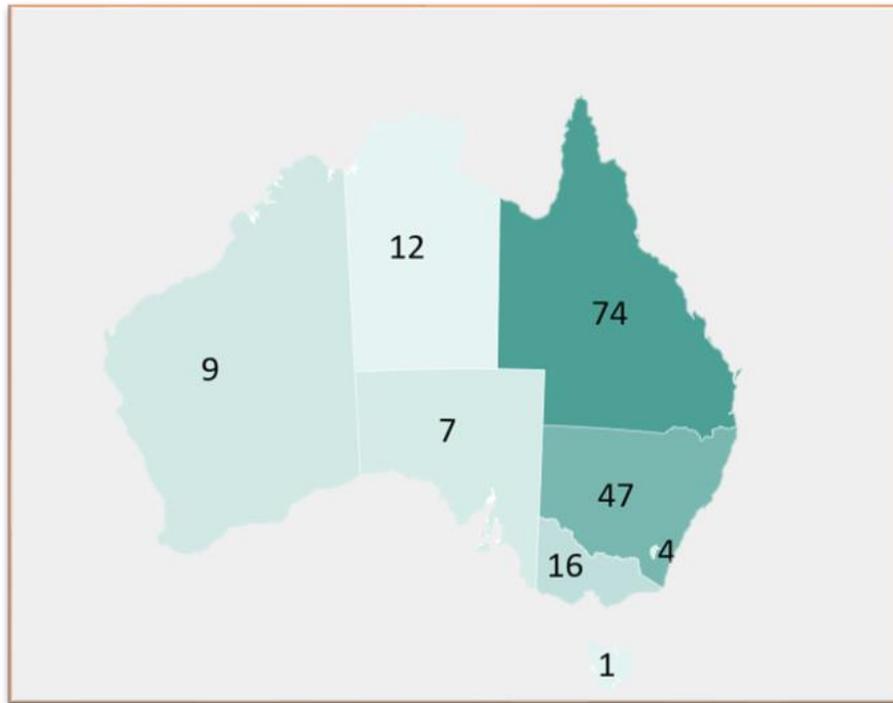
### 4. LEARNINGS FROM PAST PROJECTS



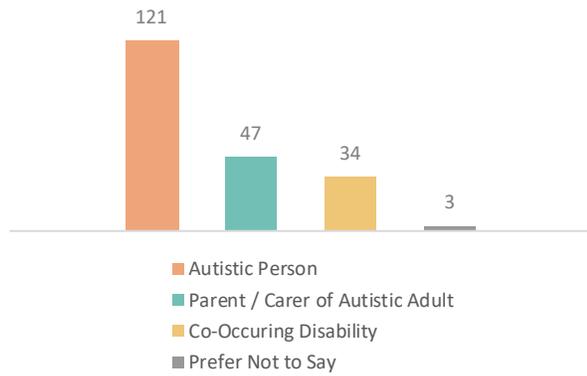
20 INFORMANTS

2 The Resilience of Farming Families of Children with Disability (2023)  
18 A New National Disability Strategy Stage 2 Consultation (2021)

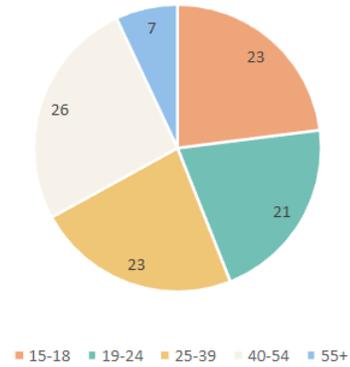
## Location of Informants



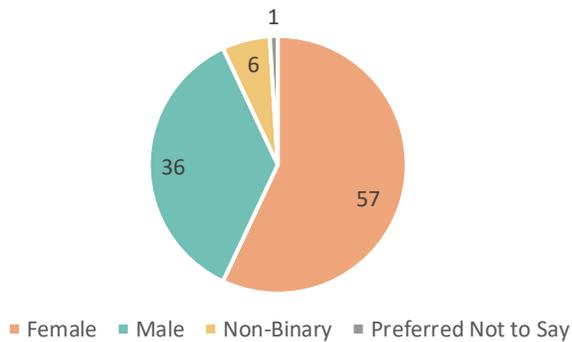
## Diagnosis - Number



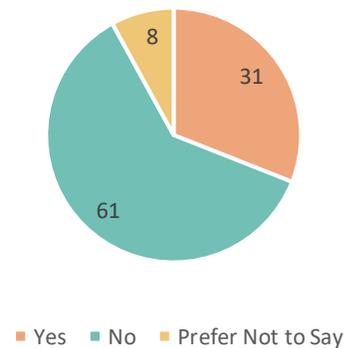
## Age - %



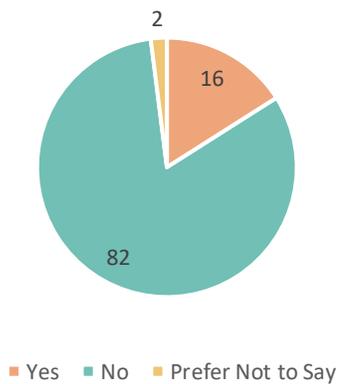
## Gender Identity - %



## LGBTQIA+ - %



## CALD - %



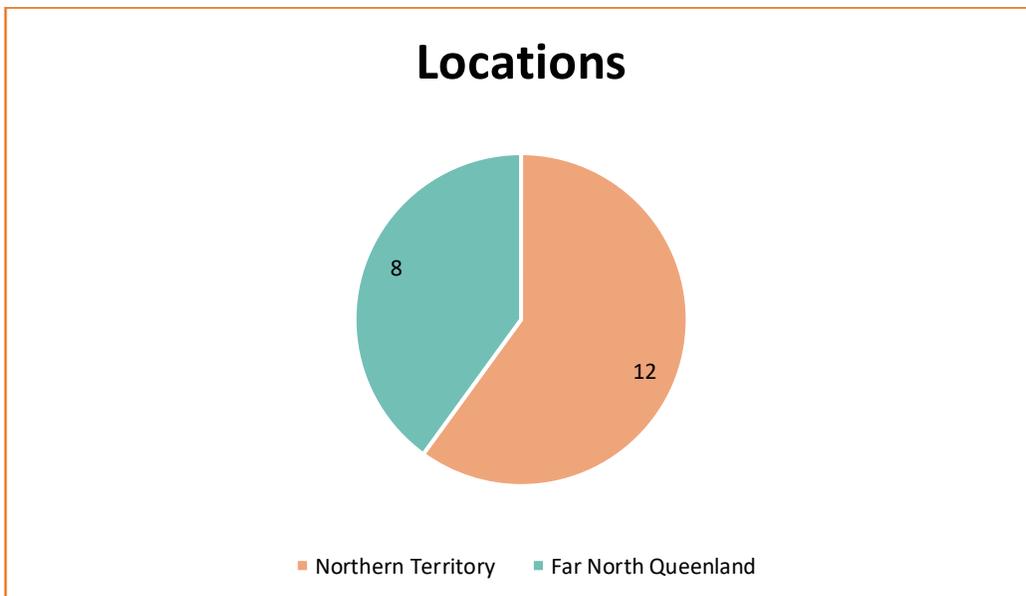
## ATSI - %



## Past Project Engagements



## Locations



### 3. PROJECT DESIGN AND ENGAGEMENT APPROACHES

Various approaches were embedded into the development and delivery of this project, to ensure it was inclusive, welcoming and person-centred.

The project was **promoted using a variety of formats**, offering people the freedom to choose their preferred method of learning more about the project. For example,

- Information about the project was accessible through AQ social media platforms and website, accompanied by a concise video describing the project aims and delivery.
- A **comprehensive asset pack** (see Appendix A) was also provided to external organisations, to facilitate their understanding of the project and extend invitations to potential informants.

Once people learnt about the project, they could easily express their interest to **participate by selecting one of three options from the AQ website**,



Complete a survey,



Individual or group engagement session (face-to-face or online), or



Submit a creative expression (such as a piece of artwork or short video).

These flexible engagement options were offered to ensure people could participate in the project, in a way that met their preferences. All online consent forms, surveys and expressions of interest were designed to be clear, respectful in their language choices and intuitive to navigate.

For people interested in participating in an engagement session (individual, group, online and face-to-face) a **Welcome Pack** (see Appendix B) was provided. This pack contained information about the project, example discussion questions, instructions on how to use Zoom (if online), location maps (if face-to-face) and payment information. The Welcome Pack was provided in two different formats to meet a range of preferences, for example,

- 1) PDF version and
- 2) PowerPoint version which included a voiceover option.

Engagement sessions were participant-led and neurodiversity-affirming, which fostered a safe space for people to openly express their thoughts, feelings, and experiences. Some informants chose to participate in a **structured PowerPoint deck** (see Appendix C), to express their experiences and thoughts on the topic. Participants could choose to complete this with someone from the project team, or a support person in the comfort of their own home.

## SIX SOLUTION-FOCUSED THEMES WERE IDENTIFIED:

- 1)  KEEP INCLUSION AT THE CENTRE
- 2)  CONNECT FIRST
- 3)  GIVE CHOICE AND CONTROL BACK TO THE PARTICIPANT
- 4)  TRAIN AND EMPOWER NDIS PERSONNEL, STAFF, AND PROVIDERS
- 5)  EMBRACE ALTERNATIVE SUPPORTS
- 6)  ENHANCE SAFETY MEASURES

The diagram below illustrates these six themes throughout the journey of a NDIS participant:

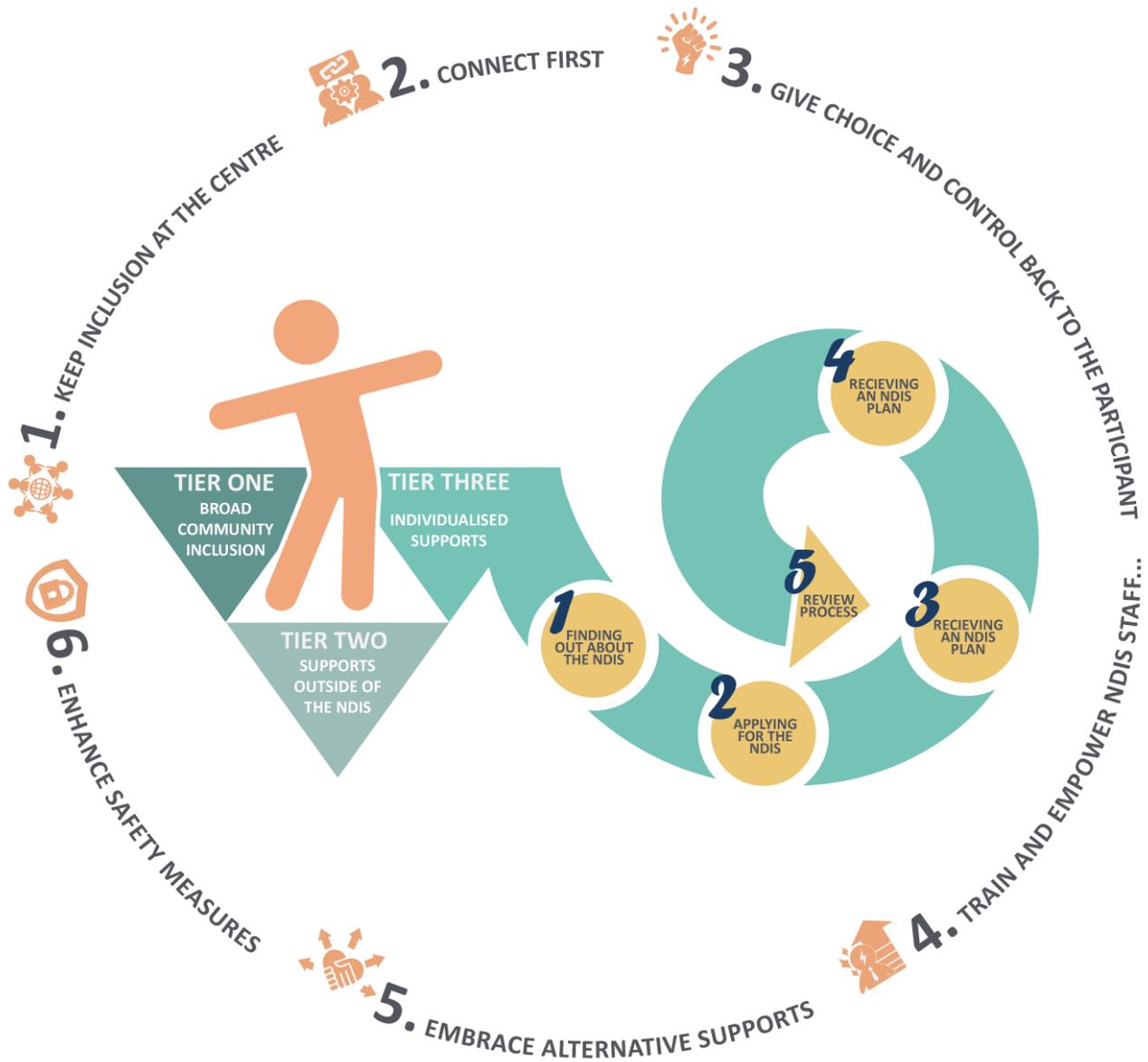


Figure 1.

*Journey Map illustrating a NDIS participants journey in accessing NDIS.*

## Theme 1: KEEP INCLUSION AT THE CENTRE



*“If the world was more inclusive, I wouldn’t need to be accessing so many supports.”*  
– (Autistic female, 40-54 years)

Inclusion emerged as a key theme and promising solution in addressing barriers and challenges faced by autistic participants and their carers throughout the NDIS journey. Participants shared stories and experiences of exclusion, inaccessibility and feeling unseen and unheard, *“My experience is that I am blamed, shamed and unheard.”* These experiences occurred throughout all stages of the NDIS journey (i.e., application, planning, accessing services, review, etc.).

Many participants described the **NDIS website as “overwhelming” and difficult to navigate**. This made understanding processes and accessing supports more challenging. Lack of clear and consistent information about the application and review processes led to many participants feeling stressed, anxious and without necessary supports.

*“I would make information about how to access, who can access and why it is helpful more accessible. Many people don't realise that they can access these services and how helpful they could be, so they just suffer in silence. If information about the NDIS was available as soon as someone got diagnosed then it would make life easier for millions of people.”*  
– (Autistic male, 19-24 years)

Furthermore, participants who preferred to **communicate in alternative ways** (i.e., text, email, face-to-face, using a support person, etc.) often felt like they were not given choice and that these preferences were not acknowledged or respected. Respondents shared feelings of frustration and disappointment at the lack of awareness towards invisible disabilities; *“She [LAC] didn’t understand me or my disabilities”* (Autistic female, 55+ years).

Participants described many **mainstream services** (i.e., employment, education, community, medical, etc.) as **inaccessible**. That is, they did not feel welcome, safe, or understood in these settings and therefore minimised accessing or utilising them. One participant described mainstream services as *“faux-accessible”* explaining that many places and services claim to be accessible, but they have a narrow view of disability (e.g., only considering physical disabilities) or they may reference an inclusion handbook or training but not actually understand or implement inclusive practices.

## NEXT STEPS:

- Co-design, with a diversity of people, a more accessible and inclusive website with clearer, more concise pathways. Consider the implementation of a chat function on the website to support users.

*“Information in plain English, removal of density and ambiguity with simple flow charts that can follow/ click on that provides the form you need or checklists or other forms of guidance – simple is more.”*

*– (Parent of autistic male, 15-18 years)*

- Acknowledge and respect different communication styles and preferences. Provide flexible options for all communication.
- Train staff on the implementation of universal design principles and inclusion throughout all areas of NDIS.
- Ensure front line staff have disability-specific training, including awareness and understanding of autism and hidden disabilities.
- Increased diversity and representation among NDIS staff and providers.

*“Employ more people with disabilities at every level of the NDIS including government. This will be an effective strategy because people with disabilities have direct lived experience of the barriers we face. Nothing about us without us!”*

*– (Autistic female, 25-39 years)*

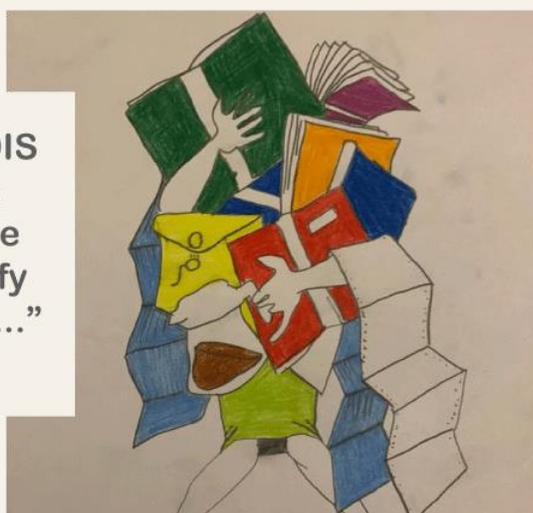
- Improve accessibility of information about supports and services available.

*“Trying to find a provider was impossible from the website – there is too much generic information and not enough options to filter by specialty or experience.”*

*– (Parent of autistic male, 19-24 years)*

“Trying to navigate the NDIS is very overwhelming. It feels like you need to have so much evidence to justify why you need the support...”

-Autistic Female, 15-18 years old. QLD.



## Theme 2: CONNECT FIRST



*“When you genuinely understand, respect, and recognise an individual as an equal, you can empathise. Empathise means you are then able to put yourself in their shoes.”*

*— (Autistic male, 15-17 years)*

When asked what good support looked like, autistic participants and their carers consistently referenced **connection** as key.

*“To me good support is that you just listen to me.”*

*— (Autistic female, 40-54 years)*

To **feel safe, understood, seen, and heard**, autistic participants need time to build trust and relationships with NDIS staff and providers. Many informants shared experiences of impersonal, rushed, and inconsistent interactions with both NDIS staff and providers. Navigating these challenging and complex interpersonal relationships is further complicated by high turnover rates and lack of consistent handover processes.

*“I shouldn’t have to repeatedly prove that I’m disabled enough [to access supports]. I don’t want to retell my experiences over and over again. It’s traumatising.”*

*— (Autistic non-binary, 15-18 years)*

A recurring pattern among participants who shared positive experiences revolved around staff (both from NDIS and service providers) who invested time in getting to know them. These staff members focused on building relationships and genuinely understanding their individual support needs.

*“Now we finally have a fantastic team because the provider listens to us.”*

*— (Parent of autistic male, 36 years)*

## NEXT STEPS:

- Increased contact between LAC's and participants to foster relationships and ensure participants' unique, individual needs are understood.

*“Good support for me would be more patient, let me get to know them – it takes me a while to feel comfortable with people. I need people that are more understanding.”*  
– (Autistic female, 25-39 years)

- Ensure consistent handover processes are in place and communicate these to participants when changes occur.

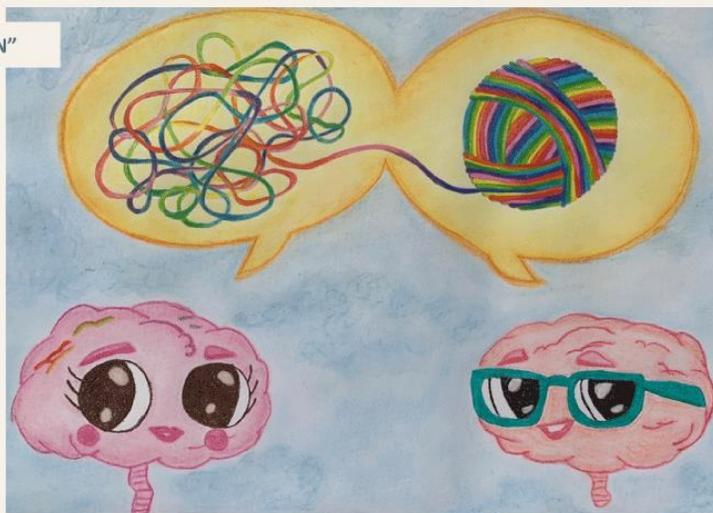
*“Have a backup plan to ensure consistency – handover processes to narrow the gap of change and increased understanding about my case.”*  
– (Carer of autistic female, 25-39 years)

- Recognise and respect different forms of communication (i.e., augmentative and alternative communication (AAC), use of chat, email or other written forms, virtual or face-to-face, etc.) Whenever possible, offer preferred options for contact.
- Increased access to independent advocacy services to support participants in communicating and advocating for their needs.

When it came to **Sandy's** experience with connecting to an autism-specific provider, to assist her with employment supports, **Sandy** shared that she found it: *“Very beneficial having that one on one connection which helped me navigate and decipher a world which was often confusing or overwhelming”*.

- Sandy, 40-57. NSW.

“TECHNICOLOR CONNECTION”



## Theme 3: GIVE CHOICE AND CONTROL BACK TO THE PARTICIPANT



*“I, like anyone else, have the right to make decisions that will give me opportunities that anyone without a disability takes for granted... I shouldn't have to be in a constant state of panic or anxiety to get my needs met.”*  
— (Autistic parent of 2 autistic participants, 55+ years)

A key theme expressed by autistic participants and their carers was a **lack of choice and control** throughout their NDIS journey. Many informants felt this lack of choice and control was a direct result of not being heard or understood during their planning meetings.

*“I do not feel like the plan is catered to my specific difficulties that are a result of being autistic, but rather for a generic stereotyped autistic person. This means there is a lot of funding allocated to services I won't or don't need to use and less funding or no funding in areas that would benefit me.”*  
— (Autistic female, 25-39 years)

Other respondents shared this sentiment, feeling like they were put in a box or treated as if they were not capable of advocating and making their own decisions. This was also true for parents and carers, who felt invalidated. For example, one parent shared, “Mum [I] knows how to advocate but it shows that as soon as you are seen as a ‘parent’ that all your knowledge, experience, and skills do not matter” (Parent of autistic male, 15-18 years).

**Inflexible funding** was another key factor impacting participants’ choice and control. Participants felt limited in how they accessed and utilised their funding. Several respondents expressed that their support needs were not fixed and static; instead, they viewed them as dynamic, fluctuating, and subject to change from day to day. However, they felt that their funding did not adequately accommodate this dynamic nature of their support needs.

**Long waitlists and lack of available services** also led to many participants not being able to use their funding which caused additional stress and fear of losing needed supports. “My first OT was not a good fit so now I am on waitlist again. Finding the right type of provider is really hard” (Autistic female, 25-39 years). Autistic participants want to **be at the centre** of all decisions impacting their lives.

*“It does not feel that any of the processes are really about me at the centre. It has become like a manufacturing site where I am just another can that goes down the conveyor belt to be packed away...”* — (Autistic male, 15-17 years)

## NEXT STEPS:

- Flexible funding tailored specifically to the individual.
- Increased communication and access to inclusive resources (i.e., clear, concise, accessible) outlining and explaining funding categories, services and support options.
- Increased understanding of autism among NDIS staff and providers to recognise the dynamic nature and diverse functional impacts experienced by participants.
- Broaden the focus of NDIS services and supports beyond just independence – increasing and enhancing quality of life should be the primary focus.

***“I prefer providers who have specific experience and understanding in autism. Without this, there is so much work I have to do to teach them about me and about autism.”***  
– (Autistic female, 19-24 years)

- All staff and providers supporting decision making, should be trained in principles of Supported Decision Making to ensure participant voice is at the forefront of all choices impacting their lives.

***“People need to move away from the idea that autistic people can’t make decisions for themselves – we need to feel empowered.”***  
– (Autistic female parent, 40-54 years)

“This image... speaks to the disjointedness and often inner chaos of my life where I am juggling many things in order to present myself for the day. It is also fun and silly which is like me, I enjoy being myself with all the weirdness that entails...”

-Emiko, Non-binary, 40-54 years old. SA.



## Theme 4: TRAIN AND EMPOWER NDIS STAFF AND SERVICE PROVIDERS



*“Taking care of a vulnerable person is a privilege. Respect that as they are relying on you to help them be the best, they can be and live their best life.”*  
– (Autistic parent of 2 autistic participants, 55+ years)

A prominent recurring theme which emerged from discussions and survey responses, highlighted the need for enhancing training for NDIS staff and service providers. People emphasised the importance for NDIS staff and service providers to be skilled in effectively working with autistic people and providing “neurodiversity affirming” care. Neurodiversity affirming care was referenced in relation to:

- Respecting and acknowledging people’s preferences for engagement and communication during NDIS meetings and expanding options for choice (such as, augmentative and alternative communication (AAC), text or utilising chat function),
- Considerations of people’s sensory processing preferences and needs (for example, reducing bright lights during NDIS meetings, limiting patterns, and offering the choice of paper forms alongside electronic options),
- Applying an intersectional lens around autism and acknowledgment that many autistic people experience mental health conditions, be culturally or linguistically diverse, indigenous and/or LGBTQIA+,
- Providing clear information and processes to facilitate informed decision making, and
- Demonstrating awareness of and employing respectful language.

Respondents often expressed a sense of responsibility to educate their LACs about autism, citing instances where they felt the need to “...educate and upskill my LAC about autism”. More broadly, people also conveyed a lack of understanding of hidden disabilities among NDIS LACs. For example, one mother shared her perspective, “They see someone in a wheelchair and they [NDIS] have more compassion than they have with someone with a hidden disability. They can’t see it”.

Consistently, people expressed a preference for service providers who possess specialised knowledge and insight into autism, underlining the need for such expertise, “I prefer providers with specific experience and understanding in autism. Without this, there is so much work I have to do to teach them about me and about autism”. Respondents perceived that their funding was being “wasted”, due to inexperienced or unskilled service providers. One example is a mother with a 20-year-old son, who recounted an experience involving an inexperienced and recently graduated therapist who struggled to connect with her son, “We had a new grad therapist who was inexperienced and didn’t understand my son, it was a waste of time and funding”.

People voiced a need for specialised knowledge to extend beyond the diagnosis and placed importance on increasing the knowledge of cultural diversity and community context. The provision of knowledge and support that can be translated into each person’s reality.

## NEXT STEPS:

- Comprehensive training on autism, neurodivergence and neurodiversity to be delivered to all NDIS employees –
  - Empower staff to gain the knowledge and confidence to effectively assist autistic NDIS participants.
  - Deliver training annually to ensure that it is consistently embedded into all aspects of the organisations' operations.
  - This training to be co-designed, developed and delivered by autistic people, to ensure the content accurately captures the lived experience.
- Current and responsive cultural and diversity training (for example, LGBTQIA+).

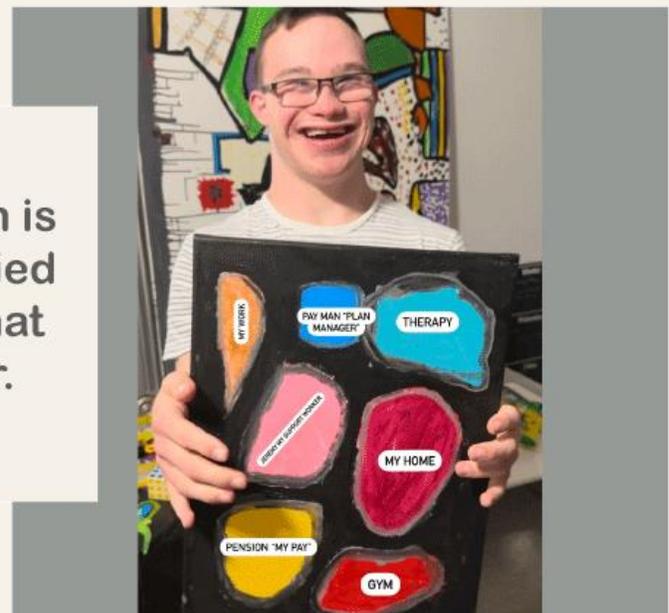
*"Integrating elders and culture into our support networks and accreditation where it's due".*

*"NDIS could better educate their employers, especially about gender-diverse people and pronoun use".*

- Embed additional opportunities throughout relevant university degrees, for students to gain practical knowledge and build confidence to excel in roles within NDIS service provision.
  - As approximately 1 in 7 people identify as neurodivergent, it is essential for students enrolled in relevant degrees, to be equipped with the knowledge to provide high-quality service delivery.

Tom's creative submission is titled "islands". He identified his supports as islands that do not talk to each other.

- Tom, 19-24 years old. QLD.



*"It's just human difference. To be inclusive and accepting of diversity, we need to shift our culture and have more acceptance. We are just another flavour of human"*  
– (Autistic female, 40-54 years)

## Theme 5: EMBRACE ALTERNATIVE SUPPORTS



*“It’s not all about therapy, therapy, therapy... there are other important things out there that need to be considered. NDIS need to think outside the square box of therapy.”*

*– (Parent of autistic son, 22 years)*

A prevailing theme emerged, advocating for the NDIS to embrace alternative avenues of support, including alternative therapies, financial assistance for parents and carers to support their adult children and more opportunities for peer support.

Many parents conveyed a sense of exhaustion and “burn out” stemming from the limited support for parents who care for their adult children at home.

*“With my children, they often say they deny supports based on parental responsibility but they do not take into account my own functional responsibility.”*

*– (Parent of 2 autistic participants, 40-54 years)*

Some parents and carers expressed uncertainty about the existence of viable options from the NDIS, for example, “NDIS haven’t really offered me anything, I don’t even know if there is anything available.” The impact of caring for their adult children was often discussed with parents and carers, such as the impact on their physical and mental health and wellbeing, lack of career progression and experiences of unemployment and financial hardship.

One solution that was identified was for the NDIS to **provide financial supports to parents and carers**, enabling them to care for their adult children without the additional financial stress and impact to their physical and mental health. For example, one mother whose 22-year-old son experiences anxiety around meeting new people, suggested for the NDIS to “fund parents to support their child to access the community and go on holidays – what if the young person doesn’t feel safe receiving support from someone outside of the family, who supports the young person to access the community?”

In addition, **alternative therapies** such as physical modalities (e.g., reiki, osteopathy) were also identified, with people expressing a desire for NDIS to be open-minded to a variety of approaches, “I want to explore alternative therapies but I don’t know if this will be funded or taken seriously”.

Autistic people also recognised the benefits of having access to peer supports, however often noted these were difficult to find and access and were often limited in variety and structure.

Similarly, in Indigenous communities, family is the primary source of support for people with disability, and yet, family are unable to be employed by those with NDIS plans. Due to the nature of complex family lines, it is likely that most people in each remote community are regarded as family – and those other traditional owners who are not recognised as family are likely to be from a poison moiety so are unable to associate or be employed by a person with disability. The rule needs to be overcome for those people living with disability in remote communities and provide them with the skills to be strong in understanding they have the right to choose who cares for them.

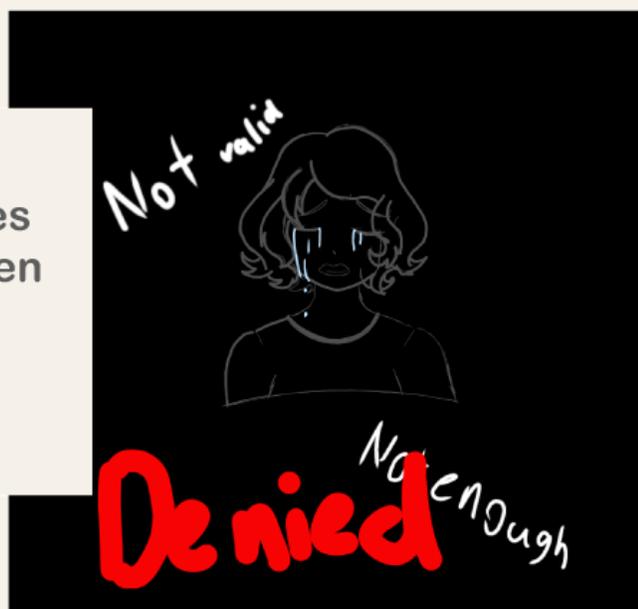
*“Being close to family for support is important.”*

## NEXT STEPS:

- NDIS to more effectively collaborate and link with mainstream services and supports to ensure NDIS participants are supported across all settings.
- More recognition from the NDIS of the benefits of peer supports for autistic people and the autism community and increased availability of sustainable peer support options.
- NDIS to explore financial support options for parents and carers who support their adult children at home.
- Recognise and support alternative care arrangements; provide participants and families with inclusive resources and information regarding these support options.

This submission describes how an individual felt, when their application to the NDIS was rejected.

- Anonymous, 19-24 years old. QLD.



## Theme 6: ENHANCE SAFETY MEASURES



*“... outcomes performance framework for all mainstream service personnel where accountability can be upheld and be executed. And those who don't uphold accountability from a higher level are performance managed.”*  
— (Autistic male, 55+ years)

Many people expressed their frustrations concerning the disparities in costs between NDIS participants and those who are not part of the scheme, with NDIS participants often paying more than non-NDIS participants for the same service. They likened this price increase to those seen in the wedding industry, stating *“The NDIS should not operate like the wedding industry... it's unethical and needs to stop”*.

Informants described the NDIS legislation guidelines as ambiguous and unclear, and identified this as a key factor contributing to issues such as miscommunication, confusion, misunderstandings and potentially fraudulent activity.

*“You can't make something clear that isn't clear in the first place”*  
— (Autistic female, 40-54 years)

Increased regulation of service providers and **price caps** emerged as a potential solution to establish consistency and prevent NDIS participants from feeling exploited or *“taken advantage of”* from service providers.

*“Most people who work in any capacity for the NDIS in our experience, see us as a paycheck.”*  
— (Parent of autistic female, 55+ years)

Additionally, people also highlighted the need for **stronger regulations** and more rigorous processes for service providers, particularly with regard to support workers. While some people valued the freedom and flexibility of engaging with unregistered NDIS workers, others felt *“...tighter regulations must be in place in order to stop just anyone to become a support worker or working for NDIS participants in any manner. Independent Support Workers and other people working for NDIS participants are answerable to no-one so they can do what they like...”*.

## NEXT STEPS:

- Enhanced regulation and auditing for service providers to ensure quality service provision.
- Price caps on services and supports to prevent NDIS participants from paying more for services.
- A focus on quality, not just availability of services.

*“More auditing and checks need to be put in place before allowing just anyone to become a Support Worker.”*

*— (Parent of autistic female, 55+ years)*

Just like space being so big and open, so is the NDIS and the resources available to those with autism and disabilities.

- Anonymous, 19-24 years old. Victoria.



## 5. DIVERSITY OF EXPERIENCES

One of the key objectives of this project, was the inclusion of a diverse range of experiences, voices and perspectives.

The following sections of this report captures the perspectives and experiences of pivotal cohorts of people including:

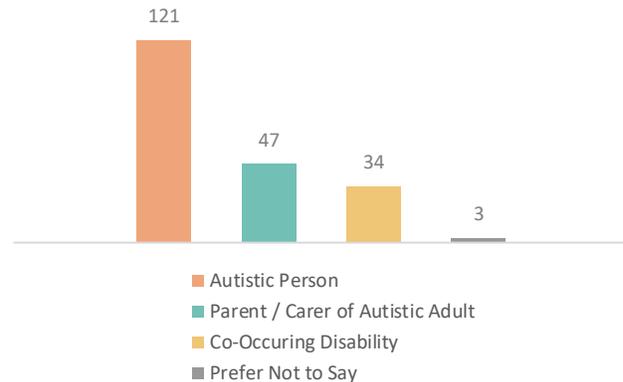
- People who experience co-occurring conditions
- Intersectionality of minority groups (LGBTQIA+)
- Aboriginal and Torres Strait Islander
- Regional and remote areas of Australia
- Culturally and Linguistically Diverse (CALD)
- Complex support needs including people who live in Supported Independent Living (SIL)

## 5.1 Co-occurring Conditions

*“Allow it to be more accessible and open minded. I believe it needs to recognise mental health more than it does. It recognises disability but not mental health issues enough than it does.”*

*- (Autistic female, 15-18 years)*

**Diagnosis - Number**



Out of all the informants, 23% identified as having a co-occurring disability with 21% indicating psychosocial disability. Informants suggested for the NDIS to recognise the impact of mental illness and mental health conditions on people’s lives,

Among those who identified with a psychosocial disability, multiple individuals emphasised the **significant value of Support Workers**, to assist with tasks related to community access and household supports, with many people rating access to a Support Worker as “extremely important”.

For example,

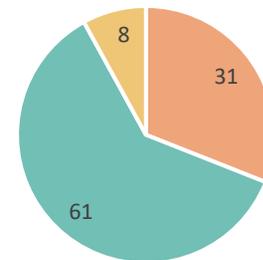
*“I have severe anxiety so bad that I am agoraphobic and have trouble leaving the house by myself and having to rely on friends or family to give up their free time to do something I want to do was stressful. But having a support worker lets me do so much more. Though sometimes I do know where to go or what to do but even then, just getting out of the house is nice.”*

*- (Autistic non-binary, 25-39 years)*

## 5.2 LGBTQIA+

*“Ask service providers to state if they are LGBTQIA+ friendly and create more spaces for LGBTQIA+ people to meet and hang out that are also disability friendly including having quiet spaces.”*  
- (Autistic non-binary, 25-39 years)

### LGBTQIA+ - %



■ Yes ■ No ■ Prefer Not to Say

This project included the perspectives, experiences, and thoughts of 32% informants who identified as LGBTQIA+. Some informants felt service providers and NDIS were not inclusive of the LGBTQIA+ community and **suggested more training for NDIS staff and service providers to enhance inclusivity**.

Some respondents also identified there should be **greater LGBTQIA+ representation** among NDIS staff and providers **and more supports and services** for the LGBTQIA+ community that are financially supported and recognised by the NDIS, for example, *“including more supports for LGBTQIA+ people as it is just as an affliction as other disabilities. As a trans-woman I suffer from gender dysphoria & body dysmorphia which has caused severe depression, suicidal thoughts, social anxiety which causes my ADHD & autism flare up”*.

*“I think it would be good if NDIS could better educate their employers, especially about gender-diverse people and pronoun use.”*  
- (Autistic non-binary, 15-18 years)

## 5.3 Aboriginal and Torres Strait Islander

In 2020, the Australian Government Department of Social Services funded Autism Queensland to talk to Aboriginal and Torres Strait Islander people with disability about what is important to them in their lives. Throughout this project, Autism Queensland connected with First nations people living in remote locations in Queensland and the Northern Territory.

**At commencement of the NDIS Review project, it was recognised that the time restraints of the review may hinder deep connection with Aboriginal and Torres Strait Islander people and as such, knowledge that was shared through yarns by Aboriginal peoples, was drawn upon to inform this current project.**

It is acknowledged that cultural and social histories of Aboriginal peoples have been impacted by colonisation and their experience may have included violence and unjust treatment. Building trustful relationships with First Nations peoples supports individual agency, lessens the power differential, and opens a mainstream for truth to flow without fear of retribution or punishment.

Having the chance to be supported by skilled workers to go with family to outstations or family camps to do hunting, fishing, cultural activities was perceived as one way to make life better. Additional incentives for skilled workers to live and work in remote communities is necessary to ensure quality services are delivered consistently to people with disability.

***“More skilled workers to support people with disability... Support workers to live in community – building trust to have them help.”***

Engaging in learning and acquiring new skills might require a pivoted focus to include cultural learning combined with everyday living skills that are implemented at a pace that suits the community.

***“Have more opportunity for learning of all types. Instead of sending to the city – learning here. Learning things that are relevant in community – hunting, learning, activities. Recognise skills that we already have and transferring those skills to jobs and other help.”***

There was overwhelming discussion about the need for creation of Supported Independent Living (SIL) options and determining how current empty facilities in communities could be utilized, *“Having a house on the land and in my community close to family is important.”* There were suggestions that so much red tape meant that buildings sat empty. Participants were not quite sure who was responsible or what level of government had control over certain assets in the community, *“It would be good to have single units for people with disability.”*

The preference was to spend time with family, live in family groups, go to family camps and outstations. Due to moiety and blood lines – there can be some restrictions around who you can speak to, look at, or associate – it is for this reason that for some Aboriginal mobs, the known family also forms the friendship group.

## 5.4 Regional and Remote Areas of Australia

In 2022-2023, AQ facilitated *The Rural Families' Resilience Project* which explored the concept of resilience for farming families of children with disability who are impacted by drought conditions in the North-West Region of Queensland. **The findings of this project are relevant to the current NDIS Review and have therefore been incorporated into this current consultation.**

The project engaged farming families of people with disability through virtual kitchen table conversations. The key themes arising throughout the consultation, highlighted the strengths of families to endure, cope, and to demonstrate perceptions of setting realistic expectations when it comes to parenting and farming.

The project found that the primary barriers to supports for farming families are distance and lack of local services to consult with them.

- Families indicated they prefer face to face support that can be translated into their reality on the farm.
- Tele-practice support is a viable support option, however, waitlists, even of tele-health services, are extensive and technological and functional applicability of these supports is challenging.
- Many people with disability in farming families are likely eligible for funding supports, however access to formal pathways to determine eligibility across a range of systems (education, health, NDIS) is difficult and financially prohibitive.
- The option of 'going it alone to keep the family together' formed a key discussion point in addition to perceptions that another family might be doing it harder so they didn't want to take the resource from those who they perceived would benefit more.

***"I had to move near to Brisbane in 2021 from our cattle farm out past Longreach so my two children with disability could access the services ... It was impossible to get disability supports on the farm. My husband has stayed on the farm to keep it running. The children miss their dad and I miss everything."***

**Adopting a localised, person-centred approach** is required to facilitate engagement and co-production of support in regional areas. This will lead to improved subjective quality of life as the individual's circumstances and perception of their quality of life is likely to be different to the perceptions of their caregivers, external services and visiting practitioners.

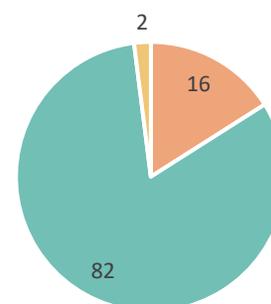
**Connecting sectors such as education (both Distance Education and face to face education), health, NDIS and community services** to form united pathways for rural families and increase communication and knowledge of available support is essential for rural families. Mapping of eligibility processes for the various bodies, identifying similarities and systemic barriers to efficient communication and when and where these services will occur.

Isolation is a factor when living remote, therefore **communicating when services are available is paramount**. Connecting key community leaders has shown word of mouth is a trusted and strong form of communication.

## 5.5 Culturally and Linguistically Diverse (CALD)

*“Fund translators – it’s not fair that NESB [Non-English Speaking Background] folks are limited to agency managed providers - many of which are large and not neurodiversity affirming. Accessing a translator privately is NOT affordable and using family members is not supporting choice and control or privacy. Provide free cultural safety training for all providers. Ensure more NESB folks know about and understand the NDIS and their concerns about it are responded to”*  
*- (Autistic non-binary, 40-54 years)*

CALD - %



■ Yes ■ No ■ Prefer Not to Say

16% of participants identified as being Culturally and Linguistically Diverse (CALD). Informants highlighted the importance for NDIS staff to engage in training to enhance their understanding of the intersectionality between disability and CALD backgrounds. Due to limiting factors associated with accessing translators for CALD or NESB (Non-English Speaking Background) NDIS participants, people frequently had to rely on family members for translation. This reliance hindered participants from exercising choice and control over their preferred supports.

Suggestions included the creation of guides and resources on the NDIS website in a variety of languages, to “break cultural stigmas”. Informants also identified the benefits of cultivating a more diverse NDIS workforce, with staff from various backgrounds, to foster understanding, sensitivity and awareness. This approach would work towards ensuring CALD and NESB NDIS participants felt heard and empowered throughout their NDIS journey. Additionally, allocating dedicated funding for translators emerged as a potential solution to empower CALD and NESB NDIS participants with a voice, and assert their right to exercise choice and control.

CREATIVE VIDEO SUBMISSION

“The NDIS should be tailored-made to each recipient, to meet their needs... NDIS can have a ‘circle of family support’ category as well, it could make it very easy and smooth sailing for migrants, and it could be beneficial for everybody.”

- Shivakuma, Male, 25-39 years old. NSW.

## 5.6 Supported Independent Living (SIL)

Informants highlighted challenges in advocating for and obtaining adequate funding within their NDIS plans for Supported Independent Living (SIL), in a way that also offered flexibility, choice and control.

People seeking SIL encountered a scarcity of choices, particularly in regional and remote areas. Informants described challenges finding SIL housing that accommodated for their preferences and support needs. For example, several informants described their preference to live by themselves with supports, however this was not an option due to limitations in their NDIS plan.

Parents often felt responsible for ensuring their adult child had secure housing. Parents spoke about providing a separate living space in the family home, like a granny flat, that offered their adult child privacy and fostered a sense of independence. Additionally, some parents expressed the anxiety associated with the need to engage in long-term “*future planning*”, which involved identifying and purchasing property to ensure a permanent home for their child.

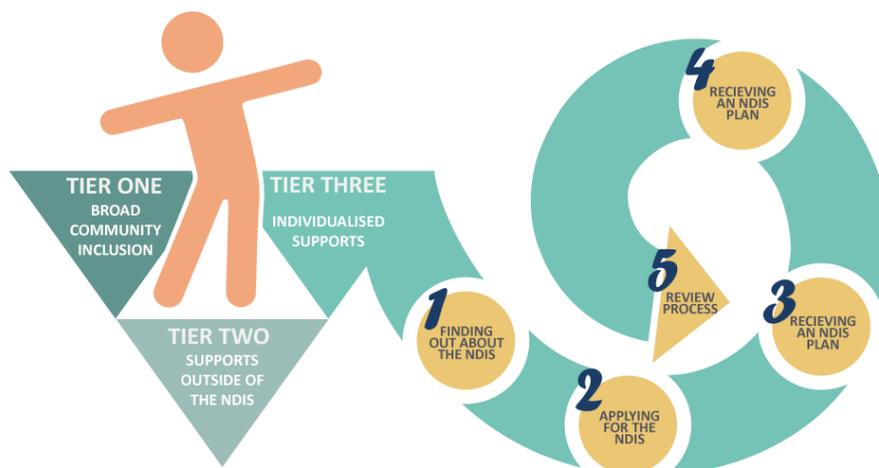
***“If I am not here tomorrow, who will advocate for my child? Who will do that and what will the NDIS do? If you listen and communicate and everything else will flow.”***  
***– (Parent of an autistic adult)***

Additionally, some parents expressed a sense of feeling excluded from discussions and decisions once their adult child moved into SIL housing. For example, one father recounted that he did not view his son’s NDIS application or plan prior to it being submitted to NDIS. The process was organised by the SIL provider, which left him feeling frustrated and isolated, “*as my son’s father, [I] should have had the opportunity to review my son’s NDIS plan before it was approved and implemented.*”

# 6. OVERALL SUMMARY OF KEY FINDINGS

The intention of this consultation report is to circulate the views and draw on the experiential expertise of autistic adults, 15 years and older and carers of autistic adults across Australia, to inform solutions to the NDIS review. Six key themes identified by informants to this consultation process include:

 <b>KEEP INCLUSION AT THE CENTRE</b>	 <b>CONNECT FIRST</b>	 <b>GIVE CHOICE AND CONTROL BACK TO THE PARTICIPANT</b>
<ul style="list-style-type: none"> <li>• Design a clear and inclusive website</li> <li>• Acknowledge and respect different communication styles and preferences</li> <li>• Train all NDIS staff on how to implement universal design and inclusion</li> <li>• Disability-specific training for frontline NDIA/NDIS staff</li> <li>• Increase diversity and representation among NDIA/NDIA staff and providers</li> <li>• Improve accessibility of information about supports and services</li> </ul>	<ul style="list-style-type: none"> <li>• Increased contact between LAC and NDIS participant</li> <li>• Consistent handover processes</li> <li>• Recognise and respect different forms of communication (i.e., AAC, chat function, and email)</li> <li>• Increase the access to independent advocacy services for participants</li> </ul>	<ul style="list-style-type: none"> <li>• NDIS to fund alternative supports</li> <li>• Recognition from the NDIA of benefits of peer supports</li> <li>• Explore financial support options for both parents and carers</li> <li>• Recognise and support alternative care arrangements for some individuals</li> </ul>



 <b>EMBRACE ALTERNATIVE SUPPORTS</b>	 <b>TRAIN AND EMPOWER NDIS STAFF</b>	 <b>ENHANCE SAFETY MEASURES</b>
<ul style="list-style-type: none"> <li>• NDIS to fund alternative supports</li> <li>• Recognition from the NDIA of the benefits of peer supports for participants</li> <li>• Explore financial support options for both parents and carers</li> <li>• Recognise and support alternative care arrangements for some participants</li> </ul>	<ul style="list-style-type: none"> <li>• Train NDIS staff on autism</li> <li>• Train NDIS staff on neurodiversity</li> <li>• Embed opportunities for university students to gain practical knowledge and build confidence, so that they can excel in NDIS service provision</li> </ul>	<ul style="list-style-type: none"> <li>• Enhanced regulation and auditing for service providers</li> <li>• Price caps (set prices) for services</li> <li>• Focus on quality, not just the availability of services/supports</li> </ul>

**Figure 2**

*Overall summary of solution focused findings*

## 7. ACKNOWLEDGEMENTS

Autism Queensland and the NDIS Review Secretariat operating out of Prime Minister and Cabinet, would like to thank our partner organisations for their efforts, in ensuring that those community members who so generously shared their stories, continue to be well supported in the places in which they follow their life journey.

This project has celebrated the autistic voices who speak on their own behalf and for the autistic community as a whole. It embraced the many different voices of autism, each with their own unique set of experiences and valued the voices of families and carers of autistic adults.

There is a well-known saying from Stephen Shore,

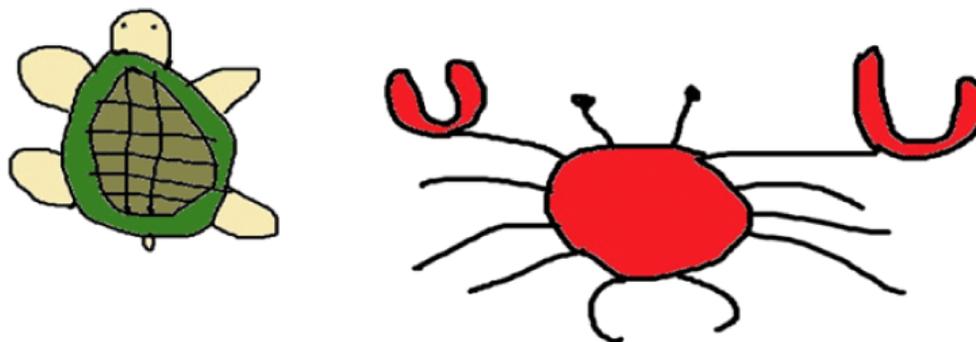
***“If you know one person with autism, you know one person with autism,”***

... meaning that everyone’s experience of and with autism is unique.

Cain described his experiences accessing NDIS supports, such as Support Workers to assist him to achieve his goals around community access. Cain described himself as a "turtle" in 2016: "I was basically a Turtle hiding in my shell popping out occasionally to do things only when I had to..."

-Cain Clifford-Marsh. 25-39 years of age. QLD.

"MY JOURNEY FROM TURTLE (2016) TO CRAB (2023)"



Through accessing NDIS supports, such as Support Workers, as well as social and therapy groups Cain has transformed into a crab: "At the moment, my life is busy like a crab scrambling around but I still have a hard shell and claws to defend me when times get tough. I am bright (red shell) and busy and aren't afraid to stand out in a crowd".

## **Appendix A: Asset Pack for Organisations**



Australian Government



**NDIS  
Review**

# **Your Supports, Your Way – *Join the Conversation***

**Engagement with autistic people and their  
communities to contribute to the  
NDIS Independent Review**



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# Introduction to the Project

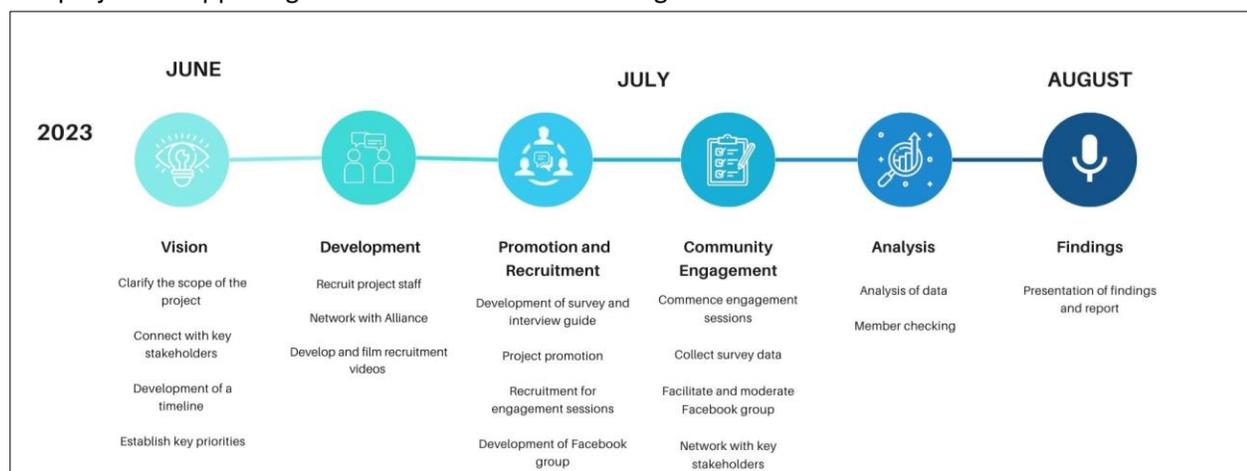
## What is the purpose of this project?

Autism Queensland (AQ) and the National Disability Insurance Scheme (NDIS) Independent Review have come together for a special project. We want to learn directly from autistic people who are 15 years and older, as well as families and carers, about their experiences with the NDIS. We are looking to gather input from a diverse range of autistic people across Australia.

This project is all about contributing to the NDIS Review. The goal is to understand what's working well and what could be improved to better support autistic people and their families.

## When does the project start?

The project is happening now and will run until late August.



## How can your organisation help?

To support recruitment of participants to the project we are seeking assistance to share information and encourage participation. There are many ways informants can participate. They can:

	Complete a survey.
	Have a chat with someone from the project team individually or as part of a group.
	Share their experiences through artwork...
	...or in a short video

The time and expertise of participants is highly valued, and as such they will be compensated for their contribution.

All queries, concerns and feedback will be directed back to AQ to minimise impact on your own service delivery.

When the engagement sessions have been completed, AQ will collate responses, analyse and present the findings to the NDIS Review.

## What will be the outcomes of this project?

This consultation process will ensure autistic adolescents, adults and their caregivers have their say and are supported to provide their lived experience expertise to support the solutions and enhancements of the NDIS review.

## Would you like more information on the project?

Our friendly team is here to help and answer any questions you may have.

	Send us an email: <a href="mailto:communityinclusion@autismqld.com.au">communityinclusion@autismqld.com.au</a>
	Learn more at: <a href="http://autismqld.com.au/ndis-review">autismqld.com.au/ndis-review</a>

*We appreciate your consideration in supporting this valuable work to inform the NDIS Independent Review.*

## The Project Team

We are a team of experienced and passionate consultants, with a strong track record in working collaboratively with organisations and achieving meaningful outcomes. **Have any questions?**

	Give us a call: (07) 3273 0000
	Send us an email: <a href="mailto:communityinclusion@autismqld.com.au">communityinclusion@autismqld.com.au</a>

Meet some of the team members below:

	<p><b>KIM SHEATHER</b>  <i>General Manager Consultancy &amp; Learning</i>                  Email: <a href="mailto:kim.sheather@autismqld.com.au">kim.sheather@autismqld.com.au</a></p>
<p>Kim is a highly experienced occupational therapist and leader within the disability sector, with a commitment to bringing supports and services to even the most remote communities. Kim’s knowledge across the disability sector ensures skill and insight of state and federal disability legislation and supports. Kim’s strengths focused leadership, identifying the diverse skills and abilities of each person is a driver for social change and inclusion for all.</p>	

	<p><b>DR CAITLIN TAGGART</b>  <i>Community Inclusion Coordinator</i>                  Email: <a href="mailto:caitlin.taggart@autismqld.com.au">caitlin.taggart@autismqld.com.au</a></p>
<p>Caitlin is a highly experienced and creative occupational therapist, with a passion for inclusion consultancy and a wealth of knowledge in legislation, inclusive and universal design, and co-design approaches. Caitlin’s collaborative energy ensures organisations feel empowered to achieve and sustain their long-term vision of inclusion.</p>	

**CHRISTINE BAGNALL***Senior Community Inclusion Consultant*Email: [christine.bagnall@autismqld.com.au](mailto:christine.bagnall@autismqld.com.au)

Christine is an innovative occupational therapist and champion for inclusion who brings international experience and expertise across the public health, education, and allied health sectors. Christine works with corporate and community organisations to uncover their 'why' for inclusion and to develop value-driven, inclusive practices to expand their reach and impact, improve customer experiences, and create meaningful organisational change.

**MERYL KEIOSKIE***Research Officer*Email: [meryl.keioskie@autismqld.com.au](mailto:meryl.keioskie@autismqld.com.au)

Meryl, a recent PhD graduate, pioneered research that harnessed the power of comics to amplify ASD awareness. With expertise in research, data evaluation, and visualization, she channels her passion to empower the autistic community. As someone personally diagnosed with ASD, Meryl is an ardent advocate for their empowerment. Driven to contribute valuable insights, she strives to foster profound understanding and unwavering support for all.

# About Autism Queensland

	Address: 437 Hellowell Road, Sunnybank Hills, QLD 4109
	Learn more at: <a href="http://www.autismqld.com.au">www.autismqld.com.au</a>

AQ is an experienced provider of professional education services and facilitation of co-designed services and research.



**VISION**

A life of participation, opportunity and choice.



**MISSION**

We partner with people on the autism spectrum, their families and communities to remove barriers and realise potential.



**VALUES**

Our core values are diversity & inclusion; strengths focus; safety & wellbeing; and evidence-informed practice.

Past and present projects supporting industries such as local area councils, transport, recreation, events, museums and the arts provide us with experience and knowledge to facilitate this project within the NDIS.

AQ professionals have expertise in autism and delivery of evidence-informed supports for autistic people. A dedicated team will deliver the project, with support from the organisation’s research and marketing teams to ensure it will be completed by late August 2023.

The organisation has extensive experience in research, engagement sessions, workshops and consultative service delivery that is customised through the lens of skill and language used by each cohort to ensure maximum application and implementation of learnings and materials. Care is taken to ensure these are inclusive and accessible to each cohort.

## Resources for Informants

### Before Engagement

There are several useful resources that provide an explanation of the project, in both written and video format. These resources ensure all informants provide informed consent and agree to the privacy terms and conditions for participation in the project.

Informants can access this information on a dedicated NDIS Independent Review web page.



<https://autismqld.com.au/ndis-review/>

On this page they will find links to resources including:



**A short video that explains the aims of the project and the ways in which people can participate.**

[Watch video here.](#) (Duration: 2:53 minutes)



**The NDIS Independent Review Privacy and Consent Easy English Booklet.**

[View booklet.](#) (20 pages)



**A short video that explains this policy.** [Watch video.](#) (Duration: 2.08 minutes)

## Experience Gathering / Engagement

Once informants have viewed these videos/documents, they will choose their preferred method of participation in the project:

### Online Survey

- Informants will access the survey through a link.
- They will also be required to read and acknowledge consent and privacy information before commencing the survey.
- To ensure anonymity, a separate link will be provided for informants to provide payment details.

### **Group and Individual Sessions**

- Informants provide some basic demographic information and asked about their preferences for engagement (for example, online or face-to-face and preferred dates and times) via a registration form.
- The project team will receive this information and contact informants via email to confirm session details.
- A Welcome Story will also be provided, with information about what to expect when participating in a group or individual session (i.e. venue details, sample questions, information about the facilitator)
- Payment details will be collected at the end of the (via a secure link provided to informants).

### **Creative Expression (submitted by Sunday 20<sup>th</sup> August 2023)**

- Informants will complete an online form capturing some basic demographic information and upload their creative expression (max 15MB). They will also be required to read and acknowledge consent and privacy information before submitting the form.
- Submissions from informants under 18 years of age will confirm they have discussed the project with their parent or guardian.
- A separate link will be provided for informants to provide payment details.

## **Following Engagement**

Informants can provide consent to be contacted by the project team to engage in additional conversations about their experiences (i.e. member checking). Member checking will be completed with informants who have engaged in individual and group sessions.

# Marketing Resources

## Social Media Tiles



[DOWNLOAD](#) (JPG, 547KB)



[DOWNLOAD](#) (JPG, 306KB)



[DOWNLOAD](#) (JPG, 523KB)

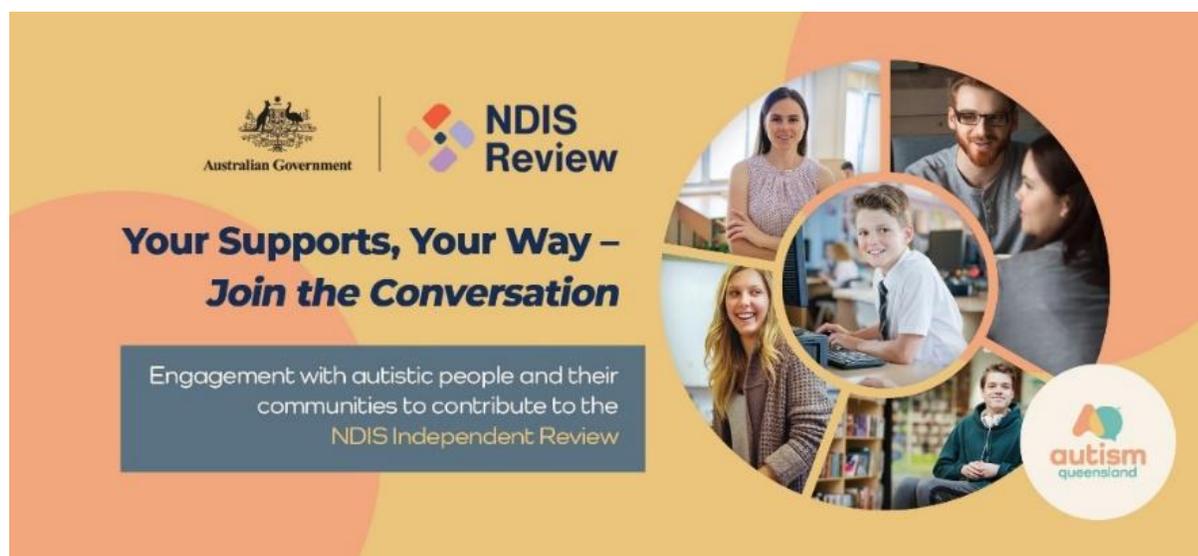
## Suggested Social Media Posts

Autism Queensland and the National Disability Insurance Scheme (NDIS) Independent Review want to learn directly from autistic people 15 years and older, as well as families and carers, about their experiences with the NDIS. Find out how you can Join the Conversation. <https://bit.ly/3K3ZTjO>

This project is all about understanding what is working well with the NDIS and what could be improved to better support autistic people and their families. Join the Conversation to provide your feedback to the NDIS Independent Review. <https://bit.ly/3K3ZTjO>

Now is the time to have your say about your experiences with this NDIS. Over the next six weeks the NDIS Independent Review and Autism Queensland want to hear from autistic people 15 years and over, as well as their friends and family. Join the Conversation today. <https://bit.ly/3K3ZTjO>

Your Supports, Your Way! Join the Conversation now and provide your feedback on the NDIS as an autistic person aged 15 years and over or as a family member and carer. <https://bit.ly/3K3ZTjO>



### Banner

[DOWNLOAD \(JPG, 646KB\)](#)

## Publish A Brief Article in Your Newsletter/On Your Website

### NDIS Independent Review – Join the Conversation Today!

Autistic Australians aged 15 years and older, their families and carers are being invited to have their say on the NDIS.

Autism Queensland is helping the NDIS Independent Review Panel by collecting feedback from the autistic community so they can understand what is working well with the NDIS and what can be improved to better support autistic families and their carers.

People interested in participating can provide feedback through an online survey, taking part in a one on one or group session, or providing a creative submission such as a piece of artwork or a video. A private Facebook group will also encourage further conversation.

The project aims to gather input from a range of autistic people and their families from across all regions of Australia.

Informants do not need to be accessing the NDIS, and all people providing feedback will be financially compensated for their time.

To access more information, resources and links for participation visit <https://bit.ly/3K3ZTjO>

### Poster



**DOWNLOAD (PDF, 493KB)**

## Appendix B. Welcome Pack for Informants

- Informants were provided with a Welcome Pack before engaging in a session.
- The Welcome Pack was provided in two different formats to meet a range of preferences, for example, 1) PDF version and 2) PowerPoint version which included voiceover option.



# Autism Queensland

**WELCOMES YOU TO...**

***YOUR SUPPORTS, YOUR WAY: JOIN THE CONVERSATION***

*This Welcome Pack will help you  
to prepare for your group, or  
individual discussion.*

***August 2023***





## Instructions

To play through this Welcome Pack, you must do so through the "*slideshow function*" on PowerPoint, this is also known as the **F5** key on your **keyboard**...

To navigate from page to page, **use the arrow keys** on your keyboard.



Audio will automatically play, when navigating from page to page. If you wish to interact with the audio, you can do so by clicking on the *speaker icon*. This will be found in the top left corner of each page.



# Inclusion Statement

*DISCUSSIONS WITH AUTISTIC PEOPLE AND THEIR COMMUNITIES,  
TO CONTRIBUTE TO THE NDIS INDEPENDENT REVIEW.*

We welcome **everyone**. During discussions, we want you to feel welcomed and comfortable being your **authentic self**.

Please let us know if there is anything we can do, that helps to **include you** and foster a sense of belonging.

*You are welcome to **use strategies** that help you to feel relaxed throughout the discussion.*



## This welcome pack will outline...

1. What are these discussions about?
2. What is the aim of these discussions?
3. What are some topics we may discuss?
4. What will you be expected to do?
5. How do I participate?
6. What are the online expectations?
7. How will the information be stored?
8. When will this take place?
9. Where will this take place?
10. Will I be paid for my time?
11. What do I need to bring?





## What are these discussions about?

**Autism Queensland (AQ)** are collaborating with the **National Disability Insurance Scheme (NDIS)**, to contribute to the upcoming NDIS Independent Review.

**Individual** and **group** engagement sessions will be offered to provide an opportunity for you to tell us about your experiences with the NDIS.

**We are seeking autistic participants who are 15 years of age and older, as well as their families and carers.** There are no requirements, other than this.

*Note: You don't need to be accessing the NDIS to participate in this project.*

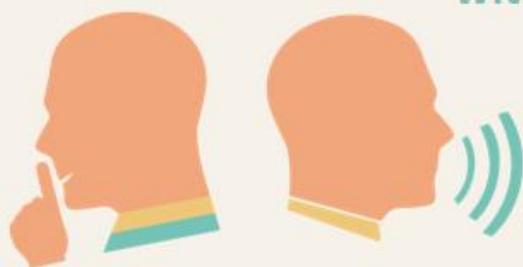


## What is the aim of these discussions?

The **aim** of this project is to **understand** what's working well in the NDIS, and what could be improved to better support **autistic people** as well as their **families**.



You will be asked about your unique experience with the NDIS.



You are welcome to **ask any questions**, throughout the discussion.



## What are some topics we may discuss?

We will discuss many different topics when it comes to your experiences with the NDIS. Here are some questions to think about before your discussion:

- ❖ What would make your experience in applying for the **NDIS better/easier**?
- ❖ How could the **NDIS** make sure everyone receives the **services** and **supports** that they **need**?
- ❖ If you could **change** one thing about the **NDIS**, what would it be?





## What will you be expected to do?



There is an option to participate in either  
an individual or group discussion.



Discussions will last for **one hour**.

*You can choose to either meet **online**, or **face-to-face** with  
a **project team member**.*



## How do I participate?



Before discussions, we **need** your **consent** to **participate**.

- Consent means that you are agreeing to participate.

To give your consent, a form must be signed by either you or your carer/ supporter and/or guardian.

The form can be found [here](#).

*Participation is completely up to you, and you can change your mind at any time should you wish to not participate anymore.*



# What are the online expectations?

For online sessions, these will take place through the video communications platform of **ZOOM**. You will be given a link that will be sent to your email.

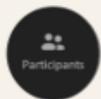
*If you are new to **ZOOM**, an in-depth guide on how to use the application can be found on [their website](#).*



← Turn webcam on/off



← Record the session



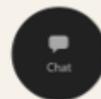
← View others in session or raise your hand



← Mute, or unmute your microphone



← End or leave the session



← Send messages/textually chat



← Change how ZOOM appears



← Share your screen with others



## How will this information be stored?



**All discussions will be recorded (audio), and then transcribed.**

Please note, that all information will be securely stored, according to Autism Queensland's [privacy statement](#).

Additionally, your contributions will be stored safely and shared anonymously with the NDIS.



## When will this take place?



Discussions will be running  
from **August 2023.**



## Where will this take place?

Autism Queensland will be engaging in discussions in various states Australia wide, from:

- ❖ New South Wales
- ❖ Northern Territory
- ❖ Queensland
- ❖ South Australia
- ❖ Western-Australia



If we are in your local area, we may be able to organise a **face-to-face discussion** at your preferred location, such as your home, in the community, or at your local service provider.

*Please let us know, by emailing us at:*  
[communityinclusion@autismqld.com.au](mailto:communityinclusion@autismqld.com.au).



## Will I be paid for my time?



- We value your contribution. You will be paid **\$140.00** for your time.
- To process payment at the end of the discussion, you will be given a secure link to provide your bank details.

*Note: Any details that you provide will be secured according to AQ'S*

*[Privacy Statement.](#)*



## What do I need to bring?



*(Please be mindful, do not bring any snacks that may produce a loud sound, or strong smell)*

**There is no need to prepare beforehand**, although please feel free to bring any items with you, that would ensure that you feel more comfortable during the discussion.

**For example:**



Water



Headphones



Sensory tools



Snacks or gum

*Note: Light refreshments of coffee/tea & biscuits will be provided at all face-to-face discussions.*



We encourage you  
to take a break as  
needed throughout  
discussions.

*Note: Should you wish to end the engagement at any  
given time, the option is always available.*





## Questions?

If you have any questions, please contact **Christine Bagnall** and/or the **Community Inclusion Team** at **Autism Queensland**:



### Christine Bagnall

Email: [Christine.Bagnall@autismqld.com.au](mailto:Christine.Bagnall@autismqld.com.au)

Community Inclusion Consultant, Autism Queensland



### COMMUNITY INCLUSION

Phone number: (07) 3273 0000

Email: [CommunityInclusion@autismqld.com.au](mailto:CommunityInclusion@autismqld.com.au)



**We** look forward to  
hearing **your** thoughts  
and feelings!

**THANK YOU FOR READING THIS  
WELCOME PACK.**

## Appendix C: Structured PowerPoint Deck

Some informants chose to participate in a **structured PowerPoint deck** to express their experiences and thoughts on the topic.

Participants could choose to complete this with someone from the project team, or a support person in the comfort of their own home.

# Autism Queensland

***YOUR SUPPORTS,  
YOUR WAY:  
JOIN THE  
CONVERSATION***

***August 2023***

[autismqld.com.au](http://autismqld.com.au)



**Participation | Opportunity | Choice**

**Autism Queensland (AQ)** are working with the **National Disability Insurance Scheme (NDIS)**, to help with the NDIS Independent Review.

**You can join an individual and group** session to tell us about your experiences with the NDIS.

We are wanting to speak with autistic participants who are 15 years of age and older, as well as their families and carers.

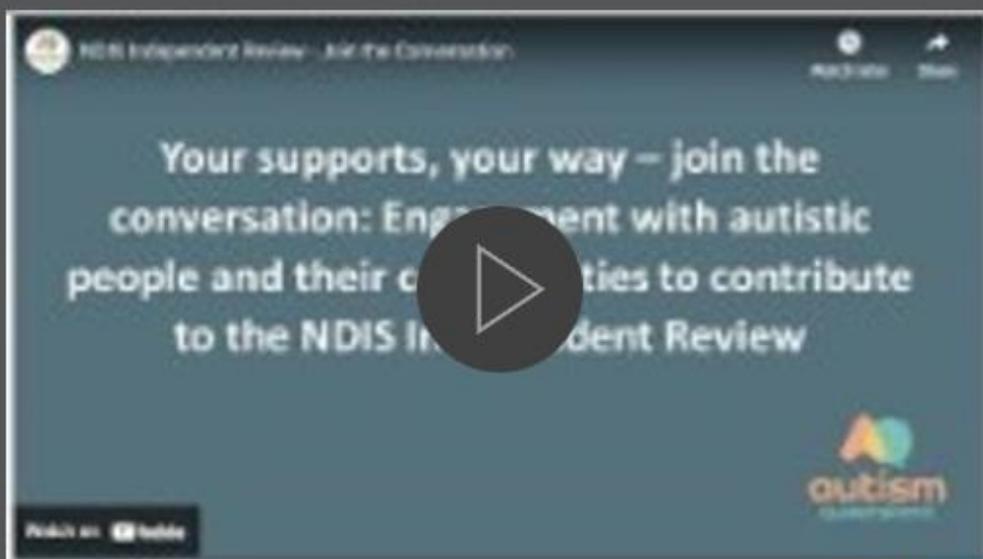
*Note: You don't need to be accessing the NDIS to participate in this project.*

[autismqld.com.au](http://autismqld.com.au)



Participation | Opportunity | Choice

# About the Project



## Discussion Topic

**Question: What does good support look like for you?**

**Answer:**

## Discussion Topic

**Question: Thinking about when you applied for the NDIS, what would have made it easier?**

**Answer:**

## Discussion Topic

**Question: If you could change 1 thing about the NDIS, what would it be?**

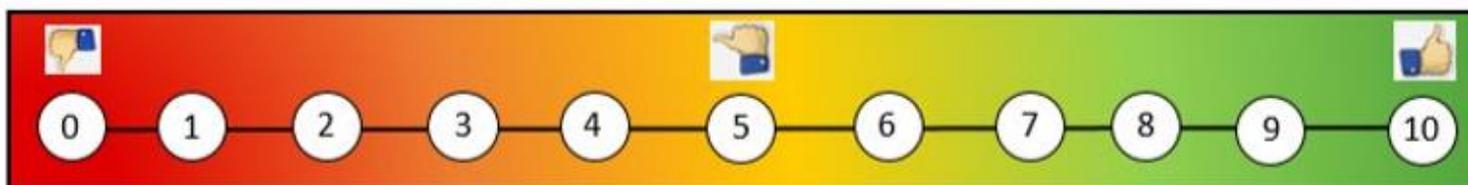
**Answer:**

The next 4  
slides ask  
questions  
about where  
you live.



Question: How happy are you with where you are living?

Answer:



Not happy with where I live

I feel okay with where I live

I am really happy with where I live

Comments:

Question: How happy are you with who you live with?

Answer:



I don't like the people I live with

I am okay with who I live with

I am really happy with the people that I live with

Comments:

## Question: How happy are you with the types of support you have?

For example, Support Workers, therapy, group supports.

### Answer:



I am not happy with the supports I have

I am okay with my supports

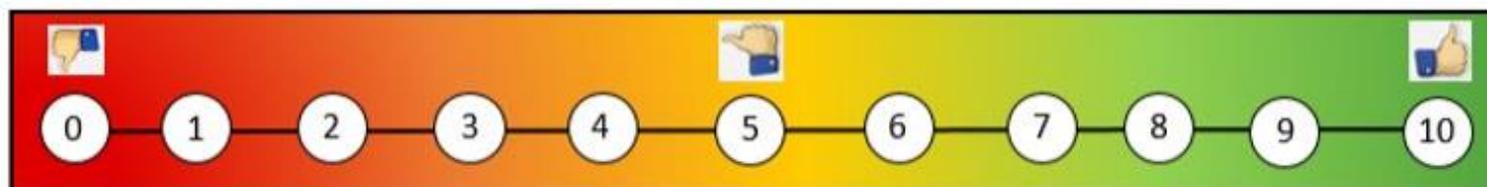
I really happy with the supports I have

### Comments:

## Question: How happy are you with the amount of support you have?

For example, you may want more time with your Support Workers or more therapy.

### Answer:



I am **not happy** with the amount of support

I am **okay** with the amount of support

I am **want** or need more support

### Comments:



## Will I be paid for my time?



We value your contribution. You will be paid **\$140.00** for your time.

To receive payment, please fill out the following, secure form:

<http://autismqld.tfaforms.net/90>

***Note:** Any details that you provide will be secured according to AQ'S Privacy Statement.*

## Questions?

If you have any questions, please contact **Caitlin Taggart** and/or the **Community Inclusion Team** at **Autism Queensland**:



**Caitlin Taggart**

Email: [Caitlin.Taggart@autismqld.com.au](mailto:Caitlin.Taggart@autismqld.com.au)

Community Inclusion Coordinator, Autism Queensland



### COMMUNITY INCLUSION

Phone number: (07) 3273 0000

Email: [communityinclusion@autismqld.com.au](mailto:communityinclusion@autismqld.com.au)

**Thank you for your  
time.**

**We value your  
thoughts and  
opinions.**

