



‘Getting out into the world’: pathways to community participation and connectedness for NDIS participants with intellectual disability, on the autism spectrum and/or with psychosocial disability

SUMMARY REPORT

Research and Evaluation Branch – Policy, Advice and Research Division

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About the Research and Evaluation Branch

The Research and Evaluation Branch is responsible for ensuring that NDIA policies, practices and priorities are informed by trustworthy and robust evidence so that decisions can be based on an understanding of what works, what doesn't and the benefit to participants and the Agency.

This document

This report presents research findings from the Community Participation Research Project.

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Enquiries about this publication should be addressed to:

National Disability Insurance Agency

Email: research@ndis.gov.au

Abbreviations

Abbreviation	Term
CALD	Culturally and Linguistically Diverse
HSC	High School Certificate
LAC	Local Area Coordinator
LGBTIQA+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual and + to represent the many more identities and affirmed genders
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PiTC	Partner in the Community
SME	Subject Matter Experts

Glossary

Term	Definition
Autism spectrum*	This term refers to a group of neurological disorders that are characterised by impairments in social interaction, communication, repetitive behaviours, and restrictive interests. Impairments can vary widely between people and may change over a lifetime.
Community	Community is a group of people that interact and support each other, they may have shared experiences, a sense of belonging, and may live close by.
Community participation	Community participation and connection involves processes of participating in chosen activities within the community that are meaningful to them.
Convivial encounters	Convivial encounters happen when different people meet briefly at a place or over a topic of common interest.
Disability ecosystem	Disability ecosystem is the network of systems in which people with disabilities interact. This can include:

Term	Definition
	<ul style="list-style-type: none"> • Government services • Non-government services (e.g. Scouts, sports clubs, drama classes) • Disability service providers
Intellectual disability	Is a term used to describe a range of conditions that impair general mental abilities including intellectual functioning (such as learning), and adaptive functioning (such as communication and living independently).
Mainstream	Mainstream refers to ideas, attitudes, or activities that are shared by most people and considered common or conventional.
NDIS participants	NDIS participants refers to people in the NDIS or their family, carers and other supporters.
NDIS service delivery staff	NDIS service delivery staff includes: <ul style="list-style-type: none"> • NDIA planners • Local Area Coordinators (LACs) • Subject Matter Experts (SMEs) • Partners in the Community (PiTC)
Person-centred planning	Person-centred planning is an approach to service planning and supports for people with disability that puts the individual at the centre.
Psychosocial disability	Psychosocial disability is a disability that may arise from mental health issues.
Research participant	A research participant is someone who participated in the research.
Survey respondent	A survey respondent is someone who did a survey.

*People prefer different terms to describe autism. To acknowledge this, we use the terms autism spectrum and participant on the autism spectrum in this report. We have used person first language to be consistent with how we refer to the other target populations. However, we acknowledge the contested nature of 'person first' and 'identity' language.

Background

People with disabilities have the same right to access community participation opportunities as the rest of the population (UN General Assembly 2006, Article 27).

Staying connected and involved in your community is important for everyone's wellbeing, health and quality of life. It can also help you build pathways to employment.

The Agency is committed to supporting participants to be a part of their community and feel more included.

Why we did this research

To better support participants we need to understand what helps or makes it harder for participants to participate in the community. Our research looked at people with intellectual disability, on the autism spectrum and/or with psychosocial disability. These groups make up 2 out of 3 NDIS participants.

By doing this research, we wanted to:

- Learn about participants' experiences in the community,
- Understand what makes it easier or harder to be in the community,
- Discover the supports participants need (including families, carers or supporters) to help them in the community.

This research is part of a larger study that included an evidence review that looked at which interventions and supports improve social and community participation outcomes for people with intellectual disability, on the autism spectrum and/or with psychosocial disability. It included over 50 published reviews of more than 500 research studies.

To read more about the larger study and the findings for the evidence review, visit Research and Evaluation on the [NDIS website](#).

What approach did we take for this research project?

We interviewed NDIS participants (families, carers or supporters) aged 14 to 44 years.

We used video calls, telephone, or email to talk with NDIS participants. They heard about this research from the NDIS Participant Engagement Group, NDIS website, peak bodies, social media and other organisations.

Using video calls, planners, delegates, Local Area Coordinators (LACs), and Subject Matter Experts (SMEs) also spoke with us. We also invited them to participate in an online survey.

Three NDIS participants worked with us to make sure the research, our approach and the findings were useful for NDIS participants.

Monash Health Human Ethics Committee approved this research (RES-20-0000-276A). The NDIA paid for the research.

Who took part?

Eighty-five NDIS participants or family, carers, and other supporters participated in interviews. These lasted up to an hour. This included:

- 39 NDIS participants
- 46 family, carers, and other supporters

Some parents spoke about more than one child. Sometimes we spoke to both the NDIS participant and their family, carer or supporter. A total of 86 NDIS participants aged between 7 and 44 years are included in this research reported:

- Autism spectrum (n=30),
- Intellectual disability or Down syndrome (n=35),
- Psychosocial disability (n=21).

Focus groups and interviews were held with LACs (n=21), planners (n=10) and other staff (n=6). We got 142 responses from the online survey (71 LACs/PiTC, 62 planners or delegates and 9 employment SMEs). Respondents lived across Australia and had different work experiences.



Jess, intellectual disability cohort, NDIS participant, aged 38 years

I would be interested in doing anything, you know, like, to learn new skills. With my social group, or with someone like with NDIS that can help me and support me. With people with disabilities and people probably with no disabilities, just sort of mixing.

What did the research find?

Community participation is important to participants

Participants in this research told us that community participation gave them:

- A feeling of belonging and connection.
- Better relationships with friends and family.
- Bigger social networks and less loneliness.
- Improved confidence and the feeling that they are safe in the community.
- More opportunities to be a part of the community, study or get a job.

Barriers and enablers to community participation

Participants told us what made it easier or harder to be a part of the community. We have grouped what participants told us into three topics:

- Common experiences across all participants
- Young people and school leavers
- Maintaining social connections



Isabel, NDIS participant, intellectual disability cohort, aged 30 years

Well, I like going to group things, and trying new things. I like going outdoors and movies, cooking, scuba diving, bowling, all the general things, and also trying new things that people are recommending, because I really want to try and get myself out there much more.

Common experiences across all participants

Participants said they did not find many good community-based activities where they felt welcomed. NDIS staff and family members also said this was one of the things that made it the hardest for NDIS participants to be in the community.

Participants told us:

- Negative attitudes about disability stopped them from being a part of their community. Some said they found a few disability-specific activities where they felt safer. But these were also hard to find sometimes.
- A lack of food and stable housing, poor mental and physical health, and being tired stopped them from having the energy and time to be part of their community.
- They didn't always have the confidence to be social in the community. Supporting participants to build their social skills and confidence is important.
- NDIS staff, providers and the community did not always understand their disability. Having supports that are individual to them and who they are, is important.
- Finding the right support worker for them was difficult. Participants talked about wanting support workers who were their age and enjoyed the same things.
- They sometimes needed support to help them to find and choose community activities that they wanted to do.
- Support workers with mental health training may be helpful for participants with psychosocial disability or other mental health concerns.
- Friends and family helped them to be part of the community. They were role-models, suggested options, and provided informal support.
- Animals gave some of them comfort and helped them meet people in the community.
- Assistive technology and disability-friendly transport supported them to move around the community.

Maintaining social connections

Participants told us that it is important to maintain your social skills, your health, and your access to money or transport so that you can continue to participate socially and be part of the community.

- As you reach different life stages you may want to learn more about new life roles, like being a parent. You may also want support to move from one life stage to the next with someone who can coach you through those changes, or who can give you peer support when you graduate from school or retire from work. Trauma, mental and physical health can stop participants being part of the community. Extra support when these things happen is needed to help them stay connected with the community.
- Making sure you were able to continue to look after your basic needs like health and housing can help give you the energy to stay connected to the community.
- Being part of work or hobby groups are good ways to help you stay connected with other people.



Emma, NDIS participant, autism spectrum cohort, aged 42 years

With NDIS it meant that I could really increase my social participation and recreational participation and things a lot more. And also have some control over it.



Harriet, mother of Alex, intellectual disability and autism spectrum cohorts, aged 11 years

Everybody knows him, and every time you go out for a ride or a walk or something and people go "Hi Alex, hi Alex!" You go to shops and it's "Hi Alex!" There's lots of disability things out there, but we've deliberately chosen to do things that are just regular things. And we've asked people to consider adjusting [the activity] or adding whatever it is that's needed for him to be able to engage with it as well.

Young people and school leavers

Participants told us that schools and home-schooling networks are important. They can:

- Support young people to try new activities and develop interests
- Help young people meet others in the community
- Provide after school programs like sport or music that help young people to connect with their local communities through networks and other school families.

You also told us that extra support may be needed to help keep these connections when young people leave school.

Participants told us that some places in the community are not always easy to access for young people with disabilities.

- Community attitudes can stop children with disabilities from participating in community activities. Parents and carers often plan to make sure their children have a positive experience, and some parents and carers choose disability-only spaces to avoid negative community attitudes. After leaving school, students can lose social connection with the community if they do not have the right supports.
- The distance from home to school can stop participants from having relationships with school peers outside of school.

What are we doing with this research?

The findings from this research project and the [evidence review](#) will help the NDIS support participants. This research will also help develop resources for participants to use their plan and assist front-line staff in their conversations with participants to help them be part of the community.