‘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

Research and Evaluation Branch – Policy, Advice and Research Division

April 2022

ndis.gov.au

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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Acknowledgements

The NDIA acknowledges the Traditional Owners and Custodians throughout Australia and their continuing connection to the many lands, seas and communities. The NDIA pays respect to Elders past and present, and extends this acknowledgement and respect to any Aboriginal and Torres Strait Islander people who may be reading this Report.

The Research and Evaluation Branch, would like to acknowledge the broader NDIA team NDIS participants who assisted in the development of this research project. Judith Drake, Gavin Burner and Katy Reid are warmly acknowledged for sharing their lived experience expertise with the team to support to the development and design of this research along with Roslyn Ryan for her work as part of her work experience.

The Branch gratefully acknowledges the NDIS participants, carers, family members and NDIS service delivery staff who participated and shared their experiences.

Suggested citation: National Disability Insurance Agency 2021. '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. Australia. Prepared by L Smith, M Bennett, B Gardner, R Morello.

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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 disorder*	Autism Spectrum Disorder (ASD) (also referred to as “autism”) is the collective term for a group of neurodevelopmental conditions affecting the brain’s growth and development. Autism is a life-long condition which can impact, to varying degrees, all areas of a person’s life, including social communication and social interaction. The behavioural features of autism are often present before a person is three years of age but in others they may not be recognised until their school years or later in life. The developmental challenges, signs and/or symptoms can vary widely in nature and degree between individuals, and in the same individual over time – that is why the term “spectrum” is used.

Term	Definition
Community	Community is “a group of people that interact and support each other, and are bounded by shared experiences or characteristics, a sense of belonging, and often by their physical proximity” (p.195, Cobigo, Martin, & Mcheimech, 2016).
Community participation	Community participation and connection for the purposes of this research project was defined as the process of engaging in self-identified activities within the community context that are meaningful and influence the community context and the individual (Bathje, 2016).
Convivial encounters	Convivial encounters refers to encounters that connect people who are different and bring them together briefly over a topic or matter of common interest and are marked by friendliness and hospitality. They can be fleeting (e.g. an exchange in a supermarket queue), intermittent (e.g. exchanges in a regularly visited café), or episodic (e.g. regular exchanges in an exercise class).
Disability ecosystem	Disability ecosystem refers to a wide and complex network of systems such as government and non-government services and the market place, as well as where the participant fits within this. NDIS participants are required to navigate this system to access supports, find activities and engage with other people in the community. The ecosystem includes local government, community organisations, and disability service providers.
Intellectual disability	Intellectual disability is a term used to describe a range of conditions originates before the age of 18 and 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 regarded as common or conventional.
NDIS participants	NDIS participants, when referred to in the findings, includes NDIS participants, family, carers and other supporters who spoke to the participant experience.

Term	Definition
NDIS service delivery staff	NDIS service delivery staff includes NDIS planners, delegates, Local Area Coordinators (LACs), Subject Matter Experts (SMEs) and 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. A person-centred planning process aims to discover how an individual wishes to live their life and what may be needed to make that possible, with the aim of influencing positive change in the person's life and supporting services (McCausland, Murphy, McCarron, & McCallion, 2021).
Psychosocial disability	Psychosocial disability refers to the social and economic consequences related to mental health conditions. It is used to describe the challenges, or limitations, a person experiences in life that are related to mental health conditions. The impact of psychosocial disability can vary over time because of the difficulties people experience with mental health conditions and many other factors in the individual's life. Not everyone living with mental health conditions will experience a significant psychosocial disability and individuals will experience psychosocial disability differently.
Qualitative research	Qualitative research methods such as in-depth interviews allow researchers to hear people's unique stories and voices and then pull it together to look at common themes.
Quantitative research	Quantitative research seeks to answer questions such as how many people had the same experience or understanding.
Research participant	A research participant is a person who participates in the research.
Survey respondent	A survey respondent is someone who has filled in 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.

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Community participation & connectedness

Social and community participation represents a **key pathway** for the **achievement of participant outcomes.** The Research and Evaluation Branch undertook a **mixed methods** project to explore the **barriers and enablers** to community participation and connectedness for **NDIS participants** with intellectual disability, on the autism spectrum, and/or with psychosocial disability.

AIMS

1. Understand & explore participants' experiences and pathways to community participation and connectedness
2. Explore the barriers & enablers to community participation
3. Identify information & supports required by participants to help them to develop their participation goals & participate in the community

METHODS

In-depth interviews	Surveys	Focus groups
85 NDIS Participants aged 14 to 44 years	**142** NDIS Service Delivery Staff	**37** NDIS Service Delivery Staff

KEY INSIGHTS

Barriers

Lack of inclusive options was **the greatest barrier** to community participation for NDIS participants. **Negative and risk-adverse attitudes** made it **difficult to access mainstream activities**. **Disability-specific activities** were often seen as safer options but **did not always** provide opportunities for **meaningful community connection.**

- Lack of available and accessible transport
- Lack of self-confidence to participate in the community
- Lack of individualised programs to make connections with peers with the same interests
- Feeling like their disability and their support needs were not always well understood
- Difficulties finding suitable and capable support workers that matched their needs, to support skill building and access to activities
- Lack of clarity around what supports participants could access to assist them to achieve their social and community participation goals

Enablers

Individualised & person-centred approaches

- Understanding the person-specific needs, wishes and goals

Appropriate support for each individual

- Appropriately skilled and socially-matched support workers

Participants' skills & confidence

- Positive experiences and regular social exposure fosters confidence
- Capacity building strategies, recovery frameworks and collaboration

Accessing & navigating opportunities

- Attitudes and expectations of mainstream community
- Choice of school and location

1. Executive summary

1.1 Background

The United Nations Convention on the Rights of Persons with Disabilities states that people with disabilities have a right to “full and effective participation in society on an equal basis with others” (United Nations, 2006). In Australia, the National Disability Insurance Scheme (NDIS) aims to support the independence and social and economic participation of people with disability, maximise a person’s inclusion in the community, and to facilitate greater community inclusion of people with disability (NDIS Act 2013).

1.1.1 Problem definition and research aims

Approximately two-thirds of NDIS participants have intellectual disability, are on the autism spectrum, and/or have psychosocial disability (NDIA 2020). People with intellectual disability, on the autism spectrum and/or psychosocial disability often experience disproportionate barriers to social, community and economic participation compared with people with either physical disability or no disability and are among the most disadvantaged and socially excluded people in society. Therefore it is important to understand the unique barriers and enablers to community participation for these cohorts to inform solutions to achieve improved participant outcomes.

This participant-focused research project sought to:

- understand and explore participants’ experiences and the pathways to community participation and connection for NDIS participants with intellectual disability, on the autism spectrum, and/or with psychosocial disability;
- explore the barriers and enablers to community participation, specific to these NDIS participants; and
- identify the information and supports required by participants (families, carers or supporters) to help them develop and implement their community participation goals.

While the focus of this research was to primarily take an NDIA lens, due to the interdependent nature of the supports funded by the Scheme and its role to influence the market place, the research also looked to understand the barriers and enablers to community participation within the broader disability ecosystem.

1.2 Research methods

1.2.1 Who took part

Interviews were held with 85 NDIS participants or family, carers, and other supporters. This included:

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

Some of the family, carers and other supporters, who participated, spoke about multiple NDIS participants (such as parents of more than one child with disability). In some cases both the NDIS participant and the person who supports them were interviewed resulting in two interviews about the same NDIS participant. Therefore, 86 NDIS participants were represented, aged between 7 and 44 years, with a primary or secondary disability of:

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

The characteristics of participants cover a broad cross-section of age, gender, location, employment status and types of employment requiring different levels of skill and education.

Focus groups and semi-structured interviews were held with LACs (n=21), planners (n=10) and other NDIS staff (n=6). Additionally, there were 142 responses to the online survey (71 LACs/PiTC, 62 planners or delegates and 9 employment SMEs). Respondents were well distributed across the states and territories and had various levels of experience.

1.3 Findings

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

- A sense of belonging and connection.
- Deeper relationships with friends and family.
- Larger social networks and reduced isolation.
- Increased confidence, self-efficacy, and safety.
- Increased opportunities for further community participation, employment or study.

A number of barriers and enablers to community participation were identified. Themes that were identified from the data have been presented under the following three categories:

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

1.3.1 Common experiences across all ages

- Lack of inclusive and appropriate community based activities to meet participants' interests was consistently noted as the greatest barrier by NDIS participants, their family, carers and supporters and NDIS service delivery staff.
- Negative and risk-adverse attitudes about people with disability was identified as a key barrier to accessing mainstream activities. Some participants turned to disability-specific activities as safer options however these were hard to find due to limited available options and long waiting lists.
- Not having sufficient foundations (such as stable housing, mental and physical health, food security and adequate sleep) meant participants were unable to find the energy and time to participate in community activities.
- Participants reported having a lack of confidence to socially interact in the community. They talked about setting small achievable goals that can act like stepping stones to work towards larger community participation goals such as developing friendships. These included foundational goals such as social skills and confidence building.
- Participants reported that their disability or support needs were not always well understood by staff, providers and the community. Individualised and person-centred service planning and supports was seen as critical to support participants to build and implement their community participation goals.
- Meaningful community participation requires good support. Participants reported difficulties finding suitable support workers, and their capabilities did not always match the expectations of participants. Support workers matched to participants' age or interests were more likely to facilitate activities that both the participant and worker enjoyed.
- Support to find options and make decisions about community participation enabled participants to identify their wishes and preferences.
- Mental health trained support workers were important for participants with psychosocial disability and other participants with mental health concerns.
- Social networks through personal or friend and family contacts provided pathways for community participation, through role-modelling, suggesting options and providing informal support.
- Animals often helped to facilitate positive encounters in the community and provide comfort for participants with anxiety about community social interactions.
- Assistive technology and accessible transport enabled greater participation in places that were otherwise not available to participants.

1.3.2 Young people and school leavers

- Community attitudes towards children with disability can be a barrier to community participation and may result in families trying to protect young people from negative social experiences by choosing disability specific activities.
- Staff and participants spoke of the importance of schools. They can provide opportunities for community participation by allowing young people to try activities and develop interests, as well as linking students with people and places in the local community. However, the transition from school can be a time when access to community

participation or maintaining those social connections may decrease without the right supports.
- The physical distance between schools and home can create a barrier to participants establishing and building relationships with school peers, their families and the community outside of school hours.

1.3.3 Maintaining social connections

- Personal circumstances including trauma, mental and physical health can interrupt community participation, requiring supports to return. Extra support during these times helped participants to maintain connections with their community.
- Maintaining and supporting base level needs enabled the continuation of community participation.
- Employment and hobby groups were ways that participants maintained connections with other people through regularly seeing the same people.

1.4 Insights and considerations

The following insights and considerations are based on the data drawn from this research project.

There were four key factors identified from the data that enable successful and meaningful community participation for NDIS participants.

1.4.1 Person-centred approaches

Person-centred service planning and the delivery of supports (putting the person at the centre), that are flexible and able to respond to changing circumstances, is essential for supporting participants to identify and engage in community activities and groups. Having sufficient foundations (such as stable housing, mental and physical health, food security and adequate sleep) is important for participants to be able to find the energy and time to participate in community activities. Supporters need to understand which foundations (e.g. health, housing) require further support to strengthen community participation and to link participants with the appropriate government agencies and services to address this. Interagency collaboration with commonwealth, states and territories is required to ensure the basic needs of people with disability are adequately being met.

1.4.2 Having appropriate and personalised supports

The quality of supports and services impacts on participants' overall community participation. Appropriate and personalised supports plays an integral role in enabling quality community participation for participants. Matching support workers to a participant's age, skills and interests can result in a more positive and meaningful experience. This can help to increase confidence about community spaces and social interactions. Assistive technology can also make community spaces more accessible (e.g. noise cancelling headphones) and less confusing (e.g. virtual social stories that show experiences of participants like them).

Working with the broader disability sector to ensure providers and the support workforce are utilising best practice principles is required.

1.4.3 Accessing and navigating opportunities for community participation

Having access to and navigating the opportunities is essential for community participation. Families, friends and acquaintances provide opportunities for participants to engage in community participation through role modelling, and providing introductions, connections and informal support. Schools and education networks also play a role in connecting participants to opportunities within the wider community through after school activities and information sharing. Participants should be encouraged to use these networks to maximise their benefit. Clear and accessible information about what is available is also required to help participants navigate opportunities in the wider community. Fully inclusive and meaningful participation in the broader community is desired by NDIS participants. Supporting models of community participation that have support and structure from disability support organisations alongside meaningful engagement with the broader community may help may help to build a person's confidence and social networks whilst providing support and friendship. Collaboration between people with disability, the community, government and other agencies and organisations is also needed to build greater disability confidence within the community. This may be facilitated by Partners in the Community (PiTC) and their staff or through Information, Linkages and Capacity Building (ILC) supports.

1.4.4 Participant empowerment, skills and confidence

Participants told us they had richer experiences, deepened relationships and gained a sense of belonging through broader community opportunities. Broader community connections that are welcoming and inclusive need to be fostered. Supporting meaningful skill-development activities can enable participants to build their confidence and experience. For some participants, developing small targets led to attaining larger goals and greater community participation over time.

1.5 What next?

Findings from this research will inform resources for participants and NDIS service delivery staff to better support the development and implementation of community participation goals.

Through dissemination of these research findings, the NDIA will continue to work with the broader disability ecosystem to promote more effective community participation pathways for people with disability.

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.

2. Introduction

2.1 Background

The United Nations Convention on the Rights of Persons with Disabilities states that people with disabilities have a right to “full and effective participation in society on an equal basis with others” (United Nations, 2006). In Australia, the National Disability Insurance Scheme (NDIS) aims to support the independence and social and economic participation of people with disability, maximise a person’s inclusion in the community, and to facilitate greater community inclusion of people with disability (NDIS Act, 2013).

Social and community participation represents a key pathway for the achievement of participant outcomes especially for those not engaged in work or education. Research has found that access to social resources (such as those derived from social relationships, networks and interactions) can lead to improved health and wellbeing, self-esteem, self-confidence, and levels of independence as well as protect individuals from experiencing poor mental health during times of life stress (Berry & Welsh 2010; Kawachi & Berkman 2001; Lakey & Orehek 2011; Milner et al. 2016; Olstad et al 2001). Higher levels of community participation has also been linked with increased opportunities for study, volunteering or paid employment with benefits to the community through improved social inclusion and economic benefits.

However, people with a disability are more likely to have lower levels of community participation and social support compared with people without a disability (Emerson et al 2012; Honey et al 2011; Milner 2017; Mithin et al 2015; NDIS 2018; Verdonschot et al 2009; WHO 2011). People with intellectual disability, on the autism spectrum and/or psychosocial disability often experience disproportionate barriers to social, community and economic participation compared with people with either physical disability or no disability (Noel, Oulvey, Drake & Bond 2017; Gooding, Anderson & McVilly 2017) and are among the most disadvantaged and socially excluded people in society (Kozma, Mansell & Beadle-Brown, 2009; Beadle-Brown, Murphy & DiTerlizzi 2009; Beadle-Brown, Murphy & Wing 2006; Emerson, Malam, Davies & Spencer 2005; Felce, Lowe, Beecham & Hallam 2000; Kozma et al. 2009; Myrbakk & von Tetzchner 2008).

Commonly cited barriers to community participation include community perceptions and attitudes, community infrastructure, access to information, policy and funding, and siloed and complex service systems (Kozma, Mansell & Beadle-Brown, 2009; Milner & Kelly, 2009). Further, community participation for people with intellectual disability, on the autism spectrum and/or psychosocial disability is often challenged by personal factors such as health, mobility, communication, poverty, support from family/carers or friends, confidence, life experience, and interests (NDS, 2018).

A report by the NDIA Independent Advisory Council (IAC) into NDIS participant social and community participation reported that factors of influence, for greater community participation include information of the pathways to positive outcomes in community participation; the role of family and peer networks; engagement with mainstream and community services; and disability providers (IAC, 2019). This report concluded that while the NDIS has a clear responsibility to support participants to achieve social and community participation outcomes, there is a need for greater understanding on how to best achieve this. It is necessary to focus on helping NDIS participants to better connect with their community and mainstream services while continuing to provide them with the right supports to pursue their goals and aspirations (IAC, 2021). This research aims to better understand NDIS participant experiences with social and community participation and the pathway by which participants can achieve improved outcomes.

The research presented in this report is part of a larger research program that included an **evidence review.** The review identifies which interventions, supports or services improve community participation for people with intellectual disability, psychosocial disability, and/or on the autism spectrum. It draws on data from over 50 published articles and reports. The findings from this evidence reviews are available on the NDIS website.

2.1.1 What is community participation?

Within the literature there are many different definitions for community participation, these are often debated and sometimes unclear. Definitions within the literature can be extensive and multidimensional (include many factors), or narrow and unidimensional (include only one factor) (Randjelovic, Giummarra & O’Brien, 2021).

For this research we defined community participation and connection as the process of engaging in self-identified activities within the community context that are meaningful and influence the community context and the individual (Bathje, 2016). There are three key components of community participant (WHO 2021).

1. Activities of interest (what);
2. Place (where people meet); and
3. Social interactions (with whom)

Community participation also includes subjective experiential elements. These may include personal experiences (Hall, 2013) and relationships (O’Brien & Lyle, 1987), and convivial encounters (Bigby & Weisel, 2011). Convivial encounters connect people and bring them together briefly over a topic or matter of common interest and are friendly and warm (Fincher & Iveson, 2008). Convivial encounters can be fleeting (e.g. an exchange in a supermarket queue), intermittent (e.g. exchanges in a regularly visited café), or episodic (e.g. regular exchanges in an exercise class) (Bigby et al 2017). People with disability often have less of these encounters compared to people without disability.

Figure 1 outlines the three key components of community participation adapted from Bigby et al 2017. Within the component ‘Place’ we use the term ‘mainstream’ to describe non-segrated settings that should be accessible to all people within the broader community.

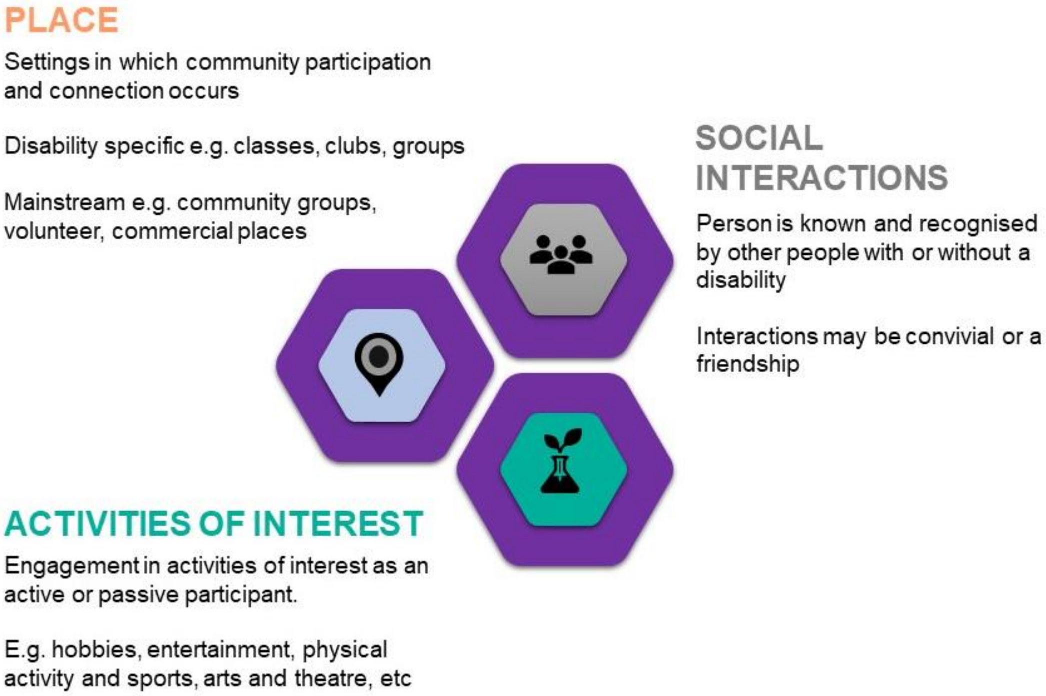


FIGURE 1: COMPONENTS OF COMMUNITY PARTICIPATION

2.1.2 What we know from the NDIS data

Social, community and civic participation is one of eight domains of the NDIS Outcomes Framework (NDIS 2020). The framework collects participant data over time to assess how well the NDIS is assisting participants to achieve their goals. The social, community and civic participation domain asks about hobbies, volunteering, involvement in community groups, feelings of safety, voting, leisure activities, and whether the participant feels they are able to have a say.

For active NDIS participants with an approved plan at June 2021 only 31% of NDIS participants aged 15 to 24 years and 33% of participants aged 25 years and older reported being “actively involved in a community, cultural or religious group in the last 12 months”, when they entered the Scheme (at baseline). And approximately third (32% of those aged 15 to 24 years and 32% aged 25 years and older) said they “did not have any friends apart from family or paid staff”.

A recent NDIA report summarised the outcomes for participants who have been in the Scheme for one year or more at 30 June 2020 (NDIA 2020). The analysis highlights a number of indicators where significant improvements were observed, for participants who have been in the Scheme for three years. Such as, the percentage of parents of little children who feel their child is welcomed and actively included when they participate in community activities (increased from 64% at baseline to 75% at third review), the percentage of 15 to 24 years who were eligible to vote who actually voted (from 71% to 84%) and the percentage of participants aged 25 years and older who have someone to call outside the home for practical and emotional support (from 82% to 89%).

However, while there has been progress, approximately two thirds of participants still stated they "wanted to do certain things in the last 12 months but could not" and 32% of participants aged 15 to 24 years and 30% of those aged 25 and older said they had had negative experiences in their community in the past 12 months.

The report also highlights areas of concern. After being NDIS participants for more than 3 years only 27% of those aged 15 to 24 years and 45% of those aged 25 years and older "feel able to advocate for themselves" and less than half (43% of those 15 to 24 years and 46% of 25 years and older) "feel safe getting out and about in their community".

Participants with intellectual disability, on the autism spectrum and with psychosocial disability make up approximately two-thirds of all NDIS participants (NDIA, 2020). It is therefore important to understand the unique barriers and enablers to community participation for these cohorts to inform solutions to achieve improved participant outcomes.

2.2 The NDIA is part of the community participation ecosystem

The NDIA is one part of the ecosystem that supports community participation for people with intellectual disability, on the autism spectrum, and/or with psychosocial disability (FIGURE 2). This ecosystem includes the Australia's Disability Strategy.

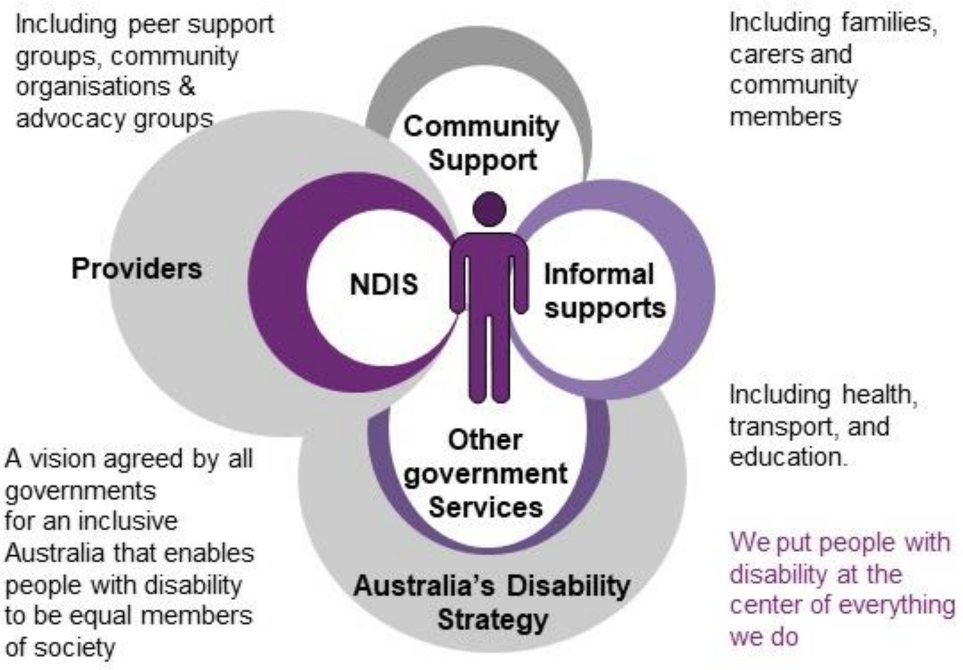


FIGURE 2: COMMUNITY PARTICIPATION ECOSYSTEM

2.2.1 What is the role of NDIS funded supports?

People with disability engage both directly and indirectly with a range of informal and formal supports and resources over their lifetime, to assist them with their everyday needs and their social and economic participation.

The NDIS funds a range of supports to increase community participation and experiences of community connectedness for NDIS participants for the three disability cohorts. It funds supports in an individual NDIS participant's plan as well as Information, Linkages and Capacity Building (ILC) supports.

Individual funded supports include:

1. Supports to enable engagement in social or recreational activities
2. Support for self-efficacy, personal and individual life skills development and training such as public transport training or developing skills for community, social skills and recreational participation
3. Assistive technology to enable engagement in social or recreational activities (such as equipment items for mobility, personal care, communication and recreational inclusion e.g. wheelchairs or vehicle modifications)

ILC supports aim to strengthen mainstream service and community capacity to be inclusive of people with disability and foster continual improvement and innovation in disability support delivery. There are five streams of service under ILC which provide support to people with disability, their families and carers, and community and mainstream services. The streams are:

1. Information, Linkages and Referrals
2. Capacity building for mainstream services
3. Community awareness and capacity building
4. Individual capacity building
5. Local area co-ordination (LAC)

2.3 The research

This participant-focused research project sought to:

- understand and explore participants' experiences and the pathways to community participation and connection;
- explore the barriers and enablers to community participation, specific to these NDIS participants; and
- identify the information and supports required by participants (families, carers or supporters) to help them develop community participation goals and get ready for work.

Findings from this research will be used to inform the NDIS and the broader disability sector on how we can better support participants to develop and implement their community participation goals.

The focus of this research was to primarily take a participant lens. However due to the interdependent nature of the system the research also looked to understand the barriers and enablers to community participation within the broader disability ecosystem. This research can also help to inform the National Disability Strategy and bring greater consistency to the experiences of participants in navigating disability supports and services.

3. Research methods

This research combined:

- consultation with NDIS participants and external research academics to inform the focus of the research
- in-depth interviews with 85 NDIS participants (families, carers or supporters) aged 14 to 44 years (representing 86 NDIS participants)
- online interviews and focus groups with 37 NDIS service delivery staff and an online survey (n=42)
- interview data from NDIS research participants were linked to data held by the NDIA

Details on the methods of each component of this research are described in detail below.

3.1 Funding and ethics

This research project was funded by the NDIA and approved by Monash Health Human Ethics Committee (RES-20-0000-276A).

3.2 Qualitative research design

The design of this participant-focused research was supported by three NDIS participant consultants who had lived experience, representing all three of the disability cohorts. They contributed to the focus (research questions), design (methods used and the delivery of the research) and the data collection tools. They also provided input into the data analysis by checking the validity of the findings and readability of the report. The participant consultants were recruited through the NDIS Participant Engagement Group. Further input was sought from an external expert panel (researchers, industry partners and NDIA subject matter experts) in social and community participation and inclusion for people with disability and lived experiences, who advised on the research design, gaps in the knowledge base and practical considerations of undertaking this research across these cohorts.

3.2.1 NDIS participant interviews

NDIS participants across Australia were invited to be part of the research if they identified as having intellectual disability, Down syndrome, autism spectrum and/or psychosocial disability. Consistent with the ages parameters used in recent NDIA research into the barriers and enablers to employment, participants were aged between 14 and 44 years old. This represents approximately 40 of the participants in these cohorts, which are the focus of this research. Parents, carers and other supporters of NDIS participants for the same disability cohorts were also invited along with parents and guardians of young NDIS participants seven years and over.

Purposive sampling (Campbell, Greenwood et al 2020) was used to match participants to the objectives of this research. Participants (and their supporters) were purposively sampled for disability type, age, gender, state/territory, level of disability impairment and employment status. We aimed to undertake 80-100 interviews with the final sample dependent on reaching data saturation (no new themes identified in the data).

Participants were mainly recruited through the Participant First Engagement Initiative at the NDIA (people who have previously signed-up to receive information about paid and unpaid feedback opportunities with the NDIA), the NDIS website, peak bodies, social media and disability providers and advocacy groups.

Due to the COVID-19 physical distancing measures, semi-structured interviews were conducted via Microsoft teams, telephone or email depending on the person's choice. Interviews lasted approximately one hour and were audio recorded and transcribed by a transcriber who had signed a confidentiality agreement. Those who chose to complete email interviews were sent the questions in a word document. Interviews took place between July 2020 and December 2020.

Research participants provided informed consent; including written consent of one parent for NDIS participants aged 14 and 17 years. Plain English and Easy Read information explained the research and gave participants the time to think about participating. Participants were encouraged to speak to someone they trusted about the research before consenting to the interview. Continuous assessment of consent and potential for distress was undertaken throughout the interview by the researcher. Participants were advised they could stop the interview at any time.

Carers, family members and other supporters who participated in the research were encouraged to seek permission from the participant to share their experiences with the research team.

Research participants were paid for their time in-line with the NDIA Participant Engagement Payment Policy.

3.2.2 NDIS staff interviews, focus groups and survey

NDIS service delivery staff (including planners, LACs, PiTC and other staff such as SMEs) from all states and territories were invited to participate in the research. They were recruited for interviews and focus groups via regional networks and through internal communication channels such as the NDIA intranet. Interviews and focus groups were conducted between June 2020 and August 2020.

An online survey, based on the themes from the interviews and focus groups, was conducted between 18th December 2020 and 19th January 2021. The survey was open to service delivery staff across all states and territories. Recruitment of staff for the online survey involved emails through internal networks and an Intranet and Huddle notice. The results from the survey were used to triangulate the qualitative findings from the focus groups and interviews and to provide greater context and perspective of the barriers being faced by participants.

3.3 Linking research to NDIA data

Consent was obtained from NDIS participants for linkage of interviews with NDIA administrative data (collected as part of participants' engagement with the NDIA). These data were used to provide a description of the sample characteristics and to enable analysis of key findings across sub groups. Most NDIS participants (87%) represented in this research gave consent for their interview data to be linked to NDIA participant administrative data. Appendix 2, Table 3, details the linked data from the research participants and compares to the data about NDIS participants in the disability cohorts.

3.4 Data analysis

3.4.1 Qualitative – interviews and focus groups

The interview and focus group data were anaylsed and coded using thematic analysis (Braun and Clarke 2014) by three of the researchers. The thematic coding involved a process of reading the interview and focus group transcripts and allocating text to different categories (codes). Emerging themes and recurring patterns of interest were also identified and coded (Braun and Clarke 2014). Iterative analysis was used where the data were examined, coded and compared until saturation was reached (i.e. no more new codes/themes were identified). This involved both inductive (from the data) and deductive coding (from pre-determined themes from the literature and internal and external consultation) (Fereday and Muir-Cochrane 2006). The resulting codes were collapsed into themes and explored in relation to the research objectives. The three NDIS participant consultants assisted to ensure consistency and interpretation of findings, checking them against their own lived experiences and understandings. Further, the preliminary findings, based on initial coding, were presented to internal NDIA stakeholders who provided expert feedback on the direction of the research. The computer assisted qualitative data analysis software, NVivo 20.3, was used to aid the coding.

Themes identified in the research are presented within each of the sections of the results with example quotes from the interviews and focus groups. Where applicable, these are supported with the findings from the survey with NDIS service delivery staff. Quotes have been edited for readability and all names and places have been changed to protect anonymity.

The qualitative themes presented in this report are ones that were common to the participants in this research and mentioned by more than a few participants. To support readers to know how common the different themes were the terms 'some participants', and 'many participants' have been used. 'Some participants' indicates that less than half of the participants mentioned this. 'Many participants' indicates that this theme or sub-theme was mentioned by more than 50% of the cohort.

'Research participants' include all of those who participated in the research. When we refer to 'NDIS participants' in the findings we include those who spoke to the participant experience such as NDIS participants, family, carers and supporters. ‘NDIS service delivery staff’ refers to data collected from NDIS planners or delegates, LACs, PiTCs and SMEs.

3.4.2 Quantitative – online survey of NDIS service delivery staff

Quantitative data were anaylsed using descriptive statistics. The survey results were compared with the staff interview and focus group data to validate the findings in a larger sample.

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.

4. Research findings

4.1 Research participant characteristics

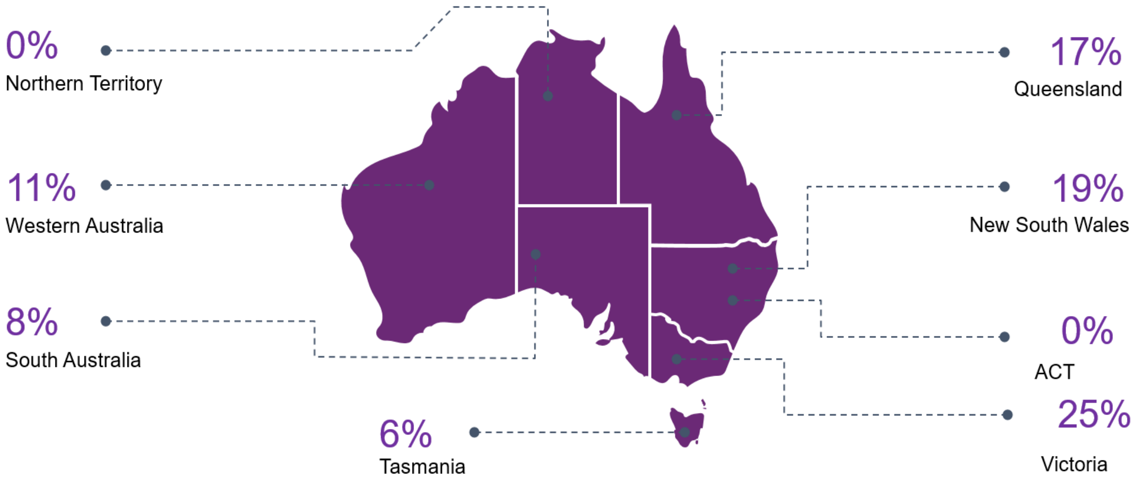
A total of 121 people participated in the interviews and focus groups (representing 85 NDIS participants, families and carers and 37 NDIS service delivery staff). A total of 142 service delivery staff completed the online survey.

Forty-six parents, carers and supporters were interviewed along with 39 NDIS participants. These interviews represented 86 NDIS participants aged between 7 and 44 years who had one of the following (participants were asked to choose their main disability if more than one applied):

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

Some of the family, carers and other supporters, who participated, spoke about multiple NDIS participants, therefore the number of interviews do not match the total number of NDIS participants (such as parents of more than one child with disability). In some cases both the NDIS participant and the person who supports them were interviewed resulting in two interviews about the same NDIS participant.

The sample of NDIS participants represented all states and territories of Australia except for the Northern Territory and Australian Capital Territory (Figure 3). Overview of the NDIS participants represented in the research is summarised in Table 1. A detailed summary of NDIS participants is described in Appendix 2, Table 3. Participant characteristics by group, and compared to the greater NDIS participant population, are summarised in Appendix 2, Table 3.



Infographic by Slidesgo.com

FIGURE 3: NDIS PARTICIPANTS' STATE OF RESIDENCE

TABLE 1: PARTICIPANT CHARACTERISTICS

Characteristics	Intellectual disability	Autism spectrum	Psychosocial disability	Total
NDIS participants represented*	35	30	21	86
Age in years				
7 – 13	1	9	0	10
14 – 17	1	2	2	5
18 – 24	12	10	1	23
25 – 34	11	6	2	19
35 – 44	9	3	15	27
State and territory				
Vic	9	5	11	25
NSW	7	10	2	19
Qld	6	6	4	16
Sa	4	2	1	7
WA	5	6	0	11
TAS	3	1	2	6
NT	0	0	0	0
Act	0	0	0	0
Gender				
Male	16	24	7	49
Female	17	5	12	36
Gender fluid	0	1	0	1
Geographical area				
Metro	22	15	10	49
Regional	9	8	7	24
Rural	2	3	1	6
Identity, culture and language				
ATSI	2	1	2	5
CALD	4	5	5	14
LGBTIQA+	1	4	4	9

ATSI Aboriginal or Torres Islander   CALD Culturally and linguistically diverse

LGBTIQA+ Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual and + to represent the many more identities and affirmed genders

*Some NDIS participants had more than one disability, so they were allocated into the cohort that they identified with the most.

Seventy-five NDIS participants (87% of represented NDIS participants in this research) gave their consent for linkage of interviews with NDIA administrative data (collected as part of participants' engagement with the NDIA). Table 3 in Appendix 2 presents the linked data from the research participants and compares to the data about NDIS participants in the disability cohorts. Key characteristics of the 75 participants whose NDIA data was accessed is also presented below.

Compared to the population of NDIS scheme participants with intellectual disability, Down syndrome, on the autism spectrum, and/or with psychosocial disability, the sample in this research were:

- higher educated (TAFE/Diploma/Other) (33% of the sample compared to 15% in the Scheme);
- more likely to have a paid job (27% compared to 12%); and
- less likely to be culturally and linguistically diverse (4% compared to 9%) or be Aboriginal and/or Torres Strait Islander (4% sample to 7%).

Table 2 summarises the NDIS service delivery staff who participated in this research. A detailed summary of the characteristics of service delivery staff who participated in the online survey is available in Appendix 3.

NDIS service delivery staff were well represented in the survey and the interviews and focus groups. Staff working in the Northern Territory (NT) and the Australian Capital Territory (ACT) were under-represented in the interviews and focus groups. The majority (71%) of survey respondents were women and 24% was a staff member with a disability.

TABLE 2: NDIS SERVICE DELIVERY STAFF

Research Participants	LACs	Planners or delegates	Other	Total
Focus groups or interviews	21	10	6	37
Completed online survey	71	62	9	142
State and territory (service delivery staff in focus groups and interviews)				
VIC	6	1	0	7
NSW	6	2	0	8
Qld	2	0	2	4
SA	3	0	0	3
WA	2	1	1	4
TAS	2	0	1	3
NT	0	0	0	0
ACT	0	0	0	0
NSW/ACT	0	5	0	5
VIC/TAS	0	1	1	2

4.2 Types of community participation

Participants described a range of different types of activities and encounters they engaged in within the community. These were mainly determined by their interests and what was available and accessible to them and could be categorised into four types:

1. Social interactions with friends and family and other known people
2. Social interactions with the broader community
3. Mainstream activities of interest
4. Virtual spaces
5. Disability specific activities and places

Social interactions with friends, family and other known people

Spending time with friends, peers and other people they knew (i.e. colleagues and neighbours) were described as opportunities to maintain connection and participate in shared activities. Activities described included eating out, going to the movies, ice skating or camping. Spending time with family or friends sometimes involved grocery shopping, family celebrations and participating in recreational activities.

Social interactions with the broader community

Participants described the importance of feeling confident in their ability to interact with people in the broader community. This included having friendly social interactions with people who were not always well known to the participant (convivial encounters), such as shop assistants, baristas, hairdressers and so forth, or saying hello to a stranger in the park or helping someone in need (like giving directions to a person in the street). Participants identified these encounters as community participation.

> *Different people say hello to her, she's not a big conversation person, but just for someone to say hello [is important] … It's understanding the local community, understanding strangers and building those connections within the community. (Caz, mother of Kara, intellectual disability cohort, aged 20 years)*

Mainstream activities of interest

A few participants engaged in mainstream (non-segregated) group activities including walking groups, car clubs, or sporting teams and classes including fitness classes such as Zumba and yoga, and other interests such as cooking classes. Participants described these activities as a way to meet other people with similar interests. By engaging in these groups, over time some participants had built relationships with group members. One off activities such as fun runs, charity walks, and concerts also captured the interest of some participants.

> *It's an open theatre group, but they have embraced Eden and she's just part of their theatre family … also extends to things like if there's some*

> *shows on or something like that, then she'll get invited as a member of that group. (Lorena, mother of Eden, intellectual disability cohort, aged 22 years)*

Virtual spaces

Participants spoke about interacting with other people and groups through virtual spaces such as social media or facilitated online groups. Many participants gained online skills during the COVID-19 pandemic. This lead to more online engagement, the opportunity to develop new connections and a broadening perspective of what community is. They explained that virtual spaces often led to new or larger social networks which sometimes moved to non-virtual, face to face, social interactions.

> *A number of [activities] that would have previously been face-to-face in Sydney or Melbourne, that I wouldn't have been able to attend, they've been online, so they've been advertised a bit wider in networks. So, I've been able to just join online. (Shannon, aged 38 years, NDIS participant)*

Disability specific activities and places

Many participants spoke about social interactions and activities with other people with disability. These included interactions with people with different disabilities and other times with people with the same disability. Some of these groups and activities were in the broader community, other times they were in segregated spaces such as in disability services.

The three key ways participants engaged in activities with other people with disability were through:

1. Self-advocacy, peer support networks. These were run for, and sometimes by, people with disability. They were often only open to people with disability and their supports rather than the broader community. They were commonly run by local government and not for profit entities and could include skill based activities or groups, short courses or facilitated sessions for peer support and advocacy.
2. Activities in groups with people with disability that take place in the wider community (in mainstream settings). These were run mostly by disability organisations and participants often paid a fee to participate. Activities included bowling or attending the movies as a group and were facilitated with support. There was often little interaction with people in the broader community.

3. Adult day programs (also known as day services or day centres). These were often delivered in community-based centres (non-residential segregated settings) and run by disability service provider organisations who can provide a variety of activities for their customers. They provided care and supervision to people with disability and are attended mostly during the day. Day programs were contested spaces for many participants including both positive and negative experiences. This is further explored in Section **Error! Reference source not found.**

4.3 Community participation increased connectedness

Community participation was described as impacting participants' lives in many ways. Participants told us that it:

- Gave them a sense of belonging and connection.
- Helped build deeper relationships with friends and family, create larger social networks and reduce isolation.
- Increased their confidence, self-efficacy, and safety.
- Increased their opportunities for employment or study.

Community participation gives participants a sense of belonging and connection

When asked what community participation meant to them, some participants reported it was the feeling of belonging to a community that stood out the most.

> *[Community participation means] belonging in the community, like taking part in what they do. (Leah, NDIS participant, intellectual disability cohort, aged 35 years)*

Participants described feeling part of the community when they experienced positive and friendly social encounters with other people (including people with or without disability) and were treated with dignity and respect.

Community participation can help participants build deeper relationships with friends and family, create larger social networks and reduce isolation

Engaging in community activities such as fun runs or attending local markets were seen as opportunities for shared experiences with friends and family, leading to deeper connections with people they already knew. Participants interacted with people in their local community by having a cup of tea together, catching up at the front gate, or seeing each other around the neighbourhood. This increased participants' social networks and reduced social isolation.

> *We've got fantastic neighbours either side of us, and we've got two elderly couples across the road, they're absolutely great with the boys. So, once a week the neighbours across the road put on a morning tea … we go over, and we sit out the front on their veranda, and she's got*

> *scones, or ANZAC bickies. (Robert, father of James and Timothy, autism spectrum and intellectual disability cohorts, both aged 17 years)*

Participants gain confidence, self-efficacy, and safety through community participation

Community participation activities were a way for some participants to have choice and control about whom they engaged with and when. Participants felt they could exercise their self-efficacy, go at their own pace, and choose places and spaces where they felt safe and therefore build their confidence and resilience in ways they could control. Social skills such as active listening, turn taking and sustained focus were practiced during these social interactions.

> *I'm thinking about [establishing a self-support group] which could [get me in] touch with the community. Having a way where I feel more in control. (Monique, NDIS participant, psychosocial disability, aged 43 years)*

Conversely, the inability to engage in community participation, due to low confidence or mental health, was noted as detrimental to participants. This included limiting opportunities to practice social skills which was identified as impacting individuals' mental health and self-esteem.

Living in a community where participants and their families know and were known by their neighbours, gave them a sense of safety. It meant that neighbours may notice if something was wrong and would reach out.

> *And from a community safety point of view, because there are so many familiar families in our local area, I know that if something were to happen, there's that community safety there where my child could go to a neighbour and feel quite comfortable asking for help. (Aphrodite, mother of Sofia, aged 10 years)*

Community participation increases employment and study opportunities

Participants explained community participation activities increased their confidence, motivation, and capability. It created pathways to study or employment activities. Community participation also decreased social isolation and can play a role in mental health recovery plans. In this sense, community participation was seen as a stepping stone to other education or employment goals. Engaging with people in the community helped one participant turn their passion of growing vegetables into a small business.

> *Yeah, he has a vegetable garden, he does like to grow vegetables. And he does that, and that helps him to engage with the community. He does have a whole backyard full of veggies, and he does give or trade*

veggies with his neighbour who has got an Asian food store close by. (Greta, mother of Josh, intellectual disability cohort, aged 43 years)

4.4 Barriers and enablers to community participation

The following section explores the barriers and enablers to community participation. Themes that were identified in the data are presented in three categories:

1. Common experiences across all ages
2. Young people and school leavers
3. Maintaining social connections

Each section includes key findings and quotes from participant interviews or staff focus groups. Online survey data is presented at the end of each section to support these data. Full survey results are in Appendix 3.

4.4.1 Common experiences across all ages

The following section explores the barriers and enablers to community participation. Many of the barriers and enablers were consistently raised regardless of participants' ages or background. Themes that evolved from the data are presented in six categories:

1. Foundations to community participation
2. The role of NDIS funding and service delivery staff
3. Matching the right support workers with participants
4. Personal and family networks facilitate greater community participation
5. Negative community attitudes and lack of inclusive mainstream options
6. Employment can lead to friendship and greater social networks

Foundations to community participation

Key points

Health and housing

- Stable housing, mental and physical health, food security and adequate sleep was required for energy and health to participate in community activities.

Assistive technology and accessible transport

- Accessible transport enabled greater participation in places that were otherwise not available to participants.
- Assistive technology supported some participants to access and participate in community activities and supports.

Decision support

- Support to identify options and make decisions about community participation enabled identification of wishes and preferences.

Self-confidence

- Lack of confidence was a barrier to social interaction. Allied health support and routine and frequent participation in familiar social situations supported confidence building.

Hierarchy of needs

The findings explored in this section can be understood through a hierarchy of needs (Maslow 1943) whereby certain needs, such as physical needs like food and adequate shelter, need to be met before subsequent human needs can be achieved. These sit at the bottom of the pyramid, forming the base upon which everything else rests. Having accessible transport and assistive technology supports participants to have more equal opportunity for community participation by enabling them to get to and from opportunities and to be comfortable and safe once there. Support for decision making from informal or formal supporters enable participants to identify and weigh-up their options. Self-confidence and self-esteem complete the foundations for equal community participation.

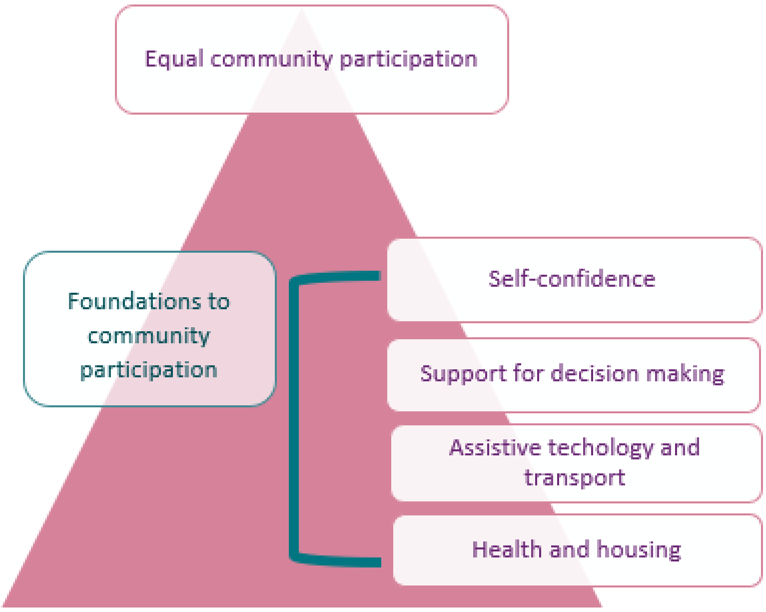


FIGURE 4: HIERARCHY OF NEEDS

Health and housing

Having foundational needs met (such as housing and health, food security and adequate sleep) was identified as essential before participants could engage in meaningful community participation. When these foundational needs were not met, it reduced the likelihood of participants engaging in actives due to energy and attention needed for attempting to meet these needs. Service delivery staff reported lack of foundational needs resulted in participants being disengaged in pursuing their community participation goals.

> *[Interviewer: Is he involved in any sort of community activities?] The Support Coordinator has just been really focused on our housing situation [instead of community activities] because it's really bad. Two of us use wheelchairs and there's not even room for one in our house. (Felicia, mother of Sid, autism spectrum cohort, aged 15 years)*

Transport and Assistive technology

Participants require accessible transport to make mainstream and disability specific places, groups and activities available to them. Lack of public transport in rural and regional areas was identified as a barrier to accessing activities in the community. For some, public transport did not feel like an option due to their mental health and therefore was a barrier to engaging in their activities of interest. For others, travel training to negotiate public transport systems or working towards obtaining a driver's license enabled transport to be more accessible.

> *Going to the beach is a bit of a logistical nightmare when you live in the country, you don't drive and you're not comfortable, necessarily, using lots of public transport … So having a support worker means I can actually start going. (Emma, NDIS participant, autism spectrum cohort, aged 42 years)*

Assistive technology was identified as enabling participation with the community in various ways. For some this included communication aids, noise-cancelling headphones, and capacity building communication applications. Assistive technology also enabled participants to access online communities and virtual spaces. During the COVID-19 pandemic participants increased their capability to engage with other people online, opening up new possibilities for building social networks and community engagement. These findings align with a recent report on participant experiences during the COVID-19 Pandemic.

Service delivery staff outlined how participants benefited from accessing supports that facilitated the use of technology and enabled their community participation. During COVID-19 restrictions, accessing online communities and activities was identified as one of the most important enablers to greater community participation (Appendix 3), particularly for participants with Autism (62% of survey respondents).

> *I use apps to write social stories he can sort of take around with him and you can record it so then he can listen to it, because he can't read. (Julie, mother of Robert, intellectual disability cohort, aged 23 years)*

Supporting participants to make decisions and choices

Making decisions about the type of community activities to undertake was described by some participants as *'overwhelming'*, especially during planning meetings. Participants spoke about the need for individual supports to assist with understanding their preferences, likes and dislikes. This was critical to helping participants develop and achieve their goals.

> *During the planning meeting, one of the challenges that the LACs faces supporting the participant with creating a goal, like when we talk about, "What would you like to achieve?" It's as simple as it sounds, it's the hardest thing to get through as well. (Lanka, Senior LAC, Victoria)*

Building self-confidence

Participants spoke of their lack of confidence and how it made them less inclined to interact with others which, in turn, exacerbated feelings of social isolation. Some participants avoided social interactions altogether, which further reduced self-confidence making attending community activities daunting and challenging. However, frequenting social situations routinely helped some to improve their confidence. Many pointed to the role of positive social experiences to increase confidence.

> *A lot of [participants] lose their confidence, particularly [those with] psychosocial [disability] , they don't have the confidence to actually join in mainstream activities without having someone there as a support or to actually get them, get the confidence up, mixing with them with the public or mixing with anyone in the community. (Francesca, NDIA Planner, Victoria and Tasmania)*

The role of NDIS funding and service delivery staff

Key points

- Participants often felt their disability or support needs were not always well understood by service delivery staff.
- Individualised and person-centred planning was seen as critical to support participants to build and implement their community participation goals.
- Setting small achievable goals can act like stepping stones for participants to work towards larger community participation goals such as developing friendships. These included foundational goals such as social skills and confidence building.

Some participants found that planning meetings did not meet their needs. They spoke of staff not fully understanding their disability, and the supports required, to participate in community activities, especially mainstream activities. Individualised and person-centred planning that involved getting to know the participant, their past experiences, and their likes and dislikes was mentioned as a solution to this by both participants and services delivery staff. Having consistent points of contact with service delivery staff meant participants could build a rapport with staff, staff could get to know the participant and the participant felt heard and able to express themselves more confidently. Service delivery staff ranked “not understanding the interests and capabilities of participants” as one of the greatest barriers to community participation, especially for participants with Autism (40% of survey respondents) (Appendix 3).

> *She gets Robert, she gets what he needs and because they’re an NDIA planner, I don’t seem to struggle getting what I need. So I’m one of the lucky ones in that respect. (Julie, mother of Robert, intellectual disability cohort, aged 23 years)*

Several participants described that setting themselves small achievable targets increased the likelihood of them achieving their goals. These included capacity building goals such as social skills and travel training. Service delivery staff agreed smaller targets can make goal attainment more achievable, which can include making and maintaining friendships

> *I think it's great that we have the opportunity to not just write the goals, but how will it be supported? What will success look like? Then we can really look at some of those strategies that can be considered and used as a bit of a guide for those capacity building funded supports. (Tony, LAC, Victoria)*

Matching the right support workers and support coordinators with the participant

Key points

- Meaningful community participation requires good support. Participants reported difficulties finding suitable support workers, and their capabilities did not always match the participants' expectations.
- Support workers matched to participants' age or interests were more likely to facilitate activities that both the participant and worker enjoyed.
- Mental health trained support workers were important for participants with psychosocial disability and other participants with mental health concerns.
- Support coordinators were also seen as playing an important role in supporting participants to understand community participation options, however participants described mixed experiences.

NDIS participants, families and carers were keen to employ support workers who met their own specific standards. For some, this included having supporters who were active in the support they provided and interacted with the participant, engaged them in the activities and facilitated interactions with other people.

> *You only want quality for your money and it means I'm hiring you to do something not just sit there. He's not a baby. He's a young man, yeah, do something. (Sammy, mother of Jasper, intellectual disability cohort, aged 22 years)*

However, many had difficulty finding support workers who met their support needs. Good support workers were often fully booked, leaving participants with mixed experiences. Some found online platforms for identifying available support workers useful. Others found these platforms lacked experienced support workers. While some felt online platforms provided an opportunity for participants to exercise greater choice and control over who supports them in different contexts and activities. However, these platforms were mostly useful for participants in urban or populated areas and were not equally available across the country.

> *[Online platform for hiring support workers] is really great and it works really well for us for Willam to have that choice. And he actually chooses the workers and if he doesn't like them he says "Mum I don't think so."*

> *(Angelina, mother of Willam, intellectual disability cohort, aged 29 years)*

Some participants, family, carers and other supporters spoke about wanting support workers who:

- have some prior disability experience (no disability experience was preferred by some);
- can learn easily;
- can support social skill building;
- were reliable and consistent; and
- had an understanding of human rights; and
- showed emotional intelligence through compassion and empathy.

Even when support workers met these criteria, participants and their family and carers still reported needing to coach and train support workers in the individual support needs of the participant.

> *And now that he has that confidence in himself that he can go he has a couple of young male support workers who are still finding their feet in a way. They're still studying Bernard because Bernard's very random with his behaviour sometimes, but we're sort of guiding them too. (Margaret, mother of Bernard, autism spectrum cohort, aged 21 years)*

Meaningful community encounters required good support which facilitated social interactions between participants and community members. Support strategies included supporting interactions behind the scenes, attending the same location on a regular basis, modeling good practice and facilitating social interactions between participants and people in the community rather than the supporter. Participants wanted support workers to be aware of what was going on around them and to instigate strategies to improve social encounters.

> *It is really, really a huge job to do, it's a huge job to be able to get out there. You're not just having a bit of lunch or going for a bowl or whatever. You're really looking and watching and seeing who he is connecting with. Who's just connected with me? I'm going to go back there again next week and connect again. (Jasmine, mother of Ty, intellectual disability cohort, aged 18 years)*

Support workers who were of a similar age as the participant was often noted as important, especially for the younger NDIS participants. By interacting with support workers their own age, participants felt more connected to mainstream activities and culture through gained knowledge which their parents and carers lacked including music preferences, popular culture and conversations around age-specific topics.

> *I particularly like having younger support workers to support Luke as they speak the same language and foster a mutually beneficial*

> *relationship. (Ian, father of Luke, autism spectrum cohort, aged 27 years)*

Likewise, support workers with similar interests to participants were more likely to engage in activities with participants. Sometimes this involved participants contacting professionals who were skilled in areas such as personal training or art and asking them if they were interested in providing support while sharing their skill or interest. Introducing flexible funding was seen by participants as a key enabler for this choice and control.

> *We like the flexibility of choosing the right support workers for the different thing. So for example, for the art we got an artist to be supporting him. (Angelina, mother of Willam, intellectual disability cohort, aged 29 years)*

Specialist support workers with expertise in mental health were important for participants with a psychosocial disability. This was due to some participants reporting a negative and/or traumatising experience with support workers who lacked mental health training or experience.

> *A disability support worker called him silly for having an anxiety attack. Whereas a mental health worker would not call him silly, they would walk him through the anxiety attack and give him strategies. (Danni, mother of Brandon, autism spectrum cohort, aged 53 years)*

Funded support coordinators played an important role in supporting some participants to navigate community participation options. Some participants had very positive experiences with support coordinators who got to know the participants and matched them with services or mainstream groups and activities that met their interests and support needs. Other participants struggled to find support coordinators who provided this kind of individualised support planning. Service delivery staff saw support coordinators as particularly crucial when participants had limited informal support networks but noted the different levels of quality coordination they provided.

> *If those informal supports aren't there, then certainly … support coordination [can] make the difference. You know, they take the time to really get to know the individual and then act almost like a substitute informal support. To have those sorts of providers available is fantastic. (Leanne, NDIA Planner, New South Wales & Australian Capital Territory)*

Having personal networks can facilitate greater community participation

Key points

- Personal networks provided pathways for participants by suggesting options, role-modelling and providing informal support.
- Informal supporters (i.e. family members) were often time and energy poor. Lack of support for the people around the participant may result in community participation opportunities being missed.

Drawing on personal and family contacts increased opportunities for participants to socially connect. This was by facilitating activities in the community such as organising grocery shopping, providing transport, inviting other people to social outings, scouting opportunities for community participation, and illustrating what can be possible. Family and carers spoke about creating space for participants to socially interact and experience independence while providing a safe environment or support if needed. Service delivery staff also ranked the use of “informal community supports” as one of the most important enablers to greater community participation in the online survey, particularly for participants with intellectual disability (64% of survey respondents).

> *So [you’re] always there but you're trying not to be. You're trying not to invade their space and give them this quality time together but at the same time, you're facilitating everything. (JB, mother of Nala, intellectual disability cohort, aged 21 years)*

However, it was noted that family members were often time and energy poor, which sometimes resulted in community participation opportunities being missed. Some families had more than one NDIS participant in the family which put strain on being able to meet everyone’s community participation needs and wants. NDIS service delivery staff were aware of the pressure on informal supporters and some spoke about including supports in plans that aimed to support the informal supporter as well as the participant.

> *We also make sure that the informal supports [are] getting the support they need and understand how important that is for the participant to progress if the carer is not coping, or the informal supports not coping, and it's all gonna fall apart. (Susie, Service Area Manager, Queensland)*

Negative community attitudes and lack of inclusive mainstream options

Key points

- Negative and risk-adverse attitudes about people with disability was a barrier to accessing mainstream activities. Some participants turned to disability-specific activities as safer options however these were hard to find due to limited available options and long waiting lists.
- Animals often helped to facilitate positive encounters in the community and provide comfort for participants with anxiety about community social interactions.
- Service delivery staff noted that the NDIA should play a greater role in challenging negative community attitudes, building community capability and linking participants to community opportunities through NDIA LACs and PiTC and their staff.

Negative attitudes towards people with disabilities was a key barrier for participants to engage in community groups and activities. Participants spoke about sometimes being ignored or made to feel invisible, spoken down to, told to leave, stared at, or feeling judged. Participants expressed feeling scared, unwelcome, or that the class or group was not adjusted to accommodate their needs. Assumptions about participants' understanding or communication capability also made some mainstream activities unwelcoming for participants as they were spoken down to or used language that was unnecessarily complex.

> *I said [to NDIS service delivery staff], "Well, I'm not refusing to do social activities", I said, "I don't do social activities because when I'm out in the community I don't get treated properly". (Lily, NDIS participant, autism spectrum cohort, aged 35 years)*

Weekday mainstream activities that included people in similar age-groups were scarce. Activities available on weekdays were often geared towards retirees (such as men's sheds, bowling leagues, or bush walking groups) or parents with young children (such as playgroups and library story sessions). While some participants chose to participate in these groups regardless of age differences, others preferred to engage with people closer to their own age. Activities such as fitness classes were not always accommodating to participants. Research participants spoke of club organisers being risk-adverse, anxious, or unwelcoming and often recommended participants only attend disability-specific activities.

> *For gymnastics, we asked for years and years to get him involved … [the gymnastics club] wanted to push us into an autism class, which wasn't at our local club, it was at a suburb further away, and we were not interested in that, we want him just to be here with his peers. (Harriet, mother of Alex, intellectual disability and autism spectrum cohorts, aged 11 years)*

Service delivery staff ranked "lack of options to meet participants' interests" as the greatest barrier to community participation (for participants with intellectual disability 54% survey respondents, on the autism spectrum 64%, with psychosocial disability

62%). Due to lack of inclusive options and negative attitudes, some participants felt coerced to pursue disability-specific activities or attend mainstream community activities within organised disability-only contexts. Disability-specific options were also seen as important for participants to build relationships and friendships with other people with disability and stay safe from negative attitudes within the wider community.

> *I think it's been a big struggle for Gia because mainstream is sometimes too hard but the groups that are designed for people who have any sort of disability, treat them like babies. (Tina, mother of Gia, intellectual disability cohort, aged 19 years)*

However, some participants found it difficult to find disability services that ran only activities in the broader community. Participants experienced long waiting lists when these were offered. Without the option for group activities, some participants engaged in one-on-one support in the community but this was described as isolating for some participants.

> *The providers of such services have shut down and will no longer run such group events. They have either gone for a 1:1 model (which is very isolating), or have opted out altogether. (Louise, mother of Morgan, intellectual disability cohort, aged 32 years)*

Despite the many barriers to mainstream communities, participants described many positive effects of community participation due to NDIS funding. This included increased control over the types of community activities that they could participate in including attending events with support.

> *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. (Emma, NDIS participant, autism spectrum cohort, aged 42 years)*

Animals such as dogs and horses supported some participants to have positive social interactions in the community, increasing their social network, confidence, and sense of belonging. Engaging with horses such as pony clubs boosted some participants’ confidence and was a shared activity with other people with similar interests. Some community members engaged with dogs being walked by a participant and subsequently talked to the participant. These interactions were often facilitated by a support worker or informal supporter. For participants with social anxiety having a dog accompany them provided comfort and somewhere to place their attention while they initially ventured into the community.

> *She really wanted to just take some dogs for walks around parks and increase her social and community participation. So I supported her to connect to a social support worker who had a dog. (Julie, LAC, South Australia).*

Service delivery staff highlighted that the NDIA had increased its marketing towards improving inclusivity in the community but felt there was more that could be done to change community attitudes towards people with disability. Taking a more active role in linking participants to community opportunities including through Information, Linkages, and Capacity support in their area. This was seen as an important role of NDIA Partners in the Community (PiTC) and their staff. Other service delivery staff saw the role of the NDIA as one of actively undertaking community development activities and some participants and families agreed.

> *I think the NDIA might need to do some more engagement activities that we can promote or jointly do with them. To make [the community] more inclusive. (Chris, LAC, Queensland)*
>
> *We would like NDIA to portray a stronger attitude, a stronger vision of people with a disability in the community to combat those attitudes. (John, supporter of four CALD NDIS participants, psychosocial cohort, aged between 32 and 44 years*

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.

4.4.2 Young people and school leavers

This section explores the pathways, barriers and enablers to community participation for young people and school leavers.

Two main themes were identified from the data:

1. Schools provide avenues to social networks but these can be easily lost post school
2. Young children need adjustments and community understanding

During school, participants have the opportunity to start building social networks and participate in community activities. However, school leavers are at risk of losing these connections and becoming isolated as they transition from school to a post school contexts. This period of transition was described as precarious by the participants in this research and therefore it is important to understand the specific barriers and enablers participants' encounter during these formative years.

Schools provide avenues to social networks but these can be easily lost post school

Key points

- Schools can provide opportunities for community participation.
- Collaborations between schools and allied health professionals may help support participants to develop social skills and parents and guardians can share information through school communication channels.
- School choice and location can impact on community connectedness and a person's ability to establish relationships outside of school.
- However, the transition from school can be a time when access to community participation may decrease without the right supports.

Schools provided opportunities to try activities and develop interests, such as enjoying curriculum-led activities like art and physical education, providing after school activities as well as linking students with people and places in the local community. Participants in specialised schools had the opportunity to participate in activities with support such as swimming and community outings. Participants being homeschooled linked in with home school communities and associations to engage in shared activities and build social networks.

Establishing support teams that included formal and informal supporters, the school, and allied health professionals, was seen as essential for students to build their social skills and experiences across different contexts. For parents of young people with similar disabilities, word of mouth (from other parents) was an important source of information about community participation activities and identifying opportunities for their school aged children. Social media groups helped facilitate these conversations and information seeking. Some schools created opportunities for parents and students to meet and spend social time together. Participants explained that this was more likely to happen in primary school and connections with other school families were harder to establish in the later years of high school. Some schools organised opportunities for parents and/or students, but it was up to families to make the most of these.

> *We've definitely taken advantage of community connection through the school … they have a very strong value system around involvement with other families, so we'll often have picnics at the park and things like that. So I try and engage in that way. (Aphrodite, mother of Sophia, autism spectrum cohort, aged 10 years)*

The physical distance between schools and home can create a barrier to participants establishing and building relationships with school peers and their families outside of school hours. Some parents chose to send their children to local mainstream schools to avoid this.

> *We live in a small coastal village, there is a special school in town which they were pushing very hard for us to send him to. But he would be on the bus at seven o'clock in the morning, he wouldn't be home until 4:30 in the afternoon. And there would not be a single person in our coastal village who would even know who he was if he was going to that school. But because he goes to his local public school up the road, everybody knows him. (Harriet, mother of Alex, intellectual disability cohort, aged 11 years)*

The transition from school (including from home school and specialised school) to post school represented heightened risk of social isolation due to networks and supports no longer being so readily available. Continuing social interactions and friendships in post school contexts was difficult for participants in mainstream, specialist schools. This was because social interactions were mostly moderated by the school which then stopped post school. For participants in mainstream schools, their peers moved on and many reported that maintaining those connections became difficult.

Young children need adjustments and community understanding

Key points

- Young children often required mainstream activities to be adjusted to meet their needs so they could access and participate.
- Community attitudes towards parents and children can be a barrier to community participation and may result in families trying to protect young people from negative social experiences by avoiding these spaces or seeking out disability-specific situations.

Young participants want to partake in a variety of mainstream activities including sports, clubs, and groups. However, many of these activities are not being adjusted to take account of sensory or communication differences.

> *[Community participation means] being able to participate in activities and groups that they want to, where their abilities or levels are able to*

> *be catered for and there’s understanding of them having different needs (Sara, mother of Alistair, autism spectrum cohort, aged 11 years)*

When adjustments, such as noise levels, chill-out rooms, and options for various levels of participation were made to accommodate participants’ needs, these barriers were eased and participants got to participate in the activities and events that they wanted. However these adjustments were often left to parents or carers to organise and this took a lot of planning and energy resulting in children participating in less opportunities. Despite meticulous planning, sometimes unforeseen barriers emerged on the day and needed to be navigated or they derailed the outing or activity.

> *But it takes a lot of planning and it takes more than just one parent to be present if we have two children. Accessing the community is sometimes not accessible to our children for varying reasons, adjustments can’t be made for noise level. (Robin, mother of Danny, autism spectrum cohort, aged 8 years)*

Negative community attitudes towards parents, carers and young participants was a disincentive for joining community activities or taking young participants to places like supermarkets or recreational areas. The stigma experienced by parents resulted in avoidance measures and meant that many young participants missed out on experiencing the community in the same way that their peers without disability did.

> *On a good day, the kids present like they could be like any normal kid until they get overwhelm[ed] and then they can become feral and people don’t understand the differences. So I guess it’s trying to avoid that. (Sara, mother of Sabina and Alistair, autism spectrum cohort, aged 8 and 11 years)*

Potentially due to the experiences of stigma and discrimination of parents and families, some families wanted to also protect their young children from negative social experiences. As well as avoiding community spaces, parents and carers sought disability specific groups including after school and school holiday programs where they felt that the risk of negative experiences was reduced. However, they spoke about potential consequences including continued segregation due to the wider community not being challenged on their attitudes as well as participants becoming more comfortable in disability-specific spaces. Service delivery staff spoke about an increase in parents requesting funding for disability-specific activities and programs for their family members. A few parents, however, spoke about innovative ways they orchestrated or modified community participation activities for their children that minimised risk. When activities were modified it lead to more positive experiences for the young person and the parent.

> *Because parents have become protective of their kids, and don't want them to be vulnerable to what was previously happening when they were trying to access Community and Social, [they] feel comfortable that their [child] can go to a [disability specific] weekend program or an*

> *after school program, and then they know they are not going to treat the child or the teenager any different. (Margot, NDIA Planner, Western Australia)*

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.

4.4.3 Maintaining social connections

Establishing social connections with other people in the community requires ongoing maintenance and support. Times of transition such as leaving school interrupted social relationships and networks as did personal circumstances including illness, trauma, and moving house or changing jobs. Participants spoke about two key influencing factors to maintaining social connections:

1. Time spent together: Regularity and consistency
2. Personal circumstances and foundational needs influence continued relationships

Time spent together: Regularity and consistency

Key points

- Employment and hobby groups were ways that participants maintained connections with other people through regularly seeing the same people.
- Having options for different ways to participate in social activities supported participants to maintain social connections with other people.

Engaging in employment or regularly participating with the same people can build social interactions over time. For some participants this included working the same shifts, or attending the same hobby group or class. Establishing routines was a strategy that some participants used to help build stronger relationships and larger social networks. Regularly attending places and activities increased participants' exposure to the same people and was a way of transitioning to more social interactions in a planned way.

> *[Interviewer: And do you get to talk to people about their bikes?] Yeah. Like how long have you been cycling? When a cyclist goes past me they say hello, and when I see them I say hello. Or wave. (Abe, NDIS participant, intellectual disability cohort, aged 28 years)*

Modifying social interactions based upon a participant's preference (such as communication style, noise levels or choosing familiar places) helped to maintain connections. However, some participants did not always want to participate in social activities with other people, but if given the option, they chose to participate in another way or for a limited time. Supporters sometimes offered various options so the participant could choose their preference.

> *On a Thursday night at the club they like the players to come for dinner and just mingle. So, we make sure Bernard* has support to go to that on a Thursday. There're some nights he really doesn't want to go. So, we'll convince him, OK, well, don't go and have dinner then, but just go and have a soft drink and then come home. (Margaret, mother of Bernard, autism spectrum cohort, aged 21 years)*

Personal circumstances and foundational needs influence continued social relationships

Key points

- Personal circumstances including trauma, and mental and physical health can interrupt community participation, requiring supports to return. Extra supports during these times helped participants to maintain connections with their community.
- Maintaining and supporting foundational needs supported and enabled the continuation of community participation.

Participants explained that health, trauma, and ill mental health often caused interruptions to social connections and made reconnecting difficult. This sometimes resulted in participants needing to rebuild the social skills and confidence they had lost due to the circumstance and the time away from social interactions and community participation. Some circumstances resulted in changes to participants' foundational needs, including economic stability, health care, and housing. When this occurred, some participants experienced an increase in social isolation and required extra supports at this time to rebuild their community participation. Participants spoke about the benefits of having flexibility in the levels of supports they used. This meant they could increase supports, when required, to support them to rebuild confidence and re-connect with the community.

> *I really want to also get friendships and relationships, [its] something I'm really finding really hard right now, but I want to get into that because I came out of a relationship in 2018, which I've now lost my confidence in myself. (Isabel, NDIS participant, intellectual disability cohort, aged 30 years)*

4.5 Day programs: what is their current role?

Nine participants spoke about their experiences with day programs during this research. For many, day programs were described as ambiguous spaces, which may result in both positive and negative experiences). Some participants spoke about the importance of day programs including capability building activities (for example cooking), however they also noted that day programs often lacked opportunities for meaningful community participation with people outside of the program. Participants spoke about a lack of variety and options for community participation and reluctance of programs to offer more individual options. Other participants had positive experiences at day programs and valued the friendships and relationships with both peers with disability and staff.

"Day services can be so rigid": Day programs were contested spaces for many participants

Key points

- Day programs can be "rigid" in their approach to support and the lack of individualisation of programs meant participants often missed out on making connections with peers with the same interests.
- Some participants saw day programs as opportunities to make friends and do activities of interest.
- Service delivery staff noted that day programs provided respite for families and carers.
- If done well they can provide opportunities for people with disability to undertake activities in mainstream settings, in a well-supported environment, and facilitate social interactions with other people in the community.

For some participants, there was a mismatch between their level of impairment and that of their peers in the day program. This led to some participants acting more as a helper to the staff than a program participant engaged in social activities that meets their interest and preferences. The following participant enjoyed the opportunity to contribute in this way but expressed frustration about the lack of opportunity to build social connections with her peers.

> *Most of the participants, you couldn't actually understand what they're actually trying to say because they weren't exactly verbal, they couldn't actually speak, like as what we can. And I found that a little bit stressful for myself to actually try and deal with … [I liked] helping the staff out as well, if they were a little bit behind on what was needing to be done. And also, try and help them with participants and things like that, as well. (Fontaine, NDIS participant, intellectual disability cohort, aged 30 years)*

Flexible and individualised options at day programs were desired by participants (and their families and carers) who were attending or interested in attending a day program but participants found that many services were inflexible or did not have the resources or inclination to offer more individualised options to support community participation.

> *I think services can be so rigid and inflexible at times that it's not necessarily the best way to go about creating something that's very individual because so many services want to fit you in to a box. (Julie, mother of Robert, intellectual disability cohort, aged 23 years)*

Some service delivery staff saw day programs as offering respite to families and carers, and the closure of some of these programs due to the COVID-19 pandemic emphasised their value for families in need. Some parents saw day programs as opportunities to build independence and they looked for services that offered this. Forward thinking day programs that used current best-practice approaches to disability support, such as mental health recovery-models that focus on moving forward, strengths and individualised planning, were preferred by some family members. Whereas participants spoke about day programs as opportunities to make friends and do activities that they were interested in.

> *[My social worker] told me there was a place that I could go to and meet new people and do different activities and things like that … apparently they're all full up and she said to me that I could go on the waiting list to join there and I said, "yeah I would". (Sarbear, NDIS participant, psychosocial disability cohort, aged 40 years)*

4.6 Key findings from NDIS service delivery staff survey

NDIS service delivery staff were asked about what they perceived to be the greatest barriers and enablers to community participation for people with intellectual disability, on the autism spectrum, and/or with psychosocial disability.

Lack of options to meet participant's interests is the greatest barrier to community participation

NDIS service delivery staff (n=129) ranked the barriers (out of a list of 9 barriers) and enablers (out of 8 enablers) to community participation that they believed would be most impactful after COVID-19 restrictions had lifted for each participant cohort.

Figure 5 graphs the top three ranked barriers to community participation (refer to Appendix 3 for full details of the results). Service delivery staff ranked 'lack of options to meet participants' interests' as the greatest barrier for all three participant cohorts.

Service delivery staff were also asked to rank the barriers they encountered when assisting participants to work towards their community participation goals. Service delivery staff ranked 'day programs being more available than other community participation activities' as the greatest barrier for participants with intellectual disability (40% of survey respondents). For participants on the autism spectrum 'understanding the interests and capabilities of participants' was ranked the highest (40% of survey respondents) and for participants with psychosocial disability it was 'participants disengaged in pursuing community participation goals' (52% of respondents).

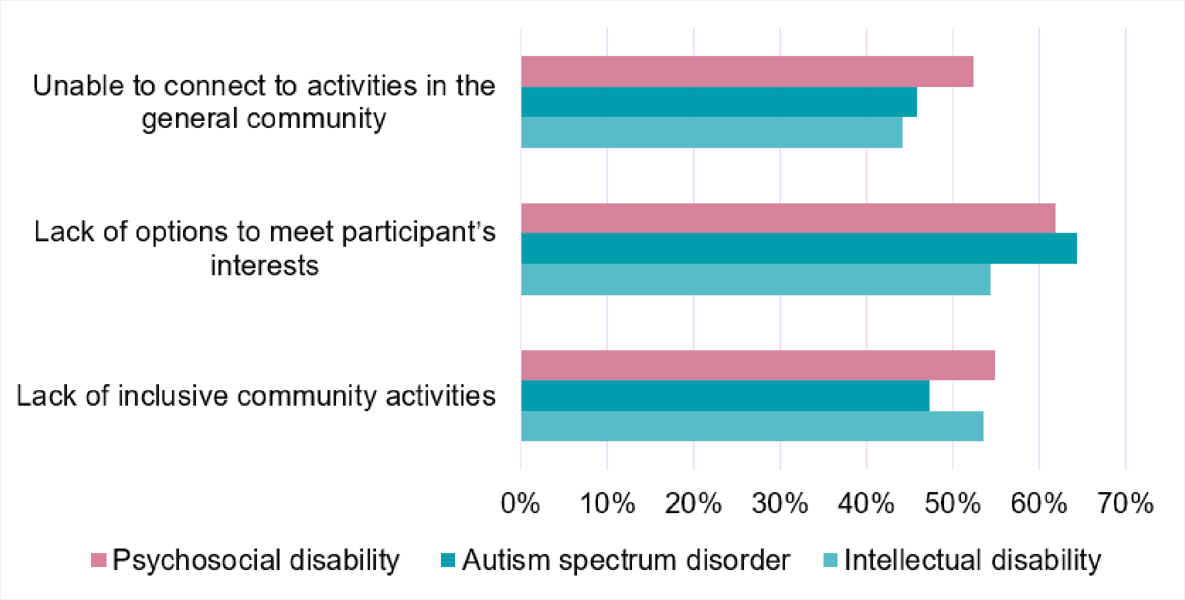


FIGURE 5: NDIS SERVICE DELIVERY STAFF, TOP RANKED BARRIERS FOR GETTING PARTICIPANTS INTO THE COMMUNITY (N=129)

Figure 6 graphs of the top three ranked enablers to community participation (refer to Appendix 3 for full details of the results). 'Utilising informal community supports such as clubs, friendship groups' was rated as the greatest enabler (out of 8) to improving community participation outcomes for participants with intellectual disability (64% of survey respondents), 'using technology to access online communities and activities' for participants on the autism spectrum (62%) and 'recovery coaches' for participants with psychosocial disability (58%).

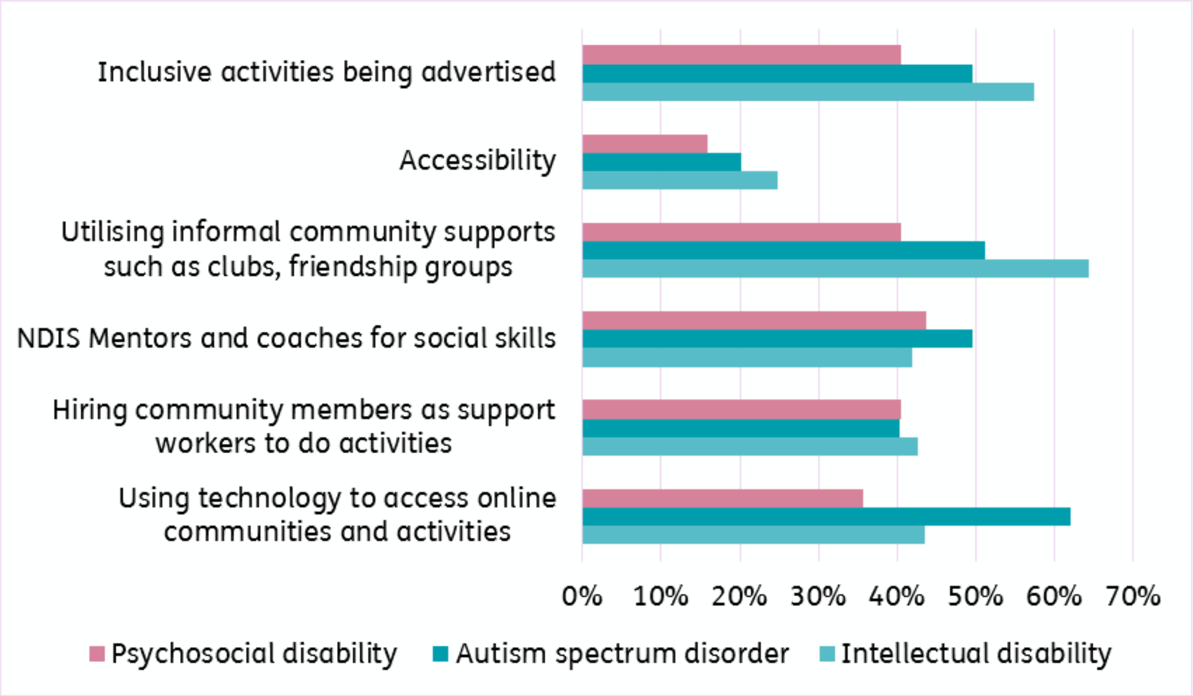


FIGURE 6: NDIS SERVICE DELIVERY STAFF, TOP RANKED ENABLERS FOR GETTING PARTICIPANTS INTO THE COMMUNITY (N=129)

Colleagues and guidelines most helpful information for service delivery staff

NDIS service delivery staff were asked to rank how helpful different information sources were for them to support NDIS participants with developing and implementing community participation related goals (out of 7 potential information sources).

When supporting participants to develop goals and understand community participation pathways, service delivery staff found talking to colleagues (82% and 76% respectively) and the NDIS intranet (71% and 63%) most helpful.

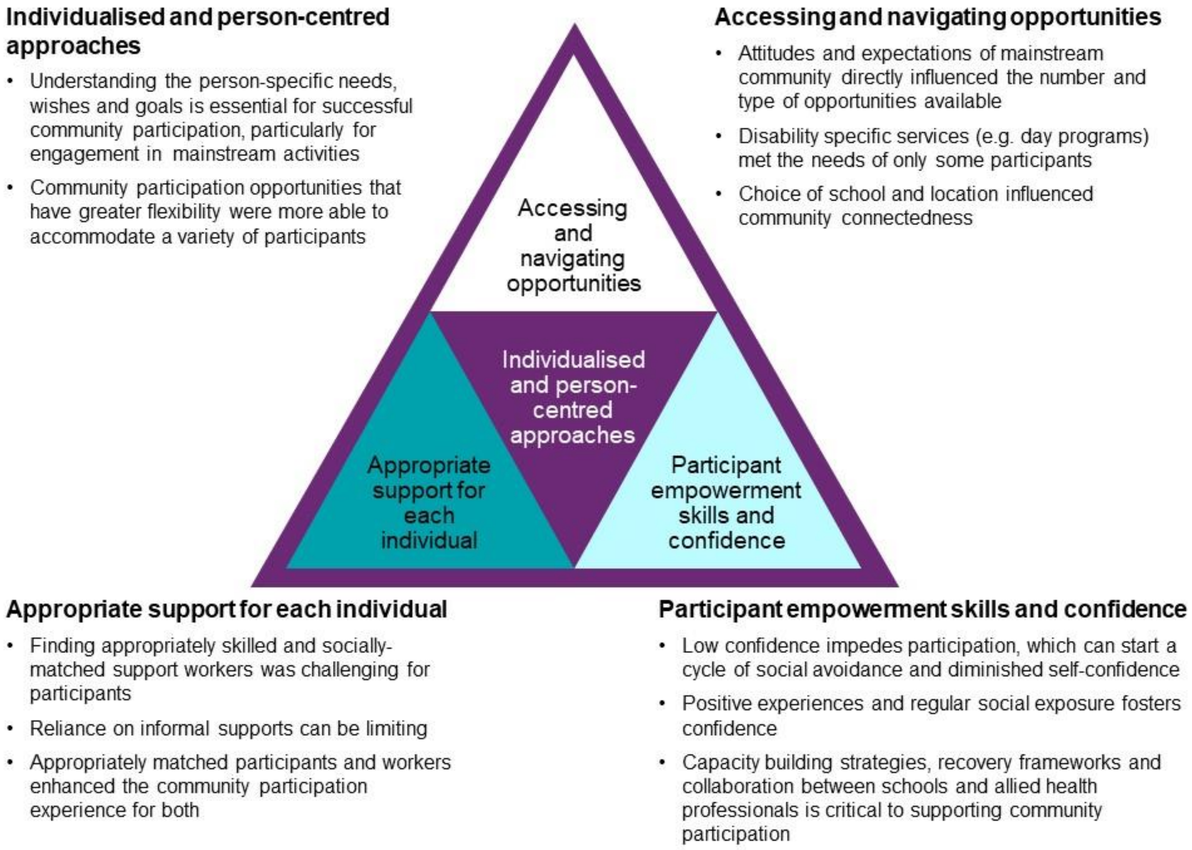
To help understand what the NDIS will fund to help participants work towards their community participation goals, the NDIS intranet was seen as the most helpful information source (88%). Planner, LAC or Partners in the Community (53% of survey respondents) and support co-coordinators (54%) were seen as the most used resources by participants.

5. Key insights and considerations

The enablers for successful and meaningful community participation for NDIS participants with intellectual disability, on the autism spectrum, and/or with psychosocial disability identified from the data, have been collapsed into four key factors.

1. Individualised and person-centred approaches
2. Appropriate support for each individual
3. Accessing and navigating opportunities for community participation
4. Participant empowerment, skills and confidence

The barriers and enablers relating to these key factors have been summarised and visually represented in Figure 7. They are detailed in Sections 6.1- 6.4 along with key considerations. As some of the identified considerations sit outside the role of the NDIS, there is an important role in disseminating this research to inform providers, the market and other government agencies to inform policy and practice.



Individualised and person-centred approaches

- Understanding the person-specific needs, wishes and goals is essential for successful community participation, particularly for engagement in mainstream activities
- Community participation opportunities that have greater flexibility were more able to accommodate a variety of participants

Accessing and navigating opportunities

- Attitudes and expectations of mainstream community directly influenced the number and type of opportunities available
- Disability specific services (e.g. day programs) met the needs of only some participants
- Choice of school and location influenced community connectedness

Appropriate support for each individual

- Finding appropriately skilled and socially-matched support workers was challenging for participants
- Reliance on informal supports can be limiting
- Appropriately matched participants and workers enhanced the community participation experience for both

Participant empowerment skills and confidence

- Low confidence impedes participation, which can start a cycle of social avoidance and diminished self-confidence
- Positive experiences and regular social exposure fosters confidence
- Capacity building strategies, recovery frameworks and collaboration between schools and allied health professionals is critical to supporting community participation

FIGURE 7: SUMMARY OF THE FOUR KEY FACTORS INFLUENCING PARTICIPANT COMMUNITY PARTICIPATION

5.1 Key factor 1: Person-centred approaches

Service planning and supports play an integral role in supporting participants to increase their community participation and connectedness. These conversations need to be person-centred to ensure the person's plan is based on their needs and interests.

Barriers	Enablers
• Participants often felt their disability or support needs were not always well understood by staff, supporters and the community to enable them to participate, especially in mainstream spaces. • Personal circumstances including trauma, mental and physical health can interrupt community participation requiring supports to return. • Not having sufficient foundations (such as stable housing, mental and physical health, food security and adequate sleep) meant participants were unable to find the energy and time to participate in community activities. • Participants were confused about what supports and services they could access through the community and what additional funding was available through the NDIS.	• Person-centred approaches were seen as playing a critical role supporting participants to build and implement their community participation goals. • Small achievable goals were identified as stepping stones to support participants to work towards larger goals such as developing friendships. • Being supported to identify options, make decisions, articulate their wishes and preferences can provide NDIS participants with more choice and control. • Assistive technology and accessible transport enabled greater participation in places that were otherwise not available to participants. • Capacity building supports to build social skills and increase confidence are required to help participants engage with the wider community.

Improving conversations and building staff and provider capability in person-centred approaches will facilitate individualised pathways for participants towards greater community participation. The following considerations are put forward for the broader disability ecosystem and the NDIA.

5.1.1 Considerations for person-centred approaches

- There is a need to build the capability of people who work with people with intellectual disability, on the autism spectrum and/or psychosocial disability on person-centred approaches, such as getting to know the participants and their life stage, interests and prior community participation experiences. This will help staff to identify supports that will enable community participation including foundational supports such as stable housing and confidence building.
- Base-level needs such as physiological (e.g. food, health and shelter) and confidence are foundational for community participation. Making sure that these are in place through the wider support ecosystem lays the foundation for meaningful community participation. Interagency collaboration with commonwealth, states and territories is required to ensure the basic needs of people with disability are adequately being met.

- Some participants need individual supports to assist with understanding their preferences, likes and dislikes. This was critical to helping participants develop and achieve their community participation goals. The Agency is currently working on a framework focused on Support for Decision Making to better support participants overcome these barriers.
- For some participants specialised supports, such as mental health support workers, may be required in some situations.
- Supports to increase confidence may help participants feel better about engaging with the wider community. Individual options may include allied health supports such as occupational therapists, using assistive technology or measures such as walking with a dog in the community, and supports to enable frequent participation in familiar social situations. Linking these with schools or other settings can ensure consistent support across locations and contexts.
- Large NDIS goals can be broken into smaller targets or activities to support participants' community exposure and positive experiences over time. Access to resources on the pathways to community participation common stepping stones will support them to work with participants to develop smaller goals that lead to larger goals. The NDIA should continue to invest in development and implementation of a person-centred goal attainment framework.
- Participants' personal networks play a vital role in facilitating community participation. Drawing on the people known to the participant for inspiration and role-modelling can also be powerful ways to support planning conversations. These networks should be harnessed as potential community pathways. However this role can require substantial planning, time and personal resources. Making sure the needs of the parent or carer/s are factored into planning conversations, such as rest and support, will help to facilitate greater community participation for participants. Staff need clear guidance on what funding supports may be available for families and carers to enable their facilitation.
- Flexibility in plans can increase participants' choice and control over the activities and places they participate in along with who supports them to do so and when. This can enable supports to be identified according to current circumstances including episodic mental health and/or allow participants to take advantage of non-planned opportunities.

5.2 Key factor 2: Appropriate support for each individual

The quality of supports and services impacts on participants' sense of belonging and overall community participation.

Barriers	Enablers
• Some participants reported encountering difficulties finding suitable support workers and that support workers' capabilities did not always match their expectations. • Informal supporters were often time and energy poor. Lack of support for informal supporters can result in community participation opportunities being missed. • Supports that were not flexible or tailored to the individual needs of the participant often resulted in less positive experiences.	• Support workers matched to participants' life-stage, age or interests were more likely to facilitate activities that both the participant and worker enjoyed. • Having support workers who were mental health trained and experienced was important to participants who experienced anxiety in social or community settings. • Some participants require support to identify options and make decisions about community participation and to articulate their wishes and preferences. • Support coordinators can play an important role in supporting participants to understand the available options but participants' had mixed experiences. • Assistive technology made community participation more accessible (e.g. noise cancelling headphones) and less confusing (e.g. virtual social stories) as well as opening up virtual opportunities to connect.

Having appropriate and personalised supports is a key enabler to community participation. The following considerations are put forward for the broader disability ecosystem and the NDIA.

5.2.1 Considerations for enabling appropriate support for each individual

- Upskilling providers and the support workforce may be required to ensure they have the right capabilities to meet participants' needs. Providers, service systems, education and other agencies need to work collaboratively to provide opportunities for upskilling, training or mentoring.
- Specialised support workers may be required for some situations in the community and this should be considered in planning conversations.

- Where possible, participants should be able to be involved in choosing and up-skilling support workers to meet their support needs and wants. Participants may need to be supported to participate in these decisions.
- Having conversations with participants to see what their interests are and any preferences they have for the people who support them (e.g. age or similar interests) are important and need to be encouraged.
- The role of support coordinators, and the barriers and enablers they face to supporting participants with community participation should be explored including through research, policy or guidelines.
- Greater governance of support coordination may be required to ensure minimum standards are met and the quality of the participant experiences are less varied. The Agency is developing online guidance to help facilitate best practice support coordination.
- Informal supporters play a critical role in supporting participants to connect and engage in the community. Participants suggested that having funding in plans to support the informal supporter as well as the participant may be needed in some circumstances.
- There needs to be clear, consistent and accessible information on funding and supports for family and carers on what participation opportunities are available through mainstream services and what additional funding is available from the NDIS.
- Planners, formal and informal supports need to ensure they explore options for assistive technology with participants to support them to further enable community participation, where appropriate.

5.3 Key factor 3: Having access to and navigating opportunities for community participation

Barriers	Enablers
• Lack of inclusive and appropriate community based activities to meet participants' interests was consistently noted as a major barrier by NDIS participants, their family, carers and supporters and NDIS service delivery staff. • Negative and risk-adverse attitudes about people with disability was a barrier to accessing mainstream activities. Some participants turned to disability-specific activities as safer options however these were hard to find due to limited available options and long waiting lists. • Community attitudes towards children with a disability can be a barrier to community participation and may result in families trying to protect young people from negative social experiences. • School choice and location can impact on community connectedness and a person's ability to establish relationships outside of school potentially leading to isolation. • Participants were often confused about what supports and services they could access through NDIS funding and what was available through other systems or services. • Social interactions were often restricted to peers and staff at day programs and for some participants, connecting with peers was difficult.	• Having options for different ways to participate in social activities supported participants to maintain social connections with other people. • Personal and family networks provide pathways to increased community participation through role-modelling options and play an integral role in supporting participants in the community. • Parents and guardians share information about community participation options through school communication channels. • Young children require mainstream activities to be adjusted to meet their needs. • Employment and hobby groups were ways that participants maintained connections with other people through regularly seeing the same people. Animals often helped to facilitate positive encounters in the community and provide comfort for participants with anxiety about community social interactions.

Community participation is a broad concept and means different things for different people. It also sits within a wide ecosystem of other social inclusion and government supports. Navigating this ecosystem can be confusing and time consuming. The following considerations are put forward for the broader disability ecosystem and the NDIA.

5.3.1 Considerations for enabling participants to access and navigate opportunities for community participation

- The disability confidence of the mainstream community needs to be raised to help change negative attitudes. This may encourage participants and their families to seek mainstream opportunities rather than only disability specific services in an attempt to avoid stigma. This will be addressed in the ILC Investment Strategy and wider Australian Disability Strategy.

- Community and local government settings provide opportunities for community participation. Activities should be available for a broad range of ages and not only parents or retirees, to cater for people who require activities during weekdays. Where required activities should be adjusted by organisers to meet the needs of the person with a disability.
- Participants and people with disability need better, and more accessible, information about what is available in their community, including what is available through the NDIS and what supports are available in the wider community. This may include routine connections to ILC funded supports facilitated by LACs or PiTC.
- Mainstream community activities and settings should offer alternative ways for people with disability to participate rather than redirecting participants to disability specific services.
- Formal education, including schools and post-secondary education, can play a role in connecting participants to opportunities within educational settings and in the wider community. Participants should be encouraged to use these networks that are available to them. Schools should try to foster networks that allow parents and guardians to connect and share ideas about inclusive community participation options.
- Service providers of day programs need to ensure best practice supports are used. This includes providing engaging capacity building opportunities and meaningful participation in the broader community. Where possible, day program providers should offer more activity options, including in mainstream settings, so that participants have greater opportunity to meet people they have similar interests with.
- Government agencies, providers and participants need to work collaboratively to challenge the negative community attitudes and build community capability and confidence to welcome and include people with disability into their groups, activities, and commercial spaces.

5.4 Key factor 4: Participant empowerment, skills and confidence

Participant empowerment can increase their confidence with making decisions about the type of community participation they would like to experience.

Barriers	Enablers
• Lack of confidence can hamper willingness to participate in the community and cause participants to enter a cycle of social avoidance and diminished self-confidence.	• Positive experiences as well as routine and frequent exposure to familiar social situations can help participants improve their confidence. • Capacity building activities and best-practice frameworks such as recovery models have supported the development of skills and confidence • Collaborations between schools and support workers may help support participants development of social skills.

Participants need clear, consistent and accessible information about:

- What is funded through the NDIS and what may be available through other systems or community based organisations
- How to access support to identify, explore and choose community participation options to help them exercise choice and control and have better experiences in the community.
- The pathways and foundations to meaningful community participation (such as having secure and appropriate food and shelter and self-confidence and social skills). Making sure that these are in place through the wider support ecosystem lays the foundation for meaningful community participation.

The following considerations are put forward for the broader disability ecosystem and the NDIA.

5.4.1 Considerations for building participants' skills and confidence

- Opportunities for regular and frequent attendance in the same places and spaces should be encouraged, as they can help to foster connections with other people including friendly social interactions. By visiting the same places regularly, participants interact with the same people and build familiarity and rapport. This can increase participants' sense of safety and reduce negative experiences, stigma and discrimination.
- The role of animals, particularly dogs, should be considered as they can increase positive social interactions in participants' neighborhoods.
- Schools should continue to, or improve collaboration with, both formal and informal supporters working with participants to support young people to develop social skills and

confidence to enable a young person’s transition towards greater independence or community living post-school.

- The opportunity for capacity building supports should be considered if participants need or want to build their social skills or confidence around community participation.
- Negative community attitudes toward people with disability can influence participants’ decisions to access non-mainstream and disability-specific options. Supporting models of community participation that have support and structure from disability support organisations alongside meaningful engagement with the broader community may help may help to build a person’s confidence and social networks whilst providing support and friendship. Collaboration between people with disability, the community, government and other agencies and organisations is also needed to build greater disability confidence within the community. This may be facilitated by Partners in the Community (PiTC) and their staff or through Information, Linkages and Capacity Building (ILC) supports.

6. Strengths and limitations of this research

This research involved over 100 interviews with a good representation of NDIS participants, their family, carers and other supporters as well as NDIS service delivery staff. This is a large data set for qualitative research amounting to hundreds of pages of text. The analysis of the data reached saturation meaning that no new themes were identified in what people told us. The interview and focus group data (from both service delivery staff and NDIS participants) was used to develop a survey that returned 142 survey responses , with good representation across key demographics and allowed us to compare the survey findings to the findings from the interviews and focus groups.

Importantly, three NDIS research consultants provided expert advice through their lived experience. This supported the development of interview questions that were appropriate to each disability cohort. The NDIS consultants checked the findings and supported researchers in gaining a deeper understanding of their implications.

While the research was undertaken in a rigorous way there are limitations to this research that should be taken into account when interpreting the findings. The recruitment of NDIS participants and their family, carers, and other supporters was mostly through a list of people who were interested in providing consultation and feedback to the NDIA. This may represent a sample bias that is weighted towards people who already had something that they wanted to say. However, it is important to note that this is a common research bias when people self-select to participate in research.

More male NDIS participants than women are represented in this research. However, this is representative of the NDIS gender breakdown.

The research was undertaken in the context of the COVID 19 pandemic. This resulted in data collection being conducted virtually or on the phone (or written). This may have excluded some people from participating.

Harder to reach populations such as CALD, Aboriginal and Torres Strait Islander people, and those with complex support needs involved in the justice system are under-represented in this research. Pathways, barriers, and enablers that are more likely to affect these populations may have been missed in this research. The lack of NDIS participants from the Northern Territory and the Australian Capital Territory is likely due to limitations of travel due to the COVID 19 pandemic. The lack of representation from these territories is a limitation of this research.

The research team received feedback that some NDIS participants had chosen not to participate due to concern that their NDIS plan would be negatively affected. While assurances were given to all participants that the research team did not have access to NDIS participant's plans and their planning staff would not know that they participated this was a barrier for some people.

LACs, Planners and other staff who participated in the interviews and focus groups were asked to nominate themselves potentially resulting in a sample who had previous experience, or an interest in, community participation. The survey, however, gives us a broader understanding of how prevalent the perceptions and experiences of the focus group and interviewees were.

7. What’s next?

This research recognises the unique insights and expertise that participants offer and the important contribution they make through research.

Findings from this research will inform resources for participants and NDIS service delivery staff to better support the development and implementation of community participation goals.

Through dissemination of these research findings, the NDIA can continue to work with the broader disability ecosystem to promote more effective community participation pathways for people with disability.

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9. Appendices

9.1 Appendix 1: Project overview

The research project

This research project aimed to explore the barriers and enablers to community participation and connectedness for NDIS participants with intellectual disability, on the autism spectrum, and/or with psychosocial disability.

This research included:

- In-depth interviews with 85 NDIS participants (families, carers or informal or formal supporters) aged 14 to 44 years;
- Focus groups and interviews were held with 37 NDIS service delivery staff (NDIS planners or delegates, Local Area Coordinators (LACs), Partners in the Community (PiTC) and Subject Matter Experts (SMEs); and
- Responses from 142 NDIS service delivery staff to an online survey.

Interviews and focus groups were conducted via video online, telephone, or email.

Key insights

Lack of inclusive options to meet participants' interests was identified as the greatest barrier to community participation for NDIS participants. Negative and risk-adverse attitudes from the community about people with disability made it difficult for participants to access mainstream activities (activities available to the general population in the community). Disability-specific activities were often seen as safer options but hard to access and did not always provide opportunities for meaningful community connection. Other barriers to community participation identified by participants included:

- Lack of individualised programs to make connections with peers with the same interests.
- Feeling like their disability and their support needs were not always well understood.
- Difficulties finding suitable and capable support workers that matched their needs, to support skill building and access to activities.
- Lack of clarity around what supports participants could access to assist them to achieve their social and community participation goals.
- Lack of self-confidence to participate in the community.
- Lack of available and accessible transport.

There were four key factors identified from the data that enable successful and meaningful community participation for NDIS participants.

1. Putting the person at the centre of planning, supports and delivery of services
2. Having appropriate and personalised supports
3. Having access to and navigating the opportunities
4. Building participant skills and confidence

9.2 Appendix 2: NDIS participant characteristics

	N = 75	% NDIS research participants	% NDIS population
Disability type			
Autism	27	36%	33%
Down syndrome	8	11%	3%
Intellectual disability	17	23%	21%
Psychosocial disability	12	16%	12%
Other	11	15%	31%
Gender			
Intellectual disability			
Female	9	53%	42%
Male	8	47%	57%
Undisclosed	0	0%	1%
Down syndrome			
Female	5	63%	45%
Male	3	38%	54%
Undisclosed	0	0%	1%
Autism			
Female	7	26%	25%
Male	20	74%	73%
Undisclosed	0	0%	2%
Psychosocial disability			
Female	10	83%	48%
Male	2	17%	51%
Undisclosed	0	0%	1%
Other			
Female	5	45%	45%
Male	6	55%	54%
Undisclosed	0	0%	1%
Total			
Female	36	48%	38%
Male	39	52%	61%
Unknown	0	0%	1%
Age			
Intellectual disability			
7 to13 years	0	0%	16%
14 to 25 years	7	41%	33%
26 to 44 years	9	53%	28%
Down syndrome			
7 to13 years	1	13%	15%
14 to 25 years	4	50%	26%
26 to 44 years	3	38%	37%
Autism			
7 to 13 years	8	30%	57%
14 to 25 years	14	52%	34%
26 to 44 years	5	19%	7%
Psychosocial disability			
7 to13 years	0	0%	1%

	N = 75	% NDIS research participants	% NDIS population
14 to 25 years	1	8%	6%
26 to 44 years	11	92%	38%
Other			
7 to13 years	0	0%	18%
14 to 25 years	1	8%	6%
26 to 44 years	8	73%	20%
Total			
14 to 25 years	29	39%	24%
26 to 44 years	36	48%	20%
7 to 13 years	9	12%	28%
State/Territory			
ACT	0	0%	2%
NSW	19	25%	31%
NT	0	0%	1%
Qld	11	15%	19%
SA	6	8%	9%
Tas	5	7%	2%
Vic	25	33%	26%
WA	9	12%	9%
Unknown	0	0%	0%
Remoteness			
Major cities	49	65%	68%
Regional - population between 15000 and 50000	7	9%	9%
Regional - population between 5000 and 15000	7	9%	5%
Regional - population greater than 50000	9	12%	11%
Regional - population less than 5000	2	3%	7%
Remote	1	1%	1%
Very remote	0	0%	1%
unknown	0	0%	0%
Locality			
Metro	49	65%	68%
Regional	25	33%	31%
Remote	1	1%	2%
unknown	0	0%	0%
Aboriginal and/or Torres Strait Islander			
No	62	83%	74%
Not stated	10	13%	19%
Yes	3	4%	7%
CALD			
No	71	95%	89%
Not stated	1	1%	1%
YES	3	4%	9%
Level of function			
Intellectual disability	Blank	Blank	Blank
high	0	0%	17%

	N = 75	% NDIS research participants	% NDIS population
Low	10	59%	35%
Mid	7	41%	48%
unknown	0	0%	0%
Down syndrome	Blank	Blank	Blank
high	1	13%	5%
Low	3	38%	52%
Mid	4	50%	42%
unknown	0	0%	0%
Autism	Blank	Blank	Blank
high	2	7%	18%
Low	6	22%	22%
Mid	19	70%	60%
unknown	0	0%	0%
high	2	17%	5%
Low	2	17%	29%
Mid	8	67%	65%
unknown	0	0%	0%
Other			
high	2	18%	33%
Low	6	55%	33%
Mid	3	27%	34%
unknown	0	0%	0%
Total			
high	7	9%	20%
Low	27	36%	30%
Mid	41	55%	50%
unknown	0	0%	0%
Daily living support			
high	40	53%	36%
Low	2	3%	6%
Mid	19	25%	19%
unknown	14	19%	39%
Paid employment			
Intellectual disability			
No and I don't want one	3	18%	29%
No, but I would like one	6	35%	23%
Yes	6	35%	18%
unknown	2	12%	30%
Down syndrome			
No and I don't want one	0	0%	36%
No, but I would like one	2	25%	18%
Yes	4	50%	19%
unknown	2	25%	28%
Autism			
No and I don't want one	5	19%	10%
No, but I would like one	7	26%	13%
Yes	5	19%	5%
unknown	10	37%	72%
Psychosocial disability			
No and I don't want one	1	8%	46%

	N = 75	% NDIS research participants	% NDIS population
No, but I would like one	9	75%	36%
Yes	1	8%	8%
unknown	1	8%	9%
Other			
No and I don't want one	0	0%	37%
No, but I would like one	5	45%	19%
Yes	4	36%	18%
Total	2	18%	27%
No and I don't want one	9	12%	27%
No, but I would like one	29	39%	20%
Yes	20	27%	12%
unknown	17	23%	40%
Paid Job Type			
Intellectual disability			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	3	18%	11%
Open employment market at less than minimum wage, i.e. Supported Wage System	1	6%	2%
Open employment market with full award wages	1	6%	3%
Other	0	0%	1%
Self-employed	0	0%	0%
unknown	12	71%	82%
Down syndrome			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	2	25%	13%
Open employment market at less than minimum wage, i.e. Supported Wage System	1	13%	4%
Open employment market with full award wages	1	13%	2%
Other	0	0%	1%
Self-employed	0	0%	0%
unknown	4	50%	81%
Autism			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	2	7%	2%
Open employment market at less than minimum wage, i.e. Supported Wage System	0	0%	1%
Open employment market with full award wages	2	7%	2%
Other	1	4%	0%
Self-employed	0	0%	0%
unknown	22	81%	95%
Psychosocial disability			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	0	0%	3%

	N = 75	**% NDIS research participants**	**% NDIS population**
Open employment market at less than minimum wage, i.e. Supported Wage System	0	0%	1%
Open employment market with full award wages	1	8%	4%
Other	0	0%	0%
Self-employed	0	0%	0%
unknown	11	92%	92%
Other			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	1	9%	2%
Open employment market at less than minimum wage, i.e. Supported Wage System	0	0%	1%
Open employment market with full award wages	2	18%	13%
Other	0	0%	1%
Self-employed	1	9%	2%
unknown	7	64%	82%
Total			
Australian Apprenticeship	0	0%	0%
Australian Disability Enterprise	8	11%	4%
Open employment market at less than minimum wage, i.e. Supported Wage System	2	3%	1%
Open employment market with full award wages	7	9%	6%
Other	1	1%	0%
Self-employed	1	1%	1%
unknown	56	75%	88%
Social. community and civic participation related goal			
Intellectual disability			
No	4	24%	27%
Yes	13	76%	72%
unknown	0	0%	0%
Down Syndrome			
No	0	0%	20%
Yes	8	100%	79%
unknown	0	0%	0%
Autism			
No	8	30%	39%
Yes	19	70%	61%
unknown	0	0%	1%
Psychosocial disability			
No	3	25%	23%
Yes	9	75%	77%
unknown	0	0%	1%
Other			
No	2	18%	38%

	N = 75	% NDIS research participants	% NDIS population
Yes	9	82%	62%
Unknown	0	0%	1%
Total			
No	17	23%	34%
Yes	58	77%	66%
unknown	0	0%	1%
Employment related goal	Blank	Blank	Blank
Intellectual disability	7	41%	45%
No	6	35%	66%
Yes	11	65%	34%
unknown	0	0%	0%
Down syndrome			
No	4	50%	71%
Yes	4	50%	29%
unknown	0	0%	0%
Autism			
No	19	70%	83%
Yes	8	30%	16%
unknown	0	0%	1%
Psychosocial disability			
No	6	50%	68%
Yes	6	50%	32%
unknown	0	0%	1%
Other			
No	7	64%	79%
Yes	4	36%	20%
unknown	0	0%	1%
Total			
No	42	56%	76%
Yes	33	44%	23%
unknown	0	0%	1%
Volunteering			
Intellectual disability			
No, but I would like to be	5	29%	16%
No, it doesn't interest me	7	41%	41%
Yes	3	18%	8%
unknown	2	12%	35%
Down syndrome			
No, but I would like to be	2	25%	16%
No, it doesn't interest me	2	25%	40%
Yes	1	13%	10%
unknown	3	38%	33%
Autism			
No, but I would like to be	4	15%	6%
No, it doesn't interest me	4	15%	14%
Yes	5	19%	3%
unknown	14	52%	77%
Psychosocial disability			
No, but I would like to be	7	58%	29%
No, it doesn't interest me	2	17%	53%

	N = 75	% NDIS research participants	% NDIS population
Yes	2	17%	6%
unknown	1	8%	11%
Other			
No, but I would like to be	0	0%	18%
No, it doesn't interest me	6	55%	44%
Yes	2	18%	9%
unknown	3	27%	29%
Total			
No, but I would like to be	19	25%	16%
No, it doesn't interest me	20	27%	37%
Yes	19	25%	7%
unknown	17	23%	40%
Education level			
Intellectual disability			
Less Than Year 12	3	18%	47%
None	1	6%	6%
TAFE/Diploma/Other	8	47%	13%
University degree	0	0%	1%
Year 12	4	24%	22%
unknown	1	6%	11%
Down syndrome			
Less Than Year 12	2	25%	38%
None	0	0%	7%
TAFE/Diploma/Other	3	38%	11%
University degree	0	0%	0%
Year 12	2	25%	32%
unknown	1	13%	12%
Autism			
Less Than Year 12	17	63%	70%
None	0	0%	2%
TAFE/Diploma/Other	6	22%	6%
University degree	0	0%	1%
Year 12	3	11%	9%
unknown	1	4%	13%
Psychosocial disability			
Less Than Year 12	1	8%	36%
None	0	0%	2%
TAFE/Diploma/Other	4	33%	27%
University degree	3	25%	13%
Year 12	3	25%	13%
unknown	1	8%	9%
Other			
Less Than Year 12	2	18%	38%
None	0	0%	2%
TAFE/Diploma/Other	4	36%	21%
University degree	3	27%	17%
Year 12	2	18%	12%
unknown	0	0%	9%
Total			
Less Than Year 12	25	33%	50%

	N = 75	% NDIS research participants	% NDIS population
None	1	1%	3%
TAFE/Diploma/Other	25	33%	15%
University degree	6	8%	7%
Year 12	14	19%	14%
unknown	4	5%	11%
Learning related goal			
Intellectual disability			
No	11	65%	77%
Yes	6	35%	23%
unknown	0	0%	0%
Down syndrome			
No	6	75%	80%
Yes	2	25%	19%
unknown	0	0%	0%
Autism			
No	14	52%	72%
Yes	13	48%	27%
unknown	0	0%	1%
Psychosocial disability			
No	9	75%	79%
Yes	3	25%	20%
unknown	0	0%	1%
Other			
No	6	55%	83%
Yes	5	45%	16%
unknown	0	0%	1%
Total			
No	46	61%	78%
Yes	29	39%	22%
unknown	0	0%	1%

TABLE 3: NDIS PARTICIPANT CHARACTERISTICS

9.3 Appendix 3: NDIS service delivery staff survey results

Where do you look for information when doing the following?		
		%
Supporting participants to develop community participation goals within their plan	101	
NDIS website (external)	52	51%
NDIS intranet	72	71%
Google	49	49%
Colleagues (including Subject Matter Experts)	**83**	**82%**
Advocacy groups (e.g. Disability Advocacy Network Australia)	11	11%
Service Delivery Group (i.e., Disability employment provider)	33	33%
Other		0%
Understand the community participation pathways available (i.e., available supports)	119	
NDIS website (external)	54	45%
NDIS intranet	75	63%
Google	60	50%
Colleagues (including Subject Matter Experts)	**91**	**76%**
Advocacy groups (e.g. Disability Advocacy Network Australia)	14	12%
Service Delivery Group (i.e., Disability employment provider)	32	27%
Other		0%
Understand what the NDIS will fund to help participants work towards their community participation goals	135	
NDIS website (external)	84	62%
NDIS intranet	**119**	**88%**
Google	33	24%
Colleagues (including Subject Matter Experts)	100	74%
Advocacy groups (e.g. Disability Advocacy Network Australia)	8	6%
Service Delivery Group (i.e., Disability employment provider)	23	17%
Other		0%
Direct NDIS participants to information about available services to meet their support needs for their community participation goals	110	
NDIS website (external)	68	62%
NDIS intranet	36	33%
Google	**69**	**63%**
Colleagues (including Subject Matter Experts)	61	55%
Advocacy groups (e.g. Disability Advocacy Network Australia)	21	19%
Service Delivery Group (i.e., Disability employment provider)	46	42%
Other		0%
Resources thought to be used by participants	142	
NDIS website (external)	35	25%
Google	57	40%
Advocacy groups (e.g. Disability Advocacy Network Australia)	18	13%
Self-advocacy groups (e.g. Voices Together)	18	13%
Planner, LAC or Partners in the Community	**75**	**53%**
Support co-coordinator	**77**	**54%**

Social media (e.g., Facebook Grassroots discussion)	42	30%
Word of mouth	44	31%
Carers/family	45	32%
Providers/support workers	46	32%

TABLE 4: WHERE NDIS SERVICE DELIVERY STAFF FIND INFORMATION

Barriers to community participation

	Intellectual disability		Autism spectrum disorder		Psychosocial disability	
What are the greatest barriers to community participation for participants with intellectual disability? *Please rank the top 3 greatest enablers from your experience*	129	%	129	%	126	%
Lack of inclusive community activities	69	53%	61	47%	69	55%
Lack of options to meet participant's interests	70	54%	83	64%	78	62%
Unable to connect to activities in the general community	57	44%	59	46%	66	52%
Lack of age-appropriate week day activities	47	36%	44	34%	32	25%
Lack of flexible funding to meet individual needs for community participation	26	20%	31	24%	23	18%
Lack of providers	40	31%	37	29%	36	29%
Lack of meaningful community participation through day programs	48	37%	41	32%	25	20%
Lack of informal support and reduced encouragement from family	16	12%	15	12%	27	21%
Other, please specify [text box]	5	4%	4	3%	8	6%
Have you encountered any of these in assisting participants work towards their community participation goals? *Please rank the top 3 greatest enablers from your experience*	129	%	129	%	126	%
Day programs offering minimal community participation activities for participants	43	33%	29	22%	20	16%
Day programs being more available than other community participation activities	51	40%	37	29%	16	13%
Difficult to find the right information on services and supports available	39	30%	40	31%	42	33%
Participants disengaged in pursuing community participation goals	30	23%	45	35%	66	52%
Understanding the interests and capabilities of participants	36	28%	51	40%	36	29%
Attitudes of community not accepting of people with disability	35	27%	34	26%	42	33%
Lack of previous opportunity for community participation	27	21%	24	19%	28	22%
Low expectations of community involvement	38	29%	34	26%	49	39%
Accessibility issues	11	9%	11	9%	4	3%
Lack of inclusive activities	39	30%	46	36%	33	26%

Changes in submitted plans (e.g., PITC submits plan and delegates thinks changes are warranted)	24	19%	21	16%	18	14%

TABLE 5: SURVEY RESPONSES BARRIERS TO COMMUNITY PARTICIPATION

Enablers to community participation

	Intellectual disability		Autism spectrum disorder		Psychosocial disability	
What are the greatest enablers for participants with intellectual disability to community participation? *Please rank the top 3 greatest enablers from your experience*	129	%	129	%	126	%
Using technology (such as during COVID-19 restrictions) to access online communities and activities	56	43%	80	62%	45	36%
Hiring community members as support workers to do activities	55	43%	52	40%	51	40%
NDIS Mentors and coaches for social skills	54	42%	64	50%	55	44%
Utilising informal community supports such as clubs, friendship groups	83	64%	66	51%	51	40%
Recovery coaches (ask only for psychosocial)					73	58%
Accessibility	32	25%	26	20%	20	16%
Inclusive activities being advertised	74	57%	64	50%	51	40%
Good relationships between PITC and NDIS delegates	17	13%	16	12%	15	12%

TABLE 6: SURVEY RESPONSES ENABLERS TO COMMUNITY PARTICIPATION