# Supporting participants to be included in the community

Independent Advisory Council to the NDIS
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## Executive Summary and Recommendations

The NDIS is a paradigm changing approach to support that is targeted at building social and economic participation and inclusion. The NDIS encourages participants to aspire to move from community presence (the use of facilities used by everyone in the community), through to community participation (being actively involved in the activities that occur in the community with a growing network of relationships that includes people with and without disability) to community inclusion (having valued social roles and a reliable network of relationships). While recognising the whole of government responsibility to facilitate welcoming communities, this paper provides advice to the NDIA Board as to what is required to ensure the realisation of this aspiration, so critical to participant outcomes and Scheme sustainability.

The paper will discuss the understanding of inclusion in Australia today sharing strategies that have been successful in supporting people with disability to be included. The paper will present outcomes data that examines the extent to which participants see themselves as being included and review NDIS levers for inclusion identifying adjustment to planned reforms to maximise the effectiveness in facilitating greater community inclusion. The paper will conclude with observations about the impact of this work on Scheme sustainability.

**Defining inclusion**

Social inclusion can be a complex phenomenon as people with disability, families, researchers, and providers argue about what genuine / authentic / inclusion means with conflicting views depending on who you ask.

Despite these differences and ambiguities, the literature[[1]](#footnote-1) agrees that paid support workers, individuals, families, and community organisations tend to lack the skills and knowledge to foster ‘genuine’ social inclusion. There are many stories of success which highlight how practical measures can improve community engagement for individuals and can improve the openness and accessibility of communities more generally. Specific skills, service configurations and resources are required, but the literature indicates a lack of consensus about precisely what these skills, arrangements and resources are. Social inclusion in this respect remains largely a policy aspiration, with little (if any) guidance on its practical implementation. The guidance that exists however, especially for people with cognitive impairment, indicates three broad elements are required: support for the individual, support for the community and skilled support with a deep understanding of the person and the dynamics of communities.

The paper acknowledges the anticipated contribution of the NDIA evidence guide to interventions to improve social, community and civic participation currently under development. The evidence guide will assist people with disability identify and purchase support “that works” in assisting them to move closer to being included in the community and feeling they belong. While awaiting the guide, the paper presents typologies and research from Australian universities that describe factors that contribute to active participation and inclusion and promising strategies in Australia today.

**Outcomes**

The paper presents participant views about the achievement of outcomes related to being included in the community from the 2020 Participant Outcomes Report for participants who have been in the Scheme for three years. The analysis includes progress of which the Scheme can be proud. It also highlights areas in which more action is required with actuarial data enabling the Scheme to identify, prioritise and target areas for action.

Progress related to inclusion of which the Scheme can be proud includes improvements in the percentage of parents of little children who feel their child is welcomed and actively included when they participate in community activities (from 63.7% to 74.8%), % of 15–24-year-olds who were eligible to vote who actually voted (from 71.1% to 84.4%) and % of adult participants who have someone to call outside the home for practical and emotional support (90%).

While there has been progress on most indicators, many record modest improvements and many continue to compare poorly with data from the general population. For example, 28.6% of the young people reported they were not able to get support in times of crisis from someone living outside their household compared to 2.8% of young people in the general population (ABS General Social Survey).

For the cohort birth to school entry, inclusion is measured by indicators related to fitting into family and community life. It is therefore of serious concern that: more than 20% of parents do not think their child with disability fits into the everyday life of the family; more than 25% of parents do not feel their child is welcomed / actively included when they participate in community activities; that more than 80% of parents/carers would like their child to have more opportunities to be involved in community activities and of this group, the vast majority see their child’s disability as a barrier to being more involved.

For the cohort school entry to 14 years, inclusion is measured by participation in school, with peers and in the community. It is disappointing to see that after 3 years in the Scheme, parents/carers report very few improvements in inclusion for their children with the low level of participation in mainstream activities as the standout message for this cohort. More than 90% of parents/carers reported they would like their child to have more opportunities to be involved in activities with other children with the vast majority viewing their child’s disability as a barrier to being more involved.

For the young adult cohort aged 15-24 years, inclusion has many forms but measures of being able to advocate for oneself and knowing people in your community may reflect signature measures of inclusion in one’s community.[[2]](#footnote-2) Sadly, the trend is going in the wrong direction with increased time in the Scheme for both these measures. For participants 15-24 years for whom outcomes data has been reported over 3 years, 73.4% feel they are unable to advocate for themselves (compared to 67.9% at base) and 40% report not knowing people in their community. The same trend is also identified in participants aged 25+ with 65.2% feeling they are unable to advocate for themselves (compared to 49.9% at base) and 30% report not knowing people in their community.

**Improving NDIS levers to support participant inclusion**

The literature and stories demonstrate that to support participants to be included in the community, the NDIA must take steps to build the capacity of the participant, support the welcoming nature of the community and provide a guide to skilfully link the two. Of course, the community has its responsibilities, but this paper will focus on those under the control of the NDIS.

The paper analyses the NDIS levers that could support inclusion to provide insights in relation to strengths, elements that are missing and enhancements to current reforms that will more effectively support participants to be included in the community.

The NDIS Act is a strong foundation for inclusion, capable of supporting participant and community facing strategies. The paper reports on the significant participant-facing work that is currently underway aimed at assisting participants better connect with their community and mainstream services while continuing to provide the right supports to pursue their goals and aspirations. Council is extremely mindful however of the community concerns related to some of proposed reforms such as independent assessments and is concerned that these do not diminish the shared focus and commitment to the broader reform process. The early resolution of the contention around independent assessments and any potential impact on plan budgets will be critical so that participants have confidence in the adequacy and reliability of their reasonable and necessary support to assist them to actively participate and be included in the community.

Proposals related to flexible personalised budgets will make an important contribution to assisting participants to be included in the community, enabling greater choice and control over how participants use their NDIS funds to implement their plan and pursue their goals. Many participants however will need extensive support if the enhanced flexibility is to translate into improved outcomes. Proposals for roll over of unspent funds will also assist participants and Council further proposes participant budgets should be released quarterly unless identified risks indicate a shorter period is required with an easy process through which participants can request a longer release time.

Greater clarity needs to be provided about the role of independent assessments and their relationship to plan budgets. NDIA reform documents indicate that the independent assessment will be translated into a draft plan and budget that will be provided to participants prior to the planning conversation. An independent assessment however cannot lead to a draft plan.[[3]](#footnote-3) At best, an independent assessment can lead to a draft budget against which participants can map their goals and develop a plan, a detailed proposal of how to use community and mainstream supports and NDIS funds to pursue their goals and meet their disability related support needs.

The planning process as outlined in recent consultation documents does not contribute as positively as it could to support participants to imagine and plan for a life in the community. The planning conversation needs to conceived as more than an administrative step currently providing only high-level focus areas of the participant’s life. It is important that the discussion of planning identify the need to assist participants to think about what community inclusion might mean for them, how to get support to be more included in the community and how to plan for their own safety, important components of a planning conversation designed to embed people in community.

More attention needs to be focused on capacity building supports. Indications are previous strategies that separated capacity building from core supports did not have the intended effect in helping participants to value investment in these areas. It is critical that the Agency not lose sight of the critical importance of building participant capacity to live ordinary lives. The Agency must develop and adopt multiple strategies to more effectively encourage participants to build their independence, their social and economic participation, and their self-advocacy skills to lead ordinary lives as well-informed consumers in the NDIS market.

Local Area Coordination is the NDIA infrastructure intended to support participants to be included in the community. Compared to the current model, the NDIA planned change is an improved approach. In its advice to the Board on Local Area Coordination,[[4]](#footnote-4) Council proposed an approach that prioritised participant and community capacity building[[5]](#footnote-5) over plan implementation. It is the view of Council that these elements would be more effective in supporting participant inclusion. Council remains concerned the NDIA planned approach will see LACs default to connecting participants to services and the value for money but more difficult work of developing relationships and non-service solutions (that require community capacity building) will be lost. Given the planned reforms to budget flexibility give participants the ability to purchase support coordination to assist in plan implementation if LAC support is insufficient, it is the view of Council that a stronger focus on community capacity building with and on behalf of participants would significantly strengthen the LAC support for inclusion.

However, whatever approach is ultimately adopted, it is critical that the impact of the changed role of Local Area Coordination is understood and planned for so that LACs in successful organisations do not default to previous practices that are not fit for purpose under a changed role. Council looks forward to reviewing the new Local Area Coordination practice framework, associated KPIs and training, including being led by people with disability to strengthen confidence in the approach.

Council believes there needs to be greater accountability to participants from all stakeholders in the NDIS ecosystem (including the NDIA, Partners in the Community, support coordinators and service providers) for the achievement of outcomes. For many participants, increased budget spends have not reduced loneliness and have not increased their ability to speak up for themselves. If the NDIA wants to ensure reasonable and necessary support assists participants to be included in the community, it is important that support for plan implementation builds empowered, informed participants who have the capability or are supported to have the capability to understand ‘evidence-based practice’, select providers based on their assessment of the provider ability to deliver skilled support and promised outcomes, develop service agreements that reflect their preferences about what, where, when and by whom support is delivered and monitor for outcomes holding providers and other stakeholders to account when they do not achieve the outcomes planned.

Council acknowledges the critical role played by ILC services and the National Disability Strategy in supporting people with disability to be included in the community. The paper does not discuss these elements however because they are outside the control of the NDIA however Council drew attention to these issues in its submission to DSS in relation to the National Disability Strategy and in multiple pieces of advice to the NDIA Board including those related to participant safety, capacity building, support for families and carers, support for participants who are parents and promoting independence.

**Recommendations**

In order to strengthen NDIA support for participants to be included in their communities, Council recommends strategies that strengthen the three elements that are fundamental to inclusion, i.e., participant capacity, welcoming communities and skilled support to facilitate the connection. This can be achieved by:

**Strategies to increase participant capacity**

1. A planning process that assists participants to:
	* focus on inclusion
	* build their independence, their social and economic participation, and their self-advocacy skills
	* supports participants to plan for their own safety
	* gain insights into services and supports that can assist them to reach their goals
	* understand the NDIS ecosystem and first points of contact
	* recognize the need for and have sources of support to strengthen / extend informal support, build personal safeguards and make complaints.
2. The implementation of plan budget flexibility including
	* support participants to use additional flexibility
	* quarterly release of plan budgets with a mechanism through which participants can request a longer release time.
3. A focus on capacity building supports including:
	* a multipronged plan to more effectively encourage participants to value and build their independence, their social and economic participation, and their ability to speak up
	* encouragement to join peer networks hosted by Disabled Persons’ Organisations.
4. Support for plan implementation including:
	* continued focus on evidence guides to strengthen participant knowledge about “what works” and to support the development of provider practice consistent with including people in the community
	* an NDIA project to strengthen the participant focus of service agreements to reflect participant preferences about what, where, when and by whom support is delivered and provide a framework for setting goals and monitoring outcomes.

**Strategies to increase the welcoming nature of community and to facilitate connection**

1. Reprioritisation of elements in the LAC role to have a stronger focus on community capacity building including
	* process in place to review LAC practice in the context of the new practice framework and KPIs.
2. Review the decision that prevents LACs working with participants in the complex pathway or require planners and support coordinators to have the responsibilities and competencies identified for LACs in this paper.
3. Continued engagement with DSS to influence the delivery of ILC services and the framing and oversight of the National Disability Strategy.

## Introduction

Advocacy by people with disability, their families and allies shifted the paradigm from the medical model of disability which situated challenges in the individual to be fixed, to the social model of disability in which people are disabled by barriers in society, not by their impairment or difference. The UNCRPD enshrined a human rights framework that aims *“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”*

In the 21st century, there has been an increased recognition that the vision of citizenship enshrined in the UNCRPD requires a whole of government approach to build inclusive communities. Disability services and supports play their part by supporting increased social and economic participation and inclusion. Most agree progress has been made but much more is required.

Deinstitutionalisation of the last quarter of the 20th century promised opportunities for better lives and while moves to group homes and boarding houses led to some improvements, many were found to be places of violence, abuse, and neglect. Social inclusion remained elusive. A 2009 study of middle aged and older people with intellectual disability who moved from institutions into the community found that: (i) residents did not form new relationships after relocation, (ii) the number of residents in regular touch with a family member decreased, and (iii) patterns of contact changed as residents aged. Some 62% of residents had no‐one outside the service system who knew them well or monitored their well‐being. [[6]](#footnote-6)

Support workers did not see inclusion as applicable to all people with disability [[7]](#footnote-7)and a 2013 study[[8]](#footnote-8) found that increased physical presence of people with intellectual disability in the community was not matched by a corresponding increase in their social relationships with other community members and participation in the social and recreational organisations that make up civic society. The illusion of inclusion was reinforced by studies [[9]](#footnote-9) that showed people with intellectual disability had small, highly restricted social networks characterised by interactions with other people with intellectual disabilities, family members, and paid workers. These study results are not surprising to many people with disability and their families who sadly know first-hand that co-presence in a space does not ensure interaction and people with disability often remain on the outside looking in. More is required to support the citizenship of people with disability and fulfil the obligations of the UNCRPD.

The NDIS is a paradigm changing approach to support that is targeted at building social and economic participation and inclusion. The NDIS encourages participants to aspire to move from community presence (the use of facilities used by everyone in the community), through to community participation (being actively involved in the activities that occur in the community with a growing network of relationships that includes people with and without disability) to community inclusion (having valued social roles and a reliable network of relationships).

While recognising the whole of government responsibility to facilitate welcoming communities and submitting a detailed report to the Department of Social Services in relation to the National Disability Strategy, this paper provides advice to the NDIA Board as to what is required to ensure the realisation of this aspiration, so critical to participant outcomes and Scheme sustainability.

The paper will:

* Define inclusion, identify factors that contribute to people with disability being included and strategies that have been successful in supporting people to be included
* Present NDIA outcomes data to examine the extent to which participants see themselves as included in the community and thereby identify cohorts for whom additional focus is required
* Review the extent to which the NDIS facilitates inclusion proposing strategies to enhance NDIS support for inclusion
* Conclude with observations about the impact of this work on Scheme sustainability.

## Defining inclusion

Defining inclusion must start with the individual and their perceptions what it means to be included. The 19 stories of inclusion in Australia [[10]](#footnote-10) describe what it means to live (and assist people to live) a full, meaningful, and inclusive life in a practical way as:

* Together with those around me, I value and hold a vision for a good life
* I’m seen for my unique identity rather than focusing on my diagnosis or difference
* I’m present in ordinary and typical places in the community rather than in segregated or special places
* I have a range of reciprocal relationships in the community
* I have all the same opportunities as all citizens to contribute to the community
* I have the support required to participate and contribute to the community
* I feel like I belong.

Bigby [[11]](#footnote-11) graphically depicts the concept and outcomes of inclusion in figure 1, providing observable measures of an elusive concept. The diagram is described accessibly in Appendix 1.



Inclusion is often seen as an ambiguous concept with conflicting answers depending on who is asked. The conceptual and practical ambiguities are highlighted in the example of a Men’s Shed program in which five of the twelve members are people with disability.[[12]](#footnote-12) It is however usually described as a 2-way process and is more likely to be successful in groups in which

* participants had equal membership status with other members
* participation is mutually rewarding for members
* participants work cooperatively toward a common goal, and
* there is effective use made of expertise to develop group capacity to support inclusion.

Despite these differences and ambiguities, the literature[[13]](#footnote-13) agrees that paid support workers, individuals, families, and community organisations tend to lack the skills and knowledge to foster ‘genuine’ social inclusion. There are many stories of success which highlight how practical measures can improve community engagement for individuals and can improve the openness and accessibility of communities more generally. Specific skills, service configurations and resources are required, but the literature indicates a lack of consensus about precisely what these skills, arrangements and resources are. Social inclusion in this respect remains largely a policy aspiration, with little (if any) guidance on its practical implementation.

### 3.1 Factors that contribute to active participation and inclusion

The 2017 systematic review of literature by Gooding et al, *Disability, and inclusion down under* [[14]](#footnote-14) identified factors related to participation and inclusion. These included

* the nature of community engagement including a) the attitude of the group leadership towards inclusion of a person with intellectual disability; b) the social processes within the group and the interactions between group members; c) the skills and characteristics of the person with intellectual disability; d) the presence of an integrating activity to promote involvement for the person with intellectual disability; e) access to expertise to develop the groups’ capacity to support inclusion; and f) adjusting practices to support a participant to actively engage in group activities.[[15]](#footnote-15)
* having a valued social role that enables a person with disability to engage with others in tasks with a shared purpose. Volunteering is a frequently used strategy to provide the opportunity for people with disability to achieve valued social roles.
* the role of paid staff in promoting (but also potentially obstructing) social inclusion with an emphasis on the importance of education, training, and ongoing support for paid staff to support successful inclusion.

Overmars-Marx et al [[16]](#footnote-16) recognise that whilst each factor is researched to some extent, there is little empirical research that focuses on the interactions between individual skills and environmental factors, critical for successful. Significantly there is agreement that social inclusion is a complex process that takes time and effort and cannot be achieved by delivering one service in a slightly different way.

### 3.2 Strategies that support people to be included

The NDIA is currently undertaking a systematic review of strategies to enable people with autism spectrum disorder, intellectual disability and psychosocial disability to participate in social, community and civic aspects of life. The review and the resulting dissemination of evidence is critical to enable participants to know “what works” in helping them to be included in the community and will contribute most significantly to informed decision making by all stakeholders.

Bigby, Anderson and Cameron[[17]](#footnote-17) published a literature review that aimed to provide conceptual clarity and a typology of different types of community participation and interventions to support it, to inform decisions about funding, planning and purchase of person-centred supports to facilitate community participation for people with intellectual disability. The resultant scoping review that included five in-depth case studies provides important guidance for the design of effective support for community participation for people with intellectual disability. The review conceptualised three different types of community participation: community participation as social relationships, as convivial encounters and as belonging. It is important however to note the fluidity between different types of community participation with successful convivial relationships often providing the starting point for social relationships and belonging.

#### 3.2.1 Community participation as social relationships

Community participation as social relationships focuses on the development of social relationships between adults with or without disability.[[18]](#footnote-18) Interventions to develop social relationships prioritise social interactions and matching with volunteers or support to meet people with similar interests. Promising strategies were those based on community builder programs that used intentional strategies and concerted effort to support the creation of community connection and meaningful relationships for people with intellectual disability.

Snow [[19]](#footnote-19) highlights the depth and meaning of relationships in Figure 1



The figure shows 4 concentric circles.

Circle 1, the circle of intimacy, includes people that are so important to us that their absence would have a significant impact. They could be family members or very close friends.

Circle 2, the circle of friendship, consists of people who are friends or relatives with whom we could share a movie or go out for dinner but are not those who we consider our most dear friends or those we must see regularly.

Circle 3, the circle of participation, includes the people and organisations with whom we interact, for example at work, school, clubs, sporting teams, interest groups. Some of the people in Circle 3 may later be in Circle 2 or 1 if a relationship develops. Circle 3 is characterised as “the garden for sowing future relationships”.

Circle 4, the circle of exchange, includes people who paid roles in our lives such as support workers, doctors, teachers, social workers, hairdressers, tradespeople.

Any strategy seeking to promote inclusion needs to bring people from the circle of exchange and participation into the circle of friendship from where some may move into the circle of intimacy.

Some programs that build social relationships[[20]](#footnote-20) match people with disability to volunteers without disability to seek friendship, creating connections to places of common interest and teaching social relationship skills to people with disability. Examples of programs designed to foster relationships include:

* Buddy programs, in which a person with disability is ‘buddied’ with a person without a disability around a common interest (e.g., Gig Buddies that facilitates buddy relationships to attend music events)
* Circles of support, an intentional strategy that invites people to meet on a regular basis to promote and support a vulnerable person’s interest, goals, relationships, wellbeing and needs in building a meaningful life. Many circles have a facilitator who helps to organise and run meetings, providing a framework for people to be involved and for planning in a practical and structured way.
* Approaches that support people with disability to create valued social roles,[[21]](#footnote-21) to engage with others in tasks with a shared purpose, provides another approach for the development of relationships.

#### 3.2.2 Community participation as convivial encounters

Community participation as convivial encounters focuses on social interactions in places where there is a shared identity or activity with others and a sense of pleasantness or warmth. Interventions to support convivial encounters prioritise place (mainstream community groups) and activities (based on individual interest) and pleasant social interactions in, for example, community groups, where a person is known and recognised.

Seen through the lens of Snow’s relationships circles, convivial encounters seek to build a bridge from the circle of exchange into possible participation and for some, ultimately friendship. Valued social roles that promote a sense of attachment and belonging are one important vehicle for moving interaction for the circle of participation to the circle on friendship.

Factors[[22]](#footnote-22) [[23]](#footnote-23) demonstrated to promote successful convivial encounters include the leadership response, characteristics of the participants, access to expertise, the presence of an integrating activity, and practices of staff that promote (as against inhibit) social interaction.

Promising strategies were identified as active mentoring, active participation in community groups, facilitative support worker practices. In a study designed to support older people with disability who had led very sheltered lives, into retirement, Stancliffe [[24]](#footnote-24) mentored interested members of community groups to support the inclusion of a new member who had a disability. Study design required that the person was supported to choose the group based on interest, there was only one person with disability per group, each group met weekly at the same time and place and each individual was assisted to take responsibility for a specific role within the group.

As a result of mentoring, group members were able to provide social support (greetings, introductions, conversations), support to undertake the activity including prompting when and how to do the activity and support to fit into group norms. The study demonstrated the skill of using paid support to foster relationships, build informal support and fade out paid support, critical processes in enabling people with disability to participate without a paid person velcroed to their side.

#### 3.2.3 Community participation as belonging

Community participation as belonging focuses on activities and places where subjective feelings of a sense of attachment and belonging to others develop. Interventions to support a sense of belonging prioritise participation in activities with the potential to lead to a new social identity and valued role, as for example an artist, in a mix of segregated and mainstream places. Many of the studies use segregated environments to develop talents as a catalyst for interaction with others. Such an approach however that views skill development as a threshold to belonging leaves people with significant disability without opportunities to belong.

Individualised work by Australian capacity building organisations such as Belonging Matters, (Victoria) WAiS, (WA), Community Resource Unit, (Queensland) and Imagine More (ACT) support people with disability, including people with significant disabilities, to build valued social roles supporting active contribution and inclusion without the use of segregated programs. Their work is highlighted in a resource of 19 stories of social inclusion[[25]](#footnote-25) that emerged from a unique collaboration between the Disability Research Initiative at the University of Melbourne, Belonging Matters and the National Alliance for Capacity Building Organisations.[[26]](#footnote-26) People from all over Australia were invited to submit their stories that capture the diverse ways that people are living inclusion. The 19 stories accompanied the systematic literature review by Gooding et al *Disability and inclusion down under.*

### 3.3 The role of staff

Significant staff skill and organisational practices are important in supporting people with disability to be included. Studies provide insights into

* the planning, preparation and maintenance work undertaken by organisations and support workers to make the first convivial encounter happen and to sustain repeat encounters, [[27]](#footnote-27)
* community development tasks such as analysis of community groups and community mapping,[[28]](#footnote-28) and
* the skills in disability support practice such as active support, active mentoring, risk enablement and support for decision making [[29]](#footnote-29)and
* the organisational structures and processes that underpin quality support.[[30]](#footnote-30)

### 3.4 Avenues for inclusion online

Connection online, especially in the context of COVID 19, is a growing place for possible inclusion. The use of social media to share information, enhance learning, and connect with an online community has grown rapidly over the past 10 years. Understanding the benefits and challenges provides insights into its contribution to people with disability feeling included and belonging.

Most studies identify positive features of online connection where participants seek and experience esteem and emotional support, informational support, instrumental support (e.g. locating services) and belonging support. [[31]](#footnote-31) Participants also report marginalisation and cyber bullying.

A systematic review[[32]](#footnote-32) of literature on social media used by individuals with disabilities and a further US study[[33]](#footnote-33) analysing communication interaction of people with disability using Facebook, discussion forums and chat rooms found that online communities provide a platform for social support similar to offline settings with interactions seeking to build knowledge, form friendships, and create social support groups. Major themes identified were that of community, cyber bullying, self-esteem, self-determination, access to technology and accessibility.

A qualitative study of social media activities of 25 gay, bisexual, transgender, and queer students with disabilities at a research-intensive university used the by-line *My voice is definitely strongest in online communities.* The study found that students went online to find validation, become involved, and manage identities contextually. The study also reported that students experienced marginalization online and feeling of isolation.

A Scandinavian literature review of young people with intellectual disability and social media[[34]](#footnote-34) identified six topics through thematic analysis of the texts: opportunities, risk and vulnerability, sexuality, identity, barriers, and support. The study concluded that the research is characterised by issues of risk, vulnerability, and support. The concept of positive risk-taking is suggested for the development of methodological approaches in practice and research.

### 3.5 Concluding observations

The key consensus in literature related to inclusion for people with disability, especially people with cognitive disability is community inclusion requires support for the individual, support for the community and a skilled facilitator with deep understandings of the person and the dynamics of communities to build the connections. There are different views as to the nature of inclusion and there are many routes to assisting a person with disability to be included and feel they belong.

So, what can the NDIA take from this brief literature review to assist people with disability to actively participate and be included?

There are thousands of providers offering community participation programs, with a sea of material advertising support for participation and inclusion. It is not always easy to discern quality and even though participants have the power to purchase services, their power can be illusory even to negotiate service arrangements that reflect their choices.

Peer support has a role in assisting participants to become savvy consumers with peer networks providing opportunities for people to gain insights, share ideas and experiences and to build confidence to negotiate what they want. In the NDIS marketplace, the LAC is the designated facilitator / guide for most participants. Significant practice guidance, training, practice reflection, supervision and peer support will be required to enable LACs to make a difference to the inclusion of people with disability in communities of choice.

Section 5 of this paper reviews NDIA levers and makes recommendations as to enhancements so that the NDIS maximises opportunities and support for people with disability to be included in their community.

## Outcomes

The success of the NDIS should be judged on progress of participants since they entered the Scheme, noting their differing starting points. Regular NDIA reports analyse change in outcomes over time providing insights into the impact of nature of disability, level of function, gender, indigenous and CALD status and geography.

How well is the NDIS doing in assisting participants to be included in the community?

This section describes participant views about the achievement of outcomes related to being included in the community using data from the 2020 Participant Outcomes Report for participants who have been in the Scheme for three years. The analysis includes progress of which the Scheme can be proud. It also highlights areas in which more action is required.

### 4.1 Participants birth to entering school

After 3 years in the Scheme, outcomes data related to inclusion indicates improvements in:

* % of children who get along with their brothers and sisters (from 87.4% to 85.6% (prior 89%)
* % of parents/carers who say their child fits in with the everyday life of the family (from 69.6% to 77.2%)
* % of children who have friends they enjoy playing with (from 34.2% to 56.1%)
* % who feel their child is welcomed/ actively included when they participate in community activities (from 63.7% to 74.8%).

However, over the same period there has been an increase in the percentage of parents/carers who see their child’s disability as a barrier to being more involved (from 80.3% to 87.6%).

Fitting into family and community life is critical for the wellbeing of children. It is of serious concern that:

* more than 20% of parents do not think their child with disability fits into the everyday life of the family
* more than 25% of parents do not feel their child is welcomed / actively included when they participate in community activities
* % of parents/carers who say they would like their child to have more opportunities to be involved in community activities increased from 59.7% to 81.9%
* the vast majority of parents/carers who want to see their child more involved in community activities with other children see their child’s disability as a barrier to being more involved.

### 4.2 Participants starting school to age 14

School is the most significant activity for this cohort and has a significant impact on the extent to which a child feels or is included. Whilst the outcomes data identifies the increasing trend toward children attending school in a mainstream class, it also indicates that over time, there is a movement toward a support class or special school placement. Given most support classes and special schools are distant from the child’s local community, moves out of the mainstream schools have an impact on children having friends in their local area.

After 3 years in the Scheme, parents/carers report very few improvements in inclusion for their children with the most positive improvements seen in relation to perceptions of whether their child is learning at school (from 58.6% to 69.0%).

The key feature of outcomes data for this cohort however is the low level of participation in mainstream activities with deterioration seen in:

* % of children who attend school in the mainstream class (from 57.0% to 51.0%)
* % of children who have been suspended from school (from 14.7% to 25.0%)
* % of parents/carers who say they would like their child to have more opportunities to be involved in activities with other children (from 79.4% to 92.3%)
* % of parents/carers who see their child’s disability as a barrier to being more involved (from 86.7% to 93.8%).

The isolation is a significant concern to almost all parents/ carers of this cohort who report wanting more opportunities for their children to be involved with other children. Base line data shows a very small percentage of this cohort spend time with friends or in mainstream group activities or use school holiday programs.

Significant resources in almost all communities provide social and recreational opportunities for children highlighting an important strategic direction for NDIA action to enhance the inclusion of children in their local communities.

### 4.3 Participants aged 15 to 24

After 3 years in the Scheme, outcomes data related to inclusion indicates improvements in:

* % in paid job (from 12.7% to 24.5%)
* % working more than 15 hours per week (from 33.1% to 52.3%)
* % who volunteer (from 11.8% to 14.5%)
* % who have been actively engaged in a community, cultural or religious group in the past 12 months (from 31.1 to 45.1%)
* % who know people in their community (from 51.6% to 58.6%)
* % who have someone outside their home to call for emotional support (from 71.4 to 71.4%)
* % who have someone to call on in a crisis (from 71.4 to 71.4%)
* % who were eligible to vote, who voted at the last Federal election (71.1% to 84.4%)
* % who have had a job in the past 12 months (from 13.2% to 30.2%)
* % who have worked in a casual job in the past 12 months (13.2% to 20.8%)

However, over the same period there has been a deterioration in:

* % who feel able to advocate for themselves (from 32.1% to 26.6%)
* % who feel safe getting out and about in their community (from 44.8% to 42.5%)
* % who currently participate in education, training, or skill development (from 47.5% to 36.4%)

Whilst the outcomes data records more improvements toward inclusion than declines over time, most of the improvements have been modest. For example, being engaged in a community group over the past 12 months says nothing about frequency or quality of participation or sense of belonging and yet more than half of the young people did not participate in a group of any type. 28.6% of the young people reported they were not able to get support in times of crisis from someone living outside their household compared to 2.8% of young people in the general population (ABS General Social Survey).

It is also pleasing to see that after 3 years in the Scheme, the percentage of participants who do not know anyone in the community is decreasing but priority action is required for the more than 40% of this cohort who do not know people in their community after being NDIS participants for 3 years.

Longitudinal data tracking percentage of participants who do not have friends other than family or paid staff is not reported but the fact that 34% of this cohort at baseline in 2020 indicated they did not have friends other than family or paid staff demonstrates the need for affirmative strategies to assist participants to develop relationships.

### 4.4 Participants 25 and over

The 2020 Outcomes Report notes that NDIS participants tend to have poorer baseline health and wellbeing outcomes than Australians overall, and despite improvements on some indicators, outcomes generally remain poorer. For example, 37.4% participants rated their health as good, very good or excellent compared to 86.6% of Australians 25 to 64. Similarly, overall life satisfaction is poorer for participants than for the general population with 39.9% of NDIS participants reporting they felt “delighted”, “pleased” or “mostly satisfied” with their life, compared to 76.9% of Australians aged 25 to 64 overall.

After 3 years in the Scheme, outcomes data related to inclusion indicates improvements in:

* % who wanted to do a course or training in the last 12 months, but could not (from 33.5% to 29.8%)
* % who spend their free time doing activities that interest them (from 69.1% to 77.1%)
* % who have been involved in a community, cultural or religious group in the last 12 months (from 36.6% to 49.0%)
* % who know people in their community (from 59.2% to 67.2%)
* % who have someone outside their home to call on for practical support (81.2% to 90.1%)
* % who have someone outside their home to call on for emotional support (from 82.2% to 89.1%)
* % who often felt lonely (from 21.8% to 19.8%)
* % who are currently volunteering (from 18.8% to 23.8%).

The fact that the approximately 90% of participants reported having someone outside their home to call for practical and emotional support demonstrates an important impact of the NDIS. Taken together with other data, this suggests that participants are expressing confidence in the availability of paid support staff.

Following 3 years in the Scheme, outcomes that provide less cause for celebration include:

* % who feel able to advocate (stand up) for themselves (from 50.1% to 44.8%)
* % who feel safe or very safe in their home (from 79.1% to 76.5%)
* % who feel safe getting out and about in their community (from 49.5% to 45.6%)
* % who are currently working in a paid job (from 25.7% to 23.3%)
* % have had job(s) in the past 12 months (from 45.5% to 37.6%)

The outcomes data suggests that the NDIS has made some difference to the inclusion of participants in their communities but that there continues to be a long way to go with more than 30% indicating they do not know people in their community. The actuarial data however enables the Scheme to target strategies to achieve best results related to age, disability, level of function, gender, indigenous and CALD status and geography.

### 4.5 Concluding observations

The NDIS has contributed to supporting people with disability to be included in the community. But those first steps into the community enable participants see opportunities that others take for granted. They rightly demand more. So, while most indicators are moving in the right direction, the movement is slow, and more is required especially where data shows that participants in all cohorts would like to be more involved in community activities.

Some actuarial data however raise red flags that cannot be ignored. Those highlighted in this paper include when after being NDIS participants for more than 3 years:

* 20% of parents of children 0-6 do not think their child with disability fits into the everyday life of the family
* more than 25% of parents of children 0-6 do not feel their child is welcomed / actively included when they participate in community activities
* the vast majority of school aged children and young people do not participate in mainstream activities
* the percentage of young adults and adults who report they can advocate for themselves is decreasing and
* the percentage young adults and adults who report they know people in their neighbourhood is also decreasing
* participant young people are ten times less likely to get support in times of crisis from someone living outside their household compared to their peers in the general population.

Targeted strategies are required, in individual plans, through ILC programs and through LAC work to respond to the calls for help identified in the Outcomes Report.

## NDIS levers to facilitate inclusion

The NDIA levers to support inclusion at the policy level are extensive. The objectives of the NDIS Act require the NDIS to support the independence and social and economic participation of people with disability (S3(c)) and its principles require the provision of reasonable and necessary supports to support people with disability to live independently and be included in the community as fully participating citizens (S4(11)(b)).

The availability and capacity of informal support, a critical element of being included in the community, is an important consideration in the planning process. Principles related to plans require the NDIA to consider, respect and where possible build the capacity of family, carers and other informal supporters who are significant in the life of the participant (S31 (b) (c) (d) (da)). Planning is also required to consider the availability of mainstream and community services (S31(e)) and importantly, support communities to respond to the individual goals and needs of participants. (S31(f)).

In addition, a new Operational Guideline related to informal support is under development and will give guidance to all NDIA staff and Partners in the Community as to what is reasonable to expect of informal supporters and the reasonable and necessary supports the NDIA may provide to strengthen informal supports.

### 5.1 System reforms

Significant participant-facing work is currently underway to assist participants better connect with their community and mainstream services and to continue to provide the right supports to pursue their goals and aspirations. Those with greatest relevance to supporting participants to be included in the community are:

* Independent assessments that will allow the NDIA to better understand an individual’s functional capacity and environment to support consistent and fair access and individual funding decisions.
* Personalised budgets and plan flexibility that will give participants more flexibility in using their supports to achieve their goals.
* Supporting young children and their families that will strengthen the delivery of best practice of child centred, family focused support delivered in natural settings.

Whilst the final state of each reform is not yet bedded down, Council has had the opportunity to contribute to each area. Council sees the planned changed roles of NDIA delegates, LAC and ECI Partners and simplified NDIS pathways as heading in a direction consistent with supporting participants to be included in community. Additional enhancements to strengthen reforms related to inclusion will be identified below.

Council is extremely mindful however of the community concerns related to some of proposed reforms such as independent assessments and is concerned that these do not diminish the shared focus and commitment to the broader reform process. It is the view of Council that there is significant community support for efforts to make the Scheme more equitable and to increase participant choice and control through personalised budgets and plan support flexibility. The current process however seems to blame participants for the inflation in plan budgets rather than resting responsibility in the Agency for overpromising on co-design, under reporting on the dual goal of Scheme sustainability, making inconsistent decisions in relation to reasonable and necessary support and providing inadequate support to enable people in be included in the community. Plan budget inflation in the context of many participants (including those with large budgets) remaining lonely and isolated from the community, demonstrates the multidimensional nature of challenges to Scheme sustainability with a lack of accountability for the achievement of participant outcomes by all stakeholders in the NDIS ecosystem.

### 5.2 Independent assessment

An independent assessment is an assessment of functional capacity, including environmental and individual circumstances, undertaken by qualified health care professionals for the purpose of NDIS decision-making. The assessment will build an overall picture of how a person functions in different areas of their life in line with the World Health Organisation’s International Classification of Functioning, Disability and Health and the activity domains described in the NDIS Act. These are communication, social interaction, learning, mobility, self-care, and self-management.

The independent assessment is designed to also take account of a participant’s personal and environmental factors including the nature and level of informal support, their living situation, whether they have behaviours of concern, their need for disability related health supports, whether they are employed and the nature of their employment and any life stage transition they may be anticipating or experiencing. Additional factors identified through the data gathering process will be explored and may also be included.

Independent assessments will replace existing processes to determine eligibility with a more transparent and consistent approach. Once a person is found eligible, the independent assessment will be used to develop a personalised budget.

#### Commentary

There is significant community concern about the extent to which the independent assessment will accurately capture the support needs arising from the participant’s functional impairment, including personal and environmental factors unique to their situation.[[35]](#footnote-35) Council anticipates that even where the community has confidence in the independent assessment and budget setting processes, there would be concern in relation to its implementation. This concern is exacerbated in the context of fresh memories of Centrelink misusing an algorithm to determine whether recipients had been overpaid.

#### Enhancements to participant inclusion related to independent assessments

There is a need for resolution of issues of contention related to independent assessments so that participants have confidence in the adequacy and reliability of their reasonable and necessary support.

Council has called for a pause in the current process to enable a) engagement with the disability community in fresh dialogue to affirm a valued meaningful partnership in working toward both equity and Scheme sustainability and b) appropriate time for feedback, reflection and refinement of concepts and operation so that any future implementation is well informed.

**5.3 Personalised budgets**

The Planning for Personal Budgets Flexibility discussion paper describes a personalised budget as a participant’s final, approved budget which represents the reasonable and necessary level of funding the participant will receive in their NDIS plan. The personalised budget is derived from a draft budget developed from the independent assessment of functional capacity[[36]](#footnote-36) including environmental and individual circumstances as well as the participant’s age and location.

The draft budget is presented to the participant prior to the planning conversation with an NDIA delegate. The discussion paper indicates that during the planning conversation, there will be an opportunity to identify additional support requirements with the final approved personalised budget having flexible and fixed categories (rather than 15 categories of core, capacity building and capital items), thereby increasing participants choice and control over the use of their funds in pursuit of their goals. It is proposed that the personalised budget be released to the participant monthly or quarterly.

#### Commentary

The process of translating an independent assessment into a personal budget is complex and there is little information in the public domain about the Plan Budget Tool. Most Australians, with and without a disability are not mathematically literate at a level that enables them to conceptualise the way in which complex factors indicative of the individual nuances of disability and environment can be captured in a formula from which a personalised budget can be derived. Given the fundamental importance of the independent assessment to determining the level of the plan budget, it is not surprising that the community is worried about a process they do not understand.

Council is of the view that flexible personalised budgets will make an important contribution to assisting participants to be included in the community by giving participants greater choice and control over how they use their NDIS funds to implement their plan and pursue their goals. Many participants however will need extensive support if the enhanced flexibility is to translate into improved outcomes.

Consistent with its views first reported in advice on self-management to the Board (2014), Council is pleased to see proposals for roll over of unspent funds but takes the view that participant budgets should be released quarterly unless identified risks indicate a shorter period is required with an easy process through which participants can request a longer release time.

#### Enhancements to participant inclusion related to personalised budgets

The implementation of plan budget flexibility

Support to use personal budgets to achieve goals including using paid support to develop informal support.

### 5.4 Planning

The proposed planning process described in Figure 1 of the Planning for Personal Budgets Flexibility discussion paper indicates that an independent assessment of the participant’s functional capacity, including environmental and individual circumstances will be used to develop a draft plan, including a draft plan budget that will be provided to the participant prior to the planning meeting. The discussion paper indicates that the planning conversation will thereby focus on the participant’s goals and how their community and mainstream supports, and NDIS funds can be used to pursue these and meet their disability related support needs.

#### Commentary

The Oxford dictionary defines a plan as a *detailed proposal for doing or achieving something.* An independent assessment cannot lead to a draft plan. At best, an independent assessment can lead to a draft budget against which participants can map their goals and develop a plan, a detailed proposal of how to use community and mainstream supports and NDIS funds to pursue their goals and meet their disability related support needs.

To have confidence in the reform process, the community needs to have confidence that the draft budget is in fact draft and that additional supports identified during this planning conversation will be added to the budget to underpin a plan that can enable the participant to pursue their goals and meet their disability related support needs.

It is the view of Council that the planning process foreshadowed in the current reforms remains an administrative step to sign off the budget providing only high-level focus areas for the participant’s life. Importantly, the discussion of planning does not focus on inclusion nor identify the need to assist participants to plan for their own safety, important components of a planning conversation designed to embed people in community.

#### Enhancements to participant inclusion related to planning

A planning process that assists participants to:

* think about what community inclusion might mean for them and how to get support to be more included in the community
* build their independence, their social and economic participation, and their self-advocacy skills
* gain insights into services and supports that can assist them to reach their goals
* understand the NDIS ecosystem and first points of contact
* recognize the need for and have sources of support to
	+ strengthen / extend informal support
	+ build personal safeguards and
	+ make complaints.

### 5.5 Capacity building supports

Under proposed reforms, 15 categories of core, capacity building and capital budget structure will be replaced with a flexible and fixed budget structure. The discussion paper indicates that funds in the flexible budget will not be allocated to core or capacity building. Participants will be able to choose which disability-related supports they purchase and can change the mix of supports whenever they wish, enabling them to capitalise on opportunities as they arise.

The discussion paper indicates that some capacity building supports will be identified in the participant’s fixed budget (e.g., for employment or home and living), participants will be able to spend further funds on some types of support and providers will not be able to claim additional money on others. [[37]](#footnote-37) Council awaits the Operational guidelines to gain further clarification.

#### Commentary

Council is alarmed that the percentage of participants who feel able to advocate for themselves has reduced for participants whose outcomes have been reported over 3 years, going from 32.1% to 26.6% for cohort 15-24 and from 50.1% to 44.8% for participants 25+.

The separation of capacity building and core items in the participant budget obviously failed to encourage participants to value these investments and build their capacity. In 2019, Council reported on the significant underspend on capacity building supports and argued that capacity building is not well understood or valued.[[38]](#footnote-38) The paper drew attention to the significant under-utilisation in the domains of relationships, daily living, home living, employment and Support Coordination, items designed to support participants to achieve the outcomes of independence, inclusion and self-management which are at the core of the NDIS. The Council paper argued that better utilisation in these domains would also lead to a reduction in the need for core supports arising from capacity building.[[39]](#footnote-39)

It is critical that multiple strategies are developed to more effectively encourage participants to build their independence, their social and economic participation, and their self-advocacy skills to lead ordinary lives as well-informed consumers in the NDIS market.

Council applauds the Agency development of evidence guides that will outline “what works” and the plan to disseminate in multiple formats for different stakeholders. This strategy has potential to influence practice.

Attention needs to be drawn to programs and approaches highlighted in this paper. In addition, Council has consistently identified peer networks hosted by Disabled Persons’ Organisations as a cost-effective approach to capacity building and highlighted the role of action learning in supporting a person to extend themselves and develop new skills.[[40]](#footnote-40) The skill set of support staff is also critical in facilitating or inhibiting the growth of an individual.[[41]](#footnote-41)

#### Enhancements to participant inclusion related to capacity building

Multiple strategies to more effectively encourage participants to build their independence, their social and economic participation, and their self-advocacy skills to lead ordinary lives as well-informed consumers in the NDIS market.

Encourage participants to join peer networks hosted by Disabled Persons’ Organisations.

### 5.6 Support to embed in community

The current reforms propose a larger and more skilled Partners in the Community network to be a consistent and helpful point of contact for participants with the time and skills to assist with their NDIS needs. LACs would focus more on core connection roles, would be based in communities, have a thorough understanding of a participant’s goals, support participants to connect to community and mainstream supports and build the capacity of their informal supports. They would also assist with plan implementation, including how to use their flexible plan budget most effectively.

A new practice framework is under development.

#### Commentary

Local Area Coordination is the NDIA infrastructure intended to support participants to be included in the community. Compared to the current model, the NDIA planned change is an improved approach. A major difference however between the NDIA plans and the Council proposal[[42]](#footnote-42) relates to the NDIA weighting of elements, prioritising plan implementation over community capacity building (enabled under S31(f) of the NDIS Act). Council remains concerned the NDIA approach will see LACs default to connecting participants to services and the value for money but more difficult work of developing relationships and non-service solutions (that require community capacity building) will be lost. Given the planned reforms to plan budget flexibility give participants the ability to purchase support coordination to assist in plan implementation if LAC support is insufficient, it is the view of Council that a stronger focus on community capacity building with and on behalf of participants would significantly strengthen the LAC support for inclusion.

The Council approach to Local Area Coordination recommended that LACs work with all participants, including those on the complex pathway on the basis that they tend to be trapped in multiple service systems that create their own dependencies and remove the person from family and community. These individuals desperately need the relationships of ordinary community life to rebuild their capacity and citizenship, potentially reducing their complexity. It appears the Agency approach will prevent LACs working with participants in the complex pathway, thereby providing a significant barrier to their inclusion. Council is of the view that the Agency needs to rethink this decision or require planners and support coordinators to have the responsibilities and competencies identified for LACs in this paper.

Other differences between the planned NDIA approach and that of Council relate to the approach to commissioning and piloting. Council is concerned that the Agency approach to commissioning will see the LAC contracts awarded to large agencies not necessarily of the community. This will reduce participant ability to choose their LAC provider and may limit the specialisation among LACs. Importantly, it will reduce the local leverage that arises through existing relationships and reduce the potency of the NDIA role in enhancing the welcoming nature of community, so vital for inclusion.

Finally, Council is concerned that the NDIA reluctance to pilot diverse approaches limits the opportunity to try significantly different approaches at this time of reform.

It is the view of Council that its proposed Local Area Coordination model will be more effective in embedding people with disability in community than the model proposed by the Agency. However, whatever approach is ultimately adopted, it is critical that the impact of the changed role of Local Area Coordination is understood and planned for. Whilst the new approach will be delivered via a fresh tender process, staff currently undertaking LAC roles in successful organisations cannot be assumed to have the knowledge and skills to undertake the refreshed role with a danger of default to previous practices that are not fit for purpose under a changed role. Council looks forward to reviewing the new Local Area Coordination practice framework, associated KPIs and the approach to training, especially being led by people with disability, to seek confidence in the approach.

#### Enhancements to participant inclusion related to support to embed in community

Adjustment to current proposals including:

* Reprioritisation of elements in the LAC role to have a stronger focus on community capacity building.
* Process in place to review LAC practice in the context of the new practice framework and KPIs.
* Review the decision that prevents LACs working with participants in the complex pathway or require planners and support coordinators to have the responsibilities and competencies identified for LACs in this paper.

### 5.7 Support for plan implementation

Under Scheme reforms, those participants who need support to implement their plans will use LACs. Participants will also be able to access support coordination (from their flexible budget) if they require more support than can be offered by the expanded LAC role. Many participants will consider they have the confidence and competence to implement their plans without support.

#### Commentary

Elsewhere in this paper, Council suggested that there is a general lack of accountability to participants for the achievement of outcomes, by all stakeholders. For many participants, increased budget spends have not reduced loneliness and have not increased their ability to speak up for themselves.

The development of evidence guides will assist participants, families and LACs to know “what works”. LACs will also have to assist people with disability to identify potential options of services and supports, discern quality in a sea of advertising, develop service agreements that represent their interests and over time, monitor outcomes.

If the NDIA wants to ensure reasonable and necessary support assists participants to be included in the community, it is important to ensure that plan implementation ensures all participants have the capability or are supported to have the capability to:

* understand ‘evidence-based practice’ that will assist them to have reasonable expectations about the support / intervention best placed to enable them to achieve their goals. In this context, current NDIA work to develop and disseminate evidence guides is a critical step with multiple broad-based strategies required to ensure informed participants.
* select providers based on their assessment of the provider ability to engage, train, and support skilled staff and deliver on promised outcomes.
* develop service agreements that reflect their preferences about what, where, when and by whom support is delivered. Council observations suggest that most service agreements reflect the significant power imbalance between the provider and the participant for whom the option of leaving the provider is not real, at least in the immediate situation. Work is required to move service agreements to documents that reflect the goals, preference, and voice of the participant.
* monitor for outcomes and hold providers and other stakeholders to account when they do not achieve the outcomes planned.

#### Enhancements to participant inclusion related to plan implementation

Continued focus on evidence guides to strengthen participant knowledge about ‘what works’ and to support the development of provider practice consistent with including people in the community.

An NDIA project to strengthen the participant focus of service agreements to:

* reflect participant preferences about what, where, when and by whom support is delivered
* provide a framework for setting goals and monitoring outcomes.

### 5.8 Processes under the responsibility of DSS

Council cannot provide advice about including people with disability in the community without noting the critical role of ILC services in building the capacity of people with disability and the community and of the National Disability Strategy in developing an inclusive Australian community.

#### Enhancements to participant inclusion related to the ILC and National Disability Strategy

Continued engagement with DSS to influence the delivery of ILC services and the framing of the National Disability Strategy.

### 5.9 Concluding observations

The strong foundations for inclusion of the NDIS Act have not yet been realised. Certainly, the failure of the National Disability Strategy to make significant progress in building welcoming communities is part of the problem as has been the NDIS in its transition mode, challenged to transition people with disability from state and territory systems into the Scheme.

Now that the NDIA is pivoting to a post transition mode, its Scheme reforms propose focusing on helping 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. Council is of the view that the Scheme reforms are moving in the right direction but has identified features that are missing and enhancements that could be made to use the NDIA levers more effectively to support participant inclusion.

## Impact on Scheme sustainability

Scheme sustainability relies significantly on participants building capacity and relationships that enable them to live ordinary lives included in community. This paper provides advice as to the way in which the NDIA can maximise the opportunities and support for participants to be included in the community. Whilst recognising the importance of a whole of government approach, the paper only focuses on the levers under the NDIA control that will be most effective in supporting this goal.

The core of support for inclusion lies in building the capacity of the individual, supporting the specific community to be welcoming and providing a skilled support to facilitate connection and mentor, support and negotiate the adjustments required.

The most fundamental difference for Scheme sustainability, outlined in this paper is the role of Local Area Coordination, the designated NDIA facilitator / guide that carries the responsibility for facilitating inclusion. It is the view of Council that its approach to Local Area Coordination proposed in the recent Council advice on this issue will be far more effective in promoting Scheme sustainability than the Local Area Coordination approach promoted by the Agency.

The effectiveness of the Council approach rests on its prioritisation of participant and community capacity building over plan implementation. The community capacity building is critical to the development of relationships and non-service, value for money options typical of ordinary lives and valuable for authentic engagement and contribution. Council understands that community capacity building is also a whole of government approach but the NDIA through its Partners in the Community has a role at the local level around individual participants with whom they work. These roles include raising awareness and understanding of disability in community organisations, mainstream services, and businesses, partnering with individual organisations to assist them to become more inclusive, building the capacity of individual organisations to become more inclusive on an ongoing basis and engaging in larger community development projects designed to have a broader social impact.

The Agency approach on the other hand is more focused on assisting participants to implement their plans, an approach that Council fears will surround participants with paid supports that can unintentionally push out and inhibit the development informal freely given support.

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## Appendix 1 Accessible figure 1

Bigby’s graphic depiction of the concept and outcomes of inclusion in figure 1

Inclusion is shown as 3 intersecting circles – circles of social, economic and political inclusion

Social inclusion means

* having meaningful relationships with family and friends
* feeling valued and welcomed in interactions with others including strangers

Economic inclusion means

* having options to participate in paid or voluntary work and contribute as a productive member of society
* having choices as a valued consumer of goods and services

Political inclusion means

* Being able to influence decisions affecting your life, for example by voting in elections or participating in civil and political activities
1. Gooding P, Anderson J, McVilly K, (2017) Disability and Social Inclusion ‘Down Under’: A Systematic Literature Review, University of Melbourne, p19 [↑](#footnote-ref-1)
2. Measures of feeling accepted by the community are not part of the NDIS Outcomes questions. [↑](#footnote-ref-2)
3. A plan is defined in the Oxford dictionary as a *detailed proposal for doing or achieving something.* [↑](#footnote-ref-3)
4. Discussed in the body of the paper [↑](#footnote-ref-4)
5. enabled under S31(f) of the NDIS Act, 2013 [↑](#footnote-ref-5)
6. Bigby (2009) Known well by no‐one: Trends in the informal social networks of middle‐aged and older people with intellectual disability five years after moving to the community [↑](#footnote-ref-6)
7. Christine Bigby, Tim Clement, Jim Mansell, Julie Beadle‐Brown, (2009) ‘It’s pretty hard with our ones, they can’t talk and the more able bodied can participate’, Journal of Intellectual Disability research v53 (4) [↑](#footnote-ref-7)
8. Craig D, and Bigby C, (2014) *She’s been involved in everything as far as I can see,* Supporting active participation of people with intellectual disability in community groups. Journal of Intellectual and Developmental Disability [↑](#footnote-ref-8)
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10. 19 Stories of Social Inclusion <https://www.19stories.org/themes> [↑](#footnote-ref-10)
11. Bigby C and Wiesel I, Supporting inclusion, Workbook for online training program Nov 2014, [↑](#footnote-ref-11)
12. If the aim of personalisation is to facilitate people’s connections to local communities based on their interests and values (not their disability), does social inclusion still encompass a Men’s shed program in which five of the twelve members are people with disability count as inclusion? [↑](#footnote-ref-12)
13. Gooding P, Anderson J, McVilly K, (2017) Disability and Social Inclusion ‘Down Under’: A Systematic Literature Review, University of Melbourne, p19 [↑](#footnote-ref-13)
14. Gooding P, Anderson J, McVilly K, (2017) [↑](#footnote-ref-14)
15. Gooding P, Anderson J, McVilly K, (2017) p15 [↑](#footnote-ref-15)
16. Overmars-Marx T, Thomése F, Verdonschot M, & Meininger H (2014) [↑](#footnote-ref-16)
17. Bigby, C., Anderson, S., Cameron, N. (2018). Full report: Designing effective support for community participation for people with intellectual disabilities. Report for Disability Research and Data Working Group. Melbourne La Trobe University, Living with Disability Research Centre. [↑](#footnote-ref-17)
18. Bigby, C., Anderson, S., Cameron, N. (2018) p43 [↑](#footnote-ref-18)
19. Resourcing inclusive communities (2019) Circles of Support, A manual for getting started, Accessed <https://www.ric.org.au/assets/Uploads/circles-of-support/fc67c032b4/Circles-of-Support-Manual-2019.pdf> 1 April 2021 [↑](#footnote-ref-19)
20. Bigby, C., Anderson, S., Cameron, N. (2018). Full report: [↑](#footnote-ref-20)
21. Sherwin, J., (2011) The desire for friendship comes quickly, friendship does not: an exploration of valued roles and relationships, The SRV Journal 1(1), 58-62. Accessed at <https://socialrolevalorization.com/wpcontent/uploads/2019/04/The_Desire_for_Friendship.pdf> 23 June 2019 [↑](#footnote-ref-21)
22. Craig D and Bigby C (2014) [↑](#footnote-ref-22)
23. Bigby C and Wiesel I, (2014) [↑](#footnote-ref-23)
24. Stancliffe R, Wilson N, Gambin N, Bigby C, Balandin S, (2013) Transition to retirement, Sydney University Press [↑](#footnote-ref-24)
25. 19 stories of social inclusion [↑](#footnote-ref-25)
26. National Alliance of Capacity Building Organisations https://www.nacbo.org.au which includes Belonging Matters (VIC), Community Resource Unit (QLD), Imagine More (ACT), Valued Lives (WA), Family Advocacy (NSW) and JFA-Purple Orange (SA), [↑](#footnote-ref-26)
27. Bigby C and Anderson C, (2020), Editorial, Performance, purpose and creation of encounter between people with and without intellectual disabilities, Journal of Intellectual and Developmental Disability [↑](#footnote-ref-27)
28. Bigby, C., Anderson, S., Cameron, N (2018) p13 [↑](#footnote-ref-28)
29. Bigby, C., Anderson, S., Cameron, N (2018) p13 [↑](#footnote-ref-29)
30. Bigby C, Bould E, Iacono T and Beadle Brown J, Organisational structures and processes associated with good Active Support, La Trobe University, Living with Disability research Centre presentation [↑](#footnote-ref-30)
31. Stetten N, LeBeau K, Aguirre M, Vogt A, Quintana J, Jennings A, Hart M (2019) Analyzing the Communication Interchange of Individuals With Disabilities Utilizing Facebook, Discussion Forums, and Chat Rooms: Qualitative Content Analysis of Online Disabilities Support Groups, Journal Of rehabilitation Assist Technology V6 (2) [↑](#footnote-ref-31)
32. Sweet K, LeBlanc J, Stough L, Sweany N, (2019) Community building and knowledge sharing by individuals with disabilities using social media, Journal of Computer Assisted learning v36(1) [↑](#footnote-ref-32)
33. Stetten N, LeBeau K, Aguirre M, Vogt A, Quintana J, Jennings A, Hart M (2019)) [↑](#footnote-ref-33)
34. Borgstrom A., Daneback K,and Molin M., Young people with intellectual disabilities and social media: A literature review and thematic analysis, *Scandinavian Journal of Disability Research*, 21(1), pp.129–140. DOI: <http://doi.org/10.16993/sjdr.549> [↑](#footnote-ref-34)
35. There are also many other areas of concern. [↑](#footnote-ref-35)
36. aligned to the six activity domains in s24 and 25 of the NDIS Act namely self-care, mobility, learning, communication, social interaction and self-management [↑](#footnote-ref-36)
37. NDIS (2020) Consultation paper: Planning policy for personalised budgets plan flexibility, p19 [↑](#footnote-ref-37)
38. Independent Advisory Council (2019) *Capacity building: Insights from NDIS data* [↑](#footnote-ref-38)
39. Independent Advisory Council (2019) *Capacity building: Insights from NDIS data,* p3 [↑](#footnote-ref-39)
40. Independent Advisory Council (2015) *Capacity building for people with disability, their families and carers* p23 [↑](#footnote-ref-40)
41. Bigby C, Bould E., Iacono T., Kavanagh S and Beadle-Brown (2020) *Factors that predict good active support in services for people with intellectual disabilities: A multi-level model,* Journal of Applied Research Intellectual Disability v33 (3) p334-344 [↑](#footnote-ref-41)
42. In its advice to the Board on Local Area Coordination (February 2021), Council argued that the design of the Local Area Coordination function should be characterised as:

	* a facilitator of change at an individual and community level
	* aiming to empower people with disability to determine their own goals, make their own decisions and work towards achieving what is important for them
	* staffed by people who work alongside a person with disability, family member or carer to help them plan for the future and link them to whatever community organisations, services or businesses in their local community will assist them achieve their goals.
	* prioritising a community engagement component involving networking, partnerships and community development activities, to support organisations and communities to become more inclusive of people with disability to create new opportunities and link individuals to community initiatives
	* supporting the development of support approaches characterised by meaningful community relationships, that can complement or substitute for paid supports. [↑](#footnote-ref-42)