NDIS Review POinters

A collection of JFA papers published during the period of the NDIS Review 2023

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ABOUT THE PUBLISHER

JFA Purple Orange is an independent social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially about policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called *Citizenhood*.

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PREFACE: RAISING EXPECTATIONS ABOUT WHAT THE NDIS CAN ACHIEVE

Following the establishment in late 2022 of the NDIS Review lead by co-chairs Bruce Bonyhady and Lisa Paul, with a report deadline of October 2023, Purple Orange wanted to support discussions around various aspects of the NDIS. Accordingly, Purple Orange designed the To The POint NDIS Review Conversation Series to explore specific aspects of the Scheme, outlining key issues and possible solutions, and with the goal of stimulating conversation.

Between February and August 2023, we released a paper each fortnight on a different topic of reform critical to the work of the Review panel. We followed the release of each paper with a 45-minute lunchtime webinar conversation inviting questions and feedback about the ideas put forward. We also engaged with the disability community, stakeholders, and researchers via one-to-one conversations, emails, social media, and other correspondence.

The input and feedback we received was rich and presented a diverse range of perspectives and insights. We deeply appreciate the generosity of the contributions so many people made and the spirit of sharing ideas that this Series has generated. Our work has been strengthened as a result. We also hope this Series has made a valuable contribution toward the deliberations of the Review panel and to a stronger and more sustainable Scheme for the benefit of Australians living with disability now and into the future. We have no doubt the NDIS is an essential component of ensuring people living with disability get a fair go at what life has to offer and deserves the strong support of all Australians. However, there are many areas in which the Scheme can be strengthened, and the 10-year anniversary of its creation has been an opportune time to reflect, debate, and learn as we strive to achieve this outcome together.

In this combined publication, we have brought in all 14 papers produced during this Series, listed as chapters 2-15, in the sequence as the Series unfolded. In each case we have added summary commentary on the feedback we received through the lunchtime webinars and other channels. This helps showcase some of the richness of the dialogue that each paper stimulated. As is to be expected, these written commentaries are only glimpses from these dynamic back-and-forth interactions, but by distilling some of the key ideas they can help underpin the ongoing debates that will undoubtedly continue beyond the Review. Of course, these conversations do not end here. We welcome continued dialogue via our socials at LinkedIn, Facebook, or X (formerly Twitter) at @JFAPurpleOrange or email robbiw@purpleorange.org.au.

In addition, we have added two new chapters that were not previously published as papers in the series. Chapter 1 looks at the question of Scheme outcome measures. It seems right that the consideration of outcomes measurement should come before all other matters, else the NDIS components have no context for assessing their success.

Chapter 16 contemplates key matters relating to the complexity of transition to a stronger Scheme.

We hope this publication is useful to the NDIS Review and beyond, and we remain committed to the pursuit of a successful and sustainable NDIS that plays its part in helping ensure Australians living with disability are afforded the same respect and the same opportunities as non-disabled Australians.

CHAPTER 1: MEASURING SCHEME IMPACT

KEY POINTS

- The NDIS is anchored on the goal of social and economic participation, which can be taken to mean participants are taking up valued roles in mainstream community life, and not just being present in community
- Purple Orange refers to these roles collectively as Citizenhood and these can be measured
- A framework called the Four Capitals can give the NDIA a mechanism for quantifying the extent NDIS individual budgets are building participant life chances, key to roles of Citizenhood

The NDIS is there for a reason; to provide Scheme participants with an individual budget that is reasonable and necessary to lift and sustain each person into social and economic participation. It is often described as being founded on principles of social insurance, but the word insurance can be confusing for some people, because the general idea of insurance is that it is an arrangement to offer some protection in the event of an unexpected loss or change. That isn't the case for the NDIS. It is more a scheme of *assurance*, where eligible persons can be assured that there are resources available to address the consequences of the person's disability.

As such, the NDIS individual budget represents an *investment* in the person by the Australian governments, intended to build the person's social and economic participation, and through mechanisms that give the person authentic choice and control. Measuring outcomes is the way the Australian governments, and importantly the Scheme participants themselves, can assess the return on that investment.

So, measuring outcomes is important.

Currently, and despite the NDIA's sincere commitment to trying to understand the Scheme's impact, the outcome measures currently used are patchy and may not be providing the level of insight needed. For example, one measure of social participation is the amount of time the NDIS participant spends in community. However, this measure does not give any detail on how that time is being spent. If it includes travel in an accessible taxi or a support worker's vehicle, and time spent walking through a park, or sitting in a café, without meaningful contact with others, then the measure is too blunt, counting *presence* in community rather than *participation*. The two are very different, and community presence does not necessarily mean the person is meaningfully participating in ways that are typical for most non-disabled people.

Measuring the right thing poorly is better than measuring the wrong thing really well, and in this case, measuring time spent in the community is measuring the wrong thing. This is because community presence by itself does not resolve the barriers that result in exclusion.

It is entirely possible for a person to be present in community in ways that reinforce separateness, otherness, exclusion. In an inclusion context, the phrase ‘community tourism’ which sounds entirely wholesome, is anything but.

So if measuring community presence is a red herring, the question moves to one of how we might best understand if a person is truly participating. A useful distinction between community presence and authentic social participation is to consider the extent to which the person is engaging with other people in community life, and in ordinary valued ways.

In a recent visit to a beautiful wetland in SA, we saw a man living with disability walking. The wetlands have a loop path and we passed this man several times. Each time was the same. He walked several paces behind his support worker, who was scrolling on their mobile phone. Currently, in the way the NDIS outcomes are being measured, this counts as a success, because it is time spent in the community. But it is no success; the man was entirely alone.

We have seen similar instances of people being taken to cafes, to shopping malls, and the like, with the same result. When this is counted as a Scheme success, it is because there is a perceived transactional benefit. A worker showed up at the person’s house and took them out. They were with them, and then they brought them back.

That is not the Scheme outcome people fought for. People fought for a Scheme that not only would mark an end to the rationing, to the waitlists for help, but also for a Scheme that would achieve the opposite of *Shut Out*; a Scheme that would help ensure each person living with disability is a valued member of mainstream community life.

Moving forward, we have to find better ways to measure authentic outcomes, and we must stand alongside the NDIA in this quest, because measuring authentic outcomes is hard. And as we’ve said above, it is better to measure the right thing poorly than the wrong thing really well.

When we published the Model of Citizenhood Support, it contemplated what it meant to be truly helpful in people’s lives. First, we described something called Citizenhood, which we assert is what lies within the Scheme’s goal of social and economic participation. Citizenhood is defined as where:

> *“…a person is actively involved as a valued member of their local community, contributing to community life.”*

This is what it means to not be *shut out*. It is what it means to belong.

As such the entire NDIS market – the disability support providers, the early childhood professionals, the employment service providers, the SDA providers, the support coordinators, the LACS, and everyone else providing NDIS-funded services – are in the business of assisting people into these valued roles in mainstream community life; into Citizenhood.

Therefore, a key measure of the Scheme's success is the extent to which it is assisting people into valued roles, and not the extent to which a person is driven to a wetland to walk alone.

This can be measured tangibly. Paid mainstream employment is a role of Citizenhood and therefore a key Scheme outcome. It is relatively easy to count, and Australia is used to counting employment statistics, so long as this outcome is not confused with employment mechanisms like Australian Disability Enterprises, where the work involves congregation of people living with disability for pocket money wages.

Other roles that can be tangibly measured include mainstream volunteering roles, mainstream community club memberships, diverse friendship networks, neighbour connections, and the like. What qualifies them all is that they are ordinary; that they bear all the hallmarks of the valued roles that non-disabled people have in their lives.

Therefore, we assert the NDIA can explore outcome measures that help reveal the extent to which a Scheme participant is taking up, and holding, valued roles in community life.

This can be taken further. We might argue that it is not the job of disability service providers to deliver people into valued roles. There are two reasons for this. First, each of us builds our life journey based on discovering the things we care about, the choices we make, and the opportunities we take. In other words, it is not a disability support provider's job to deliver a person into roles of Citizenhood. That is for the person themselves to craft, based on their choices about what's important to them. The NDIA can measure the extent this is happening for people as a result of their individual budget.

The second reason is that when disability support providers seek to deliver valued roles directly to the person, albeit with hopefully the best of intentions, the choice-making about those roles tends to shift to the service provider, on the basis of what they think they can offer. Also, the world of roles a disability service provider creates can become a facsimile world, different to the real world; housing that is different to what most people have, employment this is different to what most people have, social lives that are different to what most people have, and decision-making that is different to what most people have.

So what then is the role of the disability support provider? How is that agency to be truly helpful? Our Citizenhood model argues the disability agent/agency's job is to build the person's life chances, so the person is then able to take up, or remain in, valued roles that are meaningful and fulfilling. Citizenhood sets this out in four main ways, called the Four Capitals, and we argue these are an example of a framework the NDIA can use to build more meaningful outcome measures, that hold NDIS suppliers more accountable for the impact of their work, and which give a more authentic way for the NDIA to assess return on investment.

Below, we give a brief summary of each of the Four Capitals.

Personal capital

The first of the Four Capitals refers to the person's belief in their own value, their gifts, their capacity to grow, to take up valued roles, to see hope in their future, to have jurisdiction over their own decisions, and take purposeful actions. It is Personal Capital that gives you the belief to apply for a job, to ask someone out on a date, to create a sense of home, to take care of your health, and to take a chance on the things that are important to you.

We argue this is a central outcome for the NDIS. Given the tyranny of low expectations that have dogged the disability community for generations, it is surely meaningful if the Scheme supports a participant to reclaim their right to a fair go at what life has to offer, to imagine their valued place in mainstream community life, to see themself for their strengths and gifts and not for their deficits.

This can be measured. Easily.

Knowledge capital

The second of the Four Capitals refers to the person's knowledge and skills. It contemplates how the person is supported to make the best use of the skills and knowledge they have, and how they are supported to grow new skills and knowledge.

The NDIS currently includes a 'capacity-building' element in the individual budgets of many participants living with disability. Often this capacity-building has a therapeutic character, be it speech pathology, occupational therapy, and the like. These can be very important investments, but only if we contemplate how the benefit might be understood. Therefore, we argue that investment in such endeavours can best be measured by the extent to which it grows authentic Knowledge Capital that moves people closer to the take-up of valued roles. Otherwise, the therapeutic pathway is at risk of becoming engrossed in trying to fix the person's disability instead of trying to fix the consequences of disability. An outcome measure based on ideas around Knowledge Capital in support of Citizenhood, can provide clarity on this.

Meanwhile, it is not unusual for people living with disability in service provision to lose skill and knowledge. For all of us, the retention of our skill and knowledge is supported by us *using* our skills and knowledge. Unfortunately, it is not unusual in disability services for the service staff to do things *for* the person rather than *with* the person. This is often because it is quicker and more convenient. So, again hopefully with the best of intentions, the service provider inadvertently erodes what the person knows and can do by not giving the time and attention to supporting the person to be centrally involved in those things as part of the routine of daily supports.

Translating this into outcome measures, the NDIS might contemplate how to measure the extent individual budgets are being converted into the growth in, and defence of, participant knowledge and skills that can take them into valued roles.

Material capital

The third of the Four Capitals refers to the tangible things in a person's life. It includes the things the person owns or has control of, and also the public things the person can access, like buses, the shopping mall, the beach, community clubs, employment spaces, education spaces, and so on.

There are two important things the NDIA might measure to assess success. The first is the extent to which the participant's individual budget is used in a way that defends and advances their personal Material Capital. For example, does a support provider take good care of the person's stuff? Does a support provider assist the person to move away from poverty (the relative absence of personal Material Capital) into waged employment where the person has disposable income on the same basis as most non-disabled Australians?

The second is the extent to which the participant's individual budget is used to assist the person use mainstream community resources – *public* Material Capital –on the same basis as most non-disabled Australians. This includes things like buses, libraries and the like, and not as a 'tourist group', and not in aloneness.

These are all elements that can be measured as Scheme outcomes, in support of social and economic participation.

Social capital

The fourth of the Four Capitals refers to the people in our lives. As humans we are interdependent, we give and we take, we live in community where we take up roles that bring value to others, and in turn we gain value from the roles others take up.

But Social Capital isn't just a marketplace of mutual utility. Social Capital is about the relationships that have importance in our lives. In the many workshops we have run over the years exploring the nature of a good life, themes like *family* and *friends* always feature prominently. This taps the importance of what it means to *belong*, and this sense of belonging is at the heart of the Scheme's goal of social participation.

The NDIA could contemplate setting outcome measures that explore the extent an individual budget assists a participant to retain connection with the people in their life important to them, and at the same time the extent the participant is assisted to enter new social connections, particularly if the participant has low Social Capital. This is important because many Scheme participants will likely have levels of Social Capital where the only people in their lives, other than core family, might be other people living with disability and people paid to be there. It is a cliché of otherness to assume that the only friends a disabled person can have are other disabled people. And it is a fallacy to say a disability support worker is a person's friend, because they are not. Friends are not paid to be there.

Outside of the family each of us was born into or raised in, the most meaningful relationships in our lives – partners, best friends, close friends, sincere acquaintanceships – begin with meeting each of these people for the first time. If that first encounter does not happen, nothing else can follow.

This can be a key outcome measure for the Scheme; the extent to which individual budgets are being used in ways that assist participants into new connections and thereby growth in their Social Capital.

Conclusion

Based on the above, we argue the NDIA can build a fresh approach to measuring Scheme outcomes, based on quantifying the extent to which an individual budget is lifting the participant into valued roles in community and economy by advancing the participant's Four Capitals.

The same can apply to measuring the impact of Information, Linkage and Capacity-Building (ILC) program funds, the Specialist Disability Accommodation (SDA) framework, the use of assistive technology, and the impact of the roles of Local Area Coordinators and other intermediaries.

A set of example measures are set out in the 2013 edition of the Model of Citizenhood Support.

As with the NDIA's previous selection of standardised assessment tools, there are standardised outcome measure tools that the NDIA might consider, but the problem with these is they weren't designed with this Scheme in mind. Also, a number of these tools still include considerations of impairment.

As per our argument in an earlier paper about assessment tools, we assert the Scheme, with over 600,000 participants, can grow its own valid and reliable outcome measures, and that such measures should be anchored on the take up, and defence, of valued roles in mainstream community life.

CHAPTER 2: RESTORING SIMPLICITY AND CHOICE TO THE NDIS PARTICIPANT PATHWAY

KEY POINTS

- The NDIS participant pathway is currently too complex
- A simple pathway based on a conceptual framework of 'Indicate – Calibrate – Evaluate' would improve the participant experience
- Plans should be 'owned' by the participant, not the NDIA
- Each role attached to a simple participant pathway should be clear and the boundaries between them well-defined

'Currently nine governments fund, organise and, to a varying extent, directly supply supports to people with disability and their carers. The Commission is proposing a simpler approach…'

These are the words[1] of the Productivity Commission in its 2011 report on disability care and support in Australia. Recognising the complexity of the previous arrangements, as well as the dominance of top-down block funded services, the Productivity Commission set **simplicity** and **individual choice** as core foundational principles in how it, and indeed, the disability community, imagined a new national disability scheme could take shape.

Yet, as the new approach was designed and implemented, complexity increasingly took hold. Opportunities for authentic individual choices shrunk in the face of cumbersome processes, ill-defined roles, unclear boundaries, and a regrettable regression to block funding models in some support areas. With the 10-year Review of the National Disability Insurance Scheme (NDIS) underway, now is an opportune time to revisit the original vision and principles of the Scheme and develop new approaches in some critical areas.

We acknowledge that the National Disability Insurance Agency (NDIA) has a difficult task in delivering a fair and equitable method of investing in changing the life chances of Australians living with disability. Without doubt, achieving authentic inclusion is a challenging quest. In any reform of the size and magnitude of establishing the NDIS, it can be difficult to avoid complexity creeping into systems and processes. However, the first rule of thumb is to establish **simplicity** as the **key anchor point**. System elements and process steps tend to snowball in complexity through the development stages, but if they have a sound provenance back to simple, compelling principles, then the system is more likely to establish and retain coherence.

The current NDIS participant pathway is too complex and there is a lack of calibration between the decisions made by different NDIA staff. The pathway often involves a lot of inefficient back-and-forth wrangling between the NDIA, Local Area Coordinators (LACs), participants, and their supporters. The clear articulation of authentic choices is often lost to overwhelming complexity, rushed meetings, and delayed decisions. All of these factors routinely produce inconsistent or unsuitable outcomes and can lead to costly reviews and appeals.

Many NDIS participants highlight the importance of ‘speaking NDIS’ to the resulting budget allocations within their plans, as if there is a special language or dialect required to navigate the Scheme. Similarly, participants tell us that obtaining medical and therapy reports that are written in a particular way and having access to advocacy supports, or even a local member of parliament, can make a significant difference to access decisions and budget settings. When these factors influence outcomes, consistency and equity are lost.

Each of these common experiences of the current complicated participant pathway does not fulfil the original vision of the NDIS. This is the first topic we would like to focus the collective minds of the disability community on as part of our NDIS Review Conversation Series. Below, we kick off the conversation by presenting an alternative approach to Scheme access and planning and invite debate.

A simple participant pathway

A simple pathway based on a conceptual framework of **‘Indicate – Calibrate – Evaluate’** would improve the participant experience, produce greater consistency in decision-making, and lower the administrative burden. Via a simple, non-clinical, upfront assessment process that maps the **consequences of disability**, a participant would receive an **indicative budget** considered reasonable and necessary to change those consequences. Then, the participant (or parent/guardian of a child) builds a draft plan that focuses on what is important for them. The participant chooses who supports them in developing their draft plan or they may opt to do this themselves.

Once a plan is drafted, an NDIA delegate works with the participant to **calibrate** it so that the components are relevant and reasonable and fit within the Scheme’s parameters. The plan is then signed off. At the end of the plan’s term, the NDIA delegate and participant **evaluate** how it went, to look at what worked, how well, and what this means for the participant’s next budget. This data also helps the NDIS evolve, by identifying what types of investment produce the best outcomes, for example, in terms of mainstream employment, inclusive housing, and authentic membership in community and economy.

Participant choice and plan authorship

Each NDIS participant should be the **‘author’** of their plan. It should reflect their **authentic choices** based on their individual goals. However, the current complex participant pathway generates NDIS plans that are largely ‘owned’ by the NDIA. Complexity in the NDIA’s processes inevitably increases its control while restricting the participant’s choices.

In contrast, the proposed simple participant pathway, outlined above, facilitates the individual authorship of plans, allowing a person to draft their own plan based on an indicative budget. They can also decide if they would like assistance in developing their goals and articulating their support needs from others, such as a family member, friend, or LAC.

Another way that the current approach is eroding participant choice and individual plan authorship is through a shift back to the group consumption model; that is, the antithesis of the original vision for the NDIS. Block-funded, shared group services are continuing to be included in plans, particularly for participants with higher support needs, on what appears to be an unspoken basis of reducing costs in line with a misinformed Scheme sustainability narrative. A plan that includes block-funded supports may be the result of insufficient 'individualisation' within the pathway (for example, when residents of a group home are, in effect, assessed in the context of living with other people), and/or because limited choices have been made available to the participant, and/or because the participant has not been supported to change their expectations about what might be possible in their lives. In these ways, the plan does not pass muster as an 'individual plan', as it does not adequately reflect authentic, informed, individual choices in pursuit of personalised goals.

Clear roles with defined boundaries

Each role attached to a simple participant pathway should be clear and the boundaries between them well-defined. But currently these roles and boundaries are unclear, with LACs bogged down in the planning process and completing tasks that would be more appropriate for the NDIA delegate.

Consequently, who the LAC role is intended to serve is confused and conflicted. Does the LAC represent and work on behalf of the Scheme, or does the LAC represent and act in the best interests of the participant? This conflict is untenable for a well-functioning participant pathway and should be urgently addressed as part of the NDIS Review.

As stated above, the participant should be the 'author' of their plan. The NDIA delegate should be the **agent of the Scheme** upholding its values and parameters. And the LAC should be an **agent of the participant**, if a participant elects to access the support of one. The role of the LAC should be to stand alongside the person, supporting them to access information, make decisions, and connect to their community. To avoid conflicts and confusion, there should not be any overlap or duplication between the roles of the NDIA delegate and the LAC.

Conclusion

We believe that reform of the participant pathway is the first step toward unlocking the currently complexity across the whole Scheme. By restoring simplicity, upholding the principle of choice, and clearly defining roles and boundaries, a reformed participant pathway can underpin the efficient sustainable functioning and broader success of the NDIS in achieving its original promise of advancing the life chances of participants.

Commentary

The first webinar discussed the simple participant pathway. Attendees were enthusiastic about its benefits.

Attendees saw the first stage on the pathway – *Indicate* – as critical to ensuring fair and equitable access to, and allocations from, the Scheme. They expressed concern that significant differences in allocations between participants were commonplace and many did not receive sufficient funding to meet their needs and goals.

Attendees considered this was because allocations depended significantly on a person's capacity to self-advocate and their access to formal or informal advocacy supports. This made it essential to have the 'right' people in the room for all meetings along the pathway.

How best to support people to self-advocate was canvassed, with attendees expressing a strong preference for participants to be supported in the way they chose and with the people they chose. The use of a provider/worker for advocacy support was seen as problematic as, while they may know the participant well, they could also be seen to have a conflict of interest.

Attendees considered the pathway would benefit from a scaffold of useful questions and guidelines to ensure the most relevant information was collected and the best decisions were made. Clinical language was seen to create an unnecessary barrier and was best avoided.

Attendees spoke of the need for participants to present 'the worst version of themselves' to achieve a sufficient budget. This ran counter to the desired strengths-based approach at the NDIS and encouraged a focus on deficits and low expectations. To be consistent with a strength-based approach, attendees wanted the pathway to encourage people to imagine 'ordinary' and 'better' lives, rather than give the worse account of themselves. More training was needed to drive this change in approach.

The Scheme's 'middle-class' language was also considered problematic, especially for those whose first language is not English. Attendees stressed that a simplified pathway did not have to be a one size fits all experience. Rather, the pathway could be tailored to specific groups, either by type of disability or cultural community and tailored to accommodate variation and nuance in experience and circumstance.

Allowing participants to choose the best LAC for their needs would help address this. Attendees considered Improved clarity around the role of an LAC as the agent to be a positive change but wanted the LAC to focus on long-term relationships and community connections. They encouraged the Scheme to pilot a range of different approaches to commissioning LACs to determine the best approaches – and potentially remove those legacy elements that benefitted the scheme instead of the participants.

Endnotes

[1] Productivity Commission, 2011, 'Disability Care and Support,' Report no.54, Canberra, p.440.

CHAPTER 3: UNLOCKING GENUINE GRASSROOTS CONNECTIONS IS KEY TO LAC SUCCESS

KEY POINTS

Current situation

- Largescale commissioning of LAC providers means strong local roots, knowledge, and networks are usually absent
- Participants do not have choice of LAC
- LAC role is conflicted between serving the person and serving the Agency

What needs to change

- Engage grassroots LACs to unlock genuine local knowledge and connections within local communities
- Place participant choice at core of LAC model
- Focus on development and continuity of relationships, where the LAC is the agent of the person not the Scheme
- Co-design a new LAC model and implement a pilot program to gather data about impact this year

The role of Local Area Coordinators (LACs) under the National Disability Insurance Scheme (NDIS) is pivotal to realising the promise of advancing the life chances of Australians living with disability. Emerging in Western Australia in the late 1980s, along with broadly comparable initiatives elsewhere, the LAC approach was designed to focus on facilitating **connections** between people, families, local communities, services, and government supports. It originated as a role that would create long-term **relationships** of trust and respect that could enable individuals to pursue their personally defined life goals and fulfil their potential. It was also intended to build the **capacity** of communities to be places of welcome and inclusion where each person is an active, contributing, and valued member of community life. In 2011, the Productivity Commission’s report on Disability Care and Support identified the LAC role as key to the success of a new national disability scheme.

Unfortunately, the implementation of the LAC role has lacked the **clarity of purpose and practice** needed to ground the Scheme within the local context of each participant. LACs undertake Scheme enrolment and related functions that sit more appropriately in the realm of National Disability Insurance Agency (NDIA) staff. The LAC role is conflicted between serving the person and serving the Agency, with little to no focus on community connection. This has added considerable time and resource burdens and distracts from the beneficial elements of the original role. LACs spend most of their time connecting people to the NDIS rather than to their local community and mainstream services. NDIS participants regularly tell us their LAC has limited knowledge of – or presence in – their local community.

In the first chapter, we described the need to restore simplicity to the NDIS participant pathway. In this second Paper, we address how a reformed LAC model plays an important part in that pathway and helps maximise the promised **transformational benefits** of the NDIS for people living with disability. For this to happen, the LAC role needs to refocus on **unlocking genuine grassroots connections in local communities**, linking people to opportunities and both formal and informal supports, within the context of authentic inclusion.

Harnessing grassroots knowledge and local connections

A participant's plan encompasses what they wish to prioritise and act upon. It is likely to include both *formal* elements (things the NDIS can fund) and *informal* elements (resources and opportunities in local community life that are unlikely to need NDIS funding to make them happen). For both, longstanding local knowledge and networks are key. This means the LAC role is **inherently local**. Grassroots organisations and agencies hold the greatest prospects of delivering the best outcomes because they are embedded in the local communities they serve. They know who to talk to about what, and the most promising entry points for connecting to community life. They are *of* the communities that they serve.

This was recognised in the Productivity Commission's description of the LAC role as involving *"locally based staff, operating at a 'grassroots' level"* (p.411). Further:

> *"Local area coordinators would be based in, and have close connections to, the local community, with knowledge of local providers and NGOs, and with some scope to respond flexibly to people's needs. While the Commission sees the scheme as being based on national standards and funding, it would be locally executed, with power over such features as service delivery and capacity building at the local level. The NDIA should be about local solutions to local circumstances."* (p.446)

The current largescale commissioning of LAC providers does not achieve the objective of harnessing grassroots resources and realising positive outcomes at a community level. For example, in South Australia LAC supports are provided by three agencies, each serving vast geographic areas of the state encompassing many different local communities. It is highly unlikely that such agencies have the degree of **local roots**, **knowledge**, and **networks** necessary to provide effective LAC supports in every community they cover. Indeed, to date they have not demonstrated any advantages over what would be expected from networks of smaller, community-embedded grassroots agencies.

It is hard to imagine significant improvement if the NDIA itself were to take on the LAC role, as has been proposed by some advocates and, indeed, by the Productivity Commission back in 2011. The only way to improve the current largescale commissioning approach would be to recruit LACs from within local communities. However, these people are likely to be drawn from existing local grassroots organisations, which, in effect, would result in an unfortunate form of community asset-stripping by vacuuming up local staff into largescale agency work.

While there are additional challenges in providing LAC supports in remote areas with 'thin markets', a developmental approach to commissioning programs offers a pathway to an effective solution. This would see the NDIA partnering with local communities and local leaders to co-design and co-produce appropriate local solutions. We believe this approach would be essential in First Nations communities.

Focusing on ongoing relationships

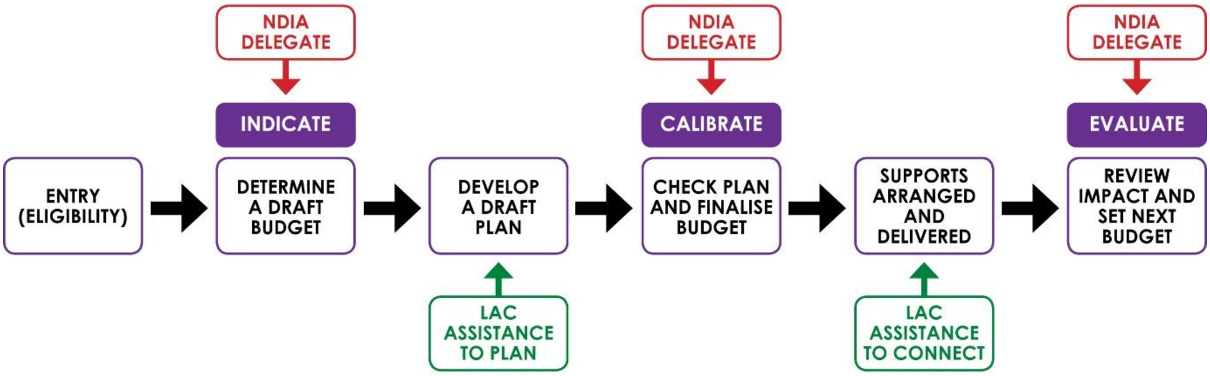
The LAC role should be anchored on the **development** and **continuity of relationships**. Participants regularly tell us that their allocated LAC changes frequently and that their interaction with them is minimal. It is critical there be strong ongoing relationships between:

- The LAC and the participant so trust and insight are built and sustained
- The LAC and the local community they are embedded in, so a shared history and depth of knowledge are built and sustained

The current largescale approach to commissioning LAC providers does not support this.

Similarly, as identified in the first chapter, the LAC role is currently conflicted between the dual functions of serving the Scheme and supporting the person. This conflict undermines the relationship and trust between the LAC and the participant. It can be resolved by clearly distinguishing between the role of the NDIA delegate as the ***agent of the Scheme***, and the role of the LAC as the ***agent of the participant***.

CLEAR ROLES IN A SIMPLE PATHWAY:



The core components of the LAC role would be to support participants (who choose to access LAC assistance) to articulate their priorities and plan the actions they would like to take. Depending on the participant's circumstances, the LAC might then assist with connections to local community resources and opportunities that bring the participant into active valued membership of local community life. Importantly, the LAC could also assist the participant to understand how to navigate agencies. As was described by the Productivity

Commission, *"[LACs] should be able to lay a clear pathway for clients to acquire the support they need. This includes through the NDIS itself, as well as advising clients on supports available through other government agencies"* (p.485). These roles require a focus on developing **long-term relationships of trust** with participants, therefore the LAC model should be underpinned by participant choice.

Embedding participant choice

'Choice and control' are fundamental and foundational **principles** of the NDIS, yet so far these have not been applied to LAC supports. Given the pivotal nature of the LAC role, it seems deeply counterintuitive that a participant is not permitted to choose or change their LAC according to their priorities and preferences. This continues to be at odds with the values that the Scheme and Agency purport to uphold. It is important the NDIS Review revisits this issue and gives particular attention to the origins of this approach, which have since been overridden.

In 2011, the Productivity Commission envisaged LACs would be employed by the NDIA and they would, among their other roles, fulfil regulatory functions under the NDIS, including in relation to participant wellbeing, provider standards, and disputes. Therefore, the Commission stated that people should not choose their LAC because this could constitute a potential conflict of interest regarding that regulatory function. However, **this is not the LAC model** that is operating under the NDIS, and nor should it be. A regulatory function would add additional conflicts to the role and take it further away from fulfilling the purpose of being an ***agent of the participant***. Hence, the original basis upon which choice was said to be inappropriate for this aspect of the NDIS does not exist in the way that the NDIS has been implemented. As such, there is no valid reason why participant choice is not enshrined in the LAC model.

We believe participant choice is essential to the role of the LAC as the ***agent of the participant*** in the NDIS. A commissioning approach that allows the participant to choose their LAC should be at the core of a reformed LAC model. The model should encourage a diverse range of LAC offerings that could include, but not be limited to, locality-based grassroots agencies, agencies specialising in specific types or consequences of disability, and agencies focused on First Nations people or culturally and linguistically diverse participants. This means the participant would have the opportunity to choose the LAC that fits them best. It could be because of a deep knowledge of the person's disability or culture, or a focus on a particular high-priority goal such as a desire to find sustainable mainstream waged employment. Participant choice would also incentivise LACs to improve the quality of what they offer so they are a provider of choice.

Rightly, an approach that embeds participant choice of LAC requires a revised funding model. One simple way to do this is to provide a baseline budget allocation to each participant seeking LAC assistance, which the participant uses to choose LAC supports. There is more we could say about this, but not in this short paper.

Tier 2 and LAC supports

In addition to the LAC service to NDIS participants, there are two further considerations. First, there needs to be local grassroots LAC support for those Australians living with disability who are not NDIS participants, primarily through information and linking services. Second, the local resources of grassroots agencies should be sustained and leveraged to build the capacity of communities to welcome and include all people living with disability as active valued members of community life.

We believe these two LAC roles could form a specific stream within a reformed Information, Linkages, and Capacity Building (ILC) program as part of what the Productivity Commission originally described as 'Tier 2'. Rather than being paid from a plan budget for the provision of LAC support to an individual participant, these LAC roles could be funded through ILC grants to grassroots organisations and agencies embedded in local communities on a population and program basis.

'Tier 2' supports and ILC programs remain essential elements of a successful NDIS, as well as a critical pathway toward ending segregated service provision and developing more inclusive mainstream options. We will delve more deeply into this topic in a future Paper in this Series.

Conclusion

To conclude, we believe that **unlocking genuine grassroots connections is the key to a successful LAC model** that produces **transformational benefits** for Australians living with disability. It is untenable to continue the current largescale commissioning of a few LAC providers to cover vast geographical areas without offering any participant choice. We have identified some guiding principles for a reformed LAC model that we hope can be advanced by an **authentic co-design** process this year. A **pilot program** of an alternative LAC model should be implemented to gather data, finetune details, and lay the groundwork for scaling up. The roll out of a new model should then be accompanied by strong accountability and evaluation mechanisms that ensure proper measurement of impact and outcomes - something that appears underdone in the current approach. These steps would set the future of the LAC role under the NDIS on a more promising trajectory.

Commentary

The second webinar focused on the role of the LAC including how best to define it and how it should interface with other roles.

Attendees voiced concern about the lack of role definition with many people confused about who should be doing what and what it should look like when done well. This meant they had no choice but to accept what was before them.

The answer was not to introduce more professionals into people lives as many were often involved already. Instead, greater clarity about each role and purpose was needed.

Similarities and overlap between the role of the LAC and the support coordinator were seen to be confusing. This could potentially be addressed by better defining the support coordinator role by separating the demand and supply-side elements. This would also address the conflicts of interest that exist in current arrangements.

The LAC role was described as local and personal, with LACs needing to be of the community they served and invested in getting to know participants closely. LACs may move in and out of people's lives, with periods of intense support needed – perhaps at the start of a plan or at a change in life stage like entering adulthood – and periods where little or no interaction was needed.

Currently, many LACs did not know their communities well which meant they could push inappropriate options onto participants. Training of LACs was therefore extremely important.

Another concern was the role of an LAC in helping people who were not eligible for individual NDIS plans – something that did not appear to be happening under the NDIS. It was suggested an LAC role for the 'so-called' Tier 2 could be a lighter touch role that focused on providing information and signposting.

One attendee suggested that the sector did not yet have much experience of what good looks like. Some were concerned that the current focus appeared to be on transactional paid services, with community resources and options overlooked. They felt the overly transactional nature of the NDIS had untethered many people from their families and communities, and suggested the NDIS was not leveraging free community resources – everything provided came with a cost.

Attendees pointed out that many high-quality community initiatives had worked well in the past, and that rather than reinventing the wheel, these approaches could be revisited and implemented.

One called for an intentional effort to 'bring back the village' because just having an activity, group, or service available was not enough to connect people to one another. Connection and fellowship often comes from the place you live, the place you work (if you haven't been shut out of employment), and places in community life that are free or did not cost much to enter: libraries, parks, shopping centres etc. Many such places were provided by local government, yet local government seemed disconnected from the NDIS despite playing a critical role in ensuring public spaces and places were accessible.

CHAPTER 4: RETHINKING THE NDIS ASSESSMENT TOOLS TO DRIVE SIMPLICITY AND EQUITY

KEY POINTS

Purpose of an assessment

- To determine if a person is *eligible*
- To ensure the response offered matches a person's needs and is *reasonable*
- To confirm that the response is *equitable* when compared to others in the Scheme

Components of an assessment

- Assess nature of disability to determine if a person is eligible for the Scheme
- Assess consequences of disability to determine a draft overall budget that is reasonable for a person's needs, and which can be understood in terms of transactional and transformational benefits, and which is equitable compared to other participants

Characteristics of an assessment tool

- Simple, accessible, respectful, and holistic
- Not focused on deficits and absences

The issue of assessments in the National Disability Insurance Scheme (NDIS) has a storied – and controversial – past. Most people in the disability community associate the topic with the National Disability Insurance Agency's (NDIA) ill-fated foray into establishing 'independent assessments,' later abandoned in 2021, although not before leaving many with deep concerns and distrust of both the Agency and politicians. Yet, unless each person is to receive exactly the same plan and budgets, it is inescapable that an 'assessment' of some sort for each participant must occur – and, indeed, has been occurring ever since the Scheme began. Therefore, the key question is not if, but rather, **how assessments are used in the Scheme**.

▶ ELIGIBLE ▶ REASONABLE ▶ EQUITABLE

The purposes of an assessment for the NDIS should be to determine if a person is **eligible**; ensure the response offered matches a person's needs and is **reasonable**[1]; and confirm that the response is fair and **equitable** when compared to others in the Scheme. The assessment process should be **as simple as it can be** to fulfill this purpose, fully accessible to the diverse range of participants, dignified, respectful, holistic, and efficient while still allowing an appropriate level of flexibility and adaptability to a person's context. It should use as few questions as is necessary to produce a clear understanding of the **consequences of disability** for a person and result in a draft budget – that is, an overall budget signal, not a guaranteed amount – that is the **reasonable and necessary** cost of sustaining, or **lifting**, a participant into **authentic valued roles in mainstream community life**.

As described in our first two chapters, this assessment should occur as part of a **simple participant pathway**. Once a draft overall budget is **indicated** to a participant, that person can use this as a guide to create a plan in accordance with their individually defined goals based on the amount of funding likely to be available. They then move through the simple participant pathway where the Plan is **calibrated** and later **evaluated**, as we have described in the first chapter. The components of the evaluation should be closely aligned with the assessment tool so that the impacts of the plan investments are clearly measured. Given the content of a participant's Plan is articulated by the participant, the supports it enables are more likely to be tailored to the individual, have a strong impact on the person's life, and increase the likelihood of the NDIS producing genuinely impactful benefits for Australians living with disability.

Avoiding a repeat of past mistakes

We acknowledge that assessments in the NDIS present many **challenges**, which are compounded by the issue of how to best determine what is 'reasonable and necessary'. However, the NDIA has also shown a problematic preference for assessment tools that are **overly complex and predominately clinical** in nature. Any assessment tool that requires a health professional to implement is not a good fit for the NDIS. It is also very unlikely to be focused on the consequences of disability for a person within the context of their individual life, which is what the NDIS is supposed to be directed toward. Gathering clinical data is also costly and time consuming, making an overwhelmingly clinical approach more inefficient.

The NDIA's attempt to establish 'independent assessments' as a core part of the access, planning, and review pathways for the NDIS reflected this focus on clinical measures and skewed too far toward the 'medical model' of disability. A number of standardised clinical assessment tools were selected for use despite the fact they were not designed for the purpose of setting individualised plan budgets and included questions of little or no relevance to the NDIS context. Non-clinical aspects of a participant's situation, such as their goals and priorities for funded support, were largely overlooked. The time required to complete the assessments was said to be about three hours – although during the second pilot phase they took on average longer than that.[2] The NDIA also compromised stakeholder confidence in the legitimacy of the pilot phase by starting to contract providers while the trial was still underway and had not yet been properly evaluated.

Despite abandoning the proposed 'independent assessment' process, the NDIA continues to use **standardised clinical tools** in its determination of budgets. For example, children and teenagers typically undergo a Pedi-CAT (Paediatric Evaluation of Disability Inventory - Computer Adaptive Test) assessment while adults usually complete the WHODAS 2.0 (World Health Organisation Disability Assessment Schedule). Both are clinical instruments that largely focus on **deficits and absences** while providing only a rudimentary picture of a person's **daily life** and **life chances**. This approach also creates perverse incentives for health professionals to over-diagnose and/or exaggerate deficits for the purpose of accessing the NDIS. This is symptomatic of an approach that is **not fit-for-purpose** in its current form.

The NDIA is now undertaking an Information Gathering for Access and Planning (IGAP) project to design a new assessment model and can be credited with taking a more robust codesign approach to this compared to ‘independent assessments’. The NDIS Review will also consider this topic. Both these processes should aim for simplicity using the aforementioned elements of **‘Eligible, Reasonable, Equitable’**.

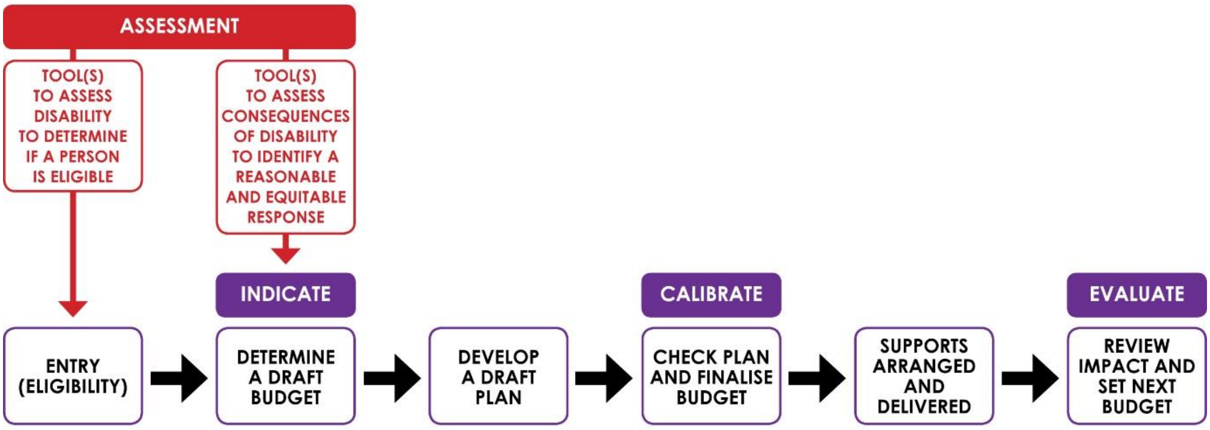
A simple assessment tool

The first component of a simple assessment tool should be to establish if a person is **eligible**. As the NDIS is designed for people living with significant and enduring disability this is the aspect of an assessment that will be clinical in nature. The necessary information is likely to be available from clinical professionals already known to the person. As such, the assessment for the purpose of determining **eligibility** is focused on **measuring disability**.

The second, more substantial, component of a simple assessment tool should focus on understanding the impact of a person’s disability on their **daily life** and their **life chances** in order to establish a draft overall budget signal that is **reasonable**. The simple assessment tool does not need a multitude of questions about each aspect of a person’s **daily life** when in each case only one or two might be sufficient. For example, questions about the amount of assistance a person needs to get out of bed, use the bathroom, get dressed, prepare a meal, clean a surface, and so on will likely produce quite similar responses so repetition seems unnecessary.

To assess **life chances**, the tool would seek information about items such as the suitability and sustainability of the person’s housing situation, their current employment or access to education and training, the range of social connections and relationships a person has in their life, the level of support they need to understand options and make decisions, and, most tellingly, the overall number of **ordinary valued roles** the person has.

ASSESSMENT IN A SIMPLE PARTICIPANT PATHWAY:



The primary source of information in the second component of an assessment should be the participant and, where involved, likely their family and allies. It would be person-centred, not clinical, in nature. Therefore, the assessment for the purpose of establishing a **draft**

budget signal is focused on **measuring the consequences of disability**, including the consequences of how our society and economy typically react to disability. Given the size of the NDIS, it is feasible – and optimal – that the NDIA **codesigns its own bespoke assessment tool** to fulfill its **specific purposes** rather than relying on existing standardised clinical assessment instruments. Once codesigned, a simple methodology using a sample of current NDIS participants with budgets that are a reasonable match to their circumstances should be used to cross-test and calibrate the assessment tool.

This instrument would also help identify those **consequences** that relate to the **lack of accessibility or inclusion** of other government and community services, programs, facilities, and resources so representation can be made to the responsible body about urgently addressing those problems rather than the NDIS bearing all the financial consequences of an inaccessible, non-inclusive society.

Transactional and transformational benefits

There are two main types of **consequences of disability** and, therefore, two main types of corresponding **benefits**. First, as described above, the **impact on daily life** can mean a person needs practical assistance to navigate their daily life. The results of the assessment should contribute to a draft budget signal for those funded supports intended to deliver the corresponding **transactional benefits**; that is, practical supports for daily living that will likely be needed repeatedly into the future.

Second, the **impact on life chances** can mean a person has far less opportunity than a non-disabled person to take up mainstream waged employment, access education, find a place to genuinely call home, establish a rich array of connections and relationship, and so on. The results of the assessment should contribute to a draft budget signal for those funded supports designed to deliver **transformational benefits** to a person's life chances; that is, funded supports to achieve a person's individually defined goals and fulfill their potential as an active valued member of mainstream community life. These benefits can also include authentic capacity-building outcomes, where a person is assisted to gain skills and knowledge, or investments in assistive technologies, that enable independence; both of which can reduce the future need for transactional benefits. These benefits should create **permanent positive change** and, therefore, a participant's budget for funded supports to increase their life chances should reduce over time as goals are achieved and sustained. For example, technology that enables a person to open and close doors and operate appliances through voice control facilitate greater independence and can reduce the need for hands-on assistance from a paid worker. Similarly, a motorised wheelchair or a vehicle modification could assist a person to travel independently to appointments or employment and reduce their need for transport assistance. Because of these possibilities, narratives that imply all budget reductions in NDIS plans represent unfair cuts are not accurate.

The **varied nature** of the impact of disability on daily life and on life chances means that it is possible that two people with similar types or degrees of disability may receive different budgets. One person already living with a full array of life chances available to them may only need funded supports for transactional benefits, while another may need extensive transformational benefits to change their circumstances of, for example, unemployment, homelessness, or loneliness.

Fair and equitable outcomes

Currently, there are **significant inconsistencies** in the budgets approved for participants with similar consequences of disability. This can be the result of a **lack of calibration** between the judgements of different NDIA staff or due to the varying capacity of individuals and/or families or supporters to advocate for their needs and assert their goals. For the NDIS, this likely means some participants receive less funding than they need while others get more than they reasonably need. The reputations of the NDIS and the NDIA are compromised due to both real and perceived unfairness, while additional inflationary pressures are placed on the overall cost of the Scheme. To reduce these cost pressures, elements in plans are often arbitrarily cut as part of the sign-off process, without necessarily reflecting a participant's priorities for funded support. That is not a coherent or sustainable solution to this difficult problem.

The utilisation of a **simple well-tested bespoke NDIS assessment tool** should assist in calibrating the decisions of NDIA staff and ensure each participant's NDIS budget is fair and **equitable** when compared to those of more than half a million other NDIS participants. This should mean that the draft budget signal produced by the assessment is both **reasonable** for the participant's needs, and **equitable** in relation to other participants. Notably, other jurisdictions have previously applied this type of approach, such as local authorities in the United Kingdom through their **Resource Allocation System** (RAS) for individualised funding, and appear to have had far fewer issues compared to the current NDIS arrangements (unfortunately, it is more difficult to see those arrangements in the Untied Kingdom now, because many of those arrangements were scaled back as a result of austerity measures following the 2008 global financial crisis). In many respects, a RAS is a key tool when thinking about the NDIS as a **social insurance scheme**.

No assessment tool, whether it is specifically designed for the NDIS or a standardised clinical tool, can ever be expected to produce perfect results. So, alongside the ability to respectfully engage with participants to test and verify the nature of their circumstances, there is a need for **sound human judgement** and for this to be **well-calibrated** across agency staff. Therefore, in addition to building a RAS, the NDIA should invest in building staff capacity as budget-setters and evaluators (not as planners because, as per chapter 2, we see that role lying outside the Agency). To assist this, the NDIA would need to invest in building a 'body of knowledge' accessible to all staff. This would comprise composite wisdom and insights from identified **good practice** among staff, plus insights from the review (evaluation) of a person’s budget arrangements to identify **what types of investment work** better than others at sustaining, or lifting, a person into **ordinary life chances**.

Conclusion

To conclude, we believe that a **simple bespoke assessment process**, based on the elements of **eligible, reasonable, and equitable** and implemented as part of a **simple participant pathway**, would strengthen the Scheme. The current NDIS Review presents a good opportunity to set aside the NDIA’s past missteps in relation to ‘independent assessments’ and look to how assessment tools can be used in the NDIS for the benefit of participants and the future of the Scheme. Ensuring that each participant receives the funded supports needed to reasonably deliver the transactional and transformational benefits that will lift or sustain them in ordinary life chances, characterised by a rich range of socially valued roles and relationships, and in a manner that is fair and equitable to all, will underpin an effective and sustainable NDIS that delivers on its promise.

Commentary

This discussion focussed on independent assessments, echoing the continued concerns manty participants and their families feel since the NDIA’s 2021 attempt at introducing a particular methodology around independent assessments.

Attendees considered that approach to independent assessments had not been consistent with independent assessments in other areas and cited assessments for aged care packages in Australia and the Resource Allocation System (RAS) in the United Kingdom as better examples.

One attendee who had been involved in the trial of independent assessments argued the proposed approach was not really connected to the task of designing a support plan. It was also difficult to achieve consistency among workers applying the assessment tool.

Numerous questions were raised including what the criteria for access should be and how the fluctuating nature of disability, including the potential for deterioration and increased consequences of disability, could be appropriately taken into account.

Attendees considered shifting the focus from clinical assessments to understanding the consequences of disability was important. One argued that the complexity of a person’s disability was too vague and that ‘severe and enduring’ might be an appropriate eligibility level.

Given the Scheme was intended to be person-centred and focus on individual support needs, attendees considered whatever tool or assessment process the NDIA selects must be sensitive to each unique person. Averaging tools and assigning typical support packages and default ‘solutions’ did not meet individual needs. By way of example, one attendee shared how their son’s placement in a group home had led to a reduction in his skills because the house rules prevented him from doing many ordinary activities and tasks.

Attendees asked whether any changes to eligibility assessments would apply to current participants and require new determinations to be retrospective. They noted the challenges for equity and fairness if participants were denied entry based on the point in time they applied to the Scheme rather than any substantive considerations. This could also be inconsistent with the original promise that participants would not be worse under NDIS compared to their pre-NDIS arrangements.

Assessments for participants led one attendee to ask about assessments for providers. Attendees agreed that many providers were failing to deliver meaningful outcomes despite the funding these services received and greater accountability was needed. One example cited was of a provider who took a participant out into the community many times, but no new connections or friendships were achieved.

Endnotes

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[1] We use the term reasonable to capture what is currently referred to as ‘reasonable and necessary’.

[2] NDIA Research and Evaluation Branch, 'Final Evaluation Report: Independent Assessment Pilot 2’, July 2021, p.23. See https://www.ndis.gov.au/about-us/research-and-evaluation/research-helps-us-improve-ndis/independent-assessment-pilot-evaluation.

CHAPTER 5: RAISING THE BAR FOR AUTHENTIC COMMUNITY PARTICIPATION

KEY POINTS

Goals for NDIS' investment in social and community participation
- Active valued roles in community life
- Meaningful community membership, connections, and belonging
- Utilising existing community resources
- Achieving a rich mix of formal and freely given informal supports

Making these goals happen
- NDIA stops funding duplicated and segregated activities and services
- Plan elements are designed to lift a participant into valued community membership
- NDIA measures the quality of community participation supports, not merely the number of hours a person is present in community spaces

> *"Few can appreciate the impact of exclusion and profound isolation on the identity and self-esteem of people with disabilities. Always defined as 'different', always defined by lack… When identity is always framed by others and always framed in a negative way, it is difficult to develop and maintain a strong positive sense of self and difficult to establish and maintain relationships characterised by equality and mutual support."*

The landmark 'Shut Out' report released in 2009 tells a shocking story of the experiences of people living with disability facing **exclusion, discrimination, and systemic disadvantage** in every aspect of their lives, as captured in the above quote.[1] Indeed, social exclusion and barriers to community participation sat alongside disability services as the most frequently raised issues in submissions to the consultation about the experiences of Australians living with disability and their families.[2] The subsequent 2011 Productivity Commission report on disability care and support repeatedly refers to the 'Shut Out' report and it is often cited as a key impetus for demands to **find a better way to support people living with disability in our communities**. The National Disability Insurance Scheme (NDIS) promised to help bring an end to the all-too-common experience of being 'shut out'.

Therefore, a significant expectation of the NDIS is that it will deliver 'social and economic participation' for participants; in other words, lift people living with disability into **meaningful valued roles** in mainstream community life. At JFA Purple Orange we refer to this as *active valued membership of community life*, and we consider this key for any of us to live a rich and fulfilling life. Likewise, a community becomes richer from the participation and contribution of all its members, bringing a diversity of experiences, knowledge, and voices. Hence, it is essential the **NDIS enables authentic community participation and connection** for participants on an equal basis, and in the same spaces, as everyone else. The NDIS cannot continue funding community activities that at best can be described as 'community tourism', or funding outdated services such as separate segregated group activities dictated by providers or support workers. This is because these types of services work against authentic community connection and, in their effects, deliver the opposite of what the NDIS is tasked with delivering.

In this fourth chapter, we focus on the need to **raise expectations about the nature of authentic community participation and connection,** and the types of supports the NDIS should fund to deliver these outcomes. We also identify a number of challenges including eliminating 'community tourism' based approaches, leveraging existing community resources to avoid costly duplication of activities, and ensuring that the NDIS participant pathway works to facilitate the identification of goals and supports for authentic community connection. Further, we highlight the importance of measuring the *quality* of outcomes of funded supports rather than narrow quantitative data about hours paid for without understanding the nature of what is being described as 'social and community participation'.

Valued roles in community life

Much of what identifies us, and that we find fulfilling, happens in **community life**. Catching up with friends over a coffee, going to the beach, joining a club, volunteering with a local group, working, accessing education or training, exercising, shopping, and many other activities all bring us into contact with our communities. In all these examples, we are taking up active roles that bring us into **mutually valued connection and relationship** with other people. At JFA Purple Orange, we use the collective term 'Citizenhood'[3] for these meaningful valued roles. They are key to a sense of **wellbeing**; our community is where we build our connections and our **sense of belonging**. This helps explain why Covid-19 pandemic lockdowns impacted us so hard – we lost this connectivity.

The Productivity Commission's 2011 report emphasises the importance of community participation, connections, and social relationships as a **key policy objective** for governments and of a new national disability scheme.[4] Among the benefits the Commission identifies are improving wellbeing and life satisfaction outcomes, enabling greater independence, lowering the long-term costs of care and support, reducing the likelihood of accidents and injuries, generating 'social capital' across society, supporting children and young people to develop and flourish, promoting diversity in all its forms, reducing individual circumstances of disadvantage, and boosting economic activity.[5]

Meaningful community membership, not 'community tourism'

If, as the antidote to the 'Shut Out' story, the NDIS is to deliver social and economic participation, this has to happen in a way that ensures NDIS participants take up meaningful valued roles in community life. As such, the key challenge for the NDIS is to look at ***how*** people are supported to connect to their community, not just the amount of time they are present in community spaces. Often, disability services, whether in a group or one-to-one, bring people into community in ways that do not foster genuine connections with other people. For example, a support worker might take a person to a café, where the person is ‘parked’ at the corner table while the worker transacts all the business with staff. Or a provider might load several people into a car or minibus and take them to a community venue like a zoo, bowling alley, or similar. These are examples of ‘community tourism’, where the person is in the community but not supported to engage in it on the same basis as other people. The person is a spectator, a visitor passing through, in ways that reinforce community perceptions that people living with disability are served in separate ‘special’ ways.

This ‘community tourism’ directly works against the NDIS goal of social and economic participation. If we think of NDIS plan budgets as an investment, these types of services are like investing your money in a venture you know has no prospects of success.

Avoiding duplicating community resources

A second problem of these services for people living with disability is that they can sometimes duplicate opportunities already present in community life, for example setting up a special art class, choir, community garden, or similar, for people living with disability when the local community already has these. When disability services create these duplicate services, not only is it a poor use of resources but it also serves to render genuine inclusion further out of reach. This is because, in their effects, these separate ‘special’ disability-focused services and programs reinforce a community perception that people living with disability are best served by having separate ‘special’ stuff. This has been termed ‘othering’. It kills true social, community, and economic participation and should have no place in NDIS decision-making.

Unfortunately, it does. For example, an NDIS participant told us they were prevented from using part of their funding to attend a local art class because it was not a ‘disability-related expense’. Instead, they were told one-to-one art therapy could be funded as an alternative. Not only is this an expensive alternative to a low-cost community resource that the participant was keen to access, but the therapist-led alternative cannot set the scene for authentic community connection and membership in the same way a local art class can.

Ordinary neighbourhood resources and opportunities available to all local people are a natural gateway to community membership. They bring meaningful valued roles **readily available in our communities**, often at low or no cost. Assisting a person to connect to these resources and opportunities can lead to a snowballing of connections and relationships for a person over time. The stories below illustrate this.

Jarrod's* Story:

Jarrod lives in a regional town and has little connection with his neighbours. As a person with high physical support needs who uses a powered wheelchair, he wonders how he might build relationships in his local community. Jarrod realises that many of his neighbours are not home during the day while he usually is. He lets his neighbours know that he can be available to receive parcel deliveries during the day so they can avoid the nuisance of following up delivery notification slips at the post office, which also has limited opening hours during the day. Jarrod's neighbours take up his generous offer and over time he begins to get to know each of them. These connections evolve into genuine relationships and Jarrod is drawn into other gatherings and opportunities as a valued member of his local neighbourhood.

Ethan's* Story:

Ethan lives with intellectual disability and is a keen member of his local Scouts group. But with his 18th birthday fast approaching, Ethan will soon be too old to continue attending Scouts, and he will lose this valued role that brings him membership in his community. He wants to continue. The Scout leaders recognise Ethan's enthusiasm, and his gift of being able to capture the attention of the younger Scouts and ensure they follow directions. They invite him to become a Scout leader and shape the role to best suit his strengths. Ethan thrives in his new role and becomes a valued and integral part of the leadership team for his local Scouts group.

Measuring the *quality* of outcomes

Currently, it seems the main way that the National Disability Insurance Agency (NDIA) seeks to understand the **impact of its investment** in 'social and community participation' is by measuring the number of hours each week a person spends in community. However, this broad measure will inevitably include data relating to community duplicates, segregated activities, and 'community tourism', where Scheme participants are *in* community but are not *of* community. This means the NDIS is not only funding the wrong thing, but also measuring the wrong thing.

The data measurement is including activities where participants are simply service recipients whose presence is passive and/or grouped together. Similarly, NDIS surveys of participants ask narrow questions like 'Has the NDIS helped you to access services, programs, and activities in the community?' or 'Has the NDIS helped you be more involved?' These do not adequately consider the *nature* of the activities the NDIS has invested in. Consequently, the data is creating a **false impression** of the Scheme's impact on 'social and community participation' because *quality* is largely overlooked.

While measuring authentic valued community participation and membership is undoubtedly more difficult, we think **it is better to measure the right thing poorly than the wrong thing well**. While no measure will perfectly capture the impact of 'social and community participation', a range of qualitative methodologies could be deployed at relatively low cost to build a more accurate picture of the impact of funded supports.

Advancing authentic community connection through a mix of formal and informal supports

If the NDIS' goal for 'social participation' is that more people living with disability are taking up their **rightful place as active valued members of mainstream community life**, then this is best achieved through a mix of formal and informal supports. Put simply, formal supports are what you buy, while informal supports are given freely through personal networks and community membership.

Formal supports, involving workers paid or otherwise, need to be very carefully constructed because they can inadvertently serve as a barrier to community connection, not just because the support worker can become the main transactor of the connections with community, but also because their presence serves to reinforce the idea people living with disability have 'special' arrangements, including a paid person who is always there.

This means support workers need to focus on some key things to ensure their day-to-day practice is person-centred and focused on creating genuine impact rather than simply filling time. First, they need to craft their work in a way that puts the person front and centre. Second, the work must have, as its primary focus, how the person is supported to build connections and relationships in community life. As such, a key goal of formal supports is to create the circumstances where informal connections are made and relationships built. It is through these connections that new, freely given, informal supports emerge. For example, any one of us might join a new community event, like a community garden, get to know other people there, and as a result start gaining mutual benefits, such as assisting each other through car-pooling, or grabbing a coffee afterwards, in the way acquaintances and friends do.

In turn, this means service providers need to shape their workforce so the centre-of-gravity is not about skills in running activities, but, instead, is about the **art and craft of facilitating opportunities for authentic connection**, with the diplomacy and advocacy that this work requires. Arguably, this is the most compelling measure of NDIS success in relation to community participation; the presence of new people in the person's life who choose to be there as friends and acquaintances, and who bring supports in the way friends and acquaintances do.

Social participation is in some ways an unhelpful phrase, because it makes it sound transactional and somewhat superficial, when really it is about authentic relationships and belonging; that is, the opposite of loneliness.

Investing to create transformational change

Currently, many individual NDIS plans seem not to include elements designed to lift a person into **authentic community participation and membership**. This must change, driven by the participant's own priorities for the things they would like to do that can nurture and sustain valued membership in community. This includes exploring who in the person's life might be approached to assist this. The person's chosen support, for example an LAC, can then assist the person to identify how to advance those connections *and* translate the priorities into any elements their NDIS plan might best be applied to. In this way, the person's **NDIS plan expenditure is driven by the outcome of valued community membership, is highly personalised, and avoids duplication**. This brings a much stronger return on investment.

And, as mentioned earlier, the NDIA should stop funding formal supports that duplicate existing community resources, or which reinforce 'othering' through segregation and 'special' activities. Instead, when signing off on a participant's individual plan, it should look for elements that hold the prospect of bringing the person into genuine community membership and belonging through support agencies that have an auditable record of achieving this.

Conclusion

The NDIA needs to reorientate its approach to 'social and community participation' and no longer fund services that duplicate community resources, or which result in 'community tourism' or 'othering'. Instead, it should invest in supports that **facilitate genuine opportunities for authentic community connection, relationships, and belonging**. This should be based on the priorities the person and their allies set and be a rich blend of freely given and formal supports. The measurement of outcomes must align with this purpose, reflecting that the *quality* of participation is critical to transformational change. Every Australian has a role to play as a neighbour, acquaintance, and fellow community member. Each of us is an informal supporter, and a mutual beneficiary, to the people we know. Part of the NDIS' job is to judiciously use its funds to help unlock this.

Commentary

A core objective of the NDIS is to advance participants' social and economic participation. This raises many questions about what genuine participation and belonging looks like.

Issues canvassed in this discussion included: ordinary participation; whether community tourism and volunteering were valid options; the lack of options in rural areas; and provider-organised activities. Participants agreed context and the need to avoid creating 'special' things for restricted groups were essential ingredients in authentic community participation.

The question of what is 'ordinary' drew interesting reactions. One attendee responded by stating that 'everything and nothing' was ordinary.

Attendees argued that ‘mainstream’ included the full variety of options and choices; the distinction was in how people accessed those options and whether they did so as most people do, or whether they were congregated or segregated to do so. This distinction made it important to measure social and economic participation in ways that captured the quality and character of the participation rather than just the quantity of hours.

Honouring choice was an important objective of the Scheme, yet choices were inevitably defined by a person’s experiences. For attendees, whether ‘community tourism’ was a genuine choice and an option the Scheme should fund depended on context. If a participant had only ever been offered ‘community tourism’, they were likely to continue to choose it unless they were supported to unlearn low expectations, ‘name the wounds’ of the past, and imagine alternative choices.

Introducing volunteers was similarly vexed. Volunteers were seen to offer opportunities to create genuine meaning and connection on the one hand while potentially reinforcing the charity model of disability on the other. It was also noted that volunteer roles were usually more akin to formal support roles than freely given relationships and connections.

Rural areas had less activities on offer, and this encouraged providers to start ‘special’ programs. Attendees considered this to be another form of ‘othering’ which did not enable participation in genuine opportunities for belonging. It could also cause resentment among community members who did not have the same access.

One example discussed was education and capacity building activities like cooking classes to increase knowledge about nutrition. The key question here was whether the activity was organised in a way that set people apart, such as classes being only for people living with disability, or whether it brought a diversity of people together to share and learn, in an ordinary way. Attendees considered creating options and resources to benefit the whole population to be the preferred approach.

Endnotes

[1] Australian Government, 'Shut Out: The Experience of People with Disabilities and their Families in Australia’, 2009, p.52, available at https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia.

[2] *Ibid*, p.3.

[3] Productivity Commission, ‘Disability Care and Support,’ Report no.54, 2011, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[4] *Ibid*, p.203.

[5] *Ibid*, pp.202-208.

CHAPTER 6: IMAGINING MORE IN NDIS HOME AND LIVING OPTIONS

KEY POINTS

What should the goal be

- Creation of an **authentic sense of home** on the same basis as for non-disabled people to enable Australians living with disability to take up ordinary valued roles in community life

How to achieve this goal

- NDIA stops funding group houses and, instead, invests in **choice-driven individual home and living options** that align with Scheme values
- NDIA stops defining group houses according to a specific number of bedrooms or residents and, instead, recognises that it is the **lack of choice** and the **character and operations** of group houses that sets them apart from ordinary homes
- NDIA ensures plan budgets are always **individualised** and not arbitrarily tied to group purchasing requirements
- NDIA recognises that there is an **array of alternatives** to group houses and these do not always cost more
- NDIA **removes perverse incentives** from funding models and, instead, ensures they are designed to enable outcomes that are consistent with Scheme values
- SDA and SIL providers are required to adopt and implement practices that **align with Scheme values**

'Few Australians without a disability can imagine what it would be like to have no say in where they live or who they live with. The freedom to choose where and with whom one lives is a fundamental freedom, but it is one few people with disabilities are able to exercise. Many people with disabilities want to live independently in the community but are unable to access the support they need to do so.'

This quote[1] from the landmark 'Shut Out' report released in 2009 tells of the frustrations Australians living with disability experienced before the National Disability Insurance Scheme (NDIS) was established. With little support available, most were unable to access independent living options of their choice, forcing them to continue living in the family home well into adulthood or find themselves stuck in inappropriate congregated living facilities usually operated by state and territory governments. Such facilities resulted in **segregation, discrimination, and exclusion**, as well as severely restricting opportunities for people living with disability to take up valued roles in community life. Residents were 'shut out' of ordinary life in their neighbourhoods and local communities.

Yet, 10 years on from the creation of the Scheme, little has changed. In fact, the National Disability Insurance Agency (NDIA) has admitted that **in 2020 more people entered congregate forced shared living arrangements than exited**, despite billions of dollars being spent through the Scheme.[2] As the type of NDIS funding that pays for staff support, Supported Independent Living (SIL) budgets give an insight into the prevalence of people living with disability being forced to live under these arrangements. Currently, there are just under 30,000 NDIS participants with SIL funding in their plans.[3]

In this fifth chapter, we focus on the need to **revitalise the Scheme's values of individual choice and control** in relation to **housing and daily living supports**. We identify what makes an authentic home and how the NDIA's continued funding of 'group houses' where people have not chosen to live together fails to achieve this. We deliberately use the term 'group houses' rather than the more common 'group homes' because, as this paper will demonstrate, the use of 'home' in this context is a misnomer, and the use of the word 'home' in the phrase 'group home' profoundly compromises its true meaning. Group houses are akin to service facilities where staff are front and centre and people living with disability are congregated, disempowered, and segregated from their communities. Moreover, living in such a facility does not fulfill the promise of the NDIS to enable all Australians to enjoy ordinary good lives.

Creating an authentic sense of home

Home is a place of comfort, rest, renewal, and belonging; where we are free to be ourselves, personalise our surroundings, and make decisions about who enters and on what terms. Home is the foundation that allows us to live ordinary good lives, pursue our goals and interests, do things that give us meaning and purpose, build and maintain relationships with friends and loved ones, and connect with our neighbours and the life of our local communities. And home is where we find a sense of safety, security, and certainty when we return at the end of our day. **Home enables choice and control** in our lives; upholds our individuality, self-determination, and status; and facilitates the use of our existing skills and the development of new ones.

To invest in the chances of an authentic sense of home, the dwelling should be accessible in line with a person's individual requirements and close to ordinary community resources, such as shops, health services, transport hubs, recreation facilities, and other public amenities. The resident/s should be in charge of what happens in the home. Appropriate assistive technologies should be utilised to meet the occupant's circumstances and preferences, to maximise personal control. Crucially, a home should be a place where a person can welcome family, friends, and visitors and build ordinary valued relationships with their neighbours. When the above elements are accomplished, a person is much more likely to take up valued roles in community life, with all the meaning, belonging, and natural safeguarding this brings.

The way in which home and living supports are provided under the NDIS is **critically important** to **fulfilling the principles and purpose** of the Scheme, particularly those of participant choice and control and social and economic participation.

When ‘home’ is, in reality, a facility

Unfortunately, the NDIS has continued to fund group houses, where people are coerced to share their living space with other people also living with disability. In its character and effect, this is a **service facility, not a home**. These facilities are not anchored on **deep familial** or **personal connections**, but on imagined compatibility based on superficially similar support needs, outdated economics of disability support, and/or a scarcity of accessible ordinary housing. None of these ‘justifications’ are acceptable. They are not consistent with proclaimed Scheme values and would not be acceptable to non-disabled Australians, so why should they be acceptable for a person living with disability? The NDIS will not achieve its intended purpose unless it delivers housing and daily living supports in ways that create an **authentic sense of home** for each person.

Much has been voiced or written elsewhere about the nature of group houses, including some views that group houses can be considered good if there is quality in the care and if the residents chose it. We do not intend to navigate the detailed points therein within this paper. Instead, we assert the group house model must be rejected because it is not an option chosen by most Australians in their own lives. There may be times, for example when young people first leave home, or go to full-time adult study, where they may be sharing with several other people in similar circumstances. But beyond instances where a household might have several adult family members, it is rare for a group of non-related adults to share a dwelling long term. The group house is not a choice most Australians make. Therefore, it is unacceptable to suggest it is suitable for Australians living with disability, let alone for it to have become their ***default*** housing option if they do not have the resources to make their own arrangements.

Further, the **nature of a group house works against the goal of inclusion**. When several people living with disability are placed in a house together, with staff comings and goings, it presents that house not as an ordinary home but as a service venue, a facility, and that changes the way the neighbours and others view the nature of any role they might have in the occupants’ lives. In short, it makes things weird. Also, the economics and habits of group houses mean a participant does not have control because this power is typically held by the paid staff, and they do not have choice because if there are four people living in the house who all want to do to something different, and only one or two staff there to support them, it is going to be impossible for each person to have their choice met.

***Home* is more than just a *house*, and it is certainly not a *facility*.** Group houses, even assuming the best of intentions are held, perpetuate segregation and marginalisation. Even with the best of support staff, the group house model is tough going, making it much harder to build momentum for authentic inclusion. Group houses do not have a good track record of delivering authentic choice and control to occupants or enabling people into authentic ordinary social and economic participation. They **fail the test** for the **values the NDIS is meant to advance and uphold**.

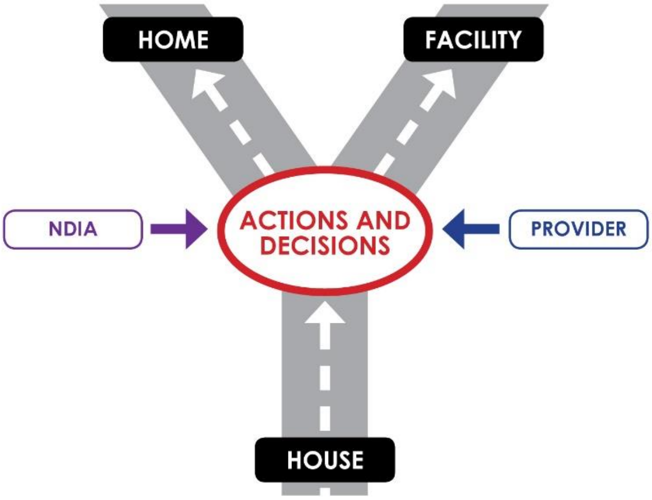
Regrettably, group houses also do **much worse**. We have heard from numerous NDIS participants about how they are pressured or forced to live with ill-matched housemates, including situations where they have been subjected to **violence** as a result. The NDIS Quality and Safeguards Commission’s ‘Own Motion Inquiry into Aspects of Supported Accommodation’ report released in January highlighted the shocking prevalence of reportable incidents occurring in group houses, with the inquiry investigating about 7,000 incidents and complaints related to the facilities of seven providers during a period of about four years.[4] The incidents include abuse, neglect, and unlawful physical or sexual contact.

The fork in the road

The NDIA and providers of NDIS housing and daily living supports, including state and territory governments, play a significant role in enabling or undermining an authentic sense of home for participants. When a house is made available, it will either provide an authentic sense of home, or become a facility. There is no middle ground, there is no ‘sitting on the fence’. Each and every decision made by the NDIA as funder, and by any support providers involved, will either advance and reinforce an ordinary sense of home, or advance and reinforce a sense of service facility.

Most Australians are themselves the primary agents for how they create a personal sense of home in the house they live in. And so it should be for Australians living with disability. However, they have other agents in their life, most notably the NDIA and support providers, and the significance of their actions and decisions in determining whether a house will become a home, or a facility, cannot be overstated. Every decision made, every action taken, is from a fork in the road, where one way leads to a rich sense of ordinary home life, and the other way leads to a facility.

INVESTING IN AUTHENTIC HOMES OR PERPETUATING FACILITIES?



The commitments Australia currently fails to uphold through the NDIS

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Australia has an obligation to ensure that citizens living with disability have the right to 'choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement'.[5] All tiers of government have also committed in *Australia's Disability Strategy 2021-2031* to ensure that 'housing is accessible and people with disability have choice and control about where they live, who they live with, and who comes into their home'.[6] In its consultation about a new NDIS Home and Living Policy, the NDIA has itself acknowledged the discrepancy between Scheme values and Australia's international obligations, on the one hand, and its current practice of perpetuating forced group living, on the other.[7] However, this rhetoric has not yet led to a substantive change in approach.

'Group houses' and quasi-block funded SIL undermine Scheme values

The proclaimed values of the NDIS in relation to participant choice and control should rightly mean each participant has a genuine individual choice about where and with whom they live, and how they receive supports. However, the NDIS currently funds a large number of arrangements where the participant was not afforded an authentic choice. If a person did not choose the group living arrangement in which they find themselves, then it is extremely unlikely that they will feel any authentic sense of home or belonging in the place where they reside. Indeed, when alternative options are genuinely available, people living with disability are very unlikely to choose to live in a group house with numerous other housemates not of their choosing for years or even decades of their lives.

The NDIA is replete with good people who readily acknowledge the discrepancy between the inclusion-driven principles and purpose of the NDIS and the continued funding of a fundamentally **flawed model** of home and living supports that appears to be delivering a new generation of institutionalised group houses that could take decades to unwind. This is particularly evident in the parameters set for NDIS Specialist Disability Accommodation (SDA), a framework designed to stimulate the supply of houses for NDIS participants with higher support needs. Given their higher support needs, their right to choose where and with whom they live ought to be particularly well-safeguarded. However, the opposite appears to be the case. In its current review of SDA pricing arrangements, which is the first comprehensive examination of the assumptions and methodologies underpinning SDA since its inception, the NDIA has benchmarked SDA support as a three-person, quasi-block-funded, forced shared housing arrangement.[8] The current SDA model does not include a funding level for a house for one person to live in. Overall, the model incentivises having multiple residents in a property to generate greater financial returns because SDA providers are paid for each resident resulting in a higher total.

The NDIA defines what it calls ‘group homes’ as ‘houses that have 4 or 5 bedrooms’.[9] It is acting to reduce the size of group houses to no more than five residents. However, as argued earlier in this paper, it is the **nature of the arrangement** and its **context**, not the number of bedrooms or residents, that determines whether a house is a group house. Reducing or restricting the number of people compelled to live together in one facility will never address the fundamental inconsistency between this approach and proclaimed Scheme values. There is little difference in the experience of being forced to live with four strangers compared to five strangers, or, indeed, two, three, or any other number of people a person does not know. Instead, the critical imperative is for the NDIA to **enshrine genuine individual choice** and **ensure that an authentic sense of home is achieved**, not to set a maximum number of other residents that a person can be forced to live and share with.

The NDIA is in similar values strife through the continued use of a funding pathway termed Supported Independent Living (SIL), which funds the supports that take place in a person’s home. SIL is largely predicated on NDIS participants living with other participants and the presence of a SIL budget in a plan likely has a high correlation with having an SDA budget; if an NDIS participant is in an SDA property, they are likely to be the recipient of SIL-funded shared supports. And it is widely known that SIL funding is inflationary and is contributing to the rising cost of the NDIS. In effect, this means the current NDIS SDA framework is inadvertently having an **adverse impact on NDIS outcomes *and* sustainability**.

SIL seems to be tethered to pre-NDIS, block-funded models even after almost 10 years of NDIS operations. SIL supports are commonly treated as a **shared group purchase** of all the people living in a group house without any real say for the individual participant about whether they want to share or who the shared support should be provided by. Often SIL staff manage group houses as institutionalised facilities, where the participant experience of choice is superficial and where the rhythms of daily life are more geared to the limitations of staff rosters and staff practice preferences. Living under these conditions heavily inhibits the creation of any sense of home, belonging, or personal authority. Recently, some SIL providers have adopted ‘committee governance’ approaches, whereby residents or their nominated informal supporter meet regularly to decide how the ‘group house’ operates. Contrary to descriptions of this as an ‘innovative’ approach, it remains far removed from how life in an ordinary home usually occurs, especially in relation to the degree of power and influence the non-occupants (the staff) have in such discussions. Again, it is critical the NDIS adheres to the principles of personalised budgeting and genuinely embeds and safeguards authentic individual choice and control in the selection of support providers and how supports are delivered.

Importantly, we are not suggesting that personalised budgets or living alone *guarantee* individual choice and control or the development of an authentic sense of home. Single resident dwellings with one-to-one supports can also resemble facilities in their character and operations, sometimes with the same extreme and tragic consequences as can happen in group houses. Rather, we argue there needs to be **both** changes to the **structure of NDIS funding** to enable genuine individual choice and control, and to the **attitudes and practices** at the core of delivering housing and home-based supports, to ensure Scheme values are fully realised for each participant. Participant plans should advance and uphold the right to choose where and with whom a person lives, as well as how they receive daily living support, including through the provision of a sufficient budget to implement their reasonable choices. Providers of NDIS housing and daily living supports must place the person at the centre of everything they do, ensuring there is genuine personalisation and an authentic sense of home is created. Importantly, the housing provider must not also be the support provider for the person, as this gives far too much power to that agency and further complicates the vested interest already present.

None of this is new to the NDIA leadership, who have initiated sincere efforts to craft a **more values-coherent home and living policy**, albeit with the risk the pace of this may currently slow to await the outcome of the NDIS Review. The principal challenge is how best the NDIA leadership draws the line in the sand to ensure new group houses and supports will no longer be funded and every effort is made to make alternative choices available to current group house residents.

Creating new housing options that uphold Scheme values

Eliminating large and small scale, institutionalised, forced shared living for Australians living with disability must be a **key imperative** of the NDIA and a significant focus of the current NDIS Review's recommendations. As a first step, the NDIA must **stop funding new 'group houses'** immediately. It should also work with the sector to co-design strategies[10] to transition away from legacy facilities and group houses. To facilitate this, it is essential a new SDA funding model is developed to underpin change and **remove the perverse financial incentives** that perpetuate forced shared living arrangements. Alongside these steps, it should proactively engage residents of existing group houses in conversations about their housing goals as part of the participant planning pathway. As the aforementioned NDIS Commission report highlighted, these types of conversations with participants are not yet occurring in the form and to the extent needed:

> *'There has been limited engagement with those people who have transitioned to the NDIS from state and territory funding arrangements about options for more contemporary living arrangements within the NDIS, should people wish to explore these. This is mainly left to their current providers to facilitate on an individual or house by house basis, and almost always limited to the options that the current providers might have available.'*[11]

The NDIA should also increase the momentum of the NDIS element termed Independent Living Options (ILO), which we consider a catch-all concept to describe any and all home and living arrangements that are **choice-driven**, not group living, and which advance an authentic sense of home. For the sake of Scheme outcomes and accountability, there needs to be a substantial and sustained investment in building ILO momentum, especially through assisting participants and their families to ‘unlearn' the expectation that ‘if you are not at home with your family, you will be going into a group facility’ and to imagine and move towards the much more ordinary socially-valued alternatives.

Undoubtedly, there is also **a broader role for governments** in increasing the supply of accessible affordable dwellings, particularly in the current national housing and rental crisis. The full implementation of the new National Construction Code (NCC) Liveable Housing Design Standard will assist in achieving this outcome. But this must occur in tandem with, and not be allowed to supplant, **new government investments** to address the **acute unmet disability housing needs** across the country. Given that less than four per cent of NDIS participants currently have an SDA budget in their plan, disability housing cannot be dismissed as something that is only relevant within the Scheme. It is essential that mainstream housing policies also address this shortfall, including through the proposed Housing Australia Future Fund (HAFF).

Conclusion

Housing is **critical to the life chances of all Australians**. To have a safe, secure, comfortable place to call home is a key foundation of ordinary daily life and strongly influences the types of **opportunities** we can access and **relationships** we can build. The NDIS, and the home and living support providers funded through it, have a **critical responsibility** to ensure participants choose where and with whom they live, as well as how they access daily living supports. The fundamental context for this responsibility must be to ensure NDIS funds, which should properly be seen as investment in participants, do not lead to the continuation of facilities or institutional practices, but instead to the **creation of an authentic sense of home** for each participant, on the same basis as non-disabled Australians.

Commentary

The discussion about home and living began with the question: Can a group house or similar ever work, assuming best practice is followed for safeguards and resident matching?

Attendees recognised that a good life was one that was embedded in community, and a place to call home was a significant element of that. It was therefore useful to identify the interests any living arrangement sought to serve and whether it offered transactional benefits (such as shelter and help with the tasks of daily living) or transformational benefits (such as social connection and access to community).

Whether a resident had a genuine choice about where and how they lived – and how they reached that choice – was key for attendees. They noted that a 'choice' was often not really a choice or was not made by the residents themselves. This made supported decision making essential to a person's right to choose.

Attendees noted that group houses provided shelter and had the potential to provide other transactional benefits through daily living supports. But they also created a barrier to authentic community participation. Good staff could make a difference, but neighbours were still likely to see the house and its residents differently to others in the street. They would notice that the group of residents had been congregated together for a particular reason – all wheelchair users for example. They would notice that staff were coming and going and would soon determine that the house was a service facility rather than a neighbouring household and home. This would reduce and change interactions with neighbours.

Group houses also worked to decrease or prevent individual choice with residents usually sharing supports. If four people lived in a house with only one or two support workers present, each person's choice about what they wished to do could not be met. This undermined social and economic participation, a key objective of the Scheme. By way of example, one attendee spoke of a person who moved into a group house and had to comply with a roster of care that was set months in advance. This was not an 'ordinary' way to live.

Despite these drawbacks, attendees acknowledged that the Independent Living Option (ILO) was not widely used. They suggested the long lead time to set up an ILO contributed to this. People usually needed a housing resolution quickly and many did not have informal supports like family to help them navigate a long bureaucratic process.

One attendee noted an important difference between a group house, where residents are forced or compelled to share, and a shared living arrangement emerging from a genuine personal choice to share with someone they were already connected to.

Another attendee highlighted that SIL is usually negotiated between the provider and the NDIA without any involvement of the residents, thus removing individual choice and control.

Endnotes

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[1] Australian Government, 'Shut Out: The Experience of People with Disabilities and their Families in Australia', 2009, p.52, available at https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia.

[2] National Disability Insurance Agency, ‘An Ordinary Life at Home: Consultation Paper’, June 2021, p.13, available at https://www.ndis.gov.au/community/have-your-say/home-and-living-consultation-ordinary-life-home.

[3] National Disability Insurance Agency, ‘NDIS Quarterly report to disability ministers: Q2 2022-23’, 31 December 2022, p.98, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[4] NDIA Quality and Safeguards Commission, ‘Own Motion Inquiry into Aspects of Supported Accommodation: Inquiry Report’, January 2023, p.7, available at https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/inquiries-and-reviews/own-motion-inquiry-aspects.

[5] United Nations, ‘Convention on the Rights of Persons with Disability’, Article 19, 2006, available at https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd.

[6] Commonwealth of Australia, *Australia’s Disability Strategy 2021-2031*, 2021, p.10, available at https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf.

[7] National Disability Insurance Agency, ‘An Ordinary Life at Home: Consultation Paper’, June 2021, p.13, available at https://www.ndis.gov.au/community/have-your-say/home-and-living-consultation-ordinary-life-home.

[8] See the ‘SDA Pricing Model – Worked Example’ available from the ‘SDA Pricing Review’ webpage at https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-pricing-and-payments/sda-pricing-review.

[9] National Disability Insurance Agency, ‘Specialist Disability Accommodation Pricing Review 2022-23: Consultation Paper’, October 2022, p.4, available at https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-pricing-and-payments/sda-pricing-review.

[10] Usually, calls for a new approach to replace forced congregate living in group houses are met with two predictable responses: ‘What’s the alternative?’ and ‘How much would it cost?’. Neither refrain has a sound basis in reality. There is an array of alternatives to suit individual needs and choices; just as there is in the housing market generally. This has been evident for a long time. We do not advocate for a single prescribed option; that too would be inconsistent with the Scheme values of individual choice and control. Instead, the NDIS should be open to the full range of reasonable alternatives, encourage genuine innovation, and take a flexible approach to how NDIS budgets can be used for housing solutions that bring an authentic sense of home. Obviously, we are not suggesting that ‘harbourside mansions’ are a reasonable request to be funded through the NDIS, but, equally, we strongly reject the argument that individual housing choices for people living with disability are somehow unreasonable or financially inefficient when this is an ordinary expectation of non-disabled Australians.

Alternative housing options do not always cost more. Indeed, there are extra costs associated with Class 3 group houses, including for fire safety requirements, that are not incurred for an ordinary residential dwelling. This is fuelling demands from some in the SDA sector to effectively declassify group houses from Class 3 facilities and pretend that they are the same as Class 1 dwellings. This not only has the potential to compromise the safety of residents living in group houses but avoids the real issues about the character of these facilities. That character includes the presence of extensive rules, signs, safety infrastructure, recordkeeping materials, and staff areas that are not found in ordinary homes and subvert any attempts to create a sense of homeliness, belonging, or personal authority. These also represent additional NDIS-funded expenses that are not present in ordinary homes.

The question of costs should also focus our minds on what type of Scheme we want. If individual housing choices are rejected as unaffordable, then the NDIS is not a Scheme anchored to principles of individual choice and advancing the chances of Australians living with disability enjoying ordinary lives on the same basis as non-disabled Australians. It is not providing what is ‘reasonable and necessary’ to live an ordinary life. And it is not delivering what taxpayers think they are paying for. In effect, the NDIA is deciding that some people are ‘too disabled’ to deserve an authentic sense of home. This is the opposite of what was promised and inconsistent with the proclaimed Scheme values.

[11] NDIA Quality and Safeguards Commission, ‘Own Motion Inquiry into Aspects of Supported Accommodation: Inquiry Report’, January 2023, p.9, available at https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/inquiries-and-reviews/own-motion-inquiry-aspects.

CHAPTER 7: BALANCING NATURAL AND FORMAL SAFEGUARDS

KEY POINTS

- Safeguarding means both preventing harm and enabling people to live good lives
- All the most valuable things in our lives involve risk, therefore we must enable risk to advance the life chances of Australians living with disability
- Effective safeguarding requires a mix of natural informal safeguards and formal regulatory, compliance, and reporting mechanisms
- Informal and formal safeguards must be both proactive and reactive
- The NDIS must give greater attention to supporting participants to access natural informal safeguards within their local communities

Effective safeguarding requires us to ensure ‘bad’ things do not happen to people *and* that ‘good’ things do. Often, there is a tendency, with well-meaning intentions, for concerns about the former to overwhelm the latter. But the quality and nature of a person’s life must be at the forefront of effective safeguarding. When we worry too much about what could go wrong, we can inadvertently remove what is most valuable from people’s lives. We must **invest in supporting people to live active meaningful lives** characterised by an array of freely given relationships of mutual support that create natural safeguards for people within mainstream community life.

The best way to ensure effective safeguarding of people living with disability and oversight of providers, workers, and others operating within the National Disability Insurance Scheme (NDIS) is through a **combination** of both **natural informal safeguards** and **formal regulatory, compliance, and reporting mechanisms**. Recent prominent examples of safeguarding failures have involved shortfalls in both informal and formal safeguards leading to devastating consequences. This is true for both individual cases, such as the tragic death of Ann Marie Smith in 2020, and for systemic failures like those highlighted in the NDIS Quality and Safeguards Commission’s ‘Own Motion Inquiry into Aspects of Supported Accommodation’ report about ‘group houses’ released in January. We must invest in both informal and formal safeguards and recognise that neither will be enough on their own.

In this sixth chapter, we focus on the **nature of effective safeguards** for people living with disability. We emphasise the importance of understanding risk as being a key part of pursuing the good things in life and, therefore, not something to be eliminated from the lives of Australians living with disability. It is a **combination of informal and formal safeguards** that can mitigate the risks in people’s lives without stifling what is valuable to them. These safeguards must have elements that are both proactive and reactive in order to provide assurance that people will lead lives free of violence, abuse, neglect, and exploitation.

What do we *mean* when we talk about 'safeguarding'

Safeguarding should never be just about preventing 'bad' things from happening; it must also be about enabling and maintaining the conditions that ensure 'good' things emerge in people's lives. We must prevent violence, abuse, neglect, and exploitation of Australians living with disability *and* we must advance and defend their valued roles in community life. Safeguarding in the NDIS should include three key elements:

- upholding the **choice and control** of each participant;
- funding **transactional supports** that are what the person needs, helpful, and not harmful; and
- investing in **transformational change** that lifts each person into meaningful valued roles in community life, enables genuine connections and relationships, and maximises authentic social and economic participation.

When we talk about safeguarding, it must always be about how people are supported to move forward in their lives, reach their potential, and take up valued roles in community life.

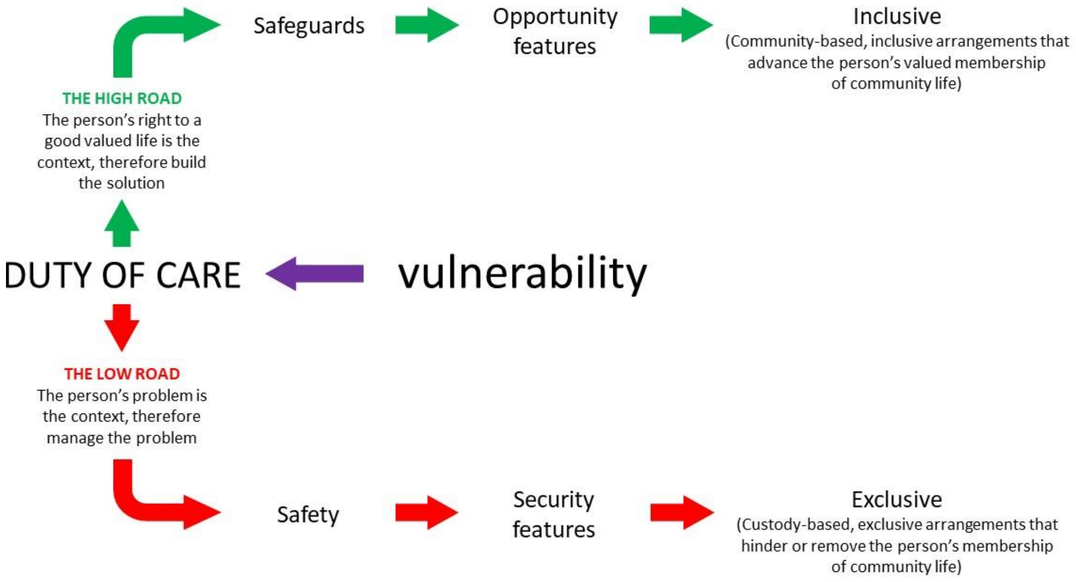
Reframing risk

Everything that is meaningful to us in life, everything that is worth fighting for, involves risk. If we only worry about what could go wrong, we lose the possibility of building good things in our lives. To live a good life is to accept and mitigate risks, not to eliminate them. Enabling risk leads to greater quality of life, wellbeing, personal growth, and development of new skills. We must place risk into the **context of ordinary life chances** and the **core NDIS values** of individual **choice and control**. It is ordinary to take risks. We willingly take on risk, for example, when applying for a new job, or asking someone out on a date, or going somewhere new, or speaking up about something that feels important. It is not the presence of risk in these situations that is the issue, it is how we plan for that risk. If a person wants to be completely safe from the risk of disappointment of a job rejection, that person simply avoids applying for jobs. But that, of course, also removes the possibility of a good outcome. Preparing well for a job interview is no guarantee of avoiding the disappointment of rejection, but it is a better option than simply not applying.

This is the difference between **safeguarding** and **safety**. Safeguarding is the means by which a person seeks to understand and plan for risk so they may pursue a meaningful goal. As such, the pursuit of a good life is the **context**. Safety, on the other hand, is often presented as its own context; safety measures are being taken so the person can be safe. While there is nothing wrong with the idea of being safe, if approaches to safety are not undertaken in the **context of good life chances**, those safety measures can serve to hold the person back, or even actively diminish their chances of a good life. This happens a lot for people who are labelled as having ‘behaviours of concern’ resulting in ‘restrictive practices’ being a feature of their support arrangements. More on this in a future paper in this series.

As we have written previously, the emphasis of the NDIS should be on **enabling positive risk taking** and maintaining a common-sense approach to duty of care. When we have a duty of care, there are two possible pathways available. We can take the ‘low road’ where the context is a person’s disability, which is considered a ‘problem’ to be managed to ensure ‘safety’ through security measures resulting in custody-like arrangements that render the person invisible to their community. Or we can take the ‘high road’ where the context is a person’s right to a meaningful valued life, and we build to this through ‘safeguards’ that enable opportunities leading to inclusive arrangements that lift a person’s participation and belonging in community life. It is this high road that provides the stronger assurance ‘bad’ things will not happen, and ‘good’ things will.

TAKING RISK SAFELY (INSTEAD OF MAKING SAFETY RISKY)



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Investing in a simple integrated safeguarding framework

The NDIS Review panel has released an issues paper[1] foreshadowing the need to ‘reset’ the approach to safeguarding in the Scheme to deliver more effective outcomes. As the first and so far only issues paper released by the Review, it is clear the question of how to improve current arrangements is a high priority for recommendations. We believe this ‘reset’ should elevate the status of **informal safeguards** so they are given the same weight as **formal safeguards.** There should be a much greater emphasis on **proactive safeguarding** to rebalance the focus given to **reactive processes**. The new framework should underscore the responsibility of the National Disability Insurance Agency (NDIA) to proactively invest in high-quality supports in participant plans that genuinely develop and sustain each person’s natural freely given relationships and community connections. Similarly, it should ensure mainstream services and systems do the same so people living with disability who are not eligible for individual NDIS plans do not fall through the cracks.

The NDIA and NDIS Quality and Safeguards Commission recently collaborated to release a new Participant Safeguarding Policy.[2] The stated purpose of the policy specifically excludes safeguarding strategies for 'cohorts or types of risks'[3] and does not address if or how such strategies will be developed. This policy document should be comprehensive and have **practical application** for cohorts, such as people living with intellectual disability, people living in group houses and other closed systems, participants who self-manage, and others, as well as cover the full range of risks, not just repeat generic references to preventing 'violence, abuse, neglect, and exploitation'.

If further separate documents are to be developed to cover these, then this continues the highly problematic practice of the NDIA producing excessive layers of documentation that only serve to create unwarranted complexity and confusion, make the Scheme more inaccessible, and ultimately undermine the safeguarding of people living with disability. As we have stated earlier in this compendium, **simplicity** must be restored to the Scheme if it is to fulfil its original promise. Safeguarding is best achieved when it is anchored in a **straightforward principles-orientated framework** with a single layer of supporting practical policies. Safeguarding will not be advanced through the layering of every possible iteration of documentation – legislation, rules, codes, frameworks, policies, applied principles, operational guidelines, practice guides, operating procedures, strategies, factsheets, inter alia – where the core messages are inevitably lost.

Importance of natural informal safeguards

People are more likely to be safer when they are connected into their neighbourhood and local community. Being an active member of local community life, and the mutually valued relationships that emerge from that, is a compelling safeguard. Freely given relationships of mutual support and benefit offer the greatest protections and safeguards for us all, and it should be no different just because the person lives with disability. As set out in our Model of Citizenhood Support, this mutuality is termed 'Social Capital' and is critical to our life chances.

Natural safeguards are reciprocal. Therefore, the focus cannot just be on building the capacity of people living with disability to 'make friends'; rather attention must be given to the **contexts and conditions** that create opportunities for **genuine reciprocal relationships** to emerge. Natural safeguarding also requires **diverse** informal relationships and community connections. Therefore, we must eliminate all forms of segregation where the context and conditions are such that they prevent the development of a diverse range of natural safeguards.

Natural informal safeguards are not separate to or outside the remit of the NDIS. The NDIS has a **critical role in investing in transformational supports** that create opportunities for genuine freely given relationships to emerge. Such opportunities include those that arise from funding authentic social and community participation rather than 'community tourism', as we highlighted in the fourth chapter. Similarly, the Joint Standing Committee on the NDIS made 30 recommendations regarding the NDIS Commission in 2021 with the Albanese Government this year supporting 21 and referring nine to the NDIS Review.[4] Among those referred to the Review are consideration of how to improve access to and strengthen natural safeguards and the need for increased proactive safeguarding approaches. Proactive engagement with natural safeguards will help ensure people are supported to move forward with their lives, while reactive safeguarding can occur when these same informal connections have a line of sight on what is happening in a person's life.

Formal safeguards for assurance and accountability

Formal safeguards by themselves will never be enough to protect people living with disability in isolation of strong natural informal safeguards. But they still have critical roles to play in providing assurance and accountability within an integrated safeguarding framework. Purposeful regulatory, compliance, and reporting mechanisms are all essential to the proper functioning of the NDIS. These need to cover proactive mechanisms, such as worker screening and organisational auditing, and reactive measures, including complaints procedures and incident investigation processes. Both the NDIA and the NDIS Commission have responsibilities to provide oversight of participant welfare and of organisations and individuals delivering supports and services funded by the Scheme.

Critically, 'auditing' a disability support provider to make sure it is compliant with quality and safeguarding expectations must go beyond a review of documentation. **Observation** is much more important. Formal safeguards must include people visiting service sites to observe what happens there and to speak with service recipients. This is more likely to reveal the character of the service, much more so than the presence of relevant documentation. Importantly, these visitor teams should include members living with disability.

Call to action: stepping up, not standing by

Each of us has a role to play in safeguarding others in our communities. We can be part of natural freely given relationships of mutual support with our family, friends, neighbours, colleagues, customers, teammates, and general acquaintances. We can say hello, engage in conversation, ask people what they need or want, respect decision-making rights, and follow up when we miss someone's presence. We can **speak up when something does not seem right**, not just stand by. We can ensure that the voices of Australians living with disability are elevated and heard in public discourse so that human rights are upheld and barriers in community life eliminated.

The NDIA should take a stronger role in elevating a national conversation about the importance of embedding informal safeguards in the lives of all Australians, as well as how we all have a role to play in ensuring people living with disability are **included** in these natural freely given relationships in our communities. Further, the NDIA should regularly explore the extent to which **Social Capital** is present in a person's life (we argue this should be a key NDIS outcome) and ensure NDIS funds are targeted at efforts that authentically build the person's take-up of valued roles in community life for the belonging and the natural safeguards that flow from this. NDIS funds should also target methodologies like Circles of Support[5] that can help build connection and Social Capital in people's lives.

Conclusion

The core aim of safeguarding should be to create and defend the **meaningful valued roles** of each person living with disability in community life. People who are isolated from others are always at far greater risk of violence, abuse, neglect, and exploitation than those with diverse networks of freely given relationships that form strong mutual safeguards. The NDIA should proactively engage with participants to understand the extent of a person's freely given relationships and invest in what is needed for each participant to **create and maintain natural informal safeguards** in their life. Alongside informal safeguards there must be **purposeful** formal regulatory mechanisms that provide assurance and accountability in aspects of how the NDIS functions. Safeguarding in the NDIS must involve a combination of **informal and formal safeguards** that are both **proactive and responsive**. This can form the basis of a new simple integrated safeguarding framework to underpin the 'reset' that the NDIS Review issues paper is calling for.

Commentary

How to balance duty of care with dignity of risk was the launching pad for this discussion. For attendees, this was a complex issue, with a genuine tension between 'do no harm', a foundational principle of Western medicine, and the risk and uncertainty inherent in pursuing anything new. Attendees considered overplaying the duty of care and eliminating the risk of failure would reduce opportunities for a person to learn and grow a rich and fulfilling life.

Attendees also explored safeguards and the limits of formal safeguards, with numerous examples of inconsistencies between the adequacy of a service provider as seen through a government audit and accreditation process and the reality as experienced by recipients. They emphasised the need to have both informal supports (such as family) and paid supports.

A discussion of the barriers to making a complaint followed, with attendees citing fear of blame and retribution, including threats of legal action; the absence of formal written complaint mechanisms; concern about being labelled 'complainers'; and too much weight being given to staff complaints about clients as barriers to be addressed.

Attendees considered a best practice safeguarding system could advance good lives by being: safe, fair and accountable; committed to continual improvement; responsive to feedback; reflective about practice; not threatened by complaints; and engaged with clients.

More training in reflective practice and identifying ways to raise problems and solutions without ascribing blame should be explored.

Endnotes

[1] Independent Review of the National Disability Insurance Scheme, ‘NDIS Quality and Safeguarding Framework: Issues Paper’, April 2023, available at https://www.ndisreview.gov.au/resources/paper/ndis-quality-and-safeguarding-framework-issues-paper.

[2] National Disability Insurance Agency, ‘Participant Safeguarding Policy’, April 2023, available at https://www.ndis.gov.au/participantsafeguarding.

[3] *Ibid*, p.7.

[4] Joint Standing Committee on the National Disability Insurance Scheme, ‘NDIS Quality and Safeguards Commission’, November 2021, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/QS_Commission/Report; and Australian Government, ‘Australian Government response to the Joint Standing Committee report on the National Disability Insurance Scheme (NDIS): NDIS Quality and Safeguards Commission’, April 2023, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/QS_Commission/Government_Response.

[5] For more information about Circles of Support, see, for example, https://cosam.org.au/national-resource-centre/circles-of-support/; https://www.scopeaust.org.au/blog/disability-advice/creating-a-circle-of-support/; or https://communitylivingproject.org.au/development/wp-content/uploads/2020/09/Circles-of-Support-overview-Sept20.pdf.

CHAPTER 8: CLOSING EMPLOYMENT GAPS ARE ESSENTIAL FOR NDIS TO FULFILL ITS PROMISE

KEY POINTS

- **Work-related goals** should be included in **all NDIS plans** for participants of working age
- The NDIS **should not fund** employment supports for arrangements that **do not uphold Scheme values**, including ADEs and **'**supported employment services**'**
- The NDIA should focus on identifying which programs aimed at advancing people into meaningful mainstream waged employment **deliver the best results** and ensure these are promoted and favoured in NDIS plans
- The NDIA should **showcase successful pathways** so that these can be replicated and scaled up for the benefit of all

> *'The disturbing reality is that labour force participation for people with disability in Australia has changed little over the past twenty years. As well as having a negative impact on individuals, such low participation remains a persistent public policy problem… The need for change is undeniable. Australia only stands to gain from increasing the workforce participation of people with disability.'*

Employment has enormous benefits for a person, their workplace, the community, and the economy, as the Australian Human Rights Commission identifies in this quote.[1] Yet many Australians living with disability continue to be **shut out of the workforce**. Data from the Australian Bureau of Statistics (ABS) in 2018 shows that just 47.8 per cent of people living with disability were employed compared to 80.3 per cent of people without disability.[2] The infrequency of data collection about people living with disability has created a significant information void since 2018, but anecdotal evidence suggests it is likely the Covid-19 pandemic has made this discrepancy even worse. **Discrimination and unfair treatment persist**, with 2018 data indicating that 45.2 per cent of workers living with disability experienced being targeted by an employer and 42 per cent by their work colleagues.[3] At the same time, the median gross personal income of a person living with disability was $505 per week, less than half that of a non-disabled person at $1016 per week in 2018.[4]

In its landmark 2011 report on Disability Care and Support, the Productivity Commission predicted that the creation of a new national disability scheme would **improve employment outcomes** and concluded that 'even conservative assumptions lead to **significant economic and employment effects**' for Australians living with disability.[5] Unfortunately, so far these effects have fallen well short of expectations. As of 31 December 2022, **just 23 per cent** of National Disability Insurance Scheme (NDIS) participants aged 15 to 64 were **employed**[6], which is unacceptably low. The Scheme's Participant Employment Strategy aims to 'ensure at least 40 per cent of working age NDIS participants have employment or pre-vocational goals in their NDIS plan.'[7] This aspiration also remains far too low.

In this seventh chapter, we highlight the **urgent need to address the poor outcomes of the current approach** to supporting participants to enter and maintain meaningful mainstream waged employment. We focus on the importance of employment to living a good life characterised by valued roles in community and the personal resources necessary to create genuine ordinary choices in life. We address the problems of segregated and exploitative work arrangements under the Supported Employment Services Award and emphasise these approaches are inconsistent with Scheme values. We argue the NDIS should focus on **identifying and investing in employment supports** in participant plans that **demonstrate the best prospects** of achieving sustainable meaningful mainstream waged employment outcomes.

Importance of employment

Meaningful mainstream waged employment is one of the foundations of living a good life and maximising the opportunities of *Citizenhood*.[8] In the fourth chapter, we focused on advancing people living with disability into valued roles in community life; **being employed** is one such **valued role**. It is self-affirming and contributes to a positive sense of self and personal wellbeing,[9] while unemployment has the opposite effect of undermining self-worth. Employment also creates opportunities to learn and grow[10] and brings new relationships and connections[11] into a person's life. As such, employment **exemplifies** the promised Scheme outcome of **social and economic participation**.

Additionally, given the impact of a **living wage** on a person's life chances, the presence of a sustainable employment income is critically important in providing this resource.[12] Disposable income is a **gateway to choice and control** because, for most of us, our choices are funded by this personal income. **Low income means low choice**. Therefore, given **employment delivers on the Scheme goals of choice and control**, as well as **social and economic participation**, it follows that finding and maintaining employment should be a key feature of NDIS plans for working age participants.

All people have a **right to work** and to **access the resources** of paid employment. As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Australia has an obligation to ensure that citizens living with disability have the right 'to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive, and accessible to persons with disabilities'.[13] Australia's ratification of the UNCRPD comes with responsibilities to ensure that people living with disability have a fair go in the labour market, are supported within their workplaces, and do not experience any form of discrimination, be it, in recruitment processes, pay and conditions, accessibility in work environments, career advancement, or health and safety.

Unlearning low expectations

The Productivity Commission's 2011 report argued 'passivity and low expectations should not be the default' for Australians living with disability.[14] However, based on ABS data, it modelled that among prospective NDIS participants without jobs, about 70 per cent would be people who 'say that they cannot work at all under any circumstances', leaving about 30 per cent as the 'main target group for employment assistance'.[15] This demonstrates the prevalence of low expectations that continue to be deeply embedded and undermine the life chances of Australians living with disability. It may also be that this model based on flawed assumptions set the Scheme off on the wrong track in relation to producing employment outcomes. Regardless, the National Disability Insurance Agency (NDIA) and others must redouble their efforts to overcome the persistent low expectations the report refers to, not only among participants, but also families, allies, support workers, teachers, employers, governments, and the broader community.

The NDIA's default expectation should be that **all plans of working age participants include a work-related goal**. The only reason that employment should not feature is if a person is already in meaningful mainstream waged employment and does not require funded support to maintain their connection to that employment (or if a person has taken retirement based on the proceeds of such employment). This default expectation will help overcome the deficits approach and focus on strengths and skills that can be harnessed for suitable work opportunities and increased life chances.

Ending segregation and exploitation

There are clear parameters that should apply to work-related goals and how the NDIS invests in participant employment outcomes consistent with fundamental Scheme values. First, we address what this should not include. The NDIS should not invest in what used to be called 'sheltered workshops' but are now given the more 'uplifting' label of Australian Disability Enterprises (ADEs). ADEs employ people living with disability, typically supervised by non-disabled managers paid a mainstream wage, to undertake work to deliver a service or product the ADE sells, for example packing services, gardening, or firewood. Typically, the workers remain on the Disability Support Pension (DSP) and are paid a very small hourly rate (recently updated to $4.75 per hour at Grade A from 30 June 2023 with a minimum wage of $2.90 per hour[16]) for their involvement with the ADE. The effect of this arrangement is workers are kept in poverty with little prospect of entering mainstream employment. On this income level, a person cannot make the range of choices that are available to other employed Australians.

Typically, ADEs operate business models based on these very low pay rates, hence the demand for taxpayer subsidies to underpin even a minor pay increase, as was provided for in last week's Federal Budget.[17] ADEs are incentivised to hold on to their most productive workers rather than enable their advancement into mainstream employment opportunities because this productivity ensures the ADE can fulfill its commercial commitments to customers. ADEs typically congregate workers living with disability and are a **segregated provision** contrary to Australia's obligations under the UNCRPD and commitment to inclusion in *Australia's Disability Strategy 2021-2031*.

Likewise, the NDIS should not fund other arrangements covered by the Supported Wage System, including where people are placed to work in a supermarket, retail store, fast food outlet, or other business, which allows these organisations to exploit a pool of low-cost labour. These workers should be directly employed by the businesses involved with the same wages, conditions, and opportunities for career progression as other staff and supported through the implementation of any reasonable modifications they require.

Currently, there are about 16,000 people living with disability working under the Supported Employment Services Award[18] at either an ADE or through a 'supported employment service'. This means 16,000 Australians are being kept in poverty. The NDIS should **not fund supports for either of these arrangements because they do not adequately reflect Scheme values**. Participant plans should be orientated toward supporting meaningful mainstream waged employment in settings where people living with disability are included not segregated. There are **training arrangements in existing mainstream awards** that provide authentic auditable employment pathways whereby a person earns an appropriate training wage for a fixed period. These arrangements should be utilised to create opportunities for people living with disability to enter the workforce with genuine prospects of progression into sustainable meaningful mainstream waged employment. These arrangements should also have sufficient flexibility to be tailored to support individual needs and any reasonable modifications.

Importantly, we are not proposing to close ADEs and leave workers unemployed, bored, and more isolated. Rather, we are arguing for an immediate transition to a new business model that would abolish ADEs in their current form, practices of segregation, and the Supported Employment Services Award that underpins the existing ADE approach of poverty maintenance, while supporting the organisations and their employees to thrive in new ways. Many who oppose change assume that all the ADE workplaces would be shut down and people would lose their employment, the opportunity to contribute, and the relationships that they hold dear within these settings. This is not what we want either. The **key to successful change is an effective transition that brings workplace practices into the** **^{2}1st century** while maintaining the positive attributes of employment, including contribution and social connection.

Investing in meaningful employment outcomes

Having described what should not be funded, the second task is to set out what the NDIS should invest in instead. The NDIS should support people living with disability to fully participate in the mainstream labour market by finding and/or maintaining suitable meaningful waged employment according to their skills, interests, and aspirations. Naturally, it should fund the individual plan supports required to maintain any participant's existing mainstream employment and for them to progress along an ordinary career pathway as their skills and experience develop. A participant's current employment situation should never be treated as static, unchangeable, or indefinite, in the same way that most people undertake a range of roles with various employers and seek advancement in position, responsibilities, and income throughout their working life.

Moreover, there needs to be a significant increase in the investment and effort to achieve employment outcomes for the 77 per cent of NDIS participants who are not currently employed. There are a range of endeavours across Australia and overseas that are seeking to lift people living with disability into sustainable mainstream employment. The NDIA should focus on learning which of these ventures hold the most promise and have the greatest success and ensure these models are promoted and favoured in plan considerations. To some, this statement may seem overly simplistic, but we argue this is because it holds a simple truth that is often lost. If something works well, and more people could benefit from it, it makes sense to tell those people about it and encourage them toward it. Conversely, if something does not work well, stop spending money on it, and try something else. Indeed, the need to restore simplicity to the Scheme and how it seeks to advance people into social and economic participation has been a central theme throughout this compendium.

We encourage the NDIA to find ways to showcase great pathways into mainstream employment, including information about how they work, so they can be replicated and scaled up, noting that the NDIS is often not the only, or best, source of funding for these pathways. For example, JFA Purple Orange is currently undertaking the Road to Employment (R2E) project funded by an Information, Linkages, and Capacity Building (ILC) grant from the Department of Social Services (DSS). This project has **demonstrated success through an industry-based approach** in the aged care, finance, and local government sectors. It provides a range of initiatives to build employer confidence and capacity to employ people living with disability, including mentoring, sector-based communities of practice, and disability inclusion training. Each industry working group has designed a tailored approach. For example, in the aged care sector a traineeship program has so far supported six people living with disability to enter ongoing mainstream employment and complete a Certificate III level qualification at the same time.

This role in showcasing pathways should include a focus on ways people living with complex disability can be assisted into employment, such as through leveraging methodologies like customised employment[19] and microenterprises[20]. It must not be assumed that a person living with complex disability is not capable of entering paid employment. When the NDIA and others **imagine the possibility of employment for a person** of working age, it **creates a future for that person that includes employment in it**. Conversely, if the NDIA or others in a person's life, do not consider this possible for the person, then that person's future has been decided for them and is bleaker as a consequence. The NDIA should hold true to the **possibility of meaningful mainstream paid employment for all working age participants** and defend this principle always.

The bigger picture: shifting perceptions of employability

Research shows **that diverse workforces perform better and create a competitive advantage** for commercial businesses.[21] Yet, Australians living with disability continue to encounter significant barriers to entering mainstream employment and it is extremely important that broader work is undertaken to change this. Under *Australia's Disability Strategy 2021-2031* and the accompanying disability employment strategy 'Employ my ability', all tiers of government have committed to increasing employment levels of people living with disability and tackling barriers. The NDIS has a **crucial leadership role to play** in shifting perceptions about employability including through helping to create a **greater presence and visibility** of people living with disability in the Australian workforce and undertaking senior roles.

Conclusion

Advancing Australians living with disability into meaningful mainstream waged employment **is a critical promise[22] of the NDIS**. Yet, as the Scheme reaches its ^{1}0th anniversary, results have fallen well short of expectations. Significant gaps in employment outcomes compared to non-disabled Australians persist and the trajectory is stagnant. Segregated and exploitative arrangements that exist under the Supported Employment Services Award are not the answer. We must focus on **identifying and replicating the pathways into mainstream employment that demonstrate the best outcomes** and when an approach does not work, try something else. Delivering on the promise of greater employment outcomes will not only have enormous individual benefits for a person's access to choice and social and economic participation, but also boost national productivity at a time of significant worker shortages across the economy.

Commentary

This webinar began by discussing the challenges faced by one organisation in attracting applicants living with disability for a well-paid role. This highlighted the need for greater accountability in meeting employment goals in NDIS plans.

The challenges of transitioning into mainstream employment for people living with disability who had been educated in segregated environments were also canvassed. Attendees considered it important to set the bar high – creating the expectation early in a child's life that mainstream employment was an appropriate and achievable end goal. Building self-advocacy skills for children (by bringing them to One Plan meetings, for example), was seen as an important strategy to encourage children to speak up.

Attendees also identified disincentives created by the design of the Disability Support Pension (DSP) including a fear of losing access to the DSP and the benefit to some service providers if clients remained on the DSP. They proposed more education for people living with disability and service providers as well as peer-workforce models such as those used in the psychosocial space. While no two people living with disability will have identical experiences, attendees considered there was sufficient commonality for peer mentoring to be valuable. Attendees were also confident that employers would become advocates when they saw what was possible.

Endnotes

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[1] Australian Human Rights Commission, 'Willing to work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability', 2016, pp.6 & 231, available at https://humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination.

[2] Australian Bureau of Statistics (ABS), 'Disability and the labour force', 24 July 2020, available at https://www.abs.gov.au/articles/disability-and-labour-force.

[3] *Ibid*.

[4] Australian Bureau of Statistics (ABS), 'Disability, Ageing, and Carers, Australia: Summary of Findings', 24 October 2019, available at https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release.

[5] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.960, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[6] National Disability Insurance Agency (NDIA), National - Quarterly Performance Dashboard, 31 December 2022, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[7] National Disability Insurance Agency (NDIA), 'NDIS Participant Employment Strategy 2019 – 2022', p.13, available at https://www.ndis.gov.au/about-us/strategies/participant-employment-strategy.

[8] The Model of Citizenhood Support sets out a framework for how people can be supported to build their chances of a good life and maximise their *Citizenhood*. It identifies four different, interrelated, types of assets we can call upon, termed the Four Capitals.

[9] A positive sense of self is a form of Personal Capital, which refers to how a person sees themself.

[10] This creates Knowledge Capital by enhancing what a person knows and learns.

[11] This helps ensure a person has Social Capital. Social Capital requires having people in our lives whom we know and know us.

[12] A wage is the optimal pathway to personal Material Capital, which refers to having money and other tangible resources in our lives.

[13] United Nations, 'Convention on the Rights of Persons with Disability', Article 27, 2006, available at https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd.

[14] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.283, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[15] *Ibid*, p.959.

[16] FairWork Commission, ‘Determination: 4 yearly review of modern awards—Supported Employment Services Award 2020’, 21 December 2022, available at https://www.fwc.gov.au/documents/sites/awardsmodernfouryr/pr749151.pdf.

[17] Commonwealth of Australia, ‘Budget Paper No. 2: Budget Measures’, 9 May 2023, pp.204-205, available at https://budget.gov.au/content/bp2/download/bp2_2023-24.pdf.

[18] Department of Social Services, ‘More opportunities and investment to support people with disability’, Media release, 9 May 2023, available at https://ministers.dss.gov.au/media-releases/11151.

[19] For more information, see for example, https://www.everyonecanwork.org.au/employment-support/ndis/customised-employment/; https://includeability.gov.au/resources-employers/customising-job-person-disability; or https://www.scopeaust.org.au/services-for-individuals/customised-employment/.

[20] For more information, see for example, https://www.everyonecanwork.org.au/employment-support/ndis/microenterprise/; https://www.ndis.gov.au/stories/5996-micro-enterprise-meaningful-employment-alternative; or https://imaginemore.org.au/resources/employment-and-microenterprise/.

[21] For example, see Australian Government, ‘Employ my ability’, 2 December 2021, p.11, available at https://www.dss.gov.au/employ-my-ability; Australian Network on Disability, ‘Business benefits of employing people with disability’, 2021, available at https://and.org.au/join-us/why-hire-people-with-a-disability/benefits; and Job Access, ‘New research review shows employers reap clear benefits by hiring people with disability’, 14 March 2023, available at https://www.jobaccess.gov.au/news-media/australian-employers-undisputed-rewards-hiring-people/.

[22] The Productivity Commission not only concluded employment outcomes would improve as a result of a new national disability scheme, its 2011 report included increased employment levels in its economic justification for the change. See Chapter 20 of Productivity Commission, ‘Disability Care and Support,’ Report no.54, 2011, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

CHAPTER 9: THINKING ABOUT NDIS VALUES MEANS VERSUS ENDS

KEY POINTS

- The fundamental goal of the NDIS is to advance **social and economic participation**
- The value set of ***choice and control*** is not an end in itself; it is the **means** by which the value set of ***social and economic participation*** is achieved
- To achieve **values consistency and coherence**, *choice and control* should operate in the **context** of advancing authentic *social and economic participation*
- Therefore, the NDIS **should not fund** choices that work against advancing authentic *social and economic participation*

> *'We desire a place within the community! This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this, great things may flourish... Perhaps then we will belong and our gifts (perhaps meagre, perhaps spectacular) freely shared. And from there will flow all the delights and tragedies of a life lived in the community, shaped not by exclusion and oppression but by everyday ordinariness (whatever that might be)!'*

These words[1] from a person living with disability in a submission to the consultation that produced the 2009 '*Shut Out*' report crystalise the **hopes of many** for what a new national disability scheme could deliver. The disability community sought access to the same services, resources, and opportunities **to participate in the social, cultural, and economic life of our society** as other Australians enjoy. This meant having the same range of fully available options for a person to make genuine choices to enable them to live a meaningful life in the community on their own terms without segregation, exclusion, or discrimination. It is the thread that carried forward to the creation of the National Disability Insurance Scheme (NDIS) in 2013 as the mechanism that could underpin such a significant transformation in the lives of people living with disability for the benefit of not just them, but the whole Australian community.

This eighth chapter explores the **nature of the values** that are supposed to define the NDIS and how it supports Australians living with disability. The Scheme is anchored on two key sets of values: ***choice and control***, and ***social and economic participation***. Each person's exercise of choice and control over their life is consistent with a range of expressions of fundamental human rights, including Article 3 of the Convention on the Rights of Persons with Disabilities (UNCRPD). Maximising the social and economic participation of people living with disability featured prominently in the Productivity Commission's 2011 report on disability care and support as one of the key functions of a new scheme, as well as a significant justification in its cost-benefit analysis.[2] Importantly, both sets of values are listed as Objects of the *National Disability Insurance Scheme Act 2013* (s3).

This paper sets out two main messages. First, the **defence of choice at the expense of authentic social and economic participation will not deliver on the Scheme's promise**, therefore, the value set of *choice and control* should be understood in the **context** of achieving *social and economic participation* – not as an end in itself. Second, the Scheme must be **recalibrated to achieve values consistency and cohesion** whereby choices that do not deliver authentic social and economic participation are not supported or funded. However, before delving into these propositions, it is important to consider what the value sets mean, and the extent to which they are present in the NDIS currently.

Choice and control

The first value set is *choice and control*. There are two distinct ideas here. The first, *choice*, reflects the importance of having genuinely available options so the person can make a decision based on whichever option is **the best fit for what is important to them**. The second, *control*, reflects the importance of the person having **central involvement in decisions** affecting them so they have personal authorship of their life. It heralds the increasing consideration of methodologies termed 'support for decision making' (SDM) that assist those with differing cognitive capacity to be their own decision-maker rather than having a substitute decision-maker fulfilling this crucial role in their lives.

These two individual values go together, and both need to be available to the person. Having one and not the other is far less impactful. If a person has very few choices available to them, the presence of control will have little impact. An example of this in the NDIS is 'thin markets' where the participant may have a budget and decision-making jurisdiction, but the choice they want to make is not available, perhaps because they live in a rural or remote location. Similarly, a wide range of options is of less value to the person if someone else is making the decision about which option the person gets. Imagine being shown an extensive menu at a café but someone else decides what you get to eat.

Social and economic participation

The second value set in the Scheme is *social and economic participation*. Again, there are two distinct ideas here. *Social participation* refers to **activities that grow connection and fellowship** with other people. The importance of fellowship with other people is fundamental to our wellbeing. Therein lies the grails of love and belonging. Yet the phrase *social participation* seems inadequate. Most of us do not use the phrase *social participation* in our lives. Instead, we talk of going out, meeting new people, making friends, falling in love, joining clubs, and getting involved in the things we care about, be it dogs, books, the footy, climate change, or nice food. In these endeavours, we bring energy and passion, and are uplifted by that of others. We impart our wisdom, and we learn from others. Friends and acquaintances share mutual warmth with us. In other words, we give as much as we take.

In reflecting on the history of supports for people living with disability, service systems have typically separated them from non-disabled people, creating much smaller networks of connection, such that a person living with disability had far fewer opportunities to make ordinary connections in life. This in turn has an adverse impact on the extent of fellowship, the chances of finding love, and the prospects for a true sense of belonging. This history is summed up in two words by the title of the report '*Shut Out*' that led to the *National Disability Strategy 2010-2020* and the NDIS.

Economic participation refers to **being productive in some way that is meaningful to the person and their community in the economy**. That economic participation is also characterised by mutuality, by give and take. We give our labour and our skills and knowledge, and we take remuneration and a sense of contribution and fulfillment. For most Australians, economic participation is achieved through mainstream waged employment.

Scheme performance against these key value sets

If the Scheme declares a commitment to *choice and control* then, for that claim to be authentic, those values should be **routinely evident in the Scheme's practice**. However, in its first 10 years, the Scheme has ***struggled to deliver choice and control*** to participants. For example, agency-managed participants have greater constraints on their options compared to participants opting to self-manage their supports. For further example, participants who were migrated into the NDIS from state-funded group house[3] or similar arrangements have their planning, and therefore their options, framed by an assumption their involvement in the current service model will continue; in other words, their budget allocation will be considered in the context of their colocation and sharing of funded supports with other participants living in the group house. For still another example, no Scheme participant has a choice of Local Area Coordinator (LAC), arguably the pivotal role for the participant's success in the Scheme.

A similar analysis can be made of *social and economic participation* where these values should also be evident in the Scheme's practice. However, the Scheme has **not made strong progress**. *Social participation* is currently being counted on the basis of hours spent in the community, but this does not discern between endeavours designed to grow ordinary connection and fellowship, and activities designed to pass time and group people living with disability together, reflecting, at best, a profound lack of imagination and, at worst, a waste of people's lives and potential. Meanwhile, contrary to the mission-critical idea that the Scheme is an investment in outcomes for people living with disability, low levels of authentic waged employment persist among Scheme participants, as explained in Chapter 7. Adding salt to that wound, Australian Disability Enterprises (ADEs) continue to be favoured, even though they seem better aligned with a value set that replaces the term *social and economic participation* with the term *segregated and poverty-based participation*.

For the Scheme's **integrity** it is important the National Disability Insurance Agency (NDIA) find **ways to strengthen the Scheme's expression of its values**. At the heart of values *integrity* is the idea that the values you claim ('stated values'), are the same as the values you believe ('felt values'), which are the same as the values evident in your decisions and actions ('lived values').[4] The only way for the Scheme to have **values integrity**, to truly advance, *and defend*, the value sets of *choice and control* and *social and economic participation* is to **ensure these values are present in every aspect of Scheme practice**.

The defence of choice at the cost of social and economic participation

The challenge with the pursuit of values integrity is the NDIA will be faced with many instances where a participant, or a participant's family, or a participant's service provider, might assert it is the person's choice to stay in a day program, or sheltered workshop, and not to pursue mainstream employment; that it is their choice to stay in segregated housing and not pursue more ordinary, individual, inclusive alternatives; that it is the person's choice to engage in more passive segregated social activities rather than connecting with other people in community life through ordinary valued roles. This can even extend to matters of daily living, where a service provider might argue it is a person's choice not to rise until much later in the day, or not to bathe, and the like.

This presents the Scheme's personnel with a values conundrum, where choice and control appear to be in direct conflict with social and economic participation. And based on the volume of segregated services the NDIA invests in (for example, group houses, ADEs, day programs, and similar), it seems that someone's exercise of choice and control is winning out against the goal of authentic social and economic participation.

So, how might the Agency navigate this conundrum?

The difference between means and ends

We suggest a simple distinction. Our experience has been that when describing a good life, most people reach for ideas about family, friendship, not being lonely, having a fulfilling job, continuing to learn and grow, feeling valued, and fostering a sense of belonging. All of these are anchored on the take up of valued roles, or *Citizenhood*. Having choice and control is important because it helps bring these things about. Friends choose each other, people apply for courses, seek jobs, select hobbies, decide what foods they like, and so on. The decisions we make, anchored on the twin virtues of choice and control, play a key role in what then happens to us.

As such, this conundrum is a matter of means and ends. A good life is characterised by *Citizenhood*, or as the Scheme would describe it, social and economic participation. That is the Scheme's true goal, which is why it is part of *Australia's Disability Strategy 2021-2031* intended to deliver inclusion.

If *social and economic participation* represents the Scheme's ends, then choice and control represents part of the means by which the ends are accomplished. Therefore, *choice and control* operate in the context of *social and economic participation* and should not be permitted to trump it. Otherwise, the Scheme is investing funds in services that are not advancing the Scheme's goal, and that make no sense.

If still in doubt about which value set is most important, consider the name of the disability community consultation report that led to the creation of the NDIS. The report was not called 'No Choice' or 'No Control'. It was called *'Shut Out'*, reflecting how people living with disability are shut out from the societal and economic opportunities available to most Australians; in other words, *social and economic participation*.

Recalibrating the Scheme

The Scheme needs to be **reset in a way that provides a consistent approach to its claimed values**. First, the value sets of *choice and control* and *social and economic participation* should feature in every Scheme policy and protocol and be at the heart of all training and all commissioning. This needs to be done in a way that is explicit and auditable. Through a *'Values in Action'* project in 2016-17, we assisted several service providers to navigate a values integrity methodology, which included social audits at each provider where their services were observed through a values integrity lens. As a result, the agencies became aware of issues of values consistency and were then able to take steps to address these.[5] The Scheme needs something similar. Only in this way can stakeholders be confident the Scheme's stated values are also the ones it believes in and acts on.

Second, those same policies and protocols should **reflect how *choice and control* operate in the context of authentic *social and economic participation***. If a participant, or someone else in their life, wishes to assert a choice that intuitively or demonstrably works *against* the goal of social and economic participation, of authentic inclusion and the valued roles that underpin it, the NDIA should decline that choice. Every time.

Therein lies the values consistency and coherence the Scheme needs if it is to have any prospect of authentic success. The Scheme is fast approaching 600,000 participants, generating a complex mesh of many thousands of NDIA decisions every week. **Establishing values consistency and coherence is the only way the NDIA can make sense of its work and deliver on its promise.** Values consistency will also strengthen Scheme **sustainability**, because it will only be investing in things that are genuinely impactful.

These values, lived, are the **foundation upon which Australia can become a world leader in investment in people living with disability**. We want other nations to follow this lead, where the NDIS is so successful it transforms how every country thinks about disability support; not as welfare but as investment in people.

Commentary

”Money doesn’t think – and more money spent thoughtlessly won’t achieve meaningful outcomes” was the starting point for this discussion. Regular review was needed to determine the effectiveness of existing strategies and whether the assumptions they were based on (for example the pre-COVID versus post-COVID reality) remained accurate.

Attendees argued that insufficient thinking was done before the NDIS was rolled out: that ILC should have been rolled out first; and that by not doing so, social capital had disintegrated. But they considered ILC was imperfect too, and more community-based options were needed.

Attendees considered the transition to the NDIS had led to greater commodification of the person – and this had led to unintended behavioural change. When you are treated like a marketplace customer, you behave like a customer. You argue over price and shop around. This is hard work. Shifting the perspective back to the Scheme as a facilitator of partnerships with shared goals was a priority.

Attendees also discussed whether legacy disability organisations had created a conflict of interest by moving into service provision while retaining pre-NDIS advocacy, policy development and education roles, and whether this hybrid-model should continue. They suggested such diversification may lead to services becoming “a jack-of-all trades, master of none”.

The use of family governance entity structures to promote the principles of ILC was discussed, as well as the interaction between ILC and LACs. Attendees considered further clarity about the functions of each was needed.

Endnotes

[1] Australian Government, 'Shut Out: The Experience of People with Disabilities and their Families in Australia’, 2009, p.viii, available at https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia.

[2] See, for example, Recommendation 3.1 and Chapter 20 in of Productivity Commission, ‘Disability Care and Support,’ Report no.54, 2011, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[3] We use the term ‘group house’ in preference to the term ‘group home’ because the usual authentic features of home are not usually present in group home models.

[4] JFA Purple Orange, ‘Values in Action Toolkit’, 2016, available at https://www.valuesinaction.org.au/ resources/values.

[5] JFA Purple Orange, ‘Values in Action project: Final Report’, 2017, Adelaide, South Australia.

CHAPTER 10: ILC IS KEY TO NDIS SUCCESS AND SUSTAINABILITY

KEY POINTS

- The Productivity Commission envisaged a 'coherent national system' comprising three tiers, with **each tier essential to the success of the others**
- Individual plans and budgets alone cannot deliver the **transformational impacts** promised by the NDIS; an **effective ILC program** is critical to the **success and sustainability** of the Scheme
- The importance of ILC-type initiatives to the Scheme's success justifies a **larger funding allocation**
- To maximise impact and fully leverage momentum, ILC-type initiatives should be **funded for much longer periods** than the current short-term approach allows
- ILC-type initiatives are a **critical investment** in the **quality of individual decision-making**, ensuring decisions are owned, informed, resourced, and supported

An individual plan under the National Disability Insurance Scheme (NDIS) was never intended to be the "only lifeboat in the ocean", as Minister Bill Shorten has frequently highlighted[1] since taking on the portfolio last year. Back in 2011, the Productivity Commission conceptualised a **"coherent national system"**[2] **encompassing multiple tiers** whereby access to funded individualised supports for people with significant support needs would comprise 'Tier 3'. 'Tier 2' was designated as providing **information, referrals, and linkages to community supports and mainstream services** to stimulate **social capital** for those with Tier 3 plans as well as the broader population of people living with disability. 'Tier 1' encapsulated the whole Australian population and society where the social and economic participation of everyone would be enabled and supported irrespective of the presence or acquisition of disability. Unfortunately, as Minister Shorten alludes to, individual plans have absorbed most of the attention and focus during the first decade of the Scheme. Yet, **Tier 2 is essential to the success and sustainability** of Tier 3 and to **realising the benefits of full social and economic inclusion** in line with the desired outcomes for Tier 1.

In the eighth chapter, we argued the **primary goal of the NDIS is to advance and defend authentic social and economic participation** by people living with disability. In terms of the volume of financial investment, the Scheme is designed to achieve that goal primarily through individual participant budgets. This is based on the idea that **participants will make potent choices** about how to use their budgets within a vibrant provider 'market' and with stewardship by the National Disability Insurance Agency (NDIA) as Scheme administrator.

However, by itself this **does not guarantee success**. The availability of material resources – in this case an individual disability support budget – does not automatically mean people will move into good lives. This truth, that money does not automatically deliver happiness and fulfilment, can be found in many aspects of life, and the NDIS is no exception. This is evidenced by the **persistent unemployment and social disconnection** experienced by many Scheme participants. In this ninth paper of the Series, we outline **some reasons** for this, and **how this can be addressed**.

Overreliance on the market of individual supports

Arguably, one reason for this is the Scheme has appeared overly reliant on the notion that the 'market' will somehow deliver, which it has not. On the supply side of the market, it might have been hoped service providers would bring **wisdom and innovation** about the types of supports that can lift people into **authentic social and economic participation** and the **sense of belonging** this brings. But service providers are not generally in a strong position to deliver this. If they were, then arguably that wisdom would have been evident prior to the advent of the NDIS. In fact, to the contrary, the Scheme has **failed to move the supply market on** from the dominant pre-NDIS service forms, such as group houses, sheltered workshops, day programs, and the like. These service forms have not demonstrated competence at delivering authentic mainstream social and economic participation. Indeed, the main supply focus at the moment seems to be on how to make sure there will be enough people to show up for disability support work, rather than how those workers can best have an impact.

On the demand side of the market, it might have been hoped Scheme participants would be able to shape the market through what they ask for. While it is true people living with disability should be the **most important narrators of their experiences and wishes**, it is also true that a person's view of what might work best for them **can be constrained** by the consequences of previous experiences. For many people living with disability, these previous experiences can include a toxic mix of segregated services, low expectations, exclusion, discrimination, and other trauma. These can and do affect how a person understands and assesses their choices, including a preference for familiar or 'safe' services.

More than an individual plan needed for transformational impacts

Therefore, by itself, an **individual NDIS plan is not enough**. Something else is needed to **support impactful decisions** by Scheme participants. This is where a different type of Scheme investment comes in, called the Information, Linkages, and Capacity Building (ILC) program. This is the core element[3] of how governments have funded what the Productivity Commission originally described as Tier 2.

The idea behind ILC is it funds information services ('information'), services that link people to other people, community, resources, and opportunities ('linkages'), and services that assist people to grow into their potential ('capacity-building'). For example, this can include the development of 'peer networks', where people living with disability are able to connect with each other, to make sense of information, to offer mutual support, and to learn from each other. Peer networks often result in their members being better-informed and developing stronger ideas about their life chances, their ambitions, and reflecting this in how they want to use their NDIS budgets. This **increases the chances of budgets being used in a way that is impactful** for the person and for the Scheme. Importantly, peer networks can include information and discussion about community resources and opportunities, increasing the chances people then take steps to access those resources and opportunities. This includes **collective advocacy** if those resources and opportunities have issues adversely affecting accessibility and welcome. Again, this can and does produce gains that relate to Scheme outcomes.

Investing in the work of disability community organisations can also play a significant role in **increasing the chances of transformational benefits being realised**. Indeed, the Productivity Commission's 2011 report envisaged what it referred to as "disability support organisations (DSOs)" (not to be confused with direct service providers) would "facilitate greater innovation in the provision and coordination of services to people with disabilities."[4] Our agency's research[5] and experience over many years has also confirmed the importance of these organisations in the provision of information, facilitation of links to community supports and mainstream services, and building the capacity and confidence of Scheme participants, people living with disability, families and allies, and communities in realising transformation change.

ILC-funded initiatives are a key Scheme investment

ILC-funded initiatives are not only a **benefit to Scheme participants** but also to **other people living with disability** who are not eligible for an individual plan. Indeed, this type of investment can help reduce the need for some people living with disability to obtain an individual plan, because their **life chances have improved**, or **been defended**, by accessing ILC-funded initiatives. This idea is echoed in other jurisdictions, including in the United Kingdom, through methodologies such as Community Led Support (CLS)[6], that seek to meet people's needs within mainstream community resources so they do not have to enter formal systems with all the labelling, the waiting, the bureaucracy, and similar, that go with it.

In this way, the ILC program should remind us that the Scheme is **not just about a 'market'** where people with individual budgets go and buy services and products. The use of market language in the Scheme and the NDIA is problematic because of the danger it **reinforces the idea people living with disability are service recipients** and nothing more. The Scheme is better seen as **a mechanism for investing in people and communities**.

ILC-funded work includes **capacity-building** initiatives that assist people and families to grow confidence, knowledge, and skill across a range of relevant matters including building a personal vision, employment, housing, education, accessing technology, using NDIS resources, developing leadership skills, and a host of other themes that can assist people to move forward with hope. These capacity-building initiatives also extend to the non-disabled community, especially to those who are **gatekeepers of community resources and opportunities**. This includes employers, local clubs, community groups, education providers, local government services, and so on. The more those people are assisted to become better-informed about disability and diversity, the more likely it is our communities will be **more welcoming and inclusive**.

For all the above reasons, the types of initiatives the ILC program funds can deliver **critical outcomes** for the disability community, for the Scheme, and for Australia's ambitions to become a truly inclusive society. Without a framework for ILC-type initiatives, the NDIS will remain largely a **'transactional benefits'** scheme, where participants buy conventional disability supports, services, and products, reinforcing a status of paid service recipiency. Instead, with a robust framework of ILC-type initiatives, the NDIS has a far better prospect of becoming a **'transformational benefits'** scheme, where participants and other people living with disability are genuinely taking up **valued membership in community life**. We described the difference between transactional and transformational benefits in the third chapter.

Reforms to boost and sustain ILC impacts

However, the ILC program currently is not having the extent of impact it could. There are several reasons for this. First, and perhaps most importantly, the funding allocated to the ILC program is tiny compared to the overall cost of the Scheme. Given the importance of ILC-funded initiatives to the Scheme's success and sustainability, there needs to be a much larger allocation of funds to ILC.

Second, ILC funding is currently allocated to specific time-limited projects. While a project basis and a timeframe can be helpful in clarifying what will be delivered, by when, with what benefit, and to which people, it does not deliver sustained benefits. This is because most ILC-type work can be described as a 'slow burn'. Based on our own long experience with the types of initiatives that are funded by ILC, and as is true for community development generally, it takes time to build momentum. People do not just show up on the first day of an initiative. It takes time to grow awareness of the opportunity; it takes time for people to decide to get involved; it takes time for a methodology to be established, tested, and evolved; it takes time for participants in ILC-type initiatives to unlearn the low expectations and biases of their past; it takes time to build belief in what might be possible, and so on. Because of this, by the time the initiative has built real momentum, the funding is coming to an end. The project finishes and the momentum is lost. Or, as has already happened in the ILC program, there is a period of uncertainty before an initiative's funding is extended, during which time project staff leave for work elsewhere because they need certainty themselves. Again, momentum is lost. Therefore, while ILC-type initiatives should be accountable for the work they undertake and how it impacts, it should be within a longer funding timeframe where momentum can be properly consolidated, so the NDIS gets the sorely needed mission-related benefits ILC was intended to deliver.

Third, ILC-type initiatives need to be **commissioned in ways that do not inadvertently exclude good agencies** who lack the skills to write winning grant applications. This has already happened in the history of the ILC program, where small local agencies with good capacity or potential to deliver ILC-type benefits have been unsuccessful in accessing funds because their skill set did not include writing a competitive grant application. This method of commissioning needs to be reworked if the Scheme is to maximise benefits from the skills of local agencies.

Fourth, ILC commissioning, with an assumed larger share of the NDIS resource pool, needs to be built around a more **strategically coherent and public-facing strategy**. This strategy should recognise the critical importance of ILC-type work, the role of a range of community agencies in delivering it, and the need for a commissioning framework that ensures a synergistic approach to awarding grants to provide good coverage and reduce the risk of duplication or gaps. The strategy should be anchored on Scheme values, Scheme outcomes, and the other points outlined in this paper.

Notably, the Productivity Commission's 2017 report on NDIS costs cautioned governments about a "false economy" of investing "too few resources for ILC" during the transition period[7] and the same principle continues to apply. Without **broader structures and supports** in place through ILC-type initiatives, particularly as the states and territories have withdrawn from funding a range of services and programs, more people are pushed toward seeking individualised supports through an NDIS plan, which can adversely affect Scheme costs and sustainability. Research from Swinburne University has also raised concerns about the limited investment in ILC and the need for longer-term ongoing funding to overcome the problems of stop-start short-term projects including the undermining of trust among participants and loss of key personnel from projects due to funding uncertainty.[8] This research also highlights the need to reconsider the current approach to commissioning, develop a clearer strategy and targets, provide greater long-term coordination, and increase knowledge sharing to facilitate the scaling of successful projects.

Unlocking high-quality decision making

As a final thought in this paper, there is another way to think about the importance of ILC-type initiatives. The Scheme's success is anchored on the **decisions** people make. This includes the decisions Scheme participants make **about how and what to spend their budgets on**, the decisions people living with disability and their families make **about connecting to community resources and opportunities**, and the decisions non-disabled people make **about their own endeavours to ensure access, welcome, and inclusion**.

Therefore, the ILC program can be viewed as a mechanism to fund work that assists people in ways that help their future **decision-making**. Using our Model of Citizenhood Support as a framework, the ILC program can be understood, and its impact measured, by considering how it strengthens future decision-making in one of four ways, that we term the 'Four Capitals':

- **Personal Capital: The decision is *owned***
  It belongs to the person, and is not made for them by someone else, and is anchored on a positive, hopeful vision of a good life.
- **Knowledge Capital: The decision is *informed***
  The person explores a range of options and comes to a view about which option holds the best prospect of a good outcome.
- **Material Capital: The decision is *resourced***
  The person is able to access resources to assist with decision-making, and resources to enact the decision.

- **Social Capital: The decision is *supported***
  The person has trusted people in their life they can test their thinking with, and who are there as emotional and practical support as the person enacts their decision.

Effective ILC-type initiatives typically have an impact in one or more of the above ways. For example, peer networks and similar initiatives support people to build belief about what is possible and to understand the potency of their own personal agency in achieving change. This is true for people living with disability and for non-disabled people in community gatekeeping roles. For further example, such networks are valuable conduits for people to access and discuss information about options and their impact, be it a network of parents exploring the merits of inclusive education compared to special education, or a group of industry employers contemplating how to make their recruitment processes more accessible. For still another example, peer networks and other communities-of-interest or communities-of-practice provide essential social and practical supports as people enact their decisions. We have seen this in networks of families exploring alternatives to group houses for their adult sons and daughters living with disability. Similarly, we have seen this in networks of employers and educators as they try out new methods that can lead to greater accessibility and inclusion.

Conclusion

The ILC program is an important investment in how people make decisions and take actions, and those decisions and actions are essential to people's life chances and, therefore, to the Scheme's prospects of success. For the reasons outlined in this short paper, the ILC program must have a more substantial profile financially and strategically in the overall Scheme arrangements, if the NDIS is to deliver on its promise. It cannot be an afterthought; it cannot be an optional extra. It is as essential to the Scheme as individual plans and budgets, and ought to be afforded the same status.

There is no commentary available for this chapter due to an online recording failure

Declaration of interest: JFA Purple Orange is a recipient of ILC funding.

Endnotes

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[1] See examples available at https://ministers.dss.gov.au/transcripts/8266; https://www.theguardian.com/ australia-news/2022/nov/10/ndis-bill-shorten-accuses-states-of-underspending-on-disability-care; and https://www.aph.gov.au/About_Parliament/Parliamentary_departments/Parliamentary_Library/FlagPost/2022/August/Disability_support_outside_the_NDIS.

[2] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.10, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[3] For information about ILC as it is currently designed, see https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/information-linkages-and-capacity-building-ilc-program; and https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-information-linkages-and-capacity-building-ilc/ilc-building-policy-framework.

[4] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.416, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[5] JFA Purple Orange, 'The DSO Project: a summary of activities and impact in support of the NDIS participant voice', Disability Support Organisation Capacity Building Initiative, 2016, hard copy; and JFA Purple Orange, 'About pre-planning: An advisory report to the National Disability Insurance Agency (NDIA) on how people can best be assisted to prepare for the NDIS', Disability Support Organisation Capacity Building Initiative, 2015, hard copy.

[6] See, for example, https://www.ndti.org.uk/resources/what-works-in-community-led-support.

[7] Productivity Commission, 'National Disability Insurance Scheme (NDIS) Costs Study Report', October 2017, p.30, available at https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf.

[8] See https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-information-linkages-and-capacity-building-ilc/summary-informing-investment-design-information-linkages-and-capacity-building-ilc-research-activity.

CHAPTER 11: THE ELEPHANT IN THE ROOM – ADDRESSING THE ISSUE OF ‘REASONABLE AND NECESSARY’

KEY POINTS

- The concept of ‘reasonable and necessary’ support is **not well understood** and is, therefore, not providing a firm and consistent foundation for determining what supports the NDIS should fund
- Despite the rhetoric of an uncapped Scheme, there are practical examples of decision making that suggest there is a **cap** on overall Scheme expenditure
- ‘Reasonable and necessary’ should be understood and applied in the context of **advancing participants into social and economic participation** and **enabling individual choice and control**
- The criteria to define the limits of ‘reasonable and necessary’ should consider **what happens for most people in Australia** and what constitutes good practice in delivering high-impact disability supports

When the Productivity Commission contemplated a new approach to disability care and support in Australia, one of its most important tasks was to **define the boundaries** of a proposed new national scheme – in other words, what should a scheme pay for and on what terms. In its 2011 report, the Commission determined the proposed scheme should not be means tested, should not involve co-payments or any insurance-style excesses, and that it should fund supports that are ‘reasonable and necessary’ for participants eligible for an individual package.[1] The use of **‘reasonable and necessary’** as the criteria to determine what supports should be funded was borrowed from state no-fault accident insurance schemes, such as the New South Wales Lifetime Care and Support Scheme and the Victorian Transport Accident Commission (TAC) scheme. However, its transfer to the National Disability Insurance Scheme (NDIS) has not been seamless and for many of those trying to navigate the Scheme its **incoherent and inconsistent application** continues to be an ‘elephant in the room’.

In this tenth chapter, we grapple with the concept of ‘reasonable and necessary’ and how it is practically applied in individual support judgements affecting almost 600,000 participants. Despite the **prominence** of this concept in the first 10 years of the NDIS, it is **not well understood** and, as such, is **not providing a firm and consistent foundation** for how the Scheme determines what funding each participant receives. Without a shared understanding, people can reach very different views about what is ‘reasonable’ and what is ‘necessary’ leading to inequity and disputation. Some participants are over-funded while others are under-funded for their needs. Therefore, to guarantee the future of a strong sustainable NDIS, it is essential to establish a **clearer understanding** of the concept and how it should be used. Below, we suggest some fundamental principles about how this might be achieved in order to support efforts already underway to address this issue.

Understanding the concept of ‘reasonable and necessary’

For many people living with disability, accessing services prior to the NDIS was characterised by inadequate provision, long waiting lists, segregation, exclusion, and little to no assistance to connect to community. The NDIS was designed to address these shortfalls and provide people with a **decent level of support according to need**. Globally, it had no readily comparable peer.[2] As such, the Productivity Commission took its guidance from state no-fault accident insurance schemes, despite their many differences compared to what the Commission was recommending be created. These schemes are much smaller, support a narrower cohort of people with injury, and rely on calibrating consistent judgements among far fewer workers. Arguably, the speed with which the NDIS was subsequently rolled out hampered the ability to navigate a way through these core differences and ensure the application of the concept was adapted and made coherent with the new Scheme’s goals and values.

Based on the Commission’s recommendation, ‘reasonable and necessary’ was enshrined in the *NDIS Act 2013* as the criteria for determining what the NDIS could fund, albeit **without a legislated definition**. Instead, six criteria were set out in Section 34 to determine what could be funded. All six criteria must be satisfied for **each and every support**[3], including that it assists the participant to reach their goals, facilitates social and economic participation, is value for money, is beneficial[4], accounts for what is expected of non-funded informal supports[5], and is most appropriately funded by the NDIS rather than another service. NDIS Rules expand on these legislated criteria and, taken together with many years of tribunal and court determinations, have produced a complicated and often ambiguous set of parameters for what ‘reasonable and necessary’ means in the NDIS. The consequences of this are not only the **significant expense** of the appeals process – the NDIA reportedly spent more than $40 million on legal fees in 10 months between 2021 and 2022[6] – but also the time consuming, inflexible, and stressful nature of the approach for participants, especially those who self-manage. Relying on tribunals and courts to clarify ‘reasonable and necessary’ has been a painfully slow and incremental process[7] that has arguably only produced losers – and no winners.

Applying ‘reasonable and necessary’ coherently within the NDIS

The NDIS is underpinned by the goal of **advancing** people living with disability into social and economic participation (otherwise known as inclusion, *Citizenhood*, and similar), and doing this via participant choice and control, as we described earlier in this compendium. Notably, the no-fault accident schemes from which the concept of ‘reasonable and necessary’ was borrowed are not designed for this purpose; rather their strong focus is on clinical treatment and rehabilitation with the aim of **restoring** a person's life chances. Therefore, the use of 'reasonable and necessary' as criteria in the NDIS requires the concept to be rendered useful for a substantially different purpose. This endeavour has proved challenging so far but is not insurmountable.

We believe 'reasonable and necessary' should be understood and applied to the National Disability Insurance Agency's (NDIA) decision making in **the context of the Scheme's fundamental goals and values**. Therefore, we think it is helpful to explore the concept by thinking about what it reasonably and necessarily takes to **lift people into authentic social and economic participation** and to do so in ways that reflect **individual choice and control**. This gives rise to questions like:

- If a participant is unemployed, what type of support is reasonable and necessary to lift that person into authentic mainstream employment opportunities in line with their skills, interests, and goals?
- If a participant needs to be housed, what type of support is reasonable and necessary to lift that person into a housing arrangement that is an authentic platform for social and economic participation, and which gives the person the same level of choice and control that non-disabled people expect for themselves?
- If a person is socially isolated and has few people in their lives who are not paid to be there, what type of support is reasonable and necessary to lift that person into community connection and authentic relationships?
- If a person needs assistance with decision making, what type of support is reasonable and necessary to uphold that person's central role in the decisions that affect them, so they are the author of their own life?
- If a person needs assistance with daily living tasks, what type of support is reasonable and necessary to uphold that person's navigation through a typical day, and which reflects the person's choice and control?

These are but five examples that demonstrate how 'reasonable and necessary' should underpin NDIA decision making in a way that is coherent with Scheme goals and values regarding some of the essential elements of how a person's life chances can be advanced.

Current limits on 'reasonable and necessary' producing perverse outcomes

There has been much conjecture about whether the NDIS is, or should be, an **uncapped or capped Scheme**.[8] For many, the fundamental values and principles of the Scheme require that it be **demand-driven** with funding allocated based on need without being limited by the total money available within the Scheme; in other words, the total funding available within the Scheme can be adjusted up or down according to the need of citizens. Pre-NDIS disability support funding arrangements were based on an overall cap of how much money state and territory governments were each prepared to allocate for this purpose. Given the NDIS was designed to supersede this approach, address unmet need, and remove waiting lists for essential supports, it follows that participants should expect to access reliable budgets sufficient to pay for supports irrespective of how many other people need to do the same. Hence, funding for reasonable and necessary supports according to demand is not curtailed by overall Scheme costs.

For others, reality dictates that resources are always **finite** and therefore the notion of an infinite amount of money available within the Scheme to meet demand can only ever be a myth. Therefore, the question once again becomes one of the extent to which governments, and therefore taxpayers, are prepared to fund the Scheme balanced against other public expenditure considerations. Politically, we have seen this dilemma play out recently as NDIS Minister Bill Shorten tried to navigate a path through the government's decision to limit Scheme growth to eight per cent per year while insisting this does not constitute a cap.[9]

Experience over the first 10 years of the NDIS suggests an **attempt to straddle both sides** of this dilemma, resulting in incoherence and inconsistency in the Scheme. Although the rhetoric of an uncapped Scheme has tended to win out, there are many **practical examples** where the Scheme does appear to have been **limited by some kind of cap**. For example, the NDIS' Specialist Disability Accommodation (SDA) framework appears to have been established and operated on an assumption there is a financial cap on the Scheme – and therefore a limit on reasonable and necessary supports – because many participants are awarded eligibility at a funding level that assumes they will share a dwelling with one or more other Scheme participants. Indeed, on numerous occasions throughout the life of SDA reference has been made to a perception that individualised housing arrangements based on choice are prohibitively expensive, inefficient, or somehow unreasonable for people living with disability in a way that seemingly does not apply to non-disabled Australians.

This contradicts Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that states people have the **right to choose where they live and who they live with**. It is also out of step with the government's oft-stated commitment to inclusion, whereby people living with disability are supported to access the same opportunities, with the same expectations, as non-disabled people. Most non-disabled people would not consider it is reasonable to be forced to live in a house with several other adults over the long term simply based on having one thing in common. Therefore, it follows that in this respect the Scheme is capped, such that when considering funding for housing for Scheme participants with higher support needs, the Scheme is working to the assumption it is not 'reasonable and necessary' that they be allowed to choose a housing arrangement typical of most Australians.

As outlined in the fourth chapter, there has also been a tendency for 'reasonable and necessary' decisions to **work against the goal of advancing people into social and economic**

participation. In that paper, we explained the example of a participant being told that attending a local art class was not 'reasonable and necessary' because it was not a 'disability-related expense', but that one-to-one art therapy could be funded. Similar perverse results arise when participants are unable to use their budget for group therapy classes such as hydrotherapy, or to undertake their established exercise programs at a public facility. Instead, they must undertake their therapy one-to-one with a therapist each time, usually at a therapy facility disconnected from their local community, something which is inevitably more expensive as well as an ineffective use of the therapist's time. In these examples, the permitted purchases seemed neither reasonable nor necessary given the mainstream alternatives had a far better fit with Scheme goals.

A more coherent application of 'reasonable and necessary'

Charting a more **coherent and consistent approach** to the application of 'reasonable and necessary' criteria within the context of the Scheme's **fundamental goals and values** would allow the Scheme to straddle the uncapped versus capped dilemma without producing the kind of incongruous outcomes demonstrated in the examples above. Scheme participants should not have to agree to move into housing arrangements that reinforce 'grouping', 'othering', and, thereby, marginalisation, as this is **profoundly at odds with Scheme goals and values**. Conversely, the decision that does adhere to the application of 'reasonable and necessary' criteria grounded in Scheme goals is to support, fund, and enable **individual housing choices** on the same basis as non-disabled Australians enjoy. If the NDIA continues to permit investment in housing construction designed for shared living, then Australia is creating the next generation of group houses, which cannot be defended in any way as being 'reasonable or necessary' in the context of participants living **ordinary valued lives**.

Of course, the application of 'reasonable and necessary' criteria grounded in the context of fundamental Scheme goals and values **does not mean there are no boundaries**. The Productivity Commission made a strong case for both **boundaries**[10] and **benchmarking**[11] to ensure that the Scheme's efforts were directed toward the best possible outcomes. The first element in setting boundaries is to consider **what happens for most people in Australia**, drawing on the framing of the Scheme in terms of enabling participants to live an ordinary life. Most people do not drive an expensive sports car; they drive more affordable vehicles that are sufficient to get from one place to another. Most people do not live in the biggest house in the most affluent suburb; they have a more affordable housing arrangement (notwithstanding the current challenges in Australia about housing availability and affordability) where they are central to decision-making within that house and create a personal sense of 'home'. If they share, it is a choice and typically with those who they have deep bonds with, like a partner, family, or friends.

The second factor to consider in determining boundaries is **what constitutes good practice in disability support and how much that typically costs**. If there are support agencies with a strong track record of lifting people living with disability into sustained, mainstream, award-waged employment, then the fair and real costs of that work can be used as a **benchmark** for setting a budget for unemployed Scheme participants to access supports to achieve this outcome. If there are support agencies with a strong track record of lifting people living with disability into genuine valued relationships in local community life, then the fair and real costs of that work can be used as a **benchmark** for setting a budget for socially isolated Scheme participants to access supports to achieve this outcome.

in this way, it becomes possible to set out what 'reasonable and necessary' looks like for each relevant aspect of a participant's circumstances, such as transport, housing, employment, community participation, and so forth. With a **clear benchmarked understanding of the typical costs of delivering impactful support** in each facet, a participant's individualised budget can be assembled by understanding which elements of an ordinary life a participant needs support to attain or defend (through a 'consequences of disability' based assessment, as described in Chapter 3), accounting for specific cost influences, such as thin markets in rural and remote areas, and then aggregating them to form a person's overall budget.

In this way, participants are assigned an individual budget that **reflects both their personal circumstances and the benchmarked population-based costs of impactful support done well**. Consequently, the NDIA can be less occupied with granular level 'reasonable and necessary' disputes and instead focus on **driving genuinely transformational outcomes**. And participants can form expectations about the impact that they can expect from their budget and seek this from support providers, thereby driving **quality improvements** among providers and workers. This, in turn, enables the **disability support market to evolve** to produce highly impactful work that lifts participants into authentic social and economic participation.

Conclusion

It is troubling that such a prominent concept in the administration of the NDIS as 'reasonable and necessary' is still not well understood and inconsistently applied. However, we believe there is a clear path to clarifying the concept and ensuring its application in NDIA decision making is rendered more coherent and consistent. 'Reasonable and necessary' should be understood in the context of the Scheme's goals of advancing people living with disability into social and economic participation, and the presence of choice and control therein. The criteria for determining the limits of 'reasonable and necessary' support should focus on matching the expectations and experiences in non-disabled people's life chances, and in identifying the typical costs of high-impact support work done well and using this as the benchmark in setting budgets for individual supports.

Commentary

The tension between 'choice and control' and 'reasonable and necessary' were central themes in this discussion.

Attendees wanted participants to be asked what their needs and wants were and how they wanted to reach their goals rather than having barriers placed in their way.

Further training was needed to help plan managers interpret ‘reasonable and necessary’; dispel the low expectations of care workers; increase understanding of the challenges experienced by people living with disability; and to encourage all NDIA staff to recognise supports as enablers of participation.

Attendees expressed concern that daily audits and requests for further evidence for line items would see plan managers lose confidence, especially if it became necessary to pay back the agency for an ‘incorrect’ determination.

Other concerns raised included the interrogative nature of NDIS audits (including the tone of voice used by NDIS staff); the cost of getting reports from additional allied health professionals; and a lack of trust in the knowledge of participants about what they needed for their own safety.

Attendees were keen to ensure the proper use of taxpayer dollars and improve public perceptions about spending. They considered a lack of understanding about the barriers that existed for a person living with a disability led to misconceptions. Examples raised were gym memberships and movie tickets. Attendees reported support workers sometimes demonstrated a “they get everything” attitude, wondering why the government “was paying for them to go to the movies but not me?”

The connotations of the NDIS being an insurance model were also discussed and attendees raised concern about NDIA staff making judgements that showed they did not understand that support was the enabler of participation. They were mindful that poor phrasing in reports written by allied health professionals could then be used as a justification for reducing budget. As one mother explained, there is a big difference between: ‘My son plays basketball’ and ‘My son plays basketball with high level support from support worker’.

Endnotes

[1] Productivity Commission, ‘Disability Care and Support,’ Report no.54, 2011, pp.22-29, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[2] The United Kingdom’s direct payment approach has some similarities, but not the size or scope of the NDIS. Direct payments may be used ‘flexibly and innovatively and there should be no unreasonable restriction placed
on the use of the payment, as long as it is being used to meet eligible care and support needs.’ There are no uniform criteria for determining what an unreasonable restriction may be. In recent times, the Government’s austerity measures applied to its direct payment approach have made it more difficult to assess the effectiveness of their scheme design. See further https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs24_personal_budgets_and_direct_payments_in_social_care_fcs.pdf.

[3] The Productivity Commission considered and rejected the idea that 'reasonable and necessary' could be applied at the level of an overall budget, believing this could incentivise the exaggeration of need. See Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.317, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[4] This criterion can be particularly difficult to apply when expert opinion varies, for example regarding the benefits of a therapy.

[5] This criterion is also particularly fraught with questions about what a reasonable expectation of family, friends, or even housemates is in terms of the provision of informal unpaid support. It also raises complex questions about equity between those with and without strong informal support networks.

[6] Michael Read, 'NDIS legal bill hits $40m as appeals quadruple', *Australian Financial Review*, 7 June 2022, available at https://www.afr.com/policy/economy/ndis-legal-bill-hits-40m-as-appeals-quadruple-20220607-p5armw.

[7] So far appeals have mainly focused on the scope of support, level of support, balance of formal and informal support, and principles of equity.

[8] See further Susan Pennings, 'Budget Resources: The National Disability Insurance Scheme', May 2023, https://www.aph.gov.au/About_Parliament/Parliamentary_departments/Parliamentary_Library/Budget/reviews/2023-24/NDIS.

[9] See media coverage, for example, https://www.abc.net.au/news/2023-04-28/ndis-funding-sustainability-budget-disability-participants/102278498; https://www.afr.com/policy/economy/bill-shorten-wants-to-save-74b-on-the-ndis-here-s-how-20230511-p5d7pl; and https://www.smh.com.au/politics/federal/crackdown-on-prices-and-junk-therapies-to-slow-ndis-spending-shorten-20230501-p5d4kk.html.

[10] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, for example pp.24-29, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[11] *Ibid*, p. 21 and Chapter 7.

CHAPTER 12: RECALIBRATING SUPPORT COORDINATION AND PLAN MANAGEMENT TO BOOST PARTICIPANT OUTCOMES

KEY POINTS

- Despite becoming a billion-dollar intermediary industry, support coordination and plan management roles remain **ill-defined** and **confusing** for many participants
- There is a **clear and useful distinction** between **demand-side** intermediary functions that support the participant to **make and commission choices** and **supply-side** intermediary functions **coordinating formal supports**
- This distinction creates **clear role boundaries** and **separation** that helps to **avoid conflicts of interest or time**; therefore an intermediary should be **either** a demand-side or supply-side intermediary, not both

During the first 10 years of the National Disability Insurance Scheme (NDIS), the provision of support coordination and plan management services has developed into a combined billion-dollar intermediary industry despite the purposes and functions of these roles remaining **ill-defined and unclear**. In the 12 months to 31 March 2023, total expenditure on support coordination was $905.6 million and on plan management was $467.5 million.[1] These roles also sit alongside those provided through the Partners in the Community (PITC) program, including both Local Area Coordinators (LACs) and Early Childhood (EC) partners, which in the 2019-20 financial year, when the number of Scheme participants was still about 480,000, cost an additional $525 million.[2] Currently, all participants are assigned a PITC, while 45 per cent of participants have funding in their plan for support coordination and 59 per cent of participants use a plan manager.[3] There is no doubt intermediary roles have become central to the operation of the Scheme and represent a significant cost within the NDIS, making it essential there be a **clear articulation of what each role is** and **where the role boundaries lie**.

The National Disability Insurance Agency (NDIA) has committed to updating its guidance on plan management during the second half of this year and providing clearer parameters for support coordination by March 2024.[4] Meanwhile, the NDIS Review will also consider the future of support coordination, plan management, LACs, EC partners, and remote community connectors this year. Released in June, its interim report 'What we have heard' identified that intermediary roles currently 'overlap, leave gaps, and are confusing'.[5] It is critically important this work is undertaken **holistically** with the aim of ensuring participants can access effective support at all stages of the pathway without the confusion that currently exists in understanding who does what.

Intermediary roles are arguably both a **product of** there being too much **complexity** in the Scheme *and* a **source of** additional **complexity** within the Scheme. Therefore, there is a risk that this complexity becomes **self-perpetuating** and feeds on itself. In this eleventh chapter, we unpack the functions of the current intermediary roles and consider how these can be provided more effectively within a simple participant pathway, see Chapter 1. We propose a **separation** between intermediary functions that occur on the demand side of the pathway and those that occur on the supply side of the pathway in order to create clearly defined roles and role boundaries, which will reduce complexity and help negate the current problem of conflicts of interest or time.

Support coordination and plan management roles in the NDIS

In its 2011 report on disability care and support, the Productivity Commission envisaged a primary role for LACs in supporting people to interact with the NDIS and a secondary role(s) for intermediaries – these being a 'new form of organisation' – to undertake brokerage and administrative functions if participants sought these types of support.[6] Specific roles were not defined. During the design and early implementation of the Scheme, LAC functions shifted from their traditional articulation of supporting the person, into a largely Agency-orientated role managing Scheme steps, as outlined in the second chapter. Additionally, the intermediary roles of support coordination and plan management emerged without a clear alignment to the participant pathway, distinct boundaries between roles, or coherence with Scheme values. These roles remain ill-defined and many participants are confused about who can assist them with which elements of the Scheme.

Aside from generating a lack of role clarity, the **loose scope of intermediary roles** and who can undertake them creates fertile ground for **conflicts of interest** that make the motivations and purposes of those entrusted to perform these roles, including questions of **who they serve**, murky. The prevalence of referrals to and among intermediaries indicates that participant choice and control may be taking a back seat to these conflicts. For example, it appears quite common that the provision of support coordination is linked to a participant's accommodation provider, sometimes even when a participant has not identified they need or want a budget for this type of support included in their plan.

Both support coordination and plan management are categorised as '**capacity building**' supports even though in their current forms these roles have a **strong disincentive** for providers to build participants' capacities because, if they do, **their own services may no longer be needed**. Hence, the roles are skewed toward being *transactional* in character rather than *transformational*, as we argued in the third chapter. Indeed, for a few years beginning with the 2019-20 Support Catalogue, there were Support Item numbers for both support coordinators and plan managers to provide 'Capacity Building and Training in Plan and Financial Management'.[7] These lines are no longer available.

Instead, while some plan managers view their role in broader terms, many appear to follow a largely ‘accounts payable’ approach; one where arguably the greatest level of system automation drives the highest profits, rather than **profitability** being **linked to outcomes for participants**. When the plan management role is limited to processing invoices and not to managing budgets and expenditure, there is a risk of overspending and a participant draining their budgets before the end of their plan. The consequence of budget overspends is indicated by the **intraplan inflation rate** – increases occurring within plans, not after reassessments – which was running at an annualised rate of 7.7 per cent during the third quarter of 2022-23.[8] If this intraplan inflation is present for participant budgets where there is a plan manager, it raises an important question about whether that role in its current form is effective in supporting participants to **manage** their plans and budgets.

Alternatives to plan management are also **overly complicated** for participants to navigate. The portal that enables participants with agency-managed supports to access information and monitor spending is not user friendly, including in basic aspects such as the names of support categories, with many given different names to what appears in a plan.[9] Self-management requires a burdensome process before a person is approved to manage their own budgets, and it is complicated to navigate all the rules that apply. While there is significant potential for more participants to self-manage, and it is so **valuable** the NDIA offers this option, it should be made easier to choose and undertake this option so that participants have real choice of management type. The NDIA is currently undertaking work to improve how payments and claims occur, and we hope the improvements make it easier for participants to consider self-management. After all, any time we bring new or more professionals into people’s lives, we should do so with caution and question what value is added to their life as opposed to creating additional complexity. We believe the NDIS goals can be well-served by more people self-managing their budgets and supports, as the **experts in their own lives**. Where participants do not wish to self-manage, we hope that the system improvements mean participants with plan managers can expect higher-value support from such intermediaries than a semi-automated payment service.

Recalibrating roles to boost participant outcomes

In the first chapter, we talked about the importance of **establishing simplicity** as the **key anchor point** for the NDIS pathway. In applying this principle of simplicity to charting the future roles of intermediaries like support coordinators and plan managers, it helps to examine the NDIS participant pathway and the types of support the participant might need at each stage.

We assert a distinction can be made between the pathway steps that **help a person to decide their priorities and translate that into a plan** the NDIA can set a budget for, and the pathway steps that then **give effect to the participant’s choices**. For those readers who like market language, this distinction might be termed as the difference between *quantifying demand* and *coordinating supply*. This distinction is important because it can help to chart the extent to which there might be a **conflict of interest** in any given situation, for example if an intermediary has a vested interest in the supply choices the participant is being supported to make. Therefore, the NDIS can evolve its arrangements by making the clear distinction between the roles an intermediary might undertake on the **demand side of the pathway**, and the role an intermediary might undertake on the **supply side of the pathway**.

The demand-side intermediary

We assert the demand side of the NDIS pathway includes the following features for an intermediary:

- Assist the participant to build a vision-based plan
- Assist the participant to connect into community, including freely given supports
- Assist the participant to choose formal supports
- Assist the participant to track their budget for utilisation and impact

Currently, some LACs might assist with some of the above, and some support coordinators might assist with some of the above, and some plan managers might assist with some of the above. Understandably, this can leave participants unclear about who assists them with what. To resolve the risk of role confusion, and the duplication or gaps the confusion creates, we assert that all of the above can be provided via the basis of the LAC model we set out in Chapter 2, where the participant is able to choose their LAC.

This means those support coordinators or plan managers currently assisting participants with one or more of the above functions are operating, at least in part, as demand-side intermediaries. As such, there would be less need to distinguish between role titles – LAC versus Support Coordinator versus Plan Manager – and instead focus on the **nature of the service being offered**. Therefore, the participant would be able to choose from a range of demand-side intermediaries and services, depending on what they reasonably needed to advance their goals and those of the Scheme.

Building on the previous list, a demand-side intermediary could offer one, some, or all, of the following supports and services:

1. **Planning**
   where the intermediary assists the participant to build a vision-based plan that includes a mix of elements: freely given supports and community resources and opportunities, and proposed formal supports
2. **Community connecting**
   where the intermediary assists the participant to make connections to community resources and opportunities, and the informal supports these links can bring
3. **Selecting formal supports**
   where the intermediary assists the participant to choose formal support providers that look to be a good match with what the participant wants to achieve

4. **Tracking budget**
   where the intermediary assists the participant to track the use and impact of their budget, including, for example, assisting the participant to respond to unreliable or ineffective providers, or needs to rethink some choices to stay within budget.

While we assert the intermediary role has a **primary responsibility to the participant**, each of the above service elements can be expected to be undertaken in a way that **also serves the Scheme's interests**, in that:

1. Good planning increases the focus on outcomes most meaningful to the Scheme's goals in relation to social and economic participation.
2. Good community connecting also delivers on Scheme goals of social and economic participation and can help reduce the demand for some aspects of formal supports.
3. Good supports-matching increases the chances the budget will be spent on more impactful formal supports that again deliver on Scheme goals of social and economic participation, and on Scheme sustainability if those supports make the best use of, and grow, the participant's capacity.
4. Good budget tracking can help make sure the participant's choices are affordable (they reduce the risk of Scheme intraplan inflation), defendable (they are within Scheme parameters), and impactful (they deliver the outcomes the participant and Scheme are interested in).

The supply-side intermediary

It is important to separate out the work of a demand-side intermediary from that of a supply-side intermediary. The first reason for this is the risk of an inherent **conflict of interest**, created when the intermediary either has a vested interest in one or more of the supply agencies involved, or when the nature of the work means the intermediary has deeper relationship with those providers than they have with the participant whose services they are coordinating.

The second reason is that when an intermediary has both demand-side role elements and supply-side elements, there can be a **conflict of time**. This happens because whenever there is a significant supply issue, the intermediary in such a role will need to respond to that quickly, and that gets in the way of demand-side work the intermediary may have planned. For example, an intermediary Jane is assisting a participant Tom to connect into community (demand-side intermediary). However, Jane is also coordinating support services (supply-side intermediary) for another participant Iko. On the morning Jane is due to meet with a local surf-lifesaving club about Tom joining, there is a disruption to Iko's supports that Jane will need to fix. In this situation, the priority is fixing Iko's supports. As a result, the meeting about Tom's community membership gets postponed. This is a fictitious example of the **time conflicts** that can emerge when an intermediary is covering both demand and supply.

In pursuit of clarity, we have identified the following elements that might be associated with the supply-side intermediary role currently:

- **‘Financial intermediary’**
  paying the bills, making NDIS budget claims in relation to those bills, and fulfilling reporting requirements (these tasks are typically associated with the plan manager role)
- **‘Service continuity intermediary’**
  making sure services show up and deliver the expected service
- **‘Service complexity intermediary’**
  a ‘case coordinator’ role for those participants whose circumstances might mean there are several providers involved, plus other agencies outside the NDIS, and where it is critically important that these are coordinated in their efforts

In terms of the ‘financial intermediary’ role, the NDIA continues to invest in ways to make the operations of payments and claims easier for Scheme participants to navigate, including through work on a Claims at the Point of Support (C-POS) project.[10] Such work should continue to help reduce the risk that current levels of demand for plan management have only been created by unnecessary complexity within the NDIS system. One of the benefits of this is that it can ‘right-size’ the overall demand for plan management and **place it back in the demand side** where the intermediary assists the person to **track budget and impact**. A further benefit of a simpler more accessible payments and claims system is that more participants may be inclined to self-manage their supports. This is good from a choice and control standpoint and may also assist the NDIA to manage inflationary pressures, because our experience is there is less inflationary pressure when people self-manage their supports.

Regarding the ‘service continuity intermediary’ role, we assert that **service providers** have a **primary duty of care** to assure the participant that services are delivered as agreed. As such, the intermediary role is to take action when a provider is failing in this regard, including assisting the participant to shift to other provision arrangements. Again, this approach would **place it back in the demand side** as part of the intermediary role assisting the participant to choose formal supports and track budget and impact.

The ‘service complexity intermediary’ is where the intermediary takes a **central role in making sure there is cohesion among different service agencies and individuals** involved in the support arrangements for a person whose circumstances are complex or who may be experiencing a period of heightened vulnerability. The NDIA currently calls this role 'specialist support coordination’, or, in some human services systems, it may be known as ‘case coordination’. To call on a metaphor, this intermediary is the conductor of the orchestra. As such, the presence of complexity demands the intermediary plays a central role in service orchestration. This should be managed as a supply-side intermediary role. So long as the intermediary has no vested interest in providing any of the supports being coordinated, we do not see a critical issue with conflicts of interest. This intermediary would have ongoing contact and relationships with service providers but would be separate from the demand-side intermediary who would be primarily involved in supporting choice-making. Therefore, the supply-side intermediary could not influence the participant's choices in a way that could constitute a conflict of interest.

This **separateness** also resolves the issue of conflict of time. Because this intermediary's role is focused on orchestration of formal supports, that becomes their specialty and does not impinge on demand-side intermediary work connecting participants into community resources and opportunities. Ultimately, the supply-side intermediary's role is to **ensure the participant's interests are being best met through careful coordination of formal supports**. In doing so, the intermediary is supporting Scheme goals by helping ensure that a complex budget is having the maximum impact through diligent coordination of various supports and the coordinated involvement of non-NDIS mainstream services, such as health or education.

Mapping the required functions

In the previous section, we have mapped demand-side and supply-side intermediary functions in a manner we think can bring additional **clarity and value**. These are:

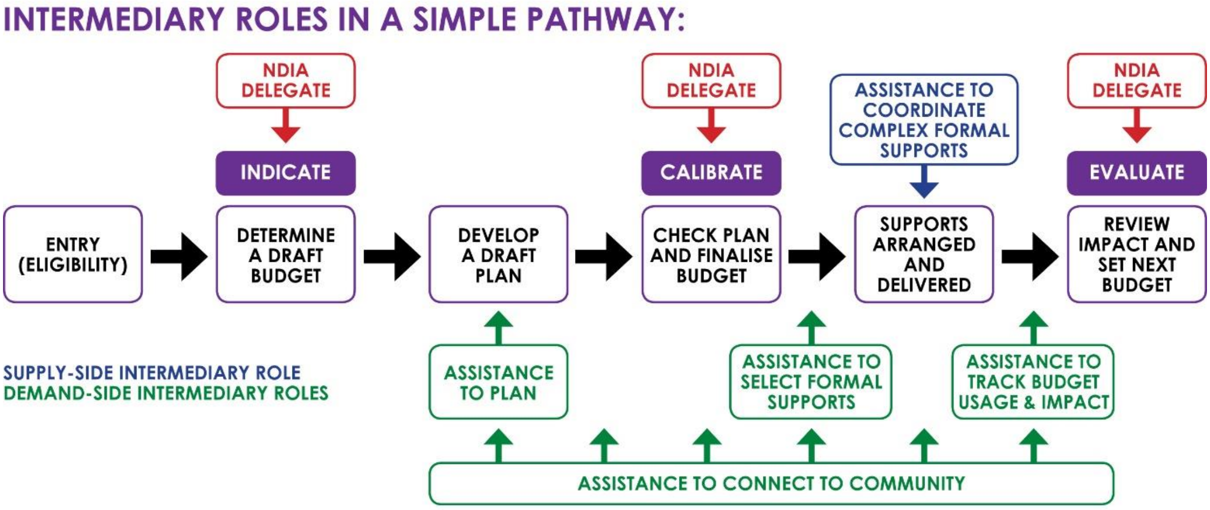
Demand-side intermediary role elements

- Planning
- Community connecting
- Selecting formal supports
- Tracking budget for usage and impact

Supply-side intermediary role elements

- Coordinating complex support and service responses

In earlier chapters, we set out a **simple NDIS participant pathway** illustration, and we return to that below to illustrate where these elements sit along the pathway.



This illustration shows where the intermediary role appears along a simple NDIS participant pathway, and how the **role elements vary accordingly**. This is anchored on the relatively simple idea that at each step of the pathway we might ask, *'What would be helpful to the participant here?'* This can help **reduce the risk of role confusion** and give **greater clarity about the practice elements** at each step.

Making changes

In implementing these proposed improvements to the intermediary roles, **key areas of attention for the NDIA** would likely include:

- Superseding current service descriptions for LACs, support coordinators, and plan managers, and replacing these with detailed components for each of the demand-side and supply-side role elements in the list above
- Resolving with the NDIS Quality and Safeguards Commission how best to credential these roles so participants have assurance of intermediary accreditation and oversight
- Resolving a new approach to commissioning these services (noting participants are currently assigned an LAC or EC partner rather than selecting and purchasing this through an individual plan budget), so that participants have **authentic choice and control** over who assists them with each intermediary role
- Resolving a separate commissioning approach for intermediary services for people in what the Productivity Commission referred to as 'Tier 2' (people living with disability not eligible for an individual NDIS plan), which would likely be a population-based purchase of information and 'wayfinding' to community resources and opportunities, anchored on the intermediary's excellent local knowledge and connections, as we identified in the second chapter
- Resolving how the NDIA, in its market stewardship role, might look at a particular type of intermediary role to address issues associated with 'thin markets', a topic we will consider in a future paper in this Series

Conclusion

In this short paper we have identified the problems of role confusion across the several 'intermediary' roles that currently feature in the NDIS pathway, and that these problems are the result of, and contributing to, Scheme complexity. We have asserted the Scheme and its participants will likely benefit by taking a fresh look at the role of all intermediaries, considering the types of assistance a participant might need to identify and advance their choices and priorities (we have termed this 'demand side'), and the types of assistance a participant might need for ongoing coordination of formal supports (we have termed this 'supply side'). Instead of drawing on role titles such as LAC, support coordinator and plan manager, we have identified five main areas of intermediary activity, and have asserted these should be commissioned in ways that give participants authentic choice and control.

In such commissioning, we have asserted that demand-side and supply-side intermediary activities are mutually exclusive, and that commissioning should reflect this.

Commentary

This webinar began with a discussion of the role of Psychosocial Recovery Coach and how it interacted with the Support Coordinator role.

Attendees considered there was a lack of clarity about the role; the use of recovery in the context of psychosocial disabilities; and whether funding was available for both a Recovery Coach and Support Coordinator. They were also concerned about the competence of Support Coordinators and their training and felt that leaving support coordination assistance until a budget had been set by the NDIA would affect a new participant's perceptions of the scheme as it meant their first interactions with their Support Coordinator would not be through the deficits/eligibility lens.

Attendees stressed the need for a 'single point of truth'. This would reduce the risk of participants being on the receiving end of workers' varying interpretations of the Scheme and plan managers becoming gatekeepers of what was reasonable and necessary without first understanding the participants' circumstances.

Potential solutions raised included clarifying the required qualifications for each role in the Scheme (particularly important for non-agency service providers); expanding the existing accreditation processes of the NDIS Quality and Safeguards Commission; and creating specialised Support Coordinator roles such as SIL, psychosocial specialists.

Endnotes

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[1] National Disability Insurance Agency, 'NDIS Quarterly Report to disability ministers: Q3 2022-23', March 2023, p.190, Table E.53, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[2] National Disability Insurance Agency, 'Partners in the Community Program - Market Engagement: Feedback Summary Report', January 2022, p.5, available at https://www.ndis.gov.au/media/4037/download? attachment.

[3] National Disability Insurance Agency, 'NDIS Quarterly Report to disability ministers: Q3 2022-23', March 2023, p.87 and Appendix E, Table E.117, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[4] *Ibid*, pp.55-56.

[5] NDIS Review, 'What we have heard: Moving from defining problems to designing solutions to build a better NDIS', June 2023, p.20, available at https://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report.

[6] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.414, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[7] The relevant Support Item numbers were 07_003_0117_8_3 and 14_031_0127_8_3. Archived Support Catalogues are available at https://www.ndis.gov.au/providers/pricing-arrangements/pricing-arrangements-archive.

[8] Office of the Scheme Actuary, National Disability Insurance Agency, 'NDIS Quarterly report to disability ministers: Scheme Actuary Presentation Q3, 2022-23', 31 March 2023, p.46, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[9] See tables at National Disability Insurance Agency, ‘Support budgets in your plan’, 17 May 2022, available at https://www.ndis.gov.au/participants/using-your-plan/managing-your-plan/support-budgets-your-plan.

[10] For more about the Claims at the Point of Support (C-POS) project, see https://www.ndis.gov.au/news/ 9165-claims-point-support-c-pos.

CHAPTER 13: MAXIMISING BENEFICAL OUTCOMES FROM POSITIVE BEHAVIOUR SUPPORT

KEY POINTS

- Positive Behaviour Support (PBS) is an **evidence-based approach** with much broader application than its use in the context of restrictive practices regulation
- PBS can help shift the focus from 'managing' behaviours at issue to the **adoption of communications and actions** more likely to lead to **positive outcomes** and a good life
- Under the NDIS currently, the use of PBS is **too compliance-orientated** and this is not achieving the beneficial outcomes for participants that it should
- PBS should be part of an approach that ensures restrictive practices are only used **sparingly** and only when a **broader plan to lift a person into valued roles** in community life is in place
- Often, respecting and enabling a person's **choices** is all that is needed to overcome behaviours at issue

Positive Behaviour Support (PBS) is an internationally recognised **evidence-based approach** that can significantly **improve quality of life outcomes** for some people living with disability and others. In Australia, it has recently gained particular prominence in association with the National Disability Insurance Scheme's (NDIS) regulatory framework regarding the use (and misuse) of restrictive practices for participants. Yet, this is a **very narrow framing** of its possible applications and benefits, such that there may be a perception that PBS only exists as a highly specialised skill set applied in the context of restrictive practices rather than one that is relevant to all everyday formal and informal disability supports. Therefore, the NDIS may be inadvertently turning a person-centred practice into an **overly compliance-centred approach** to the detriment of maximising beneficial outcomes for participants. Some participants are currently receiving individual funding and referrals for specialist PBS they may not need due to compliance requirements while others who could benefit greatly are missing out.

This, of course, is not to suggest that addressing the prevalence of restrictive practices is not an objective; just that this is not the full story. In 2014, Australia's disability ministers committed to **reducing and eliminating the use of restrictive practices** in disability services in order to 'protect the rights, freedoms, and inherent dignity' of people living with disability.[1] The 'National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector' identified PBS approaches and the development and implementation of individual behaviour support plans as key strategies to achieve this goal.[2] Initially, existing state and territory mechanisms were supposed to drive change, with a new model to be established under the full roll out of the NDIS. That model now sits under the NDIS Quality and Safeguards Commission (NDIS Commission). To date, it seems the NDIS Commission's most significant achievement has been to **increase the reporting** of the unauthorised use of restrictive practices, which is welcome, but its other efforts also need to have impact to meet the commitment to reduce and ultimately eliminate their use. In fact, data indicates that reported instances of unauthorised restrictive practice use increased from less than 290,000 in 2019-20 to more than 1.4 million in 2021-22.[3]

In this twelfth chapter, we unpack the behaviours at issue, the 'management' orientated approach of implementing restrictive practices, and the consequences this has for the rights, dignity, and life chances of those who are subject to them. We consider how PBS approaches can help **shift this focus** from 'management' of behaviours at issue to assisting the person to **adopt communications and actions** that are **more likely to lead to beneficial outcomes** and a **good life**. To underpin this change, we identify several features the NDIS should adopt regarding how PBS is applied within the Scheme. Notwithstanding this, we emphasise the importance of respecting and enacting a participant's choice and control, a simple foundation of supporting a person living with disability that can often negate behaviours at issue without the need for PBS or, indeed, any use of restrictive practices.

The behaviours at issue

The terms 'behaviours of concern', 'challenging behaviours', or 'protest behaviours' are often bandied around without any explanation of what they are or why they occur. In our *Citizenhood* model[4], we talk about how a person finds belonging, meaning, and fulfillment in life through taking up a range of roles that bring the person into valued social and economic connection with others. Such roles include family member, partner, friend, worker, club member, neighbour, dog walker, and so on. Some people have **ways of communicating or doing** that make it **harder for them to take up these roles**. These are the behaviours at issue, and they typically involve communications or actions that are troubling to others, particularly if there is a possibility of a person harming themselves or someone else, be that intentionally or not, or damaging property.

These behaviours are often not well understood by others, therefore they become the **focus of formal service responses**. When this happens, the daily character of the service is less likely to be centred on lifting the person into valued roles in community life and more likely to focus on **'managing' the 'problem'** so there are less instances of harm or damage. As a consequence of this, and of the way supports are then arranged and provided, the person can become known for these behaviours and little else. Their *Personhood* can become diminished in the views of others and their identity reduced to a set of 'problem behaviours' to be managed. Often, little or no progress is then achieved in advancing the person into ordinary valued roles in community life.

Use of restrictive practices

When the focus of the service response is on ‘managing problem behaviours’, opportunities to advance the person into valued roles are likely to be lost. In managing down the risk of harm or damage, a service provider (and sometimes family members or others involved in a person’s life) might use practices that involve restricting a person in some way. These are known as ‘restrictive practices’ and might include:

- **Chemical restraints** – such as administering medication to sedate a person or dull their senses
- **Environmental restraints** – such as preventing a person’s free access to all parts of their environment or to items or activities, for example locking a fridge
- **Mechanical restraints** – such as using restraints to prevent or subdue movement, for example applying wrist straps to a person using a wheelchair
- **Physical restraints** – such as using force to hold someone down
- **Seclusion** – such as confining a person to a room they cannot exit by themselves[5]

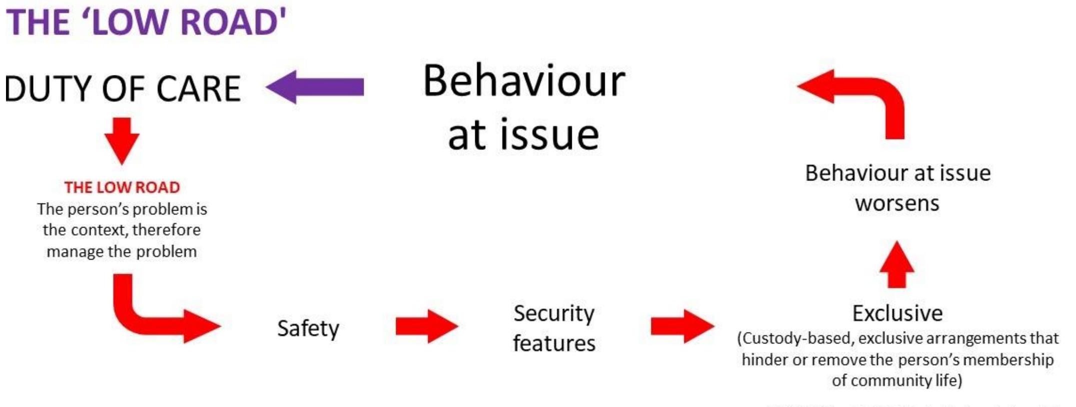
Restrictive practices are **problematic** for several reasons. Firstly, **withdrawing a person’s liberty or choice is a serious matter**. The right to make decisions, and freedom of choice and movement, are fundamental expectations in our society, and these are lost when restrictive practices are applied. This loss causes harm.

Second, this harm is exacerbated by the **compounding impacts** of repeated use and can produce the opposite outcome to that intended. When restrictive practices are applied, they can increase the chances the behaviour at issue will continue and with similar, if not greater, frequency than before.

Third, the **trauma** of being restricted in some way can also escalate to new behaviours due to these traumatising experiences. Behaviours at issue and the implementation of restrictive practices in response can become a persistent ever-exacerbating cycle without any prospect of change.

Fourth, there is a **fine line** between implementing a restrictive practice in the name of safety and doing so **simply for convenience**. We have encountered many instances of the latter. Insufficient resourcing, staff shortages, time constraints, untrained staff, reliance on entrenched but misguided ‘standard practice’ routines, workplace cultures of acceptance or indifference, extreme risk adversity, and other inadequacies in care, are all factors that can drive inappropriate use of restrictive practices.

Finally, there is little doubt that restrictive practices by their nature **stop** a person from building their **social and economic participation**; a core objective of the NDIS as discussed in the eighth chapter. We refer to approaches where a duty of care translates into ‘managing problem behaviours’ as the ‘low road’. As we described in Chapter 6, it results in safety measures that carry security features, the consequences of which include the person being excluded from opportunities and membership of community life. Below, we return to our earlier illustration to show the 'low road'.



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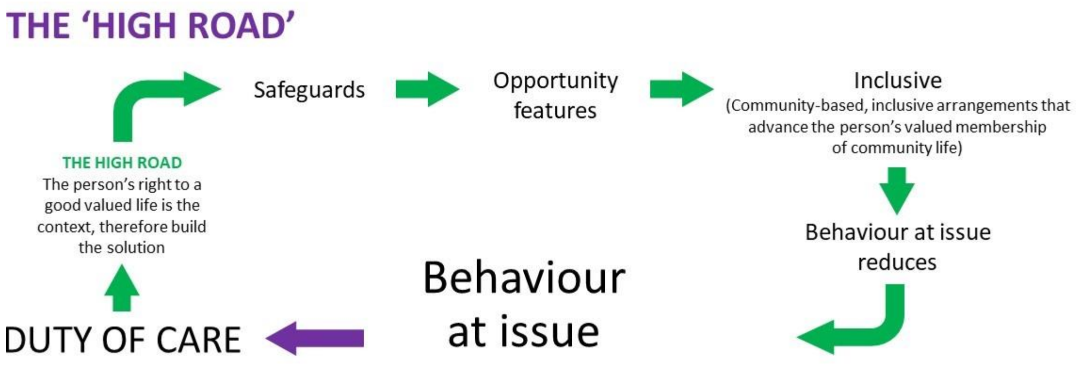
Positive Behaviour Support (PBS)

One of the general themes in psychology is the **relationship** between a person's **actions** and the **consequences** of those actions. This field of enquiry includes considering how people's behaviour can be influenced by rewards or punishments for their actions, so that wanted behaviour is encouraged, and unwanted behaviour is discouraged. For example, a traffic fine is a punishment for speeding. The avoidance of a fine is a reward for obeying the speed limit. Likewise, a child learning to play cooperatively with others is rewarded by the companionship it brings and the combined approach to imaginative play that results.

PBS applies methodologies that **assist a person to take helpful actions towards a good life**. As stated above, this approach goes well beyond situations where a person is at risk of having restrictive practices imposed, but it is linked with this because it can focus on supporting someone to adopt new behaviours without the use of techniques involving restriction or punishment. It is **anchored on the defence of a person's dignity and rights**, on creating a **positive environment**, and redirecting the person to communications and actions more likely to assist them to take up what we term *Personhood* and *Citizenhood*. We call this the 'high road', where the duty of care focus is on advancing the person's right to a fair go at a good life. This leads to safeguards, including **involving the person in decision-making** and **supporting the person** to **adopt actions and habits** that **open opportunities** for taking up **valued roles in community life**. This is summarised below, again building on the same illustration referred to above.



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Among other benefits, PBS helps shift the use of **restrictive practices** from a default first response to an **option of last resort**. It helps ensure any decisions about the use of restrictive practices are based on individual needs, genuine proportional risk assessments, and the provision of good practice support.

Key to this is **understanding the reasons for the behaviour at issue**. All behaviour is motivated by something; behaviours do not just appear from nothing. Reasons may include boredom, anger, sadness, hunger, quest for human contact, recognition, or response to previous trauma, including trauma from restrictive practices.

Once the reasons for the behaviour at issue have been understood, it is then possible to look at how the person is **supported to fulfill those needs in different ways** that also lift them into opportunities for social and economic participation and the meaning and belonging that comes with this. This requires holding true to the vision that the person can **move on from these behaviours** and is not destined to always be known for them. This demands advocacy from everyone involved, as well as **consistency and persistence of effort**.

The NDIS and PBS

Given its role in providing individual budgets to participants for formal supports, the National Disability Insurance Agency (NDIA) has a **key role to play in advancing PBS**. Additionally, the NDIS Commission is charged with **regulatory functions that are central to how PBS is implemented** for NDIS participants. However, there are problems.

First, there are issues with **how restrictive practices are understood and used**. Providers and workers have varying levels of knowledge about restrictive practices resulting in many practices being regarded as routine and legitimate when in fact they are **restrictive and cause harm**, including subtle (but definite) harm to the person every day. Further, restrictive practices should only be used as a **last resort** – or, in our view, only as an emergency measure. However, the NDIS legislation and Rules are not strong enough in this regard, or, at least, do not seem to be having the **required impact** to achieve this outcome. While the phrase 'risk of harm' is not directly accompanied by an indication of the extent of that risk, for example 'substantial risk of harm', the Rules do require a regulated restrictive practice to ‘be in proportion to the potential negative consequence or risk of harm’.[6] Yet, it appears restrictive practices are often used in cases where the risk is small, or, in some cases, entirely insignificant. This results in **unnecessary and inappropriate loss of dignity and rights** for the person and **increased costs and compliance activities** for the Scheme.

Second, using a mechanism like a Behaviour Support Plan to approve restrictive practices inevitably leads providers to approach this in ways that are **principally about securing approval** rather than improving the participant’s quality of life. Often, participants are referred to this formal process before anything else has even been tried to avoid the use of restrictive practices – utilising basic PBS tools should not require a Plan, which inevitably delays action. In essence, the process becomes a checklist and any attention to broader context and life chances is lost. For example, there is a requirement that the disability service provider consult the person about a proposed restrictive practice in their support arrangements. However, according to a recent audit, only a third of Behaviour Support Plans provide evidence this has been done.[7] Indeed, the quality of these Plans overall is currently **very poor**, with 80 per cent of Plans evaluated in the audit scored as underdeveloped or weak.[8] Additionally, too few billable hours appear to be used to directly engage with a participant while too many are spent on reports and compliance requirements.

Similarly, the focus on compliance is likely driving the production of overly lengthy and technical assessments to support the application. This may be **diverting effort and investment** away from a focus on implementing a proactive plan that lifts the person into good outcomes. A provider seeking approval for restrictive practice effectively has up to one year to find a behaviour support practitioner and implement the subsequent plan developed.[9] This is **too long** and potentially consigns a participant to a **further year of lost life chances**. Given the nature of restrictive practices, it is imperative there be a **greater sense of urgency**.

Third, the NDIS pricing arrangements include a single Line Item for ‘Specialist Behavioural Intervention Support’[10], which may be creating a ‘vanilla’ market that remains underdeveloped. People’s circumstances and needs differ greatly and require **more varied and nuanced approaches**. Additionally, this does not account for the **different level of skills and experience among practitioners**, nor the need for different skill sets whereby, inevitably, some services should be lower priced compared to others that cost more. Further, the price limit for this Line Item is **among the highest hourly rates** in the NDIS Support Catalogue,[11] yet it is clear neither the quality of this support, nor its outcomes, currently reflect this significant investment.

Fourth, there does not appear to be **clear national practice standards**, nor the **practitioner training** that would lead to consistent application of such standards. There are **no minimum qualifications or credentials** to register as a behaviour support practitioner. This means that among the 5376 practitioners[12] currently considered suitable to deliver PBS services, there are likely to be some who are much less able to make real impact, which wastes a participant's time and budget, and may in some cases even be harmful. There have also been anecdotal reports of practitioners discontinuing their services for participants considered 'more difficult' and instead taking on 'easier' cases. Aside from the ethical issues this raises, it erodes a participant's budget without producing any outcomes.

As a final reflection in this section, there are **inconsistencies** in the NDIS regarding the importance of a **vision of the possibility of change in behaviour toward better life chances**. For example, in the Specialist Disability Accommodation (SDA) framework, there is a housing classification termed 'Robust' that relates to housing development for people with behaviours at issue. This typically involves practical reinforcement features in the property design so it can better withstand damage from the person or reduce the risk of harm to the person and others. The problem with this is that SDA developments are intended to provide **long-term housing solutions** for the occupants. Therefore, even though this may be unintended, the message underpinning the current approach to SDA 'Robust' housing is that the occupants will need those robust features for many years to come. As such, this sets **an expectation the person is not capable of changing**, and this assumption will likely leech into the support arrangements for this person.

Building a stronger NDIS in relation to PBS

Drawing on the points made in the previous sections, we suggest the post-Review NDIS approach to PBS might include a number of features. First, the legislation and Rules that govern the NDIS should be updated to **emphasise more strongly** that restrictive practices should only be used **sparingly**, in the presence of **substantial and imminent risk**, and, even then, only as a **last resort**, and in a way that is **proportional** to the nature of the risk. Some might argue that the legislation and Rules already do this, but, given the reality of participants' experiences, this requirement does not seem to be conveyed as clearly and strongly as it should be.

Second, no restrictive practices should be authorised in the absence of a **broader plan** to advance the person into **ordinary life chances and valued membership of community life**. Importantly, this plan is broader than the current Behaviour Support Plan. This would require the service provider to build, deliver, and be accountable for the outcomes of a plan to lift the person into **valued roles in community life**, and in a way that **safeguards that person's dignity and rights**. This means that in order to achieve compliance, the service provider would need to be **authentically committed** to delivering 'transformational' outcomes for the person. It would also mean PBS is a **core part of internal practice** within a provider's day-to-day operations and not something that is only sourced from external practitioners in a time-limited manner. This would create a significant shift in provider practice and allow 'Specialist Behaviour Intervention Support' to be a **genuinely high-quality specialist field** for practitioners with qualifications, substantial experience, and broad expertise who would be available to assist the person, their family, and providers, in more complex situations, and assist PBS practice development.

Third, the NDIS pricing arrangements need to **better reflect the different types of PBS support** that can be helpful for participants, and to price these accordingly. This should reflect the diversity in practitioner skills and experience, allow for both support provider and specialist practitioner services, and more clearly recognise that PBS approaches **have value beyond the context of restrictive practices**. For example, a person experiencing a period of profound inactivity and absence of motivation may not be subject to restrictive practices but may benefit greatly from support anchored on PBS approaches.

Fourth, the NDIS will be greatly assisted by the establishment of a **national curriculum for PBS qualifications** and **minimum credentials for registration** of specialist behaviour support practitioners. A national curriculum with core common content could be delivered via a range of educational institutions, and with the goal of building **a more capable and consistent specialist practitioner sector**. Alongside this, *all* training related to disability support should include modules on human rights, support for decision making, and PBS, at a depth sufficient to then hold every worker in the disability support industry accountable for practice that upholds a person's rights and dignity. For specialist practitioners, there needs to be a **mandatory requirement to undertake continuing professional development**. We also recommend the development of a community-of-practice with functional links to the NDIS where PBS tools and techniques can be curated to shape industry practice and to help inform the NDIA about how it might evolve its commissioning in relation to behaviour support over time.

Fifth, the Scheme needs to assert **greater urgency** on providers where approval is being sought for restrictive practices. Any such approval should only be given for a **shorter period of time**, and with the expectation the provider moves much faster (we suggest three months as a maximum, and only for participants in the most complex circumstances) to establish a **proactive plan** to move the person away from restrictive practices and towards ordinary life chances.

When the issue is about denial of control and choice

Having charted the above narrative, we cannot close this paper without noting that it is entirely possible a person's behaviours at issue – usually termed 'behaviours of concern' in the provider setting – are a result of their **frustration at having their choice and control denied**. In our work undertaking social audits of disability services, we have seen examples where people have had restrictive practices imposed on them because, for example, their behaviour is in protest at having to live in a shared house with people they do not wish to live with. As such, the remedy is **not** the installation of a Behaviour Support Plan to support the person to adopt and adapt more helpful habits and actions. Rather, it is that the provider, NDIS, and informal supporters involved in the person's life need to **stop and listen**, and to **find a way to facilitate the person's choice**.

In this way, the problem is not a 'behaviour of concern', but a **'service of concern'**. Here, the remedy might include an independent party such as an intermediary (see Chapter 11 on this topic) spends time with the person to **understand their preferences and how these might be met**. This raises the question of how best to ensure disability services and their staff can best help to lift participants into valued roles in community life, anchored on the person's dignity and choice. This is the subject of our next paper in this Series.

Conclusion

PBS has much to offer the NDIS and its participants. However, it is currently framed and implemented in an overly compliance-orientated manner that risks constraining its potential positive impacts in upholding and defending the rights and dignity of people living with disability and advancing their life chances. A fuller application of PBS in the context of broader plans to lift people into valued roles in community life is needed if we are to maximise the benefits of PBS under the NDIS. It is critically important the NDIS and all its stakeholders hold true to a vision of the possibility of change toward better life chances for every participant, regardless of the perceived 'drama' of a participant's current situation.

Commentary

The webinar began with a discussion about the challenges of supported or substitute decision-making which attendees considered were particularly acute when transitioning a participant to a new home.

Attendees were unsure about how best to facilitate the degree of decision-making commensurate with a participant's decision-making capacity without under or overestimating this capacity.

They also raised concerns about the qualifications of Positive Behaviour Support practitioners. They discussed practice leadership; embedding knowledge of active support; regular co-ordination between service providers and allied health professionals to ensure PBS plans were implemented consistently; and using the price guide to influence provider behaviour as potential solutions.

Endnotes

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[1] COAG, 'National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector', 7 November 2014, p.1, available at https://www.dss.gov.au/sites/default/files/documents/04_2014/national_fraemwork_restricitive_practices_0.pdf.

[2] *Ibid*, p.4.

[3] NDIS Quality and Safeguards Commission, 'Unauthorised uses of restrictive practices in the National Disability Insurance Scheme', February 2023, p.6, available via link at

https://www.abc.net.au/news/2023-05-19/qld-ndis-rise-in-instances-of-unauthorised-restrictive-practices/102356712.

[4] R. Williams, 'The Model Of Citizenhood Support', 2nd edition, 2013, available at https://www.purpleorange.org.au/what-we-do/library-our-work/model-citizenhood-support.

[5] For further information, see 'National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018', Section 6, available at https://www.legislation.gov.au/Details/F2020C01087.

[6] *Ibid*, Section 21.

[7] NDIS Quality and Safeguards Commission, 'Behaviour Support Plan Quality: Summary results to December 2021', 16 August 2022, p.6, available at https://www.ndiscommission.gov.au/sites/default/files/2022-10/Behaviour%20Support%20Plan%20Quality%20Public%20Paper.pdf.

[8] *Ibid*, p.2.

[9] Under Section 13 of the Rules, the provider has up to six months to engage a practitioner, then, under Section 19, the practitioner has up to six months after being engaged to develop the Plan. See 'National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018', Section 6, available at https://www.legislation.gov.au/Details/F2020C01087.

[10] See Line Item 11_022_0110_7_3 in the NDIS Support Catalogue 2023-24, available at https://www.ndis.gov.au/providers/pricing-arrangements.

[11] *Ibid*.

[12] NDIS Quality and Safeguards Commission, 'Activity Report: 1 January – 31 March 2023', 3 April 2023, p.9, available at https://www.ndiscommission.gov.au/sites/default/files/2023-05/Attachment%20A%20-%20January-March%202023%20Activity%20Report.pdf.

CHAPTER 14: BUILDING A VALUES-DRIVEN NDIS WORKFORCE

KEY POINTS

- Much of the current focus regarding NDIS workforce issues is on **quantitative elements** such as meeting the numerical demands for workforce growth
- This overlooks **important foundational questions** about the **nature of the work** and what good disability support work looks like
- To fulfil the promise of the NDIS and ensure participants are lifted into **authentic social and economic participation** in mainstream community life it is essential to build and maintain a **strong values-driven workforce** that delivers **genuine 'transformational' impact**
- This has **substantial implications** for workforce planning, recruitment, and training because, in particular, it shifts the key competencies from 'transactional' skills like 'organising' to **'transformational' skills** like 'asking'
- Importantly, workforce planning needs to be **overhauled** based on personnel who can demonstrate an **authentic and heartfelt commitment** to an **inclusive Australia**
- Providers should be **accountable** for demonstrating their habits of values-driven workforce development through social audit methodologies

The success of the National Disability Insurance Scheme (NDIS) in achieving its goal of lifting Australians living with disability into authentic roles of social and economic participation in mainstream community life **relies heavily** on the **workforce**. Indeed, when the Productivity Commission proposed the creation of the Scheme, it flagged its concern that the existing 'shortcomings' in workforce development 'could be much greater under an NDIS'.[1] Yet, after the first 10 years of the Scheme's operations, **what good NDIS work looks like** and how to build the workforce to achieve this remains largely ill-defined. The Department of Social Services (DSS) produced the NDIS National Workforce Plan 2021-2025 with a vision to 'support and retain existing workers', 'grow the workforce', 'maintain quality of participant supports delivered by workers', and 'support sector efficiency and innovation'.[2] What is missing from the plan is a strongly articulated workforce **purpose** or mission statement and a description of what that looks like in practice. Arguably, the Plan is overly focused on quantitative elements at the expense of a **more qualitative vision** to shape the workforce that is needed if the NDIS is to deliver on its promise.

The NDIS Review's paper on 'Building a more responsive and supportive workforce' highlights the NDIS workforce has **doubled in size over the past seven years** to about 325,000 people.[3] Further, it will likely **need to expand by an additional 128,000 workers** before June 2025 to keep up with demand. With a **high rate of worker turnover** estimated at between 17 and 25 per cent – compared to an average of about 12 per cent across the economy[4] – and competition for staff from other social sectors including aged care and childcare, the importance of addressing workforce issues is clear. Yet, the magnitude of these numbers seems to lead to a somewhat narrow focus on factors like rates of pay, NDIS pricing arrangements, recruitment including from overseas, training requirements, worker screening and compliance matters, and similar issues. While all these elements are important, this tends to **overlook more significant foundational questions** about **how to build and maintain an effective NDIS workforce** that can deliver a genuine impact on Scheme goals.

In this thirteenth chapter, we argue **a much greater focus** should be on building a more ***impactful*** workforce. To adhere to the goals of the NDIS and deliver on its original promise, that ***impact*** needs to produce **genuine 'transformational' benefits** in the lives of participants. This necessitates a focus on building a **values-driven workforce** capable of creating this change and shifts the kind of training and workplace competencies that are essential for these roles from 'transactional' skills, for example, 'organising', to **'transformational' skills**, such as, 'asking'. Although this paper focuses on the workforce in the disability sector, the points we make below are **relevant to anyone in a helping role** with another person.

NDIS impact: A good life

The NDIS was established to lift participants into ***authentic*** **social and economic participation** in mainstream community life. We have emphasised the word 'authentic' here because just being ***in*** community is not enough. Having a support worker take a participant to a café for a coffee does not ***automatically*** lift a person into social and economic participation. Such activities can become a way of passing time, or filling in a day, and thereby render the participant as what has been termed a 'community tourist', where the person is ***in*** the community but not really ***part*** of it, as we described in the fourth chapter.

The key to making a person living with disability **part of their community** is the taking up of **active roles in community life**, on a similar basis as their non-disabled peers, and where those roles are valued by others so that the person becomes valued in their community for having those roles. These valued roles in life – such as friend, worker, club member, customer, dog owner, and similar – are what help each of us to build **meaningful and fulfilling lives**. At JFA Purple Orange, we call this *Citizenhood*.[5]

The difference between 'transactional' and 'transformational' benefits

The main concern with much of what is currently termed 'disability support' is that it is not **advancing people into *Citizenhood***. As we described in Chapter 3, there are two main types of consequences of disability and, therefore, two main types of corresponding benefits: **'transactional' benefits** and **'transformational' benefits**. Assistance with practical daily tasks, such as personal care, meal preparation, grocery shopping, and similar, is important but this work is a ‘transaction’, where the worker gives valued assistance, a need is met in that moment, but that need will come around again, and the assistance will be needed again. For most NDIS participants, these **transactional benefits are not enough**. For the NDIS to be successful and sustainable, it is critical that disability support delivers **transformational benefits** that do, in fact, **lift people into authentic valued roles in mainstream community life**, such as employment, social memberships, neighbourliness, community volunteering, and other contributing roles.

Therefore, the focus should be **on building a disability workforce capable of delivering transformational benefits** in the lives of participants. This has substantial implications for workforce planning. To illustrate, JFA Purple Orange worked with the families of young adults living with disability who were frustrated by their support provider’s lack of progress in connecting their family members into ordinary community opportunities. The provider was offering a typical program of daytime supports, largely centre-based, where staff had skills in organising activities for people. In discussing what hindered their family members from connecting into community life, the families spoke about how difficult they found it, due to the ever-present fear of rejection, to ask people in the community to **offer welcome and opportunities**, in effect, ‘to let their family member in’.[6] In thinking about what it means to be a good ‘asker’, the families identified skills like being confident, the ability to build rapport quickly, being diplomatic, being persistent, easily recognising a person’s gifts and strengths, and being deeply committed to the rights of people living with disability. In that moment, the families **reshaped** the concept of a daytime disability support worker from needing skills to organise activities that deliver ‘transactional’ benefits to needing skills to **ask for community welcome and inclusion** that delivers ‘transformational’ benefits.

Implications for workforce recruitment

As the example above demonstrates, when the **focus shifts** from delivering transactional benefits to transformational benefits, the **key workforce competencies change**. Therefore, the focus in recruitment also shifts from people with transactional skills in organising activities, who are usually recruited from relevant training backgrounds or similar roles, to people with rights-driven, values-driven transformational skills in asking and connecting, who may come from anywhere.

This theme can be taken further to what has been termed **‘role-based recruitment’**. To explain this, we note *Citizenhood* is both a **common experience** and a **personal experience**. It is common in that we all have similar desires for things like good health, a good job, enough money to live on, home, family, friends, growth, and so on. At the same time, it is personal in terms of how these things emerge in our lives depending on our **individual preferences and passions**. This is no less true for people living with disability. Therefore, it helps if a person’s support workers hold similar personal appreciation for a participant’s interests and gifts because this will **enhance how they support the person**. For example, if a person is a dog lover, it helps if that person’s support workers are also avid dog lovers because this will influence how they support the person to not only connect with this passion, but to find ways whereby the person's love of dogs can bring them into valued roles in community life. Whether it is dogs, footy, chess, carpentry, music, or a myriad of other interests, recruiting workers who have an easy and heartfelt appreciation of the interest will increase the chances of a 'transformational' benefit emerging.

In the case of microenterprises, where a person living with disability is supported to build a small business based on a passion or strength, the support methodology is anchored on the importance of recruiting support workers who **easily appreciate that passion or strength** and have the **skills and experience to support it**. For example, if the microenterprise involves carpentry, successful support workers are more likely to be recruited from carpentry networks than more conventional support worker recruitment channels. Hence, this approach is termed 'role-based recruitment' and brings a different perspective to finding workers.

One of the reasons why self-managed plans work well for many people is because this allows them to recruit their own support workers and **tailor their choices to their circumstances and interests**. This tailoring does not just have to be limited to self-managed support arrangements. Some of the more impressive providers we have encountered over the years are those that recruit support workers to work with specific individuals rather than for a general pool where they might be working with numerous people living with disability. This approach presents the opportunity for the worker to **build a deeper relationship** with the person they support and have more 'transformational' impact as a result.

At the core of the points made in this section are **values**.[7] Be it a commitment to the person's rights; to their strengths, gifts, and passions; to lifting and sustaining them in *Citizenhood* roles; to getting to know them really well; what lies beneath is a heartfelt and restless appreciation of the importance of these values. For the NDIS to forge a successful future, the conception of, and recruitment for, a disability workforce must be **values driven**. Importantly, the places where you find genuine values-driven workers capable of delivering 'transformational' benefits are not always the same places where you find people who can deliver 'transactional' benefits.

Implications for workforce training and development

Focusing on a values-driven workforce has implications not just for recruitment but for **how training happens**. Plenty of educational institutions offer certificate, diploma, and degree level training and education intended to equip people to enter the disability sector as support workers, allied health professionals, educators, and so on. These offerings need to be tested on the extent to which they guide their students to a **heartfelt commitment to values** and to delivering 'transformational' benefits that lift people living with disability into

Citizenhood, alongside the practical skills (for example, those mentioned above in relation to the art of asking and connecting) to bring these about.

It is important to emphasise here that **values** are not just rational ideas; they are **emotional ideas**. This raises specific imperatives for how students can be lifted and guided through these values. Lecture theatres and lecture notes are not always the primary media for building a heartfelt connection to values, nor are student placements with providers focused on 'transactional' benefits or on therapies somehow designed to try to 'fix' people living with disability rather than equipping them to advance in community life and the economy. Therefore, there is an urgent need to engage educational institutions on the **content of their courses** and how the national curricula can be evolved to **successfully engage students on values**.

Once workers enter the disability sector, there continues to be a need for **values-based training**. This means providers should regularly provide their staff opportunities to discuss the values that underpin their work, to attend relevant workshops, and to engage in **reflective practice**. In our experience, workers can learn a lot about the expression and practice of their values through talking with their workplace peers and by tuning in to the views of the people they support. NDIS pricing arrangements should reflect this and providers should be held **accountable** for it.

Auditing workforce practice

If **values-based practice is key to the success and sustainability of the NDIS**, then it should happen in ways that can be audited. We assert that as part of their continuing NDIS registration, providers should demonstrate their habits of values-driven workforce development. This can include examination of how service providers induct, train, and further develop their staff. Critically, any such audit needs to include safe channels for frontline staff, and most importantly those they support, to give feedback on the extent to which **values-based practice is present and supported**. If this happens, we could predict a decline in the part of the disability sector that exists for less wholesome or otherwise predatory reasons.

In support of the above, we believe that industry audit arrangements should be evolved to include a detailed ***social audit*** of the extent to which a provider is delivering on Scheme values and goals, especially in relation to a lived commitment to choice and inclusion.

Conclusion

The NDIS was established to deliver 'transactional' benefits that meet people's daily needs and, more importantly, 'transformational' benefits that lift people into lives of social and economic participation, which we term *Citizenhood*. Key to the emergence of 'transformational' benefits is a workforce and broader sector that focuses on the values that underpin their work. These values include a commitment to people's rights, to authentic mainstream community inclusion, to getting to know a person really well, and to being equipped with the practical skills and insights needed to genuinely advance people into social and economic participation. These commitments need to be heartfelt, otherwise 'values' are reduced to matters of regulatory compliance. A future NDIS, one that is successful and sustainable, needs an approach to workforce development that addresses how to build a workforce that is emotionally and restlessly connected to the importance of 'transformational' benefits.

Commentary

This webinar's discussion starter was how support workers see themselves as domestic workers who perform the cooking and cleaning rather than supporters who work alongside participants to help them fulfill their goals.

Examples raised were night staff thinking it efficient to order the grocery shopping despite this removing an opportunity for residents to be part of the community by walking down to the supermarket, speaking to the checkout staff etc. Or support workers cleaning residences to hospital standard while residents sat around bored and medicated. Attendees reported never seeing worker notes saying: 'Sat with resident and talked with them about their interests'.

Attendees noted that the corporatisation of service provision and the distance this created between the participant and the decision makers made it more difficult to create cultural change.

They considered better training was needed for support workers. One suggested a return to mandatory training such as a Cert IV from TAFE would help increase their knowledge and improve government and community perceptions of the industry. Another argued that without a 'piece of paper', a career in disability would be relegated to unskilled workers.

Attendees then discussed the challenge of teaching emotional intelligence to support workers. They recommended identifying, nurturing and encouraging people who already had these skills and considered the language they used to be a useful guide. For example, did they say 'client' or 'friend'? One attendee suggested a useful interview question was: 'Who do you ask about how to best support a participant?' People often cited every possible source but the participant!

However, as another attendee pointed out, workforce shortages meant it was not possible for providers to pick and choose.

Another argued that transactional benefits were essential for safety and suggested change would come more readily if plan managers were encouraged to move beyond the cheapest or most cost-effective solution and if more participants were encouraged to self-manage.

Attendees also suggested communities of practice and reflective practice could lead to practice improvements.

Endnotes

[1] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, p.694, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[2] Department of Social Services, 'NDIS National Workforce Plan: 2021-2025', June 2021, p.5, available at https://www.dss.gov.au/sites/default/files/documents/06_2021/ndis-national-workforce-plan-2021-2025.pdf; see also NDIS Quality and Safeguards Commission, 'NDIS Workforce Capability Framework', available at https://workforcecapability.ndiscommission.gov.au/.

[3] NDIS Review, 'Building a more responsive and supportive workforce', May 2023, pp.2&6, available at https://www.ndisreview.gov.au/resources/paper/building-more-responsive-and-supportive-workforce.

[4] *Ibid*.

[5] R. Williams, 'The Model Of Citizenhood Support', 2nd edition, 2013, available at https://www.purpleorange.org.au/what-we-do/library-our-work/model-citizenhood-support.

[6] On this point, we reflect on the 'Shut Out' report that helped create the impetus for the establishment of the NDIS, see Australian Government, 'Shut Out: The Experience of People with Disabilities and their Families in Australia', 2009, available at https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia.

[7] There is a range of research and reports that consider values in the context of workforce. For example, see Department of Jobs and Small Business, 'The labour market for personal care workers in aged and disability care – Australia 2017', Australian Government, Canberra, 2018, available at https://agedcare.royalcommission.gov.au/system/files/2020-06/RCD.9999.0236.0013.pdf; National Skills Commission, 'Care Workforce Labour Market Study: Final Report', 30 September 2021, available at https://www.nationalskillscommission.gov.au/sites/default/files/2022-10/Care%20Workforce%20Labour%20Market%20Study.pdf; Joint Standing Committee on the NDIS, 'NDIS Workforce Final Report', February 2022, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/workforce/Report;
J. Hurley & M. Hutchinson, 'Carers' experiences of the National Disability Insurance Scheme workforce: A qualitative study informing workforce development,' *The Australian Journal of Social Issues*, 57(2), pp.458-471, available at https://doi.org/10.1002/ajs4.181; and Sally Robinson et al., 'Understanding paid support relationships: possibilities for mutual recognition between young people with disability and their support workers', *Disability and Society*, 36(9), pp.1423-1448, available at https://researchnow-admin.flinders.edu.au/ws/files/32743745/Robinson_Understanding_P2020.pdf.

CHAPTER 15: MARKET STEWARDSHIP – FINDING THE SWEET SPOT

KEY POINTS

- The establishment of the NDIS necessitated the emergence of a **market** for supports, which is **still developing** and continues to have many characteristics of an **immature market**
- The **language of market is problematic** for a Scheme like the NDIS, because it leans into the transactional, not the transformational, and commodifies participants. It is better to focus on the language of community
- The main way the NDIA fulfils its market stewardship role is through **price regulation**, but, in practice, the price caps effectively operate as **set prices**, which strips out any real prospect for supplier diversity
- The current approach to price regulation has **implications** for what we get from the market, including the **quality** of what is on offer
- Significant investment is needed in the **capacity** of NDIS participants as **purchasers** who can help **shape the future market**
- NDIS participants can better shape the market if they are assigned **genuine flexibility and accountability** in their individual budgets
- NDIS participants can better shape a market that delivers **high impact services** if there is a comprehensive **investment in participant voice** in service design, both nationally and locally
- The Scheme will likely benefit from a careful introduction of outcome-based payments
- Responses to areas of market failure or ‘thin markets’ should be based on **community development imperatives** because people and organisations attached to communities are more likely to create **sustainable long-term solutions** than enticements for external providers

The establishment of the National Disability Insurance Scheme (NDIS) and its **utilisation of individualised plans and funded supports** was, in part, designed to move away from previous arrangements where government funders purchased disability supports directly from providers without the involvement of the intended beneficiary of those supports. The idea of NDIS individual plans and budgets was to give participants **more choice and control** about the supports they receive and who supplies them. In effect, this necessitated the emergence of a **new type of market** in **disability supports and services**. Although the Scheme is now entering its second decade of operation, the NDIS market is **yet to mature** and retains a number of commissioning features that predate the Scheme, resulting in no significant change in the services offered, which remain disability-focused rather than integrated with mainstream support sector markets.

The NDIS market also continues to present a range of **challenges** including areas of **market failure** or 'thin markets', in relation to geographic issues (for example, rural and remote areas), demographic issues (for example, supports for First Nations people), and service-type issues (for example, late-night supports, and supports for people with more complex needs). These thin markets create **significant safeguarding risks** and also compromise progress to Scheme outcomes in social and economic participation. Another market problem is the vexed issue of how to regulate pricing, and how this appears to have resulted in **low product or service differentiation** leading to what we term 'vanilla markets' in many types of support.

Most alarmingly perhaps, the NDIS market 10 years on still includes many of the commissioning features that predated the NDIS and for which, arguably, the NDIS was intended to be the antidote. This includes **block purchasing of services**, most evident through the Supported Independent Living (SIL) funding channel. The aggregate impact of the current NDIS market is that it largely comprises service offers that are **not delivering transformational benefits** for participants in line with the Scheme's goal of social and economic participation. Instead, the market comprises service offers that deliver transactional benefits at best, and often in segregated or non-inclusive circumstances. In 2011, the Productivity Commission foresaw some issues with the 'consumer choice model' it was proposing, but also offered an **optimistic view** of how the characteristics of markets would ensure well-funded, high quality, innovative, and best practice supports would become the backbone of the disability sector once providers and participants were '"unshackled" from block funding'.[1]

Given the challenges encountered, significant attention has focused on the appropriate role of governments and the National Disability Insurance Agency (NDIA) in **guiding the NDIS market** through its development, maturation, and beyond. Effective 'market stewardship' is now recognised as essential for the NDIS to deliver on its original promise, but what this looks like is still unsettled.[2] While the NDIS was never intended to be a fully *laissez-faire* marketplace, **how much intervention** and **in what forms** is **difficult to calibrate**. Nevertheless, there appears to be a growing consensus the NDIA is yet to find the 'sweet spot' in its market stewardship role. Further, its trials of alternative funding models to address 'thin markets' have so far produced mixed results as to their effectiveness.[3]

In this final chapter, we consider issues in the **NDIS market** and **how the NDIA undertakes its market stewardship role**. First, we explore the **unease inherent in applying market language** to the Scheme overall and, more specifically, to participants, many of whom have come to feel commodified within the NDIS market model. As recently as this week, in one of our focus groups, the perception of being reduced to a commodity, and the consequences of feeling this way, emerged as a major theme in discussions. Then, we address how **price regulation has impacted on what is available** in the NDIS market. We set out the **importance of investing in the capacity of participants as purchasers** to ensure they can positively influence the market's direction, for example by being empowered to demand high-quality, high impact supports, services, and products. Finally, we contemplate areas of **market failure** and argue **local grassroots approaches** based in **community development imperatives** offer the best way forward for affected participants to access the supports they need.

What is meant by 'market stewardship'?

In many markets for social supports or personal care, governments utilise **tools to guide or influence how the market operates** to ensure it fulfills their objectives. This is particularly the case when governments are the main source of money for the services or products offered within the market. Yet, there is an **unease** that arises when **the state** and **the market** come together in the delivery of **essential state-funded services**. Even under an 'insurance model', the NDIS market is no different. Many NDIS participants are uncomfortable with the extent to which they feel the market has turned them into **commodities** rather than citizens. For example, NDIS participants eligible for Specialist Disability Accommodation (SDA) or Supported Independent Living (SIL) are effectively reduced to, and judged on, their funding level category as this dictates the extent to which they fulfil the market and cost recovery imperatives of providers.

In many respects, the use of market-orientated language under the NDIS does not adequately capture **what it is the Scheme is supposed to deliver**. If the Scheme's goal is to lift people into social and economic participation, and, by association, into genuine, valued belonging, then **the NDIA is not stewarding a market; it is stewarding a community response**. Market language reinforces the transactional characteristics of the Scheme, where for a particular price, a particular person shows up at a particular time to provide a particular service. But, as discussed in the third chapter, transactional benefits do not automatically deliver on Scheme goals and there is little evidence that participants have certainty in those services.

However, if we reach for the **language of 'community'** rather than 'market', there is a **better context for NDIS commissioning**, because **social and economic participation** are grounded in the idea of ***'community'***. Therefore, instead of seeing the NDIA as the steward of a market, we can see the NDIA as a steward of **formal community responses**, at least those responses for which NDIS funds are intended to be used (as opposed to mainstream formal community responses, such as healthcare, education, housing, and similar). Using community as context instead of market, helps to frame the NDIA's 'market stewardship' role as one of **ensuring the community of formal responses deliver on the objectives of the Scheme**. Where that community fails to do so, the NDIA, as steward, needs to take decisive steps given the importance of these formal community responses to the lives of Australians living with disability.

Using the language of 'community' not 'market' can **change how the stewardship role is undertaken** because, in effect, the change of use of language signals a change in the paradigm from market development to **community development**. This is worthy of reflection, given the market stewardship has tended to be 'underdeveloped' and in need of improvement during the first 10 years of the Scheme.[4]

NDIS price regulation and its impact on what we get from the 'market'

The NDIA regards its **price regulation function** as **central** to how it performs its market stewardship role.[5] Ironically, one purpose of price regulation is to ensure the **market operates efficiently** and **Scheme costs are sustainable**, yet **excessive inflation** has emerged as a major problem for the NDIS. Additionally, there is currently **no clear link** between the use of price regulation largely based on **hourly rates of payment** and the value of what is delivered in terms of **achieving the Scheme's objectives**.[6]

About 80 per cent of NDIS payments made between October and December 2022 were **price-limited**.[7] NDIS Pricing Arrangements and Price Limits[8] control what can be charged for each type of support and are **intended to operate as caps** meaning providers and participants can negotiate lower prices. In theory, price would be one of the elements on which **providers compete for customers** in an open competitive marketplace. In practice, providers overwhelmingly treat the Support Catalogue,[9] which lists the price limit for each line item that can be claimed under the Scheme, as a **set price** even if they offer the same support, service, or product to non-NDIS participants at a lower charge. Seemingly, supply is yet to match demand for many supports so operating at the price limit does not reduce a provider's ability to **attract customers**. All of this means the NDIS market does not operate as a typical competitive marketplace and this has **significant implications** for the Scheme.

Although there are more than 800 line items in the Support Catalogue, some support categories have a **very limited range of items and prices** that can be charged. Often, price differentiation relates to the day of the week or time period when a support occurs, whether the support occurs in-person or not, and whether costs such as travel can be covered. More substantive characteristics of supports, such as the **nature and quality of what is provided**, the level of **expertise** of the person offering the support, and the **outcomes** achieved receive much less attention, notwithstanding a few exceptions. One of the consequences of this has been the emergence of what can be referred to as 'vanilla markets' in many support categories, whereby, although a participant can choose between providers, there is **little diversity in what they offer**. Where a market operates under set prices for limited line items this **disincentivises** providers from product **differentiation**, flexibility and adaptability to customer needs, innovation, and the emergence of unique or novel offerings.

It is also possible the **cost of operating** as a provider in some support categories is **not fully reflected** in the current price limits meaning some providers have little choice but to charge the price cap. A recent National Disability Services (NDS) survey found 83 per cent of providers hold concerns about their ability to operate under the current price limits, sparking concerns about an imminent exodus of providers from the NDIS market.[10] As **self-reported perceptions** that cannot be untied from providers' interests, it is **difficult to test the veracity** of this finding. Perceptions surveys usually have **more value in tracking how sentiments fluctuate over time** in response to specific market factors than as baseline data on the extent of an issue. Certainly, the numerous examples of non-NDIS participants being charged less than participants in the Scheme would tend to indicate the real costs of some supports are much lower than the price caps. Additionally, arguments suggesting higher prices reflect the report-writing demands of the Scheme, are voided when participants are charged for this in addition to the supports provided.

Another problem of price caps is that they create a market that does not include providers who want to offer a **higher-priced, higher impact service**. For example, say a provider operates a methodology that is highly effective at lifting a participant into sustained, mainstream, waged employment. And say the costs of the service per hour is 50 per cent more than the price cap. The proposition is 'we cost more but we can deliver a measurably much stronger outcome for you'. There are other aspects of life where this option is available in the market, whether it is the market for healthcare, kitchenware, or anything else in between. Yet this option is not available in the NDIS market because of price caps. And it removes the possibility of the **participant shaping the market in favour of higher impact services**, which also could cost the NDIS less in the longer term.

Consequently, price regulation requires an investment in **high quality data collection and curation** to inform **robust transparent cost models** that reflect the **genuine cost** of providing a support, service, or product, and of achieving high-impact outcomes. Such models need to be able to account for a **range of variations** including the nuances of location and distance and variations in staff costs based on experience and qualifications. In the NDIS context, the differences in costs incurred between sole traders and larger providers also requires consideration. This deeper work should ensure price regulation is an **effective stewardship tool** to bring the NDIS market to greater maturity and provide assurance that high-quality, high-impact supports are being delivered. As the market is further developed, it may become possible to **gradually step back from intensive price regulation** in the future, although general oversight and accountability will always be necessary. Without this investment over the short to medium term, there is a risk that price regulations are applied **too bluntly** and result in **perverse market outcomes**.

Empowering purchasers to drive market responsiveness: capacity-building

Markets work best when they are **responsive to consumer choices and needs**. The magnitude of the transition from the old block-funded model of disability support to an NDIS 'marketplace' built around participant choice and individual purchasing power cannot be overstated. Irrespective of its many merits, this has represented a **profound change** and required **significant adjustments** to ways of operating and behaving. While much attention has focused on how prepared providers have been to engage in the new market, it is also essential that Scheme participants are **equipped** with the **knowledge and skills** they need to make the **best choices** about how to use their budgets in this marketplace, and with what transactional and transformational benefits in mind.

Typically, **consumer choice and purchasing power** could be expected to ensure low-quality providers must improve or otherwise exit a marketplace while **high-quality providers attract customers** and do well. However, in order to exercise the consumer power that drives this outcome, NDIS participants need to know how the market works, what good quality service provision looks like, and what a reasonable price is to pay. An analogy can be drawn to street markets where locals who are **experienced and informed** through **regular interactions** are much better placed to haggle for a fair price than a tourist visiting for the first time; hence many stallholders effectively operate dual pricing schemes. In this way, participants encountering the NDIS marketplace tend to assume the position of the 'tourist', according to the above analogy, and **it takes time and support** to reach the level of a savvy local who is familiar with what is on offer, where to buy it, and how much to pay.

For the NDIS, this means there must be an **investment in the capacity of participants** to engage in the marketplace. This includes having a **clear vision** of a life of social and economic participation, weighing up the best balance between transactional and transformational benefits, and then exercising **informed choice** about who might best be able to deliver those benefits, so that the highest value is obtained from their NDIS budgets. This investment in capacity-building also includes supported decision-making approaches, as well as how best to ask for, and access, **mainstream community resources and opportunities** that reduce pressure on their NDIS budget. We note the numbers of participants **under-utilising** their plan budgets – with a national average underspend of 25 per cent between October 2022 and March 2023[11] – is likely to be, in part, a symptom of **inadequate investment** in supporting participants to engage effectively with the market in order to access the supports they need. Similarly, participant purchases of services very similar in nature to those they were accessing pre-NDIS (or having those purchases made on their behalf, for example through SIL group living purchases) are symptomatic of a **substantial underinvestment in participant capacity-building** for their role in the 'market'.

Empowering purchasers to drive market responsiveness: budget flexibility and accountability

Over and above capacity-building, it is important to consider whether the current system settings make it possible for participants to **shape the market**. Currently, some of the constraints on what participants are allowed to spend their budgets on may actually be **hampering good outcomes**. Added to this is the issue of the appearance of there being little to no consequence for a participant spending all their budget before the end of the budget term, because more funds appear to flow as a result, contributing to what is termed ‘intraplan inflation’[12]. While there may be reasons why a particular participant might reasonably need additional funds midway through their current budgeted plan, there is a **high risk** some participants may be less diligent and less discerning in their purchase choices when there is no adverse consequence; a poor purchase choice simply results in a budget top-up down the track.

As an alternative, we think there will be more effective market development in pursuit of genuine outcomes if participants are given much **greater flexibility** in how they can **use their budget** and **greater accountability** for **staying within the budget**. We think this will help unlock the power of participants to find the best possible value from their budget and be in sharp contrast to the current SIL arrangement where an agreed budget sits with the provider and where the participants have no detailed say in the choices made within that budget.

Empowering purchasers to drive market responsiveness: voice and choice

When thinking about **participant influence on the market**, some might argue this can be achieved by making sure there are a range of options for people to choose from. In this way, it might be argued participant ***choice*** shapes the market. However, the range of options might not be impactful in support of Scheme goals, and just because the participant had a choice, it does not mean the participant’s goals, and the Scheme goals, will be met. We have made a similar point earlier in this paper, in relation to ‘vanilla’ markets. If we are to see **alternative service responses** emerge that have a **greater chance of delivering social and economic participation**, then it is important the participant ***voice*** is **central to that design process** because they have the greatest stake in the outcome.

As market steward, this means the NDIA needs to **invest in service design**. Though welcome, it will not be enough for the NDIA, as steward, to simply assert the importance of there being alternatives to group homes, shared day programs, and the like. The NDIA also needs to ***invest*** in bringing this about. This is not only about the important co-design work at a system level where participant voices are present in deliberations about the Scheme’s general settings, for example in home and living supports. It is also about what happens to the local participant, **locally**. How might the NDIA assist a group of NDIS participants currently sharing a group house to **imagine what alternatives might be possible**, to build a collective or individual service design that works for them and for the social and economic participation imperative, and then take this to the market for providers to respond. In this way, in the context of the Scheme goal of social and economic participation, a smaller choice of providers offering services that have been **designed through the participant voice**, will be a more effective market than a larger choice of providers offering services that do not reflect the participant voice in their design.

Market stewardship using outcomes as a lever

Some, including NDIS Minister Bill Shorten, have recently suggested that an approach where Scheme **payments are more closely tied to the outcomes achieved** for participants may help address some of the above concerns, particularly those regarding quality.[13] Outcome payments are an attractive idea because they are a good way for the steward to give a **clear signal** about what is wanted from the market/community. While holding **providers accountable for delivering impact is essential**, such an approach is not without its **challenges**. It is possible for a high-quality provider to work hard on behalf of a participant and still not achieve the intended outcome because of forces that may be largely outside their control. As a result, outcome payments could **deter** providers from offering supports to **participants they perceive to have more complex needs** or circumstances, something that may be already occurring in relation to Positive Behaviour Supports (PBS) as we highlighted in the twelfth chapter.

These unintended consequences will need to be **carefully navigated** when considering a framework of outcomes payments. Elements might include regulating providers on their capacity to make impact, including through a **demonstration of delivering on Scheme values and objectives** at a holistic level rather than in each individual case. Certainly, the focus here must be on **provider accountability** and **continuous improvement**, not compliance for compliance's sake. A further element might include making outcomes payments based on the aggregate impact of the provider's work across a number of NDIS participants, and which also takes into account the degree of complexity in that population (to avoid providers only working with participants for whom the provider deems it easier to deliver outcomes).

Thinking about market failures

The NDIS market has developed at different rates across the country and there are areas of **market failure** or 'thin markets'. In regional, rural, and remote areas, the NDIS faces similar challenges to the health sector: **comparatively lower demand** compared to metropolitan areas and spread widely, often across vast distances. By introducing an individualised funding model, demand risk has been added to the equation for would-be providers contemplating whether to deliver services in a location: will **actual demand** live up to anticipated demand? Given the increased costs associated with regional service provision, such as employing fly-in-fly-out workers, the prospect of demand risk has arguably contributed to a further thinning of already sparse markets.

For First Nations communities, the challenges mentioned above are further exacerbated. According to the NDIS Review's paper entitled 'Alternative commissioning for remote and First Nations communities' published in June, more than **one in three** participants who have been in the Scheme for more than a year are **not accessing their funded daily living supports** while more than **one in four** are **not accessing their funded therapy supports**.[14] With limited options to choose from, First Nations participants often receive services 'delivered by professionals that are qualified or subjected to non-cultural scrutiny, perpetuating interactions that are culturally unsafe, therapeutically inadequate and considered rigorous only from a mainstream, Western lens.'[15]

When a part of the NDIS market fails, the potential consequences are severe; not only are the **Scheme's objectives unlikely to be met**, but it can also mean **fundamental human rights are not upheld** and **people are placed at risk**. Therefore, options to address market failures must be carefully considered and closely monitored when implemented to ensure adverse outcomes are avoided. Robust data is required to identify and address areas of need not being met by the market. Once market gaps are identified, it is likely the most effective solutions will be found by focusing on **community development imperatives** through **local knowledge, skills, ideas, and connections**. This is an illustration how the language of ***community*** is a more potent guide for the NDIS steward than the language of ***market*¸** because it may be more impactful to resolve 'thin market' issues by calling on elements of community development rather than elements of market development. This is because grassroots led responses are key to resolving the NDIS 'thin market' problems. People with **strong attachments** to their communities are more likely to **stay engaged over the long term** and **produce more sustainable outcomes**. Although there may be some need for specialists to fly or drive into communities, the **core of any solution should be embedded within the local context**. In most communities, there are likely to be important sources of knowledge, experience, and leadership, to assist the emergence of these types of solutions, whether it be active local leaders, community or First Nations organisations, local governments, and similar. At JFA Purple Orange, we have personnel who have been involved in such development in other jurisdictions and we have seen the **power** of the community-led solutions that emerge in response to 'thin markets'.

Therefore, if sustainable long-term solutions to market failures are most likely to emerge from within local communities themselves, what does the NDIA's market stewardship role look like? Given the NDIS represents such a profound shift in roles and responsibilities, these **solutions are unlikely to emerge organically**. So, an effective stewardship role involves **connecting, facilitating, coordinating, and supporting** the mobilisation of local leadership in pursuit of **grassroots solutions**, undertaken with the **strong mandate** of the NDIA but **located on the ground** in local communities.

As one example, this could be accomplished through the characteristics of the reshaped Local Area Coordinator (LAC) role. Throughout this compendium, we have emphasised the need to **rethink the nature of the LAC role** and **how it is commissioned**. In the second chapter, we identified an **LAC role that stands alongside a participant** as they navigate the NDIS pathway funded through individual plan budgets. We can also imagine a particular version of the LAC role in response to thin markets, where the LAC undertakes their work in vision-building, community connection, and brokerage, not on behalf of one NDIS participant, but on behalf of a community where there are a number of NDIS participants. As such, the solution that is then developed is as much about that community as it is about the NDIS participants, and that community will likely include people living with disability not on the Scheme, the so-called 'Tier 2'.

As such, investment in LACs to perform a **community broker-type role** to work with local communities affected by NDIS market failures to create **bespoke, community-led solutions,** offers strong prospects for **addressing unmet needs**. In some cases, this might involve integrated solutions that address gaps not just in the provision of NDIS supports, but also in other social services, such as those for older people, and also broader local issues such as unemployment and low levels of community amenities. For example, for a remote community First Nations participant whose support needs include a high level of laundry, the more sustainable solution might not be an individual washer-dryer for that person, but a launderette for the whole community.

The NDIA has been trialling a number of **alternative commissioning approaches** including direct, integrated, and community commissioning.[16] The focus of these trials is on **contestability** in the commissioning as a substitute for competition in the market. All seem to involve enticing existing providers into communities to fill market gaps. Under this approach, it is unlikely the enticement could ever be withdrawn because the provider/s would simply exit as well. Therefore, the **grassroots approach** to developing solutions from **within** communities, as outlined above, would likely be **more durable and sustainable** than these trial approaches. Additionally, despite being labelled as 'community commissioning', the application of this option to address gaps in supports can still cover large geographical areas resulting in decision-making that is generally removed from the most affected participants. For example, the proposed 'Far North Queensland (FNQ) Connect' approach covers 21 Local Government Areas (LGAs) under a 'Leadership Table' that includes government and provider stakeholders alongside people with lived experience of disability and First Nations representatives. Its impact is yet to be ascertained, but this should be **measured against an alternative grassroots community development approach** to ensure the most effective models are identified.

Conclusion

The NDIS market has not yet matured. To get there, we need to equip the more than 610,000 participants[17] to know what high quality supports are and demand they get them. Poor quality providers should be managed out of the market so that better ones can thrive. Where there is market failure or 'thin markets', the focus should be on local community responses, based on community development imperatives. Enticing external providers into these markets is not a sustainable long-term solution. Instead, people and organisations with strong attachments to communities affected by market failure should be supported and resourced to develop their own solutions from within. The NDIA has a mandate to underpin this work, but it is essential the support is provided on the ground, with a reformed LAC approach probably best placed to deliver this outcome. The NDIS has achieved much in its first 10 years, however there are also many important lessons to learn as we chart the course for the next decade and beyond. For one, the Scheme must be about impact, not commodification.

Commentary

This webinar focused on the NDIS as a market, with attendees discussing research that showed utilization was often linked to the amount of social capital an NDIS participant had around them, particularly when they were in a rural or remote area or a lower socio-economic group.

They considered the paper was consistent with anecdotal evidence about NDIS planning and raised concerns about the lack of continuity of planners and the lack of skill. They told of reports not being read and scant attention paid to capacity building in the planning process. This led to participants dropping out; poor attendance at planning meetings; or parents and service providers overshadowing the role of participants.

Attendees discussed the potential of values-based reimbursement and payments for results, highlighting US and UK innovations in the intellectual disability sector. They argued that the absence of incentives under the NDIS provided a perverse incentive to increase service provision. The quality, trustworthiness and consistency of available data also made it difficult to evaluate the effectiveness of expressed outcomes.

The absence of price signals for SDA housing was raised, with vacancy rates seen as the only market signal. Attendees were concerned about a potential oversupply as SDA suppliers raced to open first, causing the market to deflate when accommodation became unoccupied.

They argued the existing tendering model operated like a subsidy for overseas investors to fund disability housing and was a form of corporate welfare.

Attendees also raised concerns about the growing group of middle-aged people who had acquired disability through an accident and would need additional assistance with accommodation.

Attendees suggested microboards, an alternative tendering process; and disability trusts, where parents could leave assets for their children living with disability (and already in place overseas), as potential solutions.

Endnotes

[1] Productivity Commission, 'Disability Care and Support,' Report no.54, 2011, pp.50-54, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[2] See for example, Productivity Commission, 'National Disability Insurance Scheme (NDIS) Costs Study Report', October 2017, available at https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf; McKinsey & Company, 'Independent Pricing Review: National Disability Insurance Review - Final Report', February 2018, available at https://www.ndis.gov.au/news/561-independent-pricing-review-update.

[3] For examples, see NDIS Review, 'Alternative commissioning for remote and First Nations communities', June 2023, available at https://www.ndisreview.gov.au/resources/paper/improving-access-supports-remote-and-first-nations-communities.

[4] Productivity Commission, 'National Disability Insurance Scheme (NDIS) Costs Study Report', October 2017, pp.41,60,277 and elsewhere, available at https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf.

[5] Ibid, for example p.311.

[6] See further, NDIS Review, 'The role of pricing and payment approaches in improving participant outcomes and scheme sustainability', May 2023, p.33, available at https://www.ndisreview.gov.au/resources/paper/role-pricing-and-payment-approaches.

[7] *Ibid*, p.2.

[8] For more information, see https://www.ndis.gov.au/providers/pricing-arrangements.

[9] *Ibid*.

[10] National Disability Services, 'New data projects "unconscionable" closure of disability services', 31 July 2023, available at https://www.nds.org.au/news/new-data-projects-unconscionable-closure-of-disability-services.

[11] National Disability Insurance Agency, 'NDIS Quarterly Report to disability ministers: Q4 2022-23', June 2023, p.86, Table D.29, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[12] See further, Office of the Scheme Actuary, National Disability Insurance Agency, 'NDIS Quarterly report to disability ministers: Scheme Actuary Presentation Q3, 2022-23', 31 March 2023, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[13] See for example, National Disability Insurance Agency, 'Media release from the Minister - National cabinet commits to a sustainable NDIS', 26 April 2023, available at https://www.ndis.gov.au/news/9087-media-release-minister-national-cabinet-commits-sustainable-ndis.

[14] NDIS Review, 'Alternative commissioning for remote and First Nations communities', June 2023, p.3, available at https://www.ndisreview.gov.au/resources/paper/improving-access-supports-remote-and-first-nations-communities.

[15] Jody Barney, 'Indigenous ways of knowing, being and doing, and responding to NDIS Thin Markets', in Mhairi Cowden and Claire McCullagh (eds), *The National Disability Insurance Scheme: An Australian public policy experiment*, 2021, Palgrave Macmillan, Singapore, pp.245-255.

[16] NDIS Review, ‘Alternative commissioning for remote and First Nations communities’, June 2023, available at https://www.ndisreview.gov.au/resources/paper/improving-access-supports-remote-and-first-nations-communities.

[17] National Disability Insurance Agency, ‘NDIS Quarterly Report to disability ministers: Q4 2022-23’, June 2023, p.5, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports

CHAPTER 16: MANAGING TRANSITION

KEY POINTS

- For the NDIS to systematically build capacity to deliver the hoped-for impact, it needs an approach to design that incorporates not only co-design but process design
- Coordinated change management will be needed to orchestrate complex system change
- The NDIA will need to draw a line in the sand on congregate and segregated service models, if it is to authentically advance the goal of social and economic participation
- Fairer and more equitable systems will mean difficult decisions for some Scheme participants whose individual budget might be lower as a result, but this contrast effect can be offset by giving participants greater flexibility in how they can use their budgets

In the preparation work for each paper we produced, the issue of transition emerged with increasing regularity. Four key imperatives emerged. First, the drama is always in the detail of any design, and therefore the design work needed to be sufficiently methodical, detailed, and connected.

Second, for a system as complex as the NDIS, there will likely be a range of projects running concurrently and these must be carefully and mutually coordinated to ensure an integrated implementation.

Third, if the Scheme is to authentically move away from congregate and segregated models of support, it will need be clear about this so can begin redirecting funds into more inclusive support arrangements.

Fourth, in transitioning to a more successful and sustainable Scheme, it is likely there will be refinements about who is eligible for the Scheme and how their individual budget is resolved, and this might mean delivering some difficult messages to Scheme stakeholders.

The remainder of this chapter contemplates each of the above transition imperatives.

Designing for strong Scheme outcomes: the importance of Process Design

For the past two years the NDIA has undertaken a sincere approach to codesign, seeking ways to involve people from the disability community in its policy and practice considerations. This effort has helped strengthen the relationship between the NDIA and the disability community and other stakeholders.

One of the benefits of codesign, when undertaken with sincerity and intention, is it brings key beneficiary voices to the table, and this can help ensure the subsequent design has the best chance of delivering good outcomes to the beneficiary group. Involvement of those voices in the decisions about design is key to this.

However, for more complex issues it is not unusual for codesign to struggle to deliver a workable design, or for codesign participants to become frustrated at the slow pace. When this happens, as has been the case on occasion with codesign work at the NDIA and elsewhere, it is not because of a lack of sincerity or effort. Rather, it's because the codesign process is missing a key methodology: process design. Process design is a methodology that, in general terms, systematically moves from identifying and quantifying the presenting problem and its underlying causes, to the development of solution design elements, the quantification of expected benefits, the build process, the testing of the build elements, refinement, and then scaling up via a rollout plan. When this type of methodology is missing, the design work can struggle to move from expressing the presenting issue at a high-level to a corresponding high level aspirational view of how things could be. When this happens, participants (including the sponsoring agency) can struggle with the limited progress.

The use of a process design methodology, and careful facilitation of it by an accountable party, will be key to the NDIA's work in leading transition to a more effective set of Scheme arrangements. There are plenty of different flavours of process design methodology, and plenty of agencies offering them. Therefore, it is key that the NDIA, or whichever government agency commissions the work, opts for a process design methodology that is accessible, avoids gimmicks, isn't expensive, and where the process design supplier/facilitator is held properly accountable for the quality of the deliverables.

Navigating complex system change: the importance of change program management

In commencing service deinstitutionalisation in 2004, SA agency Julia Farr Services ran over 70 concurrent projects to deliver integrated change. It was a similar story with mental health reform in New Zealand in the 1990s. Complex system change means there will be a significant number of component projects running concurrently.

There is no doubt the NDIA and other government agencies already know this. However, we make this point here because the NDIA's efforts to improve the Scheme over the past decade have not appeared integrated. It has not always been clear how different active projects are related to each other, and sometimes a project appears to be running in isolation, even though its own success might be critically dependent on the prior resolution of other matters outside the project scope.

Therefore, assuming it is the NDIA leading the post-Review transition to a stronger Scheme, we recommend a Change Program office be established, to identify the range of required projects, to map the milestones and timelines for their work and, critically, to map and manage the interdependencies. The Change Program office will also need to run a proactive, transparent, and highly inclusive communications program with stakeholders.

Inclusion vs congregation: drawing a line in the sand

Segregated and congregated services do not support people into inclusive lives in the way well-orchestrated inclusive services do. Proper inclusive education is better than segregated special education at positioning students for an inclusive adult life. Mainstream employers with an appreciation of workforce diversity offer more inclusive and fairer-waged employment than Australian Disability Enterprises. Housing that reflects what most Australians have, is better than group houses at positioning the occupants for ordinary community relationships.

If there is to be a successful transition to a Scheme committed to inclusion, to social and economic participation, the NDIA will need the courage, and the support, to draw a line in the sand, to set a date after which no participant will receive funding to enter congregated or segregated arrangements. This does not mean existing participants in congregated and segregated services need to be forcibly removed, because they and their families may have come to rely on those arrangements, however suboptimal such arrangements are at lifting people into good lives. Such services can be classified as heritage services, but not be permitted to receive new NDIS-funded clients into those services.

Such a line in the sand provides clarity of purpose and signals an authentic commitment to delivering true inclusion in Australia.

Managing the contrast effect: dealing with the impact of a better-calibrated Scheme

In psychological terms, the idea of the contrast effect is when our perception of a thing becomes heightened when set in contrast with something that is different. For example, a dark square might seem darker when set within a lighter square. For further example, a sale price for a household item might seem more attractive when set alongside the previous higher price for that item.

In the NDIS, the adoption of new assessment and budget-setting arrangements will bring much needed clarity to the business of being fair and equitable across a participation population of over 600,000 people. Such a move will also bring about the contrast effect. For some participants it might be a pleasant contrast effect, where their individual budget is increased compared to what it was before.

However, there will be other participants for whom the contrast effect will be less palatable because, by establishing stronger fairness and equity across the 600,000 participants, their individual budgets are reduced, or not topped up should they consume all the resources before the end of the budget period.

Because of this contrast effect, those participants may react more adversely to their revised budget than if those were the budget circumstances in the first place. Even though to a neutral bystander the updated budget arrangements might seem fair to the person’s circumstances, the contrast effect will be there for the participant.

This adverse contrast effect may also emerge from the shadows for a participant whose NDIS budget is reduced because they have made good progress from the use of their previous budget, and as a result their circumstances have changed for the better, which may mean in some cases the participant is allocated a smaller budget.

As a result of the contrast effect, it is entirely possible some affected participants or their allies may stimulate activity in the appeals process and in the public domain. This will likely feel very uncomfortable for the NDIA and its stakeholders. However, if the Scheme is to be fairer and more equitable, these contrast effects and consequences seem inevitable and perhaps unavoidable if we wish to see a stronger, fairer Scheme.

This presents the NDIA with a difficult challenge. However, there are at least two options we can think of that can help. First, we encourage the Scheme to deeply involve key stakeholders like the disability representative organisations (DROs) and similar organisations in the design work and the change program coordination. The NDIA has already built momentum in its relationship with DROs. This can help properly test the emerging design and its impact on participants, provides important transparency, and increases the chances of a public discourse that recognises the extent of fairness in the changed arrangements.

Second, based on what we saw in the UK experience of individualised budgets 10-15 years ago, we think there is merit in maximising the amount of flexibility participants have in how they can make the best use of their budget. The people we met with in the UK at that time who were budget recipients, talked much more about the importance and value of flexibility in how they used the budget, rather than whether the budget was exactly the right amount.

On that basis, we suggest that the positive contrast effect of greater flexibility in how to use the budget can help counter the negative contrast effect of a reduced budget.

Conclusion

The Scheme needs to grow into its original promise, which is to advance and sustain Scheme participants in social and economic participation, or what we term meaningful and fulfilling lives as valued members of the community.

To deliver this promise, there is need for a range of well-designed, interconnected initiatives that lead to a genuine transformation in disability supports. It is going to take courage, but that is what Australia needs if it is to create a world-leading and highly impactful disability support system.

For this to happen, there needs to be sustained, values-driven, collaborative leadership, not just at the NDIA but also across all government stakeholders, in partnership with people living with disability, their families and allies, and with community leaders committed to inclusion.