



Inclusion Australia

Inclusion Australia response to NDIS Support Coordination Discussion Paper

September 2020

Introduction

Inclusion Australia welcomes the opportunity to present this submission about support coordination to the National Disability Insurance Agency (NDIA). Support coordination is important for most people with intellectual disability who are NDIS participants and essential for others. Therefore, Inclusion Australia is committed to working with the NDIA to get it just right.

We acknowledge the many recommendations made recently about improvements to support coordination including in the *2019 Independent Review of the NDIS Act* by David Tune, the *Safeguarding Task Force Report* recently released by the South Australian government, and Alan Robertson SC's *Independent review - Report to the Commissioner 2020*.

Consult with people who need and use support coordination the most

While surveys are good, focus groups are great, one-on-one interviews are perfect for some, and online events work for others, many participants with intellectual disability with a lot of direct experience using support coordination can't easily tell the NDIA what's working and what's not working. This includes people with intellectual disability who have complex support needs, people who have limited intentional communication, and people who are predicted to need long-term support coordination to maintain safety and wellbeing.

The NDIA also needs to find out what is happening for people who need someone else to communicate the facts on whether support coordination is achieving individual outcomes for them. We can help with that.

Inclusion Australia's members are disability advocacy organisations that can use their local networks and expertise to consult with people who need different ways to be part of consultations including group discussions facilitated by self-advocates, families interviewing families and complex case reviews.

Critically, Inclusion Australia can connect the NDIA with participants who have the most complex support needs through scenario planning that shows how particular individuals will be impacted by government policy changes. This is essential to ensure that taxpayer funds are not wasted on ill-fitting policies that are unlikely to work for people who need ongoing intensive funded supports. We have presented five scenarios in this paper that demonstrate the need for more detailed discussions with the NDIA on how support coordination might work for every participant who needs it.

This submission

This submission is a summary of reports made to Inclusion Australia by our members who work directly with thousands of people with intellectual disability, their families, and supporters each year. It is also informed by the casework of paid individual advocates who assist people with intellectual disability, including people with multiple disabilities and complex communication and behaviour support needs.

When we ask people with intellectual disability and their families what makes a good support coordinator, they tell us they want someone who

- is on their side
- listens carefully
- is highly organised

- does the work on time
- has the right training and experience, and
- is an expert in the job they need to do for the person in front of them.

Our members report that the key issues they see with support coordination include

- lack of an individualised approach to determining levels of funding for support coordination
- lack of guidance about the duties and limitations of the support coordination role
- a hands-off approach to plan implementation for participants who previously had and need disability case management
- dubious billing practices
- the absence of a coordinated crisis response that fits individual circumstances
- widespread market failure for people with complex support needs
- availability of a skilled and specialised workforce
- increases in guardianship applications as a fix for NDIA planners and support coordinators dealing with decision-making gaps
- dangerously limited knowledge of relevant disability legislation, policy, and human rights frameworks
- huge pressure on statutory, government and advocacy organisations to provide urgent assistance to participants where support coordinators have failed
- a noticeable increase in people with intellectual ending up in health and justice systems as a last resort.

This submission covers both the problems we see with the implementation of support coordination, as well as positive suggestions on how to improve policy, and practical solutions that we think will work for people with intellectual disabilities and their families.

About Inclusion Australia

Inclusion Australia (IA), previously the National Council on Intellectual Disability (NCID), has been the national voice for Australians with intellectual disability since 1951. IA members are leading intellectual disability organisations of each state. IA's purpose is to make the Australian community one where people with intellectual disability have the same opportunities as people without disability. Inclusion Australia is the national disability representative organisation for people with intellectual disabilities and meets the definition of an 'organisation of persons with disabilities' under the UNCRPD.

IA provides inclusive and holistic policy expertise and advice to government departments and other organisations to drive systemic change in Australia. To develop this advice, IA collaborates with people with intellectual disability and draws on local networks, including families and other supporters. In addition to having people with intellectual disability on the Board, Inclusion Australia also receives advice from Our Voice. Our Voice is a committee of the Board, the membership of which is exclusively people with intellectual disability representing all states and territories.

The critical elements of success

- ✦ **Codesign:** Support coordination role & program design to be genuinely co-designed with participants, families, and disability representative organisations
- ✦ **Choice & control:** A participant decision making strategy that includes independent support for decision making
- ✦ **Independent workforce:** NDIA recognises that key supports such as support coordination and support for decision making must be independent of other supports and develops a workforce strategy to increase the number and skills of independent intermediaries, including support coordinators

Priority actions

1 | Inclusion of support coordination

- When determining the need for and amount of support coordination, preference must be given to the needs as expressed by the participant and their close supporters
- Support coordination to be automatically added to the plan of participants with an elevated risk profile
- NDIS indicators used to decide whether support coordination is needed to be based on complex scenarios presented by participants, families, and disability representative organisations
- Where modelling work is required to redesign the current three-level structure and determine new individualised approaches and funding benchmarks, the NDIA to consult with participants, disability representative organisations, and intermediary industry groups

2 | Understanding the role of a support coordinator

- The support coordination role to be clearly defined
- The role of support coordinators to be expended to allow for case management to be provided to some participants including:
 - a central contact point who has responsibility for holding and maintaining essential personal information (e.g. medical, financial) and can provide afterhours service in a crisis
 - a whole-of-life, person-centred approach that can cross service-system borders
- The relationship between support coordination and independent disability advocacy to be clearly defined by agreement between the NDIA, the NDIS Quality and Safeguards Commission and Disability Advocacy Network Australia (DANA).

3 | Quality of service and value for money

- The NDIA must affirm participants right to choose their own support coordinator
- The NDIA should not rush to impose mandatory qualifications or accreditations that limit participant choice in any way
- Provide information and peer support to participants about how to choose the right support coordinator so that they retain full flexibility
- Ensure adequate and ongoing training is available for support coordinators to develop skills working with marginalised participants and mainstream services
- The NDIA to develop a strategy that builds the capacity of independent intermediary bodies to improve the profile, professional standards, and networking opportunities for support coordinators

4 | Capacity building for decision making

- The NDIA to invest in trials of innovative models of independent support for decision making so that participants have access to participant-designed, peer-led programs separate from paid services
- The NDIA to resolve the question of funding for individualised decision-making support for participants

5 | Conflict of Interest

- The NDIA to provide support (e.g. incentives) for small organisations to develop independent support coordination, preferencing participant-led proposals
- Build the diversity of the support coordination market by investing in the development of user-led and family-governed service development (e.g. Lifestyle Options Inc - Queensland)

Scenarios

Inclusion Australia's members have contributed some examples of how support coordination has been working for people with intellectual disability. These scenarios frame our submission because they illustrate some of the key problems to be addressed for NDIS participants with intellectual disability in the provision of support coordination.

- ❖ Shelli is 22 years old and lives in a group home in the inner suburbs with four other young people. All five have intellectual and psychosocial disabilities. She receives SDA, SIL and support coordination from the same organisation. She isn't sure how the support coordination was chosen but she is clear that she wants to move into a one-bedroom unit with her boyfriend as soon as possible. Shelli's boyfriend lives in a group home and has support coordination with the same provider as her. Shelli talks to her mum, who also has an intellectual disability, about her everyday decisions, but she is not Shelli's Plan Nominee and doesn't want to be.

Shelli has asked her support coordinator for help to move out for more than two years. The support coordinator did look for vacancies in the same provider's other SDA properties, but Shelli had already told her she doesn't want to live in a group home anymore. The support coordinator often suggests Shelli look up private rentals, but Shelli needs assistance to figure out how much she can afford. Her support coordinator warned her that she'll lose SDA eligibility if she leaves and that her rent elsewhere will be unaffordable.

Shelli has tried to look for other support coordinators herself, but she struggles to give clear instructions about what she needs over-the-phone, and she doesn't have a copy of her plan so can't confirm hours available.

- ❖ Ryan is 40 years old and lives alone on a big bush block on the outskirts of a regional town. Ryan has intellectual disability, autism, bipolar disorder, epilepsy and uses a few familiar words and phrases to communicate with people he knows well. When he was a teenager, he went to live in a disability group home where he was assaulted by staff and co-residents. He was also subjected to extreme environmental and chemical restraints for fifteen years before finally moving into his current home. Ryan has trouble sleeping, often feels angry and afraid, and he takes a long time to trust new people.

Ryan's family recruit disability support workers directly. He is becoming more involved in hiring, training, and firing workers. His family have also asked his siblings and friends to form an incorporated association that will provide support for decision-making for Ryan. His paid team meet monthly and include 12 disability support workers, a practice coach, occupational therapist, psychologist, speech therapist, Behaviour Support Practitioner, and a specialist support coordinator. Ryan does not speak with support coordinators or NDIS planners when they visit.

Ryan has had four independent support coordinators in three years. His family report that skilled support coordinators have been hard to find, and that each one has struggled to clearly define their role or offer any substantial assistance. Ryan's family want a support coordinator to take more responsibility for the tasks that they can't or don't want to do.

- ⊕ Jim is 60 years old and is living in a metropolitan public hospital following surgery and rehabilitation for a broken hip. Jim has Down syndrome, intellectual disability and uses a few gestures to communicate. Until recently, he lived in a disability group home, and before that he lived with hundreds of others in a large residential disability institution. Jim was institutionalised as a newborn and has had no contact with his family since. He does not have any friends who can provide support with his decision-making. Group home and day program staff make Jim's day-to-day decisions when he can't. Two staff at the group home have known him for more than thirty years.

After recovering in hospital, Jim's support needs have changed. He now needs full physical assistance from staff for most things and room for a hoist in his bedroom and bathroom. Jim's SIL provider have decided that they can't provide the physical space or staffing support and have suggested to hospital staff that they move him into residential aged care. Jim is unable to make the decision himself. Jim's independent support coordinator is unsure about what she should do and calls an independent advocate for advice.

- ⊕ Tan and Hien are siblings in their twenties who live together in the inner metropolitan suburbs. They both have intellectual disability and autism. Their mother died last year, leaving them the family home. Their uncle, Chinh, who lives an hour away, drops in to visit every week. He helps with reading the mail and paying bills, but he doesn't understand how the NDIS works. He knows that support workers are supposed to be coming in every second day, but he's not exactly sure how well it's going. Sometimes Chinh receives service agreements in the mail to sign. He is not a Plan Nominee or a legally appointed guardian.

Over the past few months, the house has become untidy inside and out, there's rarely enough food in the house and they're losing weight. Chinh called the support coordinator to ask for help - she works for the same organisation providing disability support workers. The support coordinator explained that they 'don't have many hours left' and 'won't be able to do anything until after a plan review'. The support coordinator says that disability support staff have been coming regularly to Tan and Hien's house, and offers to email Chinh information about how to submit a Change of Circumstance review for more support coordination. Chinh needs assistance to write up a review from a support coordinator.

- ⊕ Jen, a support coordinator, calls an independent advocacy service to make a referral. She is working with Chris, a 30-year-old participant with intellectual disability who says she wants to get a job. Jen says that Chris finds it hard to talk to her mother, who she lives with, about what she wants and that she's against Chris leaving her day program. Jen thinks that Chris' mother is stopping her from making her own decisions and is being overprotective. Jen wants an advocate to talk to the other mother to help her understand what Chris' rights are. She says she will withdraw support coordination services unless an independent advocate is appointed.

1 | Inclusion of support coordination

People with intellectual disability are more likely than most to need a support coordinator to help with plan implementation. Navigating the Scheme is extremely complex for all participants, and near impossible for participants with severe intellectual disability, like Jim. Without funding for support coordination that offers intensive, ongoing, on-call, whole-of-life case coordination, some participants are at extreme risk of harm.

The chaos caused by underfunded, under-skilled support coordination is not only dangerous and unacceptable, it is avoidable. Given NDIS participants are inevitably people with 'permanent and significant' disability, it should not be a surprise that some will need ongoing, funded, professional coordination to get a great life.

Factors to be considered

Trust

The key factor to be considered when determining if, when and for how long support coordination should be funded is this: trust what participants, their families and closest supporters say about what they need.

We know the NDIA needs to consider how funded supports fit with the financial sustainability of the Scheme. We also know from examples overseas, particularly in the UK and Canada, that:

- ⊗ people with disabilities and their families are a good judge of what they need when asked
- ⊗ person-centred planning can offer creativity beyond funded supports, and
- ⊗ trust (with a side order of peer support) offers better value for money over time.

Participants with intellectual disability face a unique dilemma when it comes to trust. The NDIS Act 2013 presumes that all participants have capacity to define their own goals, aspirations, and needs, and can develop the skills to direct their own planning and supports. If the participant lacks capacity for a decision - for whatever reason - they are less likely to be considered a reliable source of information by the NDIA on their own needs. A Plan Nominee and/or support coordinator is then needed to fill the information and decision-making gap.

But even Plan Nominees and support coordinators report they are unlikely to convince a planner that a participant needs more funding – they too are considered conflicted. And so, for people with intellectual disability, the NDIA often requires detailed, quantifiable evidence from allied health therapists to make its decisions. Sometimes, the report required to prove the need costs more than the support requested. The task of commissioning the therapists, reading and interpreting reports, presenting the evidence in a detailed submission against the reasonable and necessary criteria is so complex, support coordinators become absolutely essential in proving what is often obvious to the participant and their family.

Risk

Participants are put at significant risk of harm by the NDIA if support coordination is not included in a participant's plan when it is needed. Or, for Tan and Hien, who need more support coordination hours and a provider who takes real responsibility for their welfare. The best way to resolve the risk is for the NDIA to have a clearer view on the safeguarding role of support coordination, and to ensure participants are proactively identified according to a set of agreed indicators.

There is still work to be done to determine what 'at risk' or 'vulnerable' means for participants with intellectual disability. The indicators the NDIA recently used in identifying participants for the outbound call effort during COVID-19 are a great start; it is important that people living in disability group homes and closed settings remain on any new list created.

The NDIA needs to know how it can be sure that a person answering questions on behalf of a participant during an over-the-phone 'check-in' is reliable and trustworthy, especially if the person only has paid workers speaking on their behalf. While there are other factors to be explored with the NDIA, it is critical that people with disability and families ultimately define what risk and vulnerability mean in different scenarios. This is work we recommend the NDIA does in partnership with disability representative organisations and their members.

Roles

It is essential that support coordinators interact with other NDIS supports and mainstream services as the participant needs and asks them to. Support coordinators need to have a clear framework to understand their NDIA-given responsibilities to a participant beyond their own 'terms of business'.

The three-level structure currently in place is arbitrary to most participants – they just want enough funding in the plan so that the coordination tasks can get done, as soon as possible, by someone who knows what they are doing. Instead of the three-level structure, a person-centred approach would be to build each support coordination arrangement as a custom fit for the participant. Funding could then be applied according to the unique circumstances of the person at the time and relative to the complexity of the tasks.

A custom fit would mean that:

- the right amount of support coordination hours is included in the plan to get the work done by the best person, even if it costs more in the short-term
- the participant has proactive assistance to find the right support coordinator and get started
- a support coordinator could be paid more for intensive work or specialist work with people with rare or multiple disabilities and/or complex support needs
- participants can more easily choose someone with the right skills, knowledge and track record to do the work
- funding for support coordination cannot be exhausted by the provider but is monitored by the NDIA as a critical oversight - participants cannot be left without critical supports because of a business decision by a provider who has emptied the support coordination budget (yes, this happens)

Plan utilisation

The primary reasons participants are not spending support coordination budgets are because they do not know how to find one, they give up after trying two or three times to find a capable candidate, and because their support coordinator doesn't understand the tasks they are supposed to do.

Inclusion Australia suggests the fastest way to see improvements in plan utilisation is to define and uplift the support coordination role so that everyone knows what to expect (see Section 2, Understanding the role of a support coordinator).

Priority Actions

- The NDIA to review the approach taken by LACs and planners in determining the need for and amount of support coordination - preference must be given to the needs as expressed by the participant and their close supporters
- Support coordination to be automatically added to the plan of participants considered at risk
- The indicators used by the NDIA to decide whether support coordination is needed to be based on complex scenarios presented by participants, families, and disability representative organisations
- Where modelling work is required to redesign the current three-level structure and determine new individualised approaches and funding benchmarks, the NDIA to consult with participants, disability representative organisations, and intermediary industry groups.

2 | Understanding the role of a support coordinator

The responsibilities and tasks of a support coordinator depend to a large extent on the individual needs and wishes of the participant, and on their current circumstances. The tasks and scope of the role should be defined in detail by the NDIA as soon as possible, and made available to participants in every possible format.

Case Management

While it is true that most NDIS participants will only need time-limited support coordination, the NDIA needs detailed, co-designed support coordination frameworks for participants who need long-term, intensive and/or ongoing assistance. Participants with intellectual disability may need a person acting as a central point of contact who has responsibility for maintaining essential personal information (e.g. health, housing, finances) as well as coordinating supports. Yes, just like case management!

Some participants regularly need afterhours coordination in a crisis; others will need the security of longer-term support coordination funding. Many people with intellectual disability need support coordinators to provide a whole-of-life, person-centred approach that can cross service-system borders. There are thousands of people with intellectual disability across Australia who have no next of kin and only paid supports who need a whatever-it-takes approach to support coordination for now.

Advocacy

'Advocacy' is one of the three prohibited tasks of support coordination (the others are staff rostering and personal care). Support coordinators tell advocates that if they are assertive or disagree with an LAC or planner, or even if they repeat themselves, they are reminded they must not 'advocate'. However, the NDIA has never published a definition of advocacy that would help support coordinators understand the boundaries of their role.

Instead, the NDIA has used lots of interchangeable terms for advocacy in different policies and initiatives without distinguishing the difference or engaging with funded independent disability advocacy organisations to get it right. Terms used by the NDIA, like 'formal advocacy', 'informal advocacy', 'paid advocate' - and in this discussion paper, 'personal advocacy' - are not recognised or understood by anyone else.

The consequences of confusion

As a result of the confusion, advocacy organisations have been inundated with calls from support coordinators requesting that an advocate be appointed to do whatever they perceive they are not 'allowed' do. Inclusion Australia's Victorian member, VALID, reports that up to 35% of all requests for individual advocacy come from support coordinators.

Few actually require advocacy assistance; they simply do not know how to do the basics of the job and prefer to avoid conflict with the NDIA and other services if possible. Some, like Chris's support coordinator, see advocacy services as way to escape from situations involving difficult dynamics in families. The toll on participants, families, small advocacy organisations and mainstream services is unreasonable and extreme.

The Disability Advocacy Network of Australia (DANA), the national representative body for disability advocacy, describes advocacy on their website like this:

Advocates need to:

- listen to the person they are working with
- find the issues that they can help them with
- give the person information about their options for addressing the issues
- help them to present and express their views and wishes to others
- help them to understand and defend their rights
- be independent and be on the side of the person with disability and no-one else's.

DANA distinguishes between the doing of 'advocacy' (as above) and 'individual advocacy' like this:

"Individual advocacy is when a professional advocate supports a person with a particular problem. An individual advocate either supports a person one-to-one or supports them to advocate for themselves. The advocate will support someone with an issue they've not been able to solve on their own. An individual advocate must be independent, only be on the side of the person with disability, and only represent their interests."

Support coordinators have an advocacy role

There should be no doubt that support coordinators have an advocacy role. In fact, NDIS-registered support coordinators are required under the NDIS Practice Standards to do almost everything described as advocacy by DANA above.

For example:

DANA's Definition	NDIS Practice Standards Indicator
<i>Listen to the person they are working with</i>	Active decision-making and individual choice is supported for each participant including the timely provision of information using the language, mode of communication and terms that the participant is most likely to understand (pg. 6)
<i>Find the issues that they can help them with</i>	With each participant's consent, work is undertaken with the participant and their support network to enable effective assessment and to develop a support plan. Appropriate information and access is sought from a range of resources to ensure the participant's needs, support requirements, preferences, strengths and goals are included in the assessment and the support plan (pg. 13).
<i>Give the person information about their options for addressing the issues</i>	Each participant's right to the dignity of risk in decision-making is supported. When needed, each participant is supported to make informed choices about the benefits and risks of the options under consideration (pg. 6).
<i>Help them to present and express their views and wishes to others</i>	Where appropriate, and with the consent of the participant, information on the support plan is communicated to family members, carers, other providers and relevant government agencies (pg. 13).
<i>Help them to understand and defend their rights</i>	Each participant's legal and human rights are understood and incorporated into everyday practice (pg. 5).

And, all NDIS-funded workers are bound by the 'NDIS Code of Conduct' which includes elements of advocacy too:

- *act with respect for individual rights to freedom of expression, self-determination, and decision-making in accordance with relevant laws and conventions*
- *respect the privacy of people with disability*
- *provide supports and services in a safe and competent manner with care and skill*
- *act with integrity, honesty, and transparency*
- *promptly take steps to raise and act on concerns about matters that might have an impact on the quality and safety of supports provided to people with disability*
- *take all reasonable steps to prevent and respond to all forms of violence, exploitation, neglect, and abuse*
- *take all reasonable steps to prevent sexual misconduct.*

So, where does a support coordinator, or any NDIS-funded service provider, draw the line between service provision and advocacy? What is the role of the support coordinator in plan reviews? Or in supporting participants to make complaints? Or giving information to the Administrative Appeals Tribunal?

The difference between the role of a support coordinator and an independent advocate

There is definitely a difference between the role of a support coordinator and an independent advocate who works for a government-funded disability advocacy organisation. The key difference is that an independent advocate is always *'on the side of the person with disability and no-one else's'*. Most support coordinators understand that their loyalties are divided between the NDIS participant (who presumes the support coordinator is on their side), their employer (who relies on billable minutes and repeat business), and the NDIA which is an essential source of participant referrals.

The relationship between support coordination and independent advocacy needs to be clearly defined and agreed to by the NDIA, the NDIS Quality and Safeguards Commission and DANA as a priority. Most importantly, support coordinators - and all providers working under the NDIS Practice Standards - need to know when to call in an independent advocate.

In general, we suggest good practice for support coordinators includes contacting an independent advocate when

- There is conflict about choices or decisions that need to be made that cannot be resolved by talking it over with the person, family, friends and paid staff
- The participant is under undue or inappropriate influence by any person or organisation
- The person and their support network do not have the advocacy skills or knowledge to resolve it themselves (e.g. an abuse investigation, making an application to a Tribunal)

Priority Actions

- The NDIA should expand the role of support coordinators to allow for case management to be provided to some participants including:
 - a central contact point who has responsibility for holding and maintaining essential personal information (e.g. medical, financial) and can provide afterhours service in a crisis
 - a whole-of-life, person-centred approach that can cross service-system borders
- The relationship between support coordination and independent disability advocacy needs to be clearly defined by agreement between the NDIA, the NDIS Quality and Safeguards Commission and DANA.

3 | Quality of service and value for money

People with intellectual disability often need support making informed decisions and then proactive assistance to make choices come to life. The knowledge and skills necessary to provide high quality support coordination for people with intellectual disability should not be underestimated.

Support coordinators may need to both take the lead but not override the participant's wishes themselves. They need to weigh up their duty of care to a participant who is making a choice that might cause harm, even if it means risking the relationship. They need to provide some protection from the undue influence of friends, family, and other services, while not imposing their own will on the person. Support coordinators need to do these things while also taking into consideration the cost impacts of their decisions on the businesses that employ them.

Qualifications & Accreditation

Participants and families reserve the right to choose their support coordinator, and to have assistance to make informed decisions about the relevance of qualifications, skills and knowledge to the particular job to be done. This is especially important for people like Ryan who need a support coordination with a unique combination of knowledge and skills that rarely come off the shelf. We remain unconvinced that setting minimum qualifications or accreditation requirements will drive supply, innovation or quality in support coordination.

Ideally, support coordinators working with people with intellectual disability would have:

- skills in person-centred planning, supported decision-making, case management, service design, quality monitoring, transition planning, and budgeting, and
- knowledge of disability rights and legislation, and
- networks with specialist disability services, mainstream services, and local community services.

We know that support coordination is here to stay. And that it should have the professional recognition necessary to ensure that the best people are interested in working and staying in the field. Relevant professional bodies, such as the Australian Association of Social Workers, National Disability Practitioners, and Disability Intermediaries Australia, have an interest in ensuring that committed people find a pathway into disability careers. Strong professional intermediary associations are essential to the development of practice leadership in support coordination. They are likely the best home for support coordination training courses and peer support. Training programs and platforms should be designed in consultation with participants who are most likely to need intensive, long-term support coordination.

IA refers NDIA to the 2017 Summer Foundation report '*Support Coordination: a Changing Landscape*' that outlines these and other competencies that should be considered by the NDIA in this review.

Effective Measurements

Inclusion Australia suggests the NDIA should hesitate before introducing standardised measures of support coordination success such as goal achievement - sometimes the goal set is not achieved but something much better happened. Scheme satisfaction surveys are inaccessible to many participants with complex support needs like Ryan and Jim. Plan utilisation rates are important, but low utilisation might not be bad news for the participant. Not everyone wants or needs to increase their access to the community, and many will never become 'informed consumers' who choose their

service providers. The measures chosen to determine whether support coordination is working should be specific to the participant and their circumstances as much as possible. How would Tan and Hien define success in their current situation?

When determining measurement tools for support coordination, Inclusion Australia suggests the NDIA invests in research on the outcomes frameworks used by similar programs overseas, for example, Independent Facilitators in Canada, and Professional Support Brokers in the UK.

It is critical that:

- measurement tools are co-designed by, and meaningful to, people who regularly use support coordination, with people who need full assistance to communicate their experience at the centre of the process
- outcomes frameworks must focus on human rights and quality of life
- data collection must be unobtrusive for participants and families and inform good provider practice.

Pricing

Inclusion Australia does not have the expertise or resources available to give specific advice about support coordination pricing. However, we caution the NDIA against linking goal progression or achievement with payment for support coordination because:

- Many participants with intellectual disability require long-term support to make progress and patience can produce spectacular outcomes
- Support coordinators do not necessarily have control over the levers of success, particularly where the person has 24/7 support from one provider
- Unforeseen circumstances can happen in any plan period
- Some participants, even with expert intensive assistance over months and years, will not 'become more independent'
- Support coordination is so frequently underfunded that they simply cannot be expected to achieve the plan goals with the resources provided.

Priority Actions

- The NDIA must affirm participants right to choose their own support coordinator
- The NDIA should not rush to impose mandatory qualifications or accreditations that limit participant choice in any way
- Provide information and peer support to participants about how to choose the right support coordinator so that they retain full flexibility
- Ensure adequate and ongoing training is available for support coordinators to develop skills working with marginalised participants and mainstream services
- The NDIA to develop a strategy to build the presence of independent intermediary bodies to improve the profile, professional standards and networking opportunities for support coordinators

4 | Capacity building for decision making

Providing support for decision-making is a fundamental to support coordination. Inclusion Australia is aware that the NDIA is currently working on a new approach to supported decision-making and we look forward to an announcement soon. For people like Shelli, one-on-one support for decision-making will mean she can finally seal the deal with an independent support coordinator. We know that Ryan will need access to intensive supported decision-making on each choice for the rest of his life.

Informed Choice

Support coordinators are already obliged to assist participants with decision-making support in line with the UNCRPD, NDIS Act 2013, NDIS Practice Standards and NDIS Code of Conduct. However, the NDIA is yet to resolve critical issues of participant consent, authority to act, privacy, the role of independent advocacy, and substitute decision-making.

Support coordinators face many dilemmas working with participants who need intensive decision-making support including

- Standard NDIA processes that are not fit for purpose; participants must provide consent for their support coordinator to access their NDIS plan and there is no formal process to follow if the participant cannot give consent for plan sharing and does not have a Plan Nominee
- Persistent views held by service providers that all participants must have a signed service agreement to receive support and that any willing party can sign it – this means that participants who cannot sign off on an agreement are left with very few service options, and that many participants have service agreements signed by someone (anyone!) without any legal authority (this makes the agreement void anyway)
- Widespread confusion about which decisions disability support workers can make; when a Plan Nominee is needed and what they are supposed to do; when to call an independent advocate; and what a legally appointed guardian does and does not do.

Supported Decision-Making

There are some distinctions to be made between the role of the support coordinator, and the tasks of providing support for decision making. A support coordinator is primarily intended to build the capacity of participants so that they can navigate the NDIS as independently as possible in the future. It is important to note that independence is not a goal that every participant wants, or can achieve.

Support coordinators typically determine the actions they will take based on what the participant says they want, and in line with their approved NDIS plan. Without direction from the participant, the support coordinator must either make a judgement on the person's behalf (e.g. between two occupational therapists) or ask other disability services involved for their views ('Is there an OT you use for other residents?'). Support coordinators also have to navigate informal decision-making support provided by family, partners and friends. This is even more complex for people like Chris who are torn between wanting more independence but reliant on one family member to be the safety net if their decisions end in bad outcomes.

In the same way that independent advocacy might be necessary when support coordination cannot resolve a problem, independent support for decision-making is fundamental to ensuring that support coordinators are taking direction, not making decisions.

Some participants need independent support for decision-making to ensure that there is a clear separation between life decisions (e.g. where to live) and NDIS decisions (e.g. in-home personal care services). This can be via individualised funding to facilitate the set-up of a circle of support, or with a volunteer program like Citizen Advocacy, or through peer groups run by Disabled Peoples Organisations. Independent support for decision-making is most important for participants who will predictably need long-term, collaborative decision-making supports (e.g. circle of support).

Advocacy role

(see Section 2, Understanding the role of a support coordinator)

Priority Actions

- The NDIA to resolve the question of funding for individualised decision-making support for participants
- The NDIA to invest in trials of innovative models of independent support for decision making so that participants have access to participant-designed, peer-led programs separate from paid services.

5 | Conflict of Interest

The problem of support coordinator conflict of interest was raised before the launch of the NDIS and many times since. Lack of supply has been particularly problematic for participants with complex support needs and people in rural and remote areas. Some providers work hard to separate service offerings and manage conflicts of interest, others take advantage.

Single provider

Shelli's story is an ideal example of the fundamental problem with single providers. She lives in a house owned and operated by the same provider, who also provides support coordination. In many ways, Shelli has capacity to give direction to her support coordinator – she wants to move out. But if she challenges the support coordinator on why there is no progress, her key worker at home finds out. Her key worker tells her that she 'can't move out' because she's 'not independent enough yet'. If Shelli complains about her key worker to the supervisor, the key worker makes sure Shelli misses a visit with her partner. She worries she will lose access to all supports if she pushes too hard for change.

This is not just a problem for participants who cannot easily hire and fire support coordinators. Client capture is expensive for the NDIA. If Shelli moves out, she is unlikely to need more than a few hours of 1:1 staff support per day at home. She is currently receiving 24/7 SIL supports and SDA funding she does not need. The NDIA would benefit from considering how it can identify participants with intellectual disability who are receiving SIL and support coordination from the same organisation and offer independent alternatives.

Independence requirement

Participants should only receive multiple supports from a single provider when they actively choose to. Some participants will need independent decision-making support to make an informed choice and to navigate any unintended consequences. It should be extremely unusual in the near future for any participant to have support coordination from the same provider as other supports.

Impact of stricter rules

People with intellectual disability need support coordination from people they can trust, and the NDIA needs to know that support coordinators are doing the right thing. Inclusion Australia would welcome changes to support coordination that establish independent support coordination as the gold standard and default option for all participants.

We predict that an endorsement of independent support coordination by the NDIA will

- Lift the profile of the benefits of independent support coordination to participants
- Give confidence to providers who offer independent intermediary services as a point of difference to participants
- Create the constructive tension that the market requires - demanding consumers and proxy bidders
- Encourage small support coordination organisations to settle in, expand and specialise
- Inspire user-led and family-governed start-ups to design intermediary services completely differently

Priority Actions

- The NDIA to provide support (e.g. incentives) for small organisations to develop independent support coordination, preferencing participant-led proposals
- Build the diversity of the support coordination market by investing in the development of user-led and family-governed service development (e.g. Lifestyle Options Inc - Queensland)