

Independent Advisory Council to the NDIS

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# Enhancing self-direction and self-management in the NDIS: Recommendations from the co-design self- management workshop

December 2016

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**Independent  
Advisory  
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to the 

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## Introduction

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Architects of the NDIS understood the value of self-directed funding and support drawing on the evidence of its association with improved health and wellbeing. Research<sup>1</sup> also suggested that self-directed funding is likely to cost less than alternative service models. Today, the case for enhancing self-direction and self-management of participants in the NDIS is well understood: it is pivotal not just for improved outcomes for participants; it also provides economic benefits to the Scheme, financial benefits to the Agency, is consistent with insurance principles and is fundamental to the sustainability of the Scheme.

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<sup>1</sup> Productivity Commission Inquiry into Disability Care and Support, (2011) Appendix E

For most participants, the motivation to want increased self-direction over their support and self-management of their plan is the desire to have more control over their support because they want to have more control over their lives.

Enhancing self-direction is about assisting participants to have more control of the what, when, where and by whom of support so that paid support can address their challenges in ways that complemented and not drive out informal support provided by family, friends, workmates etc. Many people with disability face challenges in developing relationships and harness them to become informal support, in finding opportunities to belong and make a contribution and in leading ordinary lives of social and economic participation. Grouped activities in disability services do not assist participants to overcome these challenges and so participants must forge their own way. The paper argues that NDIS reasonable and necessary support may not provide the 'enabling' support critical to overcome these challenges, and may inadvertently hinder opportunities for participants to get the support they need to lead the lives they choose. This poses a serious barrier to increased self-direction.

Self-management refers to participants managing the funding in their plans. The issue of NDIS self-management was the subject of negative social media following the removal of the float in July 2016. The IAC interviewed ten disability advocates across Australia who either work with self-managing participants and/or who self-manage their funds to scope the issues and potential solutions. Their insights led the IAC to host a co-design workshop on self-management on 4 November 2016 that has contributed significantly to this paper.

The purpose of this paper is to examine current NDIS practice aimed at stimulating the motivation, skill and confidence of participants both to direct their own support and manage the funding in their plan and to propose strategies to strengthen that effort. The outcome of enhanced effort could be measured through the number of participants who self-manage or use registered Plan Management Providers.

The paper will:

- define the terms self-direction, plan management, self-management and Plan Management Provider and describe their inter-relationships
- identify elements necessary to transform self-directed funding into self-directed support
- explore the benefits to participants and the Scheme when participants self-direct their support and self-manage their funds
- outline current approaches to promote self-direction and self-management and their challenges

- make recommendations to strengthen the support for self-direction and self-management in the NDIS.

## 2. Terms defined

The NDIS has given new meaning to terms with which participants are familiar from State and Territory systems. This has caused some confusion that may at times be mistaken for a perception that it is all ‘too hard’. The lexicon below seeks to clarify the roles and relationships between self-direction, plan management, self-management and Plan Management Provider under the NDIS.

### 2.1 Self-direction

The term ‘self-direction’ is a generic term for an approach that gives people with disability greater control over their support **and** their lives. The concept is often broken into component parts of self-directed planning, self-directed funding and self-directed support. Self-directed support can be managed through a service provider, a financial intermediary or via a direct payment (self-management).

NDIS staff often argue that all participants self-direct because they are able to choose their service provider. Whilst this is true (except where participants are using in-kind services), the choice of provider is a low bar for control over one’s life. This is particularly the case where participants are unfamiliar with other options, have no confidence or experience in making choices and where a thin market means that there is only one provider.

### 2.2 Plan management

Plan management refers to the way in which the NDIS funding in the participant’s plan is to be managed with options being:

- a. The participant, or
- b. A registered plan management provider, or
- c. The NDIA, or
- d. The plan nominee.

The concept of plan management is not one familiar to participants because under State and Territory provision, funding was allocated to service providers and the very vast majority of service users had no choice about who managed the funds.

## 2.3 Self-management

The NDIS refers to self-management as:

*“A participant or their nominee taking responsibility for the whole or a part of the package with the Agency allocating the budget directly to the participant (or nominee) who is responsible for all aspects of administration of the package including:*

- *Sourcing and arranging supports,*
- *Making payments to providers, including ensuring that providers receive their payment on time,*
- *Managing plan expenditure, including submitting My Plan Purchases forms to the National Disability Insurance Agency (NDIA) and*
- *Keeping records of all plan purchases and providing these to NDIA”*

A participant who self-manages their supports can undertake all the above responsibilities themselves or pay an intermediary to undertake one or more of the functions on their behalf. The key point that differentiates self-management from other forms of plan management under the NDIS is that the package or part thereof is paid directly to the participant.

## 2.4 Use of a Plan Management Provider

This is a completely new concept to people transitioning into the Scheme.

The NDIS describes a registered Plan Management Provider as

*“a term used to describe an individual or organisation that undertakes the management of funds of the supports in a participant’s plan.*

*A registered Plan Management Provider might undertake financial intermediary activities, or financial and service intermediary activities. It is expected that the registered plan management provider will assist*



*participants in increasing their skills in these activities.*<sup>2</sup>

Whilst a small number of participants are familiar with the role of a financial intermediary, the role of a service intermediary focusing on administrative elements of sourcing support is not familiar. The service intermediary activities cannot be purchased except with financial intermediary activities and their relationship to Support Connection and Support Coordination remains unclear. It is not surprising the early NDIS Quarterly Reports indicated nil utilization of Plan Management Providers and currently no data is collected on this aspect of plan management.

The closest analogy to a Plan Management Provider is the concept of shared management introduced by State and Territory jurisdictions to assist participants effectively use individualised funding. Under shared management, the service provider holds the funds but the participant or their nominee can take the level of responsibility and capacity building they choose over specific functions of planning, staffing and finance. Shared management provides a capacity building approach that enhances the level of self-direction experienced by participants.

### 3. Transforming self-directed funding into self-directed support

The NDIS provides funding that is self-directed, i.e. the funding is under the direction of the participant and broadly can be used to purchase support from a range of providers.

The NDIS self-directed **funding** is useful, but neither a prerequisite nor a guarantee for an ordinary life. There is a history of innovative, person centred support delivered under block funding regimes (where funding was not allocated directly to individuals) and conversely we see the use of individualised funding to purchase a place in a group home or traditional day program. Hence self-directed funding may not be the key that unlocks improved health and wellbeing and control over life.

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<sup>2</sup> NDIS fact sheet

Self-directed **support** is the more important ingredient in achieving positive outcomes. Self-directed support facilitates control of the what, when, where and by whom of support, aspects that are fundamental to an ordinary life. The key question is what enables participants to turn self-directed funding into self-directed support. Observations of shared management arrangements under State and Territory provision provides some insights.

There are two key elements that appear to transform self-directed funding into self-directed support under State and Territory shared management. These are:

- the ability to use funding flexibly to achieve independence, social and economic participation and inclusion
- the provision of 'enabling assistance' to guide the participant in using paid supports in creative ways that complement (rather than push out) the freely given support by family and friends (i.e. informal support). For most participants, this enabling assistance is critical to build an ordinary life of valued roles, authentic relationships, a sense of belonging and avenues for contribution

In the NDIS environment, service agreements provide an additional process that can assist a participant to negotiate quality of service provision to transform self-directed funding into self-directed support. A key function of LACs and Support Coordinators is to ensure that participants develop service agreements that support person centred and self directed service provision.

### 3.1 Flexible use of funding

Vision building seminars are filled with stories of people with significant disability leading good lives included in their communities. These stories come from people with disability who are supported by family and friends and have the ability to plan and use their resources flexibly within their budget. The Community Living Initiative (CLI) of WA and the Supported Living Fund (SLF) of NSW are examples of the potency of genuinely flexible funding.

The CLI and the SLF provided incentives for people with disability (supported by their families) to move out of the family home and into their own home. A relatively small amount of money was made available (up to \$20,000 in WA and an average of \$50,000 in NSW) as an incentive for people to plan, strengthen their informal support and show the way in which they would use government resources to live in their own homes in a sustainable manner. Whereas the usual state systems rewarded crises (by providing funding and accommodation for those in 'greatest need'), the CLI and SLF used State funds to rewarded initiative. Applicants needed to demonstrate that they had (or were

in the process of) planning, building informal support, facilitating community membership and valued roles, so that the funds for living were significantly less than would have been the case in traditional supported accommodation.

The flexible use of funding was a critical element to the success of these initiatives.

Participants had flexibility within their budget to purchase goods and services and pay for activity costs that promoted greater independence and social and economic participation. Government funds were not just used to pay for support; they were also used to facilitate membership in mainstream community places with very intentional strategies to build informal networks in those places.

For example, many recipients of the CLI and SLF used the resources to afford a 2 bedroom flat, subsidizing the rent of the home sharer who in return committed to the provision of informal support at a level significantly in excess of the monetary value of the rent subsidy. Importantly it enabled the person with disability to live with a 'mate' rather than a paid carer and this was pivotal to developing a connection much stronger than a paid relationship. This seemed to enhance the sustainability of the relationship.

This example recognizes that informal support is pivotal to a good life; that relationships don't come easily for many people with disability and very intentional strategies, ongoing support and small incentives and tokens of appreciation are needed to sustain informal support.

The strategies to sustain assistance provided by family, friends, members of the gym, the choir, the sport's club (i.e. informal support) are seldom recognised in a participant's NDIS budget and the NDIS prohibits the small incentives and expressions of appreciation such as periodically paying for a tank of petrol for a friend who always drives, paying for a cinema ticket or reducing the rent of a house sharer who provides negotiated informal support. It is critical to stress in these examples that the person with disability meets his/her own personal responsibility, paying his/her own rent and paying his/her own cinema ticket. The subsidised rent and the purchase of a cinema ticket<sup>3</sup> is the small incentive for unpaid support. As the examples in Appendix A demonstrate, the small incentive can provide genuine value for money.

The current rigid interpretation of personal responsibility for day-to-day costs undermines the NDIS promised flexibility and hence many of the creative, innovative

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<sup>3</sup> For some participants, a companion card would meet this cost. The variable eligibility based on out dated State and Territory funding programs means that many participants who need support to participate in the community are not eligible.

stories used in vision building seminars. When the application of the NDIS Rules turns 'support for informal supporters' into paid support, the cost increases enormously. Appendices A and B provide the comparative costing under State and NDIS provision.

Payment for these small incentives and expressions of appreciation may fit under S5.2(a) NDIS Supports for Participants Rules that states that:

*S5.1 A support will not be provided under the NDIS if it*

*S5.1(d) relates to day-to-day living costs (for example, rent, groceries and utility fees) that are not attributable to a participant's disability support needs.*

*S5.2 The day-to-day living costs referred to in paragraph 5.1(d) do not include the following (which may be funded under the NDIS if they relate to reasonable and necessary supports):*

*(a) additional living costs that are incurred by a participant solely and directly as a result of their disability support needs;*

*(b) costs that are ancillary to another support that is funded or provided under the participant's plan, and which the participant would not otherwise incur.*

The case can be made that the ability to substitute support hours for the ability to reduce the rent of the home sharer is an additional cost related to disability for a person who is unable to stay alone at night (S5.2(a)). For a person who is unable to participate in the community and go to a movie without support, the cost of the additional ticket relates directly to their support need and provides a cost effective response if they go with a mate.

## **Observations from co-design workshop**

Workshop participants reported that in the NSW system, a participant has the flexibility of using their budget to achieve their outcomes without the continuous scrutiny of day-to-day decisions required in the NDIS. More flexible approaches to funding have also been positively evaluated with the NSW Lifetime Care Authority and in the UK.

Board members and Senior NDIS staff agreed that the rigid interpretation of personal expense that reduces flexibility relates to operations and implementation and is not a feature of Scheme design. The tension between promotion of self-management and the management of risk relates to Agency uncertainty as to appropriate checks and balances and where the liability for bad decisions is perceived to lie. There was general

agreement that the NDIS system is over engineered and benefits would be achieved by managing risk with greater flexibility, autonomy and responsibility.

At the Scheme level, commitment to increased flexibility will require discussion of the benefits and safeguards of a positive approach to risk with the Auditor General and politicians. At the participant level, genuine co-design between the individual participant and the Agency to identify the line of responsibility in relation to risk will provide an important defence if the matter ends up in court.

The co-design workshop recommended that the Agency undertakes further work to increase the flexibility of funds related to the achievement of outcomes in ways that promote maximum innovation.

## Recommendation

That the Agency undertakes further work to increase the flexibility of funds related to the achievement of outcomes in ways that promote maximum innovation.

This could be achieved by enabling participants to substitute support hours for participation costs in mainstream activities, for negotiated informal support from home sharers where appropriate safeguards are in place and for small pieces of equipment where this:

- represents value for money (less than cost of disability alternatives) AND
- addresses barriers to social and/or economic participation AND
- leads to increased
  - Independence
  - social and/or economic participation
  - inclusion

The increased flexibility would be within the current boundaries of core, capacity building and capital. In addition, as a safeguard to cost blow out, the NDIS could enable this flexibility within the participant budget for one plan. At plan review the practice could be withdrawn if there is no evidence of the promised value for money and increased independence, social and economic participation and inclusion.

## 3.2 ‘Enabling assistance’

People who have lived their lives in rationed service centric systems require ‘enabling assistance’ to turn self-directed funding into the options available through self-directed support. They need guidance to understand how to translate control over the budget

into control over their lives, how to activate and implement their vision and use support creatively to achieve their goals.

In theory, during full scheme roll out, enabling assistance for participants with informal support is provided by LACs. It is unrealistic however to expect that LACs have the expertise and time to assist participants gain control of the what, when, where and by whom of support, facilitate relationships and gain authentic social and economic contribution. This means that the very people who want to and could be assisted to self-direct their support are starved of the expert enabling assistance that would build their capacity to do so.

Support Coordination is the current 'enabler' for participants in the intensive and super intensive streams but its operationalisation through the recent Practice Guidance<sup>4</sup> does not provide the key to activate self-directed support and control of their lives. Support Coordination will manage the vast majority of participants into services but will not give them the 'enabling assistance' required to make a difference to their life chances. Support coordination needs to be reconceptualised if it is to assist participants are to achieve significant and sustained positive outcomes.

## **Recommendation**

That the Agency ensures that participants who want to self-direct their support have access to enabling assistance to strengthen their skill and confidence. Enabling assistance could be available through a combination of reframed Support Coordination, intermediary services, plan management providers and peer networks.

## **3.3 Service agreements**

In the NDIS environment, service agreements provide an additional process that can assist a participant to negotiate quality of service provision to transform self-directed funding into self-directed support. A key function of LACs and Support Coordinators is to ensure that participants develop service agreements that support person centred and self directed service provision. The Agency has developed fact sheets on Service Agreements but these are of a very general nature and are of little assistance for a participant seeking to transform self-directed funding into self-directed support.

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<sup>4</sup> NDIS, (2016) Practice Guidance, Plan Implementation and Monitoring, Guidance for Planners, LACs and Delegates v1.01

## Recommendation

That the Agency strengthen participant capacity to negotiate service agreements that clearly articulates their expectations in relation to support by:

- using co-design to develop resources to assist participants to negotiate service agreements
- strengthening expectations of staff who assist participants to implement plans about the elements of service agreements that facilitate increased independence and an ordinary life.

## 4. Benefits to the NDIS

Research into the benefits of self-direction for participants and the Scheme are clear<sup>5</sup>. Importantly, the research reported by the Productivity Commission drew on studies with different fund management arrangements. Differences are related to variations on two **who holds the funds** and **who controls the funds**. Some studies reported on direct payment (NDIS self-management) and the majority reported on mechanisms in which a service provider shared control with the individual.

Productivity Commission evidence demonstrates that the positive impacts of self-direction **for the participant** are consistent irrespective of whether the individual manages the funding or the responsibilities are shared with a service provider or intermediary. This raises the question of why a participant would take the added time and responsibilities required to self-manage when they can achieve the same beneficial impacts using an intermediary. One could argue in fact that participants may achieve greater benefit using an intermediary because it enables choice and control over the 'what, when, where and by whom' of support, assisted by expert technical advice and delegated financial management.

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<sup>5</sup> Productivity Commission Inquiry into Disability Care and Support, (2011) Appendix E

It is rational for the Agency to encourage participants to use plan management options other than Agency managed for a number of reasons. Firstly they deliver greater value for money because non-Agency managed options enable the participant to guide paid support with sharper focus to complement and strengthen the potency of informal support. Secondly non-Agency managed options are economically beneficial to the Scheme because they reduce the cost of plan management because the participant / nominee or a provider undertakes the management functions that would otherwise fall to the Agency. Finally, non-Agency managed options are financially beneficial to the Agency because they reduce the administrative costs of plan management.

Given the savings to the Agency through plan management options other than Agency managed, the case can be made that the Agency should provide active assistance and support for participants who choose the plan management options of self-management and use of Plan Management Provider.

## 5. Building demand for self-direction and self-management

A first step in building demand is facilitating transformational experiences in which participants recognise the opportunity to have an ordinary life afforded by self-direction and self-management. It would be hoped that over time, NDIS participants who have grown up in the flexible, person centred citizenship approach of the NDIS will not require visionary transformation but certainly for the next decade, participants will require exposure to stories of people like themselves having ordinary lives in order to build their appetite for self-direction and ultimately self-management. There is evidence from the UK<sup>6</sup> that disabled persons user led organisations had a significant impact on building demand and capacity for self-direction. Elsewhere the IAC and IDRG have recommended the use of user led organisations for capacity building in the ILC. Their potency is especially encouraged to capacity building for people with disability and families.

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<sup>6</sup> IAC, (2014) Capacity building for people with disability, their families and carers at 90,91



## Recommendation

That the Agency builds demand and for self-direction and self-management through a multi pronged approach of:

- training and development for NDIA staff, outsourced planners and LACs to ensure they provide maximum opportunities for encouragement and capacity building to participants
- ensuring that all community engagement sessions provide information on self-management and the use of Plan Management Providers
- providing specific information / capacity building sessions that assist interested participants
- increased flexibility of support
- implementation of recommendation 9 on streamlined administration and support for people who self-manage.

## 6. Current strategies to promote self-direction and self-management and their challenges

### 6.1 Training and development for NDIA staff, outsourced planners and LACs

#### Current practice

All NDIA staff, outsourced planners and LACs receive training, support and supervision to undertake their roles. Their understanding of the full range of plan management options however is limited.

#### Discussion

The concept of plan management is foreign to most participants entering the Scheme. Under State and Territory provision, government and non government organisations held the contracts for service provision on behalf of individuals. People have no appreciation of the possibilities enabled via the range of plan management options.

The consistent message from people interviewed for this paper was that NDIS information about plan management is inadequate in enabling potential participants to understand options other than Agency managed. Indeed, it was felt that NDIA staff, outsourced planners and LACs did not themselves understand the options.

## Recommendation

That the Agency takes steps to ensure that all NDIA staff, outsourced planners and LACs have the competence to explain all plan management options in a neutral manner.

## 6.2 Agency provided Information and capacity building

### Current Practice

The Agency has a commitment to self-direction for participants and acknowledges that self-management is one way in which participants can self-direct their supports. In May 2016, Ian Maynard<sup>7</sup> reported that strategies to promote self-direction and self-management include:

- A series of factsheets released for use by participants from 1 August 2015, to coincide with the new price guide introduction. These were user-tested with participants and their feedback was incorporated into the final products.
- Two modules published on the NDIS website and distributed with the Plan handover packs to self-managing participants:
  - Understanding and Self-Directing my NDIS Plan and
  - Self-Managing Budgets in my NDIS Plan
- A variety of workshops and information sessions are held in each trial site which include information about participant's options to manage the funding for the supports in their plan.
  - Information on self-management and plan management is included in pre-planning and participant workshops and information sessions.

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<sup>7</sup> IAC meeting 20 May 2016

Some sites provide specific workshops on self-management. These sessions also provide assistance to participants with accessing My Gov and the participant portal. Plan implementation workshops are also held which can assist to link participants with providers, including support coordinators and plan-managers.

- The Agency is aware of a number of external providers also providing information and conducting external workshops on self-management and plan-management. Some of these are funded through the Sector Development Fund or CICD grants.
- The Agency acknowledges that sometimes there is limited information provided on self-management and plan-management in the general community engagement sessions. These sessions are generally tailored to the audiences and will include more or less information on certain topics depending on the audience.

## Discussion

The IAC is pleased to see this planned approach however anecdotal information from trial sites and now national roll out suggests that in fact participants are actively discouraged from considering self-management as 'too hard'. The information sessions do not always contain information on self-management and if they do, it is of a very general and discouraging nature. Also, sessions do not include information about intermediary assistance that can help participants self-manage by taking on the administrative, planning, staffing and financial load.

Many participants report a lack of clear, easily identifiable information that supports them to consider non-Agency managed plan management options.

## Recommendation

That the Agency takes steps to ensure that all engagement with NDIS staff, outsourced planners and LACs and all preplanning and planning material provides adequate information about all plan management options. This includes:

- amending training materials for NDIA staff and outsourced planners and LACs to ensure competence in explaining all plan management options in a neutral manner
- amending NDIS readiness material to clearly explain plan management options
- developing specific resources about what is involved in each of the plan management options.

## 6.3 ILC

### Current practice

The ILC Commissioning Framework is very broad. Eligible organisations are not asked to demonstrate the way in which funding proposals will increase the capacity of people with disability and families to self-direct their support and their lives.

### Discussion

The ILC will be pivotal to build demand for and capacity to self-direct and self-manage. The IAC recognises the enormous demands on the ILC however in its current approach it is highly likely that many participants will not have access to ILC services that strengthen their capacity to self-manage.

### Recommendation

That the Agency:

- requires services funded through ILC must demonstrate how they assist participants to increase skill and confidence in directing services and their lives
- funds specific initiatives to support participants to self-direct their support and self-manage their funds

## 6.4 Plan Management

### Current practice

In May 2016, Ian Maynard<sup>8</sup> reported that the Agency takes active steps in the planning process to encourage participants who are currently self-managing in the State and Territory systems to continue self-management in the NDIS.

Participants for whom their first plan is developed through the guided process will have the same options to manage their plan as the full planning process (including the options to self-manage or use a plan-manager). In the information gathering phase, participants are asked about their preferences for how their plan is managed and their capacity to self-manage is explored. Participants who self-plan will also have the same

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<sup>8</sup> IAC meeting 20 May 2016

options to express preferences for how their plan is managed. The questions designed for the self-planning process allow the participant to indicate their preference for self-management, and their capacity to self-manage.

This information then forms a recommendation to the delegate about how the participant's plan should be managed. The delegate will make a determination about how the participant's plan is to be managed, in line with the NDIS Act 2013.

*TABLE 1 PROPORTION OF PARTICIPANTS WHO HAVE AGENCY-MANAGED PLANS, SELF-MANAGE THEIR PLANS, OR USE A COMBINATION OF BOTH<sup>9</sup>*

State	Agency Managed	Combination	Self-Managed
NSW HTR	49%	50%	2%
SA	66%	21%	13%
TAS	50%	46%	4%
VIC	72%	27%	1%
ACT	40%	45%	15%
NT	94%	5%	1%
WA	55%	37%	8%
NSW NBM	76%	12%	12%
<b>Total</b>	<b>58%</b>	<b>35%</b>	<b>7%</b>

<sup>9</sup> Note: plan management is no longer included in this table in the Quarterly Report to CDRC as this specific variable no longer includes this information.

Table 1 shows two important facts.

Firstly it demonstrates the significant variation in self-management rates nationally. The Agency believes that the variation in types of plan management is due to the different participant populations as well as arrangements such as in-kind which are unable to be self-managed.

Secondly it demonstrates that the use of Plan Management Providers, an option under S42 of the NDIS Act has been dropped from data collection.

## **Discussion**

Whilst it is encouraging to see that overall 7% of participants self-manage their funding, the table identifies a range of questions that require further inquiry including the % of participants who use registered Plan Management Providers, the impact of the mobility allowance and consumables such as continence products on the rates of self-management in the combination category and the reason for the variable take up in trial sites with similar populations e.g. Hunter, Barwon and the ACT.

The IAC believes that a number of factors contribute to the majority of participants using Agency management. Firstly, as noted above, there is a shortage of in depth information that assists participants to understand and genuinely think about non-Agency managed options. Secondly anecdotal evidence suggests that participants are actively discouraged from options other than Agency managed as being 'too hard'.

The IAC believes that an exploration of strategies across trial sites may yield valuable insights into variable approaches that lead to variable rates of adoption of self-management.

## **Recommendation**

That the Agency

- analyses the variable take up rate of self-management and plan management across Australia with a view to developing strategies to promote more widespread utilisation.
- develops resources to demonstrate the function and pros and cons of each of the plan management options.

## **6.5 Self-management**

### **6.5.1 Risk assessment**

## Current practice

The NDIS risk assessment processes are not finely tuned to identify capacity building desired or required to enable a participant or their nominee to successfully-self manage.

## Recommendation

That the Agency enhances its risk assessment processes in relation to self-management to ensure skill development targets specific areas and minimises risk to both the participant and Agency.

## 6.5.2 Administration of self-management

### Current practice

Prior to July 2016, a float was made available to participants in trial sites who chose to self-manage their funds. The float was one month's advance payment so that people self-managing their funds could pay for services and supports in a timely manner.

In August 2016, Ian Maynard<sup>10</sup> reported that the participant float had been discontinued for new participants from 1 July 2016. Reasons include:

- learning from trial was that the advance payment was an administrative burden for the Agency and caused confusion for some participants
- some participants feared they would have a debt at the end of their plan
- the advances were problematic to recoup at the end of the plan.

The advice reported that instead of providing floats at the start of the plan, self-managing participants can:

- request an invoice for service from their provider and then claim the expense through the Scheme. Claims will be processed quickly (generally within 48 hours) and then the participant can pay their service providers
- choose to pay a service provider up front and claim the expense back through the scheme or
- make a request to the NDIS for an advance in emergency circumstances if required.

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<sup>10</sup> IAC meeting 4 August 2016

## Discussion

The administration of self-management is perceived to be unnecessarily complicated. Recent online discussion<sup>11</sup> as well as discussion with self-managing participants and DSOs across Australia has highlighted concerns related to the lack of a float, the requirement for invoices for payment, the 'clunky' nature of the participant portal and the lack of support for participants who want to self-manage. The negative feedback was a major motivation for the co-design workshop held on 4 November 2016.

## Observations from the co-design workshop

### Compliance requirements

Frequency of compliance is of significant concern. Compliance reporting is invoice by invoice whereas compliance reporting for the Australian Charities and Not for Profits Commission and the Australian Tax Office is annual. The BAS reporting for small business owners is quarterly and more frequent PAYG reporting is only required when a business is over a certain size. In addition, the requirement for each service to be backed up by an invoice inhibits the purchase of items or services where an invoice is not possible.

Ironically, whilst the demands for participant reporting against budget are demanding, there is almost no scrutiny of reports by the Agency leaving it open to criticism by the Australian National Auditor Office (ANOA).

The tone of reporting was also identified as a concern with the perception that the Agency is checking to reduce the chance of fraud rather than assisting participants to use their budget to meet their outcomes in the way in which the NSW, Victorian and UK systems do.

In the NSW system, compliance reporting may commence monthly or quarterly with new self-managing participants but moves to 6 monthly or annually when participants demonstrate competence. In the Victorian system, compliance is annual with a report of less than one page as the standard. A similar system is in practice in WA and in the UK where the level of fraud is less than 2% and many participants willingly refund unspent funds with an eagerness to ensure that resources are available to other needy participants.

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<sup>11</sup> <https://www.linkedin.com/pulse/sabotaging-ndis-christina-ryan?trk=hp-feed-article-title-publish>



Workshop participants were comfortable with the requirement for a separate bank account. Discussion ensued as to whether this is a bank account owned by the participant at their local bank or owned by the Agency in the name of the participant, the latter providing the Agency with security of being able to see the account as required. Views on this topic were mixed within the group. The key message however was a requirement that in store debits can be made from the account so that participants can gain value for money on consumables and are not forced to use more expensive disability providers for items that can be purchased at better value from mainstream outlets e.g. purchasing wheelchair tyres through the local bike shop as against a specialist equipment provider.

Note: 35% of participants self-manage part of their plan. Whilst the data has not yet been analysed, the IAC suggests that a significant proportion of this group self-manage funds for mobility allowance and consumables. The requirement of a separate account for these funds may cause significant additional pressure on participants.

## Recommendation

That compliance requirements are reduced to an assurance framework that relies on:

- periodic self reporting against the core element of the plan and budget including the outcomes framework that supports the plan
- simple compliance reporting of less than one page
- a random audit regime in which a participant's plan is audited and funds acquitted, say every 3 to 5 years
- a separate bank account

## The float

Removal of the float has caused significant concern to participants who see themselves as living hand to mouth, unable to directly employ staff (because of the delay in being able to pay staff) and purchase items such as consumables on sale at retail outlets. In response to cash flow challenges, participants need to process invoices immediately thereby increasing the level of administration.

Many perceive that the previous float of one twelfth of the annual budget was inadequate because it assumed each month was the same and prevented larger outlays in months with, for example, a holiday or a period where informal carers were not available.

While the lack of float remains, participants felt it was critical for the Agency to provide specific guidance to people transitioning into the Scheme from direct funding initiatives in which a float is provided

## Recommendation

That the float be reinstated as 'funds in advance' to enable self-managing participants to draw down funds as required. Three options identified by participants are reported in Appendix C.

## Roll over

The NDIS does not permit roll over of funds. Any unspent funds must be returned to the Agency at the end of the plan.

The lack of roll over provision is perceived to be a disincentive for participants to budget and seek value for money. In the NSW system, 5% of the budget can be rolled over into the next plan; In the Victorian system, expenditure over or under budget by \$1500 is carried forward into the next plan.

## Recommendation

That NDIS makes changes to enable participants to roll over a certain percentage of their plan.

### 6.5.3 Support for self-management

#### Current practice

There is no coordinated NDIS approach to enhancing the competence and confidence of participants to self-manage the funding in their plan. The most proactive strategy reported was that of the Perth NDIS office where the finance team run regular open sessions to enable interested participants to find out more about self-management.

Some user led Disability Support Organisation run information and capacity building sessions around self-management demonstrating its value, de-mystifying requirements, providing templates and assisting participants in making first claims. These sessions provide opportunities for peers to share their knowledge and experience and seem to be universally valued by members. A West Australian

organisation<sup>12</sup> is funded by the State Government to provide a telephone hotline on technical issues associated with self-management such as those associated with employment and tax. Apparently it is working well and providing a level of support that is reasonable and people are wanting.

In a review self-managed support in the UK, Canada and the US, Bruggeman and Johnson (2013) reported that many initiatives provided support for participants who wanted to self-manage including in initiatives in the UK, Alberta and Manitoba. User-led organisations were a preferred approach to support and capacity building. Observations suggest however that no country provides systematic and effective support for people who self-manage.

## Discussion

There was widespread agreement among interviewees that supporting participants to self-manage their funding would be value for money for the NDIS. Even for participants on income management, support to self-manage a small part of their package may contribute significantly to their confidence and competence to manage their lives.

## Observations from co-design workshop

Workshop participants confirmed that NDIS engagement sessions describe self-management as 'too difficult' and provide little or no information about intermediaries and Plan Management Providers that can assist. Many participants who seek to self-manage their funding or ask for support from a Plan Management Provider find their plans returned as Agency managed.

Planners and LACs do not encourage self-management. They appear to lack the cultural framework necessary to understand its value. This reluctance is strengthened in the absence of self-management assistance on the ground.

Workshop participants reported inconsistent planning experiences leading to variable outcomes in relation to both support as well as achievement of self-management. All agreed it is in the interest of the Scheme to achieve higher rates of self-management.

Many participants want to self-manage but want assistance to do so. Good intermediaries and peer support are essential but are generally not available for NDIS participants. The UK Direct Payments Support Service provides an example of a

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<sup>12</sup> West Australian Individualised Support Services

national network of agencies that assists participants in all aspects of self-management including providing ongoing assistance as required. The UK national advice line on self-management was felt to be of vital assistance for self-managers. Intermediaries could also call on assistance of the advice line.

The NDIS approach to support participants self-manage is not consistent. Some participants have access to peer networks but most do not. It was noted that the gap in readily available support for self-management may push participants toward Support Coordination which may not drive independence. Some participants are allocated Support Coordination, others are informed that Support Coordination is specifically not available to self-managing participants. Certainly the technical skills to assist self-managers is not in the skill set of most Support Coordinators. In addition, it was noted that there may be perverse incentives whereby poor support for self-management may lead to increased dependence and increased work for an intermediary in managing the participant plan. Some participants however will always want intermediary assistance to remove the administrative burden of self-management.

Assistance is required to maximise the number of participants who self-manage. Self-management<sup>13</sup> assistance is required in relation to matters including employment, insurance, tax, superannuation, the development of agreements and workplace health and safety. Suggestions of supports for self-management include receipt of a budget for self-management support in a participant plan with the capacity to use more resources from core supports if useful and that the portal include award, legislation, induction process.

## Recommendation

That self-management is considered the default option for plan management with people who self-manage in State and Territory systems automatically considered to self-manage under the NDIS.

That the Agency provides support to enable participants to self-manage including:

- the allocation of self-management assistance to each participant who wants to self-manage their funding
- capacity building strategies in the ILC

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<sup>13</sup> Assistance to self-manage was described as ‘technical assistance’ during the workshop. To avoid confusion, the author recommends the use of the term ‘self-management assistance’.

- development of resources to support self-managers including watch any time videos and You-tube clips, guidelines and templates
- support the development of peer networks to provide a local point of support in the community
- trouble-shooting phone support.

That the Agency implement recommendations in relation to the administration and support for self-management in a pilot commencing no later than July 2017.

## 6.6 Plan management providers

### Current practice

Anecdotal information suggests that NDIS planners and LAC partners do not understand the use of plan management providers and do not bring the option to the attention of participants.

No data is formally reported on the use of plan management providers

The administrative requirements for plan management providers appear to be unnecessarily onerous. A small number of plan management providers who were interviewed indicated that there is no mechanism in the portal for plan management to make service bookings for plan managed services.

### Discussion

There is a circular process in play. Staff undertaking planning do not understand this plan management option so do not draw it to the attention of participants. Its subsequent low utilisation rate is awkward for the NDIA so this data is dropped from public reports.

The lack of administrative access to the portal by Plan Management Providers reinforces the view that plan management providers is undeveloped and unvalued by the Agency.

Experience from States and Territories suggests that use of a plan management provider would be a popular option if its unusual language were explained to participants. This is because it most closely resembles the popular option of shared management in which the participants controlled the 'what when, where and by whom of support' and the intermediary undertook the financial and legal responsibilities.

## Recommendation

That the Agency develops strategies to enable participants to understand the role and function of Plan Management Providers and intermediaries as part of the tool box of technical assistance to increase choice and control. This includes ensuring that:

- all staff undertaking a planning function understand and can provide clear information to participants about the use of plan management providers
- the option of using a plan management provider is included in all community engagement sessions.
- data on the use of plan management providers is reinstated into the data collection

## 6.7 Intermediaries

### Current practice

A draft NDIA paper on intermediaries<sup>14</sup> acknowledges that many more intermediary type functions will emerge in response to participant demand as the market evolves. In fact, there are already intermediaries providing employment platforms and a new platform has developed linking people who need assistive devices with the global community of designers and makers is about to launch.

The paper places the intermediary functions outside the Agency, guided by a strong policy framework and clear operating rules. It argues that *“as participants gain greater confidence and as further plan reviews are undertaken, intermediaries will have a valuable role in helping participants build their capacity to either self-manage or exercise greater consumer choice and awareness of supports delivered by a variety of services both by disability and mainstream providers”*.

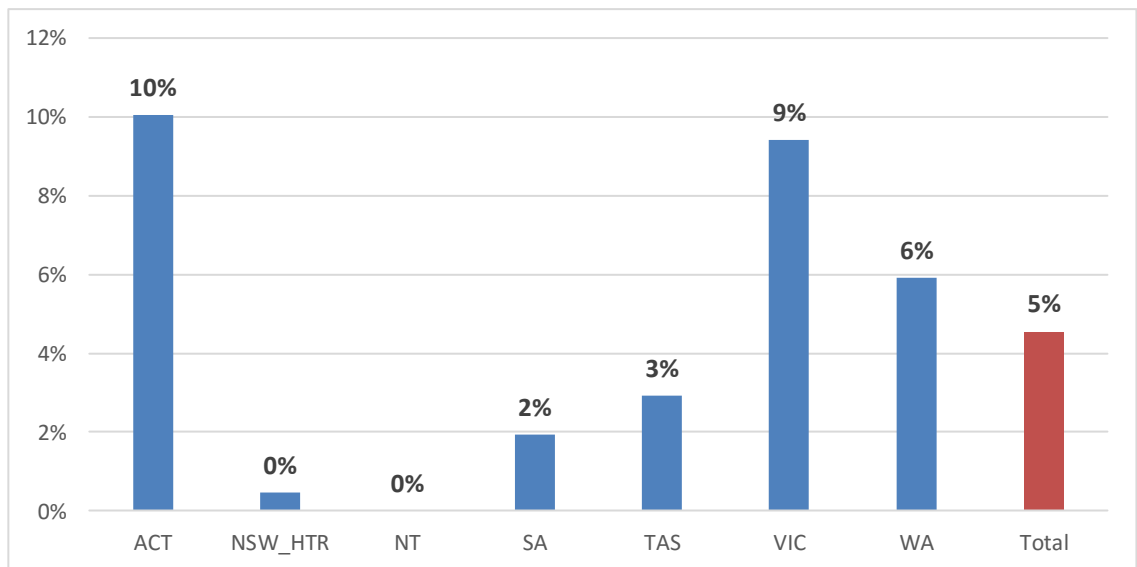
Figure 1 shows the proportion of plans that use financial intermediary support. This is the only type of intermediary supports on which data is available.

#### **Figure 1 Proportion of plans with financial intermediary supports<sup>15</sup>**

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<sup>14</sup> Provided to Sylvana Mahmic and Belinda Epstein-Frisch for feedback September 2015

<sup>15</sup> This analysis is based on 31 March 2016 data. However, plans commencing from 1 August 2015 onwards have also been excluded from the analysis as the new support catalogue does not include



## Discussion

Intermediaries are an area of NDIA practice and ‘technical assistance’ that is under-developed. Intermediaries can enable participants to have control over the what, when, where and by whom of support, assisted by technical expertise and delegated financial management.

The IAC believes that the utilisation of financial intermediaries in Figure 1 reflects existing opportunities under State and Territory provision, not growth and development in the use of intermediaries under the NDIS. For example, in the Hunter trial site, there was only one financial intermediary (developed by attendant care consumers) that had little presence in the Hunter having closed its books to all other than those on a small State based program of attendant care.

Use of intermediaries is important in broadening choice and control for participants. Participants (or their nominees) with capacity will be able to access intermediaries by themselves. Participants with less confidence or capacity could use a registered Plan Management Provider to access this avenue of increased choice and control.

## Recommendation

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the same level of detail with regards to committed support, and hence it is not possible to identify plans that include financial intermediary supports.

That the Agency provides information to participants about the role and function of intermediaries and promotes them as a strategy to increase choice and control

## 6.8 Support Coordination

### Current practice

Support Coordination Framework has been replaced by *Practice Guidance, Plan Implementation and Monitoring, Guidance for Planners, LACs and Delegates* (Practice Guidance) and defines Support Coordination as primarily being:

*Assistance to strengthen participants' abilities to coordinate and implement supports and participate fully in the community. It can include initial assistance with linking participants with the right providers to meet their needs, assistance to source providers, coordinating a range of supports both funded and mainstream and building on informal supports, resolving points of crisis, parenting training and developing participant resilience in their own networks and community.'*

Current Practice Guidance prevents the use of Support Coordination for participants who have informal support and makes the assumption that if participants self-manage, they do not need Support Coordination. The time constraints on the allocation of Support Coordination to eligible participants means the activation of the First Plan and the resolution of crises are often the only outcomes.

### Discussion

Support Coordination may be one of the possible strategies to 'enable support' described as important for increasing self-direction in participants. Support Coordination is also identified as one of the possible strategies for self-management support.

The IAC has been debating the issue of Support Coordination for some time. There is consensus that the capacity building elements of the role need to be enhanced, that the skill and experience set need to be identified and reflected in the provider registration process, that specialist roles need to be identified to provide more effective support and the Agency needs to stimulate the market to ensure greater choice of Support Coordinator providers.

### Recommendations

That the Agency:



- strengthens the capacity building elements of Support Coordination
- extends the market of appropriately skilled providers of Support Coordination by:
  - identifying the skill base required for effective Support Coordination
  - changing the registration requirements to reflect the requisite skill base
  - identifying specialist Support Coordination roles to reflect work with target populations and allocate it as required including participants:
    - i. who want to self-direct their support and self-manage their funds
    - i. in touch with the criminal justice system
    - ii. who are eligible for SDA
    - iii. with complex behaviour
    - iv. with complex health
  - stimulating the market to ensure greater choice of Support Coordination providers

## 7. Conclusion

The benefit of self-direction to health and wellbeing of participants is clear irrespective of whether the Agency holds the funding, the participant self-manages the funding or the participant uses a Plan Management Provider. The NDIS gains greatest benefit however when participants self-manage or use a registered Plan Management Provider because these non-Agency managed options provide economic benefits to the Scheme, financial benefits to the Agency and are consistent with insurance principles and fundamental to the sustainability of the Scheme.

It is therefore imperative that the Agency takes steps to enhance participant motivation, skill and confidence toward self-direction and provide active assistance for participants to self-manage or use a Plan Management Provider.

The paper has argued that there are many steps the Agency can take to increase participant self-direction and self-management. These are outlined in the recommendations.

## 8. Recommendations

### **Recommendation 1: Promote self-direction and self-management**

That the Agency strengthens strategies to promote self-direction and self-management by participants

### **Recommendation 2: Inform participants of all plan management options**

That the Agency takes steps to ensure that all engagement with NDIS staff, outsourced planners and LACs and all preplanning and planning material provides adequate information about all plan management options. This includes:

- amending training materials for NDIA staff and outsourced planners and LACs to ensure competence in explaining all plan management options in a neutral manner
- amending NDIS readiness material to clearly explain plan management options
- developing specific resources to explain what is involved in each of the plan management options.

### **Recommendation 3: Increase flexibility**

That the Agency undertakes further work to increase the flexibility of funds related to the achievement of outcomes in ways that promote maximum innovation.

This could be achieved by enabling participants to substitute support hours for participation costs in mainstream activities, for negotiated informal support from home sharers where appropriate safeguards are in place and for small pieces of equipment where this:

- represents value for money (less than cost of disability alternatives) AND
- addresses barriers to social and/or economic participation AND
- leads to increased
  - Independence
  - social and/or economic participation
  - inclusion

The increased flexibility would be within the current boundaries of core, capacity building and capital. In addition, as a safeguard to cost blow out, the NDIS could enable this flexibility within the participant budget for one plan. At plan review the practice

could be withdrawn if there is no evidence of the promised value for money and increased independence, social and economic participation and inclusion.

#### **Recommendation 4: Provide ‘enabling assistance’**

That the Agency ensures that participants who want to self-direct their support have access to ‘enabling assistance’ to strengthen their skill and confidence. Enabling assistance could be available through a combination of reframed Support Coordination, intermediary services, plan management providers and peer networks.

#### **Recommendation 5 Strengthen service agreements**

That the Agency strengthens participant capacity to negotiate service agreements that clearly articulates their expectations in relation to support by:

- using co-design to develop resources to assist participants to negotiate service agreements
- strengthening expectations of staff who assist participants to implement plans about the elements of service agreements that facilitate increased independence and an ordinary life.

#### **Recommendation 6: Build demand for self-direction and self-management**

That the Agency builds demand for self-direction and self-management through the multi pronged approach of:

- training and development for NDIA staff, outsourced planners and LACs to ensure they provide maximum opportunities, encouragement and capacity building support for participants to self-direct their support and self-manage their plan
- ensuring that all community engagement sessions provide information on self- management and the use of Plan Management Providers
- providing specific information / capacity building sessions on self-direction and self-management for interested participants
- increasing flexibility of support
- Implementing recommendation 9 on streamlined administration and support for people who self-manage.

#### **Recommendation 7: Increase capacity building initiatives**

That the Agency builds capacity for participants to direct their support and their lives by ensuring that the ILC:

- requires all services funded through ILC to demonstrate how they assist participants to increase skill and confidence in directing services and their lives
- funds specific initiatives to support participants to self manage their funding and support.

**Recommendation 8: Support consistent adoption of self-management across similar cohorts and jurisdictions**

That the Agency:

- analyses the variable take up rates of self-management across Australia with a view to developing strategies to promote more widespread utilisation
- funds specific initiatives to support participants to self-direct their support and self-manage their funds

**Recommendation 9: Assist participants to self-manage their funding**

- a) That the Agency streamline the administration associated with self-management including
  - i. enhance the risk assessment processes in relation to self-management to ensure skill development targets specific areas and minimises risk to both the participant and Agency.
  - ii. reduce the compliance requirements to an assurance framework that relies on:
    - periodic self reporting against the core element of the plan and budget including the outcomes framework that supports the plan
    - simple compliance reporting of less than one page
    - a random audit regime in which a participant's plan is audited and funds acquitted, say every 3 to 5 years
    - a separate bank account
  - iii. reinstate the float as 'funds in advance' to enable self-managing participants to draw down funds as required. Three options identified by participants are reported in Appendix C.
  - iv. enable participants to roll over a certain percentage of their plan.

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- b) That self-management is considered the default option for plan management with people who self-manage in State and Territory systems automatically considered to self-manage under the NDIS
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- c) That the Agency provides support to enable participants to self-manage including:
  - i. the allocation of self-management assistance to each participant who wants to self-manage their funding
  - ii. capacity building strategies in the ILC
  - iii. development of resources to support self-managers including watch any time videos and You-tube clips, guidelines and templates
  - iv. support the development of peer networks to provide a local point of support in the community
  - v. trouble-shooting phone support.
- d) That the Agency implement recommendations in relation to the administration and support for self-management in a pilot commencing no later than July 2017.

**Recommendation 10: Promote the use of plan management providers and intermediaries**

That the Agency develops strategies to enable participants to understand the role and function of Plan Management Providers and intermediaries as part of the tool box of technical assistance to increase choice and control. This includes ensuring that:

- all staff undertaking a planning function understand and can provide clear information to participants about the use of plan management providers
- the option of using a plan management provider is included in all community engagement sessions
- data on the use of plan management providers is reinstated into the data collection

**Recommendation 11: Improve Support Co-ordination and make it available to participants who want to self-direct their support and/or self-manage their funding**

That the Agency:

- Strengthens the capacity building elements of Support Coordination

- Extends the market of appropriately skilled providers of Support Coordination by:
  - identifying the skill base required for effective Support Coordination
  - changing the registration requirements to reflect the requisite skill base
  - identifying specialist Support Coordination roles to reflect work with target populations and allocate it as required including participants:
    - v. who want to self-direct their support and self-manage their funds
    - vi. in touch with the criminal justice system
    - vii. who are eligible for SDA
    - viii. with complex behaviour
    - ix. with complex health
  - stimulating the market to ensure greater choice of Support Coordination providers

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National Voices (2014) *Supporting self-management* Viewed 4 Sept, 2016 at <http://www.nationalvoices.org.uk/publications/our-publications/supporting-self-management>

Productivity Commission Inquiry into Disability Care and Support, (2011) Appendix E

## Appendix A Flexible use of support

The stories described below represent real people and their experience under State and Territory provision and the NDIS. They demonstrate where strategies the participants and supporters believe will be most effective in enhancing independence, social and economic participation and community inclusion comes into conflict with NDIS understanding of items that are the responsibility of the individual.

### Addressing personal care and social support needs in the mainstream

- A person who is independent in all areas of personal care other than the ability to wash her own hair
  - NDIS is prepared to fund 5 hours of support worker time
  - Woman prefers to have her hair washed twice weekly at local TAFE twice per week which costs less and increases her community participation and connection
- A man who needs assistance with shaving
  - NDIS prepared to fund support worker time
  - Man and his family prefer a weekly visit to the local barber which costs about the same but increases his independence and assists him to be better known in his community
- A woman who wants to wax monthly
  - NDIS prepared to fund 1 hour of support worker time (where support worker is unlikely to be expert in waxing) or pay for the woman to attend a 'pampering day' at a local congregated day program
  - Woman prefers to go with her sister to a local TAFE beautician salon and use the resources otherwise allocated to a support worker waxing to pay for beautician
- A family with a teenage daughter with profound and complex disability
  - NDIS prepared to fund significant drop in support
  - Family used the funds to employ a nanny who cost significantly less and provided more normative support. This also overcame the frustration the family experienced as a result of the lack of reliability of rostered staff. The mother reported that "*her marriage was back on track*".
- A man with a psycho social disability who has a chaotic lifestyle really enjoys singing and wants to participate in a singing group.
  - The NDIS is prepared to fund 3 hours for a support worker time to help him get to the group.

- Supporters of this man believe it would be more effective to provide \$10 for transport to and from the group (the main barrier to his participation is that he never has the public transport costs available) because it is cheaper and because a support worker hanging around in the singing group will in fact inhibit others coming forward to engage with him (i.e. the opportunity for informal support)
- A man with autism who lives in a rural area reduces his stress by walking. He is very fit and likes to walk from town to town. He used to sleep rough on those occasions exposing himself to significant risks.
  - The NDIS is prepared to pay for time in a day program
  - People who know the man well believe that paying for him to stay in a motel when he is stressed and goes on his long walks would be a more effective use of the NDIS resources. It would continue to promote his independence and keep him safe.

## Using support resources to purchase small pieces of equipment

- Many families of people with cognitive impairment are interested in new 'watches' that have built in reminders and alerts that are preprogrammed for when the wearer is worried or in the event of an emergency
  - Families believe this technology will support increased independence of their family member while providing a personal safeguard to enable positive risk.
  - The NDIS is not prepared to meet the cost because a watch is a personal responsibility
- A man with significant physical disability is alone overnight and needs to establish an emergency plan. He has identified a system by which he can use a touch pad in bed that allows him to call up to 6 numbers and talk directly to people available for emergency assistance. The system however requires him to purchase a special telephone
  - The NDIS is prepared to pay for the monthly fee for Vital Call but not the one off establishment cost of the special telephone (for which there will be no monthly charges)
- A young man with intellectual disability needs assistance to manage his day to day commitments and travel independently in the community.
  - The NDIS is prepared to fund a support worker to take him to appointments and activities in his plan
  - His family would like to help him use apps available on an I-Phone or I-Pad that will significantly increase his independence.



- The NDIS is not prepared to pay for the purchase of the I Phone or I Pad that would enhance his capacity and reduce long term support costs
- The Intensive Family Support Guidelines of the Disability Services Commission of WA was able to fund such items/initiatives under a principle that *“the initiative builds the parent/carer/family member’s care capabilities and capacities and will reduce the reliance upon formal supports”* (2009)

## Using support resources to purchase mainstream community participation

- A young woman who needs assistance to participate in the community
  - The NDIS will pay for her to attend a disability Zumba class at a day program where she would not have to pay for the class. The NDIS would pay for the day program.
  - She would like to use resources to pay for the local community Zumba class with a support person going along to the first 3 classes to assist her to connect with others in the class
- A woman with physical disability wants to have a one week holiday
  - The NDIS is prepared to pay \$7,386.12 for support during a 7 day/night holiday.
  - The woman wants to go away with a friend who provides personal care support from time to time. The friend does not want to be paid. The woman with disability would like to pay her friend a stipend of \$100/day for ‘out of pocket expenses’. The NDIS is reluctant to approve these costs
- A teenager with high and complex needs has never been away on a holiday with the family
  - The NDIS will pay over \$7,000 for support during a 7 day/night holiday
  - The family would prefer to pay for the rent on an adjoining apartment for their cousins who will provide take turns to provide support for the young man during the much desired combined family holiday
- A woman with disability has indicated an interest in singing that she would like to pursue with her NDIS support. She is however very shy and isolated.
  - The NDIS is prepared to pay for a support worker to accompany her to a local choir or to attend a day program that has singing as an activity
  - People who know the woman well believe that better outcomes will be achieved if the NDIS pays for 6 singing lessons to build her confidence and short term facilitation to help members of the choir to provide

informal support. They argue that this approach builds her capacity in order to reduce her longer term support needs.

- The NDIS will not pay for singing lessons but on the DSP she cannot afford the lessons

## Home modifications

- A family needed to modify their bathroom for their son who used a wheelchair.
  - The NDIS allocated \$26,000 to rearrange the bathroom making it technically accessible but too small for function.
  - The family wanted the bathroom made bigger and found a builder who was prepared to do the job for \$17,000
  - Given that funds for home modifications must be Agency managed, the family were forced to use the more expensive, less useful home modification provider.
- A blind man needed a railing at the edge of his porch for safety.
  - He was grateful that the NDIS was prepared to pay for a standard functional railing but wanted to add some money from his own resources so that a more attractive railing could be used. He was prevented from doing so.
- A man needed bathroom modified. His family and friends were skilled and prepared to do the work but they lacked the resources to purchase the material
  - Under the Community Living Fund in WA, funds were provided for the materials and his family and friends undertook the work
  - The NDIS requires the use of an approved home modification provider at significantly higher cost.

## Appendix B Innovation in home sharing

### Introduction

Many people with disability want to live with a person without disability with a negotiated agreement of informal support in lieu of rent. Those who live in social housing are eligible for an additional bedroom and in some jurisdictions, the income of the co-resident or home sharer is not taken into account in determining the household

income for the purpose of rent. This allows the person with disability to offer the room rent free in appreciation for negotiated informal support.

People who rent on the private rental market are not so fortunate. If they are not able to stay at home alone overnight, they need to rent a 2 bedroom unit but are limited in what they can offer the co-resident home sharer in appreciation for negotiated informal support.

It is critical to emphasise that in all cases, the participant pays for his/her own rent.

The ability of people with disability to subsidise the rent of co-resident home sharers who provide negotiated informal support increases their opportunity to attract housemates.

The aim of the paper is to argue the case for participants being able to use reasonable and necessary support to subsidise the rent of home sharers where this is:

- beneficial for the participant
- where adequate safeguards are in place AND.
- where it represents value for money to the NDIS

This paper prefers the term ‘home sharer’ to ‘co-resident’ to emphasise the intention of creating a home via the arrangement rather than a shared house with little connection between the tenants.

## Background

Object 3(g) of the NDIS Act “*promote(s) the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community*”. The opportunity for people with disability (particularly people with high support needs) to share their home with housemates who do not have a disability could be described as ‘high quality and innovative’ because it is a relatively new approach to supported living and to facilitates ordinary lives for people with disability.

The approach is also evidence based, supported by research into the *Effectiveness of Supported Living in Relation to Shared Accommodation* (SPRC: 2007)<sup>16</sup> for people requiring 24 hour care.

Many people with disability use reduced or rent free accommodation as an incentive to attract home sharers who provide negotiated informal support and assist the person in extending their networks, thus further developing informal support opportunities.

## **Benefits of reduced or free rent in exchange for informal support**

### **It is cost effective**

- Home sharers sleep at home a minimum number of nights per week, which is comparatively less costly than paying overnight support workers for equivalent hours.
- Home sharers offer support and contribution in daily living tasks like shopping, cooking and cleaning, saving dollars that would be spent on drop-in paid support for these tasks.
- Home sharers are often instrumental in widening the networks and friendships of people with disability, saving costs associated with providing paid support to undertake this work.
- If and when co-residents decide to move out they can often find a replacement through their networks, which in many cases will have already met the person socially. This reduces expenses and time associated with sourcing and familiarising with potential home sharers.

### **It improves the quality of life and outcomes for people with disability**

- People with disability expand their relationships, friendships and opportunities through the relationships they develop with home sharers. In turn this increases people's safety and security in their community and their valued status as housemate.

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<sup>16</sup> Social Policy Research Centre, (2007) *Effectiveness of Supported Living in relation to Shared Accommodation*, at <http://www.sprc.unsw.edu.au/research-areas-and-strengths/effectiveness-of-supported-living-in-relation-to-shared-accommodation-56.html>

- Home sharers often go above and beyond what was originally expected of them once a relationship has developed between them and the person.
- Home sharers reduce a person's dependence on paid people in their life. While home sharers receive an incentive to take up the arrangement, this is not comparative to the costs and differing dimensions of relationship associated with paid support workers.

## **Paying a home sharer changes the nature of the relationship**

Directly paying a home sharer for the support they provide is likely to transform their role from 'house mate' into 'employee' or 'support worker', and the person with disability from 'housemate' to 'recipient of paid support'. House sharing lends itself to natural, freely given relations that are typical of more informal arrangements between people sharing accommodation in the community. This could be inhibited when people are in a paid role: they are likely to do the tasks that they are being paid for (in the 'job description') and go no further. The social activities and friendships that so often blossom between housemates are far less likely to occur in paid, professionalised relationships when people with disability are associated with 'work'.

## **Developing safeguards**

This advice recognises the vulnerability of people with disability who invite a person to live in their home. Whilst some home sharers will be known, others may be recruited from house sharing websites, advertisements and the like. It is thereby critical that a framework for building personal safeguards is implemented for participants proposing to home share.

## **State Government policy on rent subsidy**

### **Queensland Housing**

Queensland Housing enables overseas students to live in a home stay arrangement with an Australian resident of the Queensland Department of Housing. The rent that the student pays to their Australian hosts is deemed as non-assessable income and therefore does not impact on the household income for rent. People with disability have used this provision in social housing to negotiate the provision of informal support from a home sharer who pays no rent.

### **Western Australia Community Living Initiative**

The CLI provides funding up to a maximum of \$20,000 p.a. with additional administration funding provided to agencies (approx. \$4000 p.a). The CLI enables people with disability to use their funding flexibly with no cap on the amount of money that can be used as a rent subsidy for a home sharer as long as it is an approved part of a person's plan.

## Housing NSW

Housing NSW does not take into account the income of a home sharer of a person with disability when calculating the household income as the basis for rent. This enables people with disability in social housing to offer rent-free accommodation for a housemate who provides negotiated informal support.

The shortage of social housing means that most people with disability do not have access to affordable housing and many are in private rental experiencing housing stress. They are not in a position to contribute the rent on behalf of a housemate who provides informal support.

## Case studies

### Case study 1

John is a man with Autism, in receipt of the DSP, has significant support requirements. He and his family were keen for him move out of home and believed they could not wait for social housing with its anticipated wait time of ten years. The private rental market was however out of his reach due to high cost unless someone helped pay the rent.

Using the flexible funding of the WA Community Living Fund, the family found a suitable person to live with John and set up an option whereby the home sharer paid no rent and provided supervision & assistance with day to day tasks, companionship, social contact and interaction. The free rental component went back into the cost of the rent of the unit that equated to \$250 per week. This innovative and low cost support arrangement was approved by the funding body (State govt) and worked well for over two years.

John is now a participant of the NDIS. His first plan rolled over the state arrangement. At the year 2 review, the NDIA made it clear that it would not pay for costs associated with housing. The arrangement needed to change and the family was requested to provide a quote for the services of the home sharer listing the activities and costs for the provision of support. This has been provided and has resulted in more than threefold increase in the NDIS funding required and a

formalisation of the living arrangement whereby the home sharer is effectively now a paid carer who is paying rent, has a service agreement and has had to be formally employed.

The impact is that an effective informal relationship of freely given support has been turned into a paid relationship with an employee who now only provides those hours of support for which he is formally paid. The cost to the NDIS is significantly higher and the cost to the man is the loss of an important freely given relationship.

## Case Study 2

Susan is a young woman who lives in Queensland in a three-bedroom house provided by Queensland Housing. She had autism and needs regular support so that she can live in her own home. Susan shares her home with two housemates. One is a student from Kenya who lives with Susan in a home stay arrangement and is not required to pay rent in return for the support she provides. The other is an Australian student who pays approximately \$50 per week as calculated by Queensland Housing through an income/asset test.

Susan's home sharers both signed agreements that set out their obligations and the arrangements for living in Susan's home. For example, at least one housemate is required to be at home between 7pm – 8am four nights a week and both assist Susan with daily tasks like having breakfast, getting ready each day and getting to bed. Susan's home sharers are expected to pay their share (one third) of all utility bills and shared food items. They also pay a bond in the case that something in Susan's home is damaged.

In addition, Susan has a team of six paid support workers who assist her with daily living, complimenting the informal support from home sharers. Susan's family believe that home sharers have made a big difference to Susan's quality of life. One of her past home sharers has maintained contact and is now a part of Susan's circle of support.

## Case study 3

Rahul is a 26-year-old man who moved from a rural area of Western Australia to Perth. He has Asperger Syndrome, and while he may present as being highly capable, he finds it extremely difficult to make and sustain relationships, do everyday tasks like showering, shopping and cooking and often displays challenging behaviours. Rahul has a Community Living Fund of approximately \$20,000, and uses \$17,000 of this to enable 2 home sharers to live with him at reduced rent and provide informal support (the house sharers each pay \$90 per week and split the utility bills evenly). This highly

reduced rent is in the recognition that Rahul is not an easy person to live with. The home sharers agree to support Rahul in a variety of ways including ensuring one person is always home over night and assisting with household duties like shopping, cooking and cleaning. They also know that part of their role as Rahul's housemate is to help him to expand his relationships and friendships, and hosting BBQs and gatherings at the house (from time to time) is encouraged.

When Rahul first moved to Perth he had no connections or friendships. Through his housemates his networks have expanded vastly, although he continues to need substantial support in maintaining these relationships. Rahul's agency plays a facilitative role in supporting Rahul and his home sharers to form positive, healthy and friendly relationships. For example, they provide information and advice to Rahul's home sharers and are available if they have any questions or concerns.

Rahul receives approximately 10 hours a week of paid support in his home.

## Case study 4

Jennifer is a middle-aged woman who has significant cognitive impairment. She has lived in her own home for many years with paid support that come in daily to assist with personal care and daily living. During the day, Jennifer attends a day program. Integral to Jennifer's wellbeing is the fact that she has shared her home with Wendy for the past 3 years. Wendy works full time and has committed to spend time with Jennifer in the evening, sharing a meal, watching TV and helping Jennifer get ready for bed including assisting with her medication. In addition, Wendy prepares Jennifer's breakfast before she leaves for work in the morning. Wendy believes she is very fortunate to live with Jennifer. She enjoys Jennifer's company and does not pay rent.

Jennifer has substituted hours of paid support for Wendy's contribution to the household rent to enable Jennifer to live in a 2 bedroom flat.

## Considerations in the use and level of rent subsidy for home sharers

That participants be able to use reasonable and necessary support to subsidise the rent of a home sharer if the home sharer:

- Provides negotiated informal support
- Reduces the need for paid support
- Contributes to the quality of life of the person with disability
- Contributes to the sustainability of a supported living arrangement



Ownership of the property is not a relevant consideration because the rental subsidy is provided in recognition of support provided.

The level of rent subsidy should be determined in relation to:

- The level and nature of support that will be required from home sharers – taking into account the amount the housemate would be paid if the assistance was provided by a support worker
- The temperament of the person with disability and how easy/difficult they are to live with

## Recommendation

That NDIS allow participants to use their reasonable and necessary support to subsidise the rent of home sharers where this is

- beneficial for the participant
- where adequate safeguards are in place AND.
- where it represents value for money to the NDIS

## Appendix C Options for the payment of funds for self-managing participants:

### UK: Direct payments finance and pre-paid cards

Disability support is provided by Local Authorities in the UK. The information provided here is from Merton Local Council

- Merton Council has partnered with Advanced Payment Solutions Ltd<sup>17</sup>, a private company to deliver direct payments to people on the direct payment scheme. Participants are provided with a pre-paid card onto which their direct payments for community services are loaded to enable the participant to purchase goods and services to meet the needs set out in their plan

#### Using the card

- The card is MasterCard enabled so participants can use it anywhere they could use MasterCard. It is similar to a debit card and can enable transfers to another bank on line, payments over the phone or by direct debit. If participants want to withdraw cash they are directed to a direct payments service that permits cash payments.
- Participants can check the balance online or by phone
- There is no payment for using the pre-paid card. There are transaction fees for payment of bills by direct debit or payments direct into a bank account but these can be avoided by payment online, by phone or in person at the point of cash sale.

#### Receiving payments

- Participants receive an initial payment that includes set up costs including payroll and insurance and payments are made into the account every 28 days thereafter.
- Participants are advised that if they employ their own personal assistants, they register with a payroll company that will work out tax and insurance and send

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<sup>17</sup>

<https://promisepay.com/?gclid=Cj0KEQIA9ZXBRC29cPdu7yuvrQBEiQAhyQZ9PAKJy1FL2mirWS6lcwUGJayfCXRLlsrIB9x9ht1hisaAv8T8P8HAQ>

participant a payslip to let them know what they need to pay the personal assistant. They are provided with a list of payroll agencies

### **Monitoring payments**

- The Council monitors direct payments with the first contact at 6 weeks and then again at 3 months to check to see how things are going. Frequency of contact depends on personal circumstances and is indicated in the planning process.
- The Council conducts 2 types of audit:
  - Light touch audit: checking the pre-paid card amount whenever necessary, contacting the participants where there are discrepancies or problems
  - Full audit: at least once per year depending on participant circumstances
- Participants are required to keep bank statements, invoices from agencies, payslips and receipts.

### **Payroll and tax**

- Participants are encouraged to pay personal assistants every four weeks in line with direct payments
- The Council provides the participant money for a qualified person or payroll company to pay employees so ensure proper tax and insurances are paid

### **Support**

- The Council provides easy read written material, offers face to face, phone and email support from the Direct Payments team

## **Features of a system of ‘payment in advance’ by Christina Ryan**

- Funds would be paid advanced for 12 months. In some circumstances with very large plans over \$100,000 this might be for a shorter period like 3 or 6 months. This should be negotiated with the participant based on their ability to manage a large amount. Those participants with experience in self-management would expect to have the full 12 months advanced.
- Funds are placed in a targeted bank account set up by the participant. This has been a requirement of the NDIS until recently when the float / advance funds system was removed, so most participants already have specific allocated bank accounts to run their NDIS funds through. All monies going in and out of this account are for the delivery of the participant’s plan so the bank statement becomes an acquittal tool.
- A simple template or other device (several new software packages are now

coming onto the market including from companies like Westpac) is used to run a cash flow system to track the funds. This could be a cash book, an excel spreadsheet, or targeted software; it's up to the participant to manage their funds against the goals in their plan against the relevant NDIS codes. The NDIS could provide simple templates

- The bank statement alongside the spreadsheet / cash book becomes the annual financial acquittal.
- A short annual statement of outcomes against each goal becomes the outcomes acquittal. No more than a page.

Participants would interact with the NDIS once a year at plan review. They would then set up with a new plan, a new advance of funds, and a new template / spreadsheet.

## NSW Direct payments

NSW direct payment participants

- Are funded month in advance
- report their expenditure at a frequency dependent on the skill and experience of the participant. Most begin by reporting monthly.
- Participants prepare an annual report and if there is a surplus, they can apply to retain unspent funds up to 5% of their budget

## Appendix D Challenges to provider registration in relation to support coordination and capacity building

**Purpose:** To ensure a diversity of organisations skilled at providing Support Coordination and capacity building.

### Challenge

- The current registration process prevents many capacity building organisations from registering under the Assist Life Stages Transition cluster
- Registration under the Assist Life Stages Transition Cluster does not require evidence of skill and experience in capacity building

### The registration process

For a potential provider (registrant) to become a registered provider of support, the organisation must register on the basis of its staff who need to:

1. Identify the profession of which they are apart. This is a threshold that then enables the potential provider to
2. Identify the Support Cluster in which they want to provide services.
3. Provide evidence of relevant experience
4. Provide evidence of capacity

<http://www.ndis.gov.au/providers/suitability#services> outlines the types of professions and evidence of experience and evidence of capacity requirements against each of the support Clusters. For example

Support Cluster	Professions	Evidence of experience	Capacity Requirements Evidence of:
<p><b>Provider Portal Name:</b> Assist-Life Stage, Transition</p> <p><b>Assistance in coordinating or managing life stages, transitions and supports</b> This cluster includes short and long-term supports that focus on strengthening the participant's ability to coordinate their supports, and to assist them to live at home and participate in their community.</p>	<ul style="list-style-type: none"> <li>• Disability Support Worker</li> <li>• Occupational Therapist</li> <li>• Social Worker</li> </ul>	<p>Please provide details of delivery of person centred services in the community or in their home.</p> <p>For peer support – lived experience of disability or mental illness and relevant experiences and skills or training to perform this activity</p> <p>IF Diploma in Disability Services studies provide details of at least two years of experience</p> <p>IF Certificate III in Disability Services provide details of substantial years of relevant experience and specialist skills sufficient to perform these activities</p>	<ul style="list-style-type: none"> <li>• Risk Management</li> <li>• Specialist Disability Service State Approval</li> <li>• National Police Check</li> <li>• Working with Children / Vulnerable people check</li> </ul>

## The challenge in relation to capacity building

Professional designations are a threshold to registration: To access the Assist Life Stages Transition cluster, the registrant must have qualifications as a disability support worker, a social worker or an occupational therapist. The only way to demonstrate qualifications in social work or occupational therapy is by membership of a professional association, without which the registrant is prevented from registering for the capacity building cluster and proceeding to the next step of providing evidence of experience.

The problems are fourfold:

- Qualifications are used as a threshold of capacity to deliver a service preventing the provision of evidence of experience

- The list of qualifications deemed appropriate is unnecessarily limited
- Evidence of qualifications is unnecessarily limited
- The employment of one individual with the appropriate evidence for registration enables an organisation to deliver the service with no reference to the skills and experience of multiple staff delivering the service on the ground or the training development and supervisory structures to assure quality.

For example, if the registrant is a social worker, membership of the Australian Association of Social Workers is the threshold for registration for the Assist Life Stages Transition cluster. Without this evidence, the registrant is unable to provide any evidence of experience or capacity.

\* required

**Profession: Social Worker**

Attach a copy of your membership with Australian Association of Social Workers

Select Evidence Type Accreditation

Enter the expiry date of your membership in the Valid to date field

Attach a copy of your membership

To submit additional evidence for this profession click Save, then Add More Evidence, otherwise Click Add/Update to save and return to the Professions list

Evidence Type:\*

Qualification:

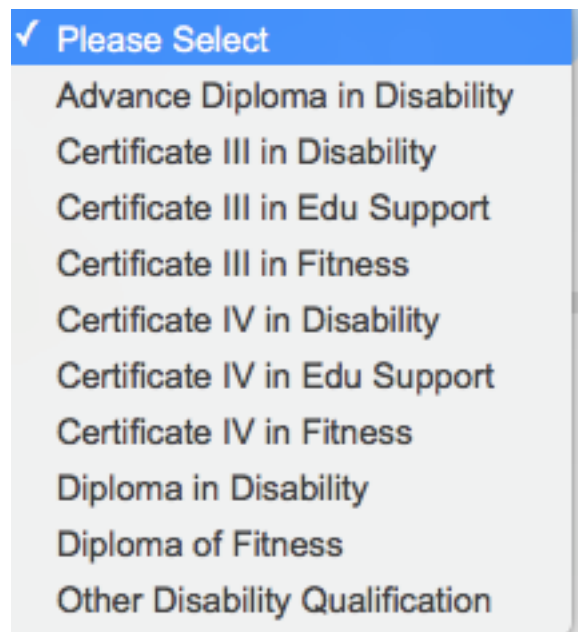
Valid To Date:

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Please provide more details (Limit approx 330 words, 1,999 characters):\*

Attachment (Size restricted to 25MB):

If however the registrant is a disability support worker, the list of qualifications is broader and the attachment of the qualifications provides evidence.



Once a registrant has passed the qualifications threshold, the person is able to registers for possible clusters and has 330 words (or less than one page) to demonstrate experience. See screen below:



**Support Cluster: Assist-Life Stage, Transition**

This cluster includes short and long term supports that focus on strengthening the participant's ability to coordinate their supports, and to assist them to live at home and participate in their community.

Please provide details of delivery of person centred services in the community or in their home.

For peer support – lived experience of disability or mental illness and relevant experiences and skills or training to perform this activity

if Diploma in Disability Services studies provide details of at least two years of experience

if Certificate III in Disability Services provide details of substantial years of relevant experience and specialist skills sufficient to perform these activities

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Experience Details (Limit: approx 330 words, 1,999 characters):\*

[Save](#)

## Evidence of capacity requirements

The registrant can demonstrate his/her capacity to provide assistance under the Assist Life Stages Transition cluster by the provision of support material related to risk management, Specialist Disability Service State Approval, National Police Check and Working with Children/Vulnerable People Check. At least in NSW the Specialist Disability Service State Approval does not demonstrate capacity to deliver capacity building assistance.

The NDIS will be more likely to enhance the quality of capacity building support by developing a capacity requirement for this cluster whereby registered providers need to demonstrate evidence of:

- Use of evidence based practice to improve self efficacy
- Policy and practice guidelines related to (among other things) enhancing support for decision making, self advocacy and personal safeguards as core requirements

The capacity requirements to be co-designed with capacity building organisations

## Recommendation

That registration process for the capacity building clusters is changed to:

- Emphasise evidence of experience rather than accreditation with qualifications as one among many ways to demonstrate experience.
- Require registrants to demonstrate capacity requirements related to capacity building
- A co-design process between the NDIA and capacity building organisations is used in developing the changed registration requirements