

Independent Advisory Council to the NDIS

Attachment A

Self-Management: Value and Strategies for Growth

Background Paper

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**Independent
Advisory
Council**
to the **ndis**

Table of Contents

- Self-Management: Value and Strategies for Growth 1**
- Table of Contents 2**
- 1. Introduction 3**
- 2. Self-management explained 3**
 - 2.1. Removal of Float 4
- 3. The value of self-management 4**
 - 3.1. Self-management improves participant outcomes 4
 - 3.2. Self-management can reward initiative and provide value for money 5
 - 3.3. Self-management can disrupt the market 5
 - 3.4. Self-management is fiscally sound 6
 - 3.5. Self-management can expand the workforce 6
- 4. What is needed to support the growth of self-management? 6**
 - 4.1 Flexible Funding 6
 - 4.2 Assistance to develop an ordinary life included in the community 9
 - 4.3 Service agreements 9
 - 4.4 Encouragement to self-management 9
 - 4.5 Development of systems to support self-management 10
 - 4.6 Address the skill deficit in the sector 14
- 5. Conclusion 14**
- References 15**

1. Introduction

The purpose of this paper is to provide background to self-management under the NDIS, to outline its value to the Scheme and to participants and to identify what is needed to support the growth of self-management in an efficient, effective, risk mitigating¹ and sustainable manner.

Self-management is one of three plan management options identified in the NDIS Act. Using the self-management option, a participant² takes responsibility for the whole or a part of the package with the NDIA allocating the budget directly to the participant who is responsible for all aspects of administration of the package. States and territories described this option as a direct payment.

Participants are confused about the option of self-management. The term has a different meaning in state and territory disability systems and NDIS information about self-management (in NDIS readiness material and communicated by staff undertaking the planning function) has been discouraging.

Self-management is however an important goal to be pursued by the NDIS for its positive impacts on both participants and in promoting Scheme sustainability.

2. Self-management explained

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 Payment Requests to the National Disability Insurance Agency (NDIA) and
- Keeping records of all plan purchases”

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.

¹ Addressed in Appendix 2

² Or their nominee

In practical terms, a participant who self-manages the funding in their plan receives an invoice or receipt (including one for each support worker directly employed) and submits a Payment Request to the NDIA, generally via the online Portal *myplace*. The Payment Request is processed provided there is money remaining in the participant's support budget for the relevant type of support. The payment is generally be deposited into the participant's nominated Bank Account within 48 hours.

2.1. Removal of Float

During the trial period (prior to July 1, 2016) participants who made the decision to self-manage their package received one twelfth of the value of their self-managed supports as an advance payment or float at the commencement of their plan. Participants would spend these funds on their supports, and then submit claims to the Agency for payment. At the end of the plan (generally 12 months) final claims were to be acquitted against the advance, however this did not always occur. Information was provided to support participants to understand the concept of the float and float repayments, however an independent Liability Review (commissioned by the Agency in 2015) found the practice to be overly complex and often confusing for participants.

With the introduction of new payment system in July 2016, the Agency decided advanced payments would no longer be administered to self-managed participants at the beginning of their plan. Currently, participants generally receive payments from the Agency within 48 hours of processing a payment request and do not have to directly handle and reconcile larger advanced payments. The Agency is working to consider how the current payment systems and self-management practices could be enhanced so that anyone who has costs in their plan that may result in an 'out-of-pocket' expense has access to funds needed in advance.

3. The value of self-management

3.1. Self-management improves participant outcomes

A significant body of research³ consistently reports that self-directed funding and support is associated with greater satisfaction levels, perceptions of greater power and control over life decisions, improvements in quality of life, spending time with people you like, taking part in the community, feeling safe and secure at home, personal dignity, economic wellbeing, increased social networks and the perception of improved quality of supports.

³ Productivity Commission Inquiry into Disability Care and Support, (2011) Appendix E

3.2. Self-management can reward initiative and provide value for money

Self-management strengthens the NDIS paradigm of choice and control and can be structured to create an environment that rewards participants who plan, build informal support and spend their reasonable and necessary support wisely.

When participants control the 'what, when, where and by whom of support', they are able to target it effectively to complement rather than push out informal support provided by family and friends. The control over support enables participants to engage more effectively in the community, enabling the development of relationships and belonging and increasing opportunities and incentives to develop informal support. In addition, within current NDIS policy in relation to bundling of core supports, participants who self-manage can act on judgements about the best use of their support, for example deciding between more support or support of a higher quality to suit their specific need and preference.

3.3. Self-management can disrupt the market

Increased self-management has the capacity to disrupt the current patterns of service provision to be more aligned with the aspirations of the NDIS, to be a place where more participants are able to access innovative solutions and gain more choice and control, choose staff for their ability to assist them experience their lifestyle of choice, use mainstream and community services and seek and work toward greater independence, autonomy and citizenship.

NDIA managed participants can only access registered provider which leads them down the path of traditional service provision

Evidence indicates that self-management can create new markets of participants seeking value for money and an ordinary life. In the main, these participants are less interested in traditional specialist disability services and want their reasonable and necessary support to pursue an ordinary life included in the community.

Support for these ordinary life aspirations however is not readily available from traditional disability services, especially from grouped activities. With encouragement and assistance, an increased number of participants will self-manage their budget and others will use a range of new intermediaries to assist them to take control.

This changed participant behaviour has the capacity to impact on the market and lead to:

- mainstream and community services becoming more inclusive as they respond to requests one person at a time. It is easier for mainstream and community services to respond to and welcome one individual than welcome groups of people with disability
- pressure on specialist disability services to provide something different
- the emergence of new services or sections of existing services that are responsive to changed demand.

3.4. Self-management is fiscally sound

Changed participant and provider behaviour will enhance the sustainability of the NDIS because participants with increased independence, self-reliance and inclusion require less support over their lifetime. This is the fundamental premise of the insurance approach of the NDIS: the recognition that increasing the capacity of participants reduces their long term need for care and support.

Self-management aligns the interests of people with disability and the Scheme. It produces positive outcomes for participants and enhances the sustainability of the Scheme with evidence suggesting that self-directed funding is likely to cost less than alternative service models⁴.

3.5. Self-management can expand the workforce

In its 2011 report into Disability Care and Support, the Productivity Commission suggested that self-directed funding would expand the workforce as participants recruited friends and neighbours as support workers. There is not yet systematic evidence on this point but discussion among participants who self-manage indicates recruitment patterns outside sources of recruitment used by disability service providers as self-managing participants prioritise shared values and interests over formal qualifications in staff selection.

4. What is needed to support the growth of self-management?

NDIS individualised 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.

If the NDIS is interested to maximise the number of participants that self manage, it is important to assist participants to transform their reasonable and necessary support into a vehicle that gives them control of their lives and implement strategies that will make it easier for participants to self manage. Elements critical to that transformation are identified below.

4.1 Flexible Funding

⁴ Productivity Commission Inquiry into Disability Care and Support, (2011) Appendix E

Flexible use of funding facilitates improved quality of life outcomes for participants as well as more competition in service provision. It can also be used to reward initiative.

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 reward 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 used to meet outcomes, to facilitate membership in mainstream community places with very intentional strategies to build informal networks in those places.

For example, some 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 helpful in sustaining informal support.

The incentives and gratuities to sustain informal support are seldom recognised in a participant's NDIS budget and the NDIS prohibits a participant from using their reasonable and necessary support to pay for a tank of petrol for a friend who always drives, to pay for a cinema ticket for an accompanying friend or to reduce 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 ticket⁵ are the small incentive and tokens of appreciation for unpaid support.

It is generally agreed that participants are best placed to decide how to make their paid support most potent. NDIA restrictions on this flexibility reduce participant capacity to seek value for money.

Increased flexibility also affords significant market based benefits to participants. It provides more choice, which drives competition and would likely also allow providers to deliver more targeted or specialised services. This means that participants would be afforded services that suit them better and likely at low or at least more efficient prices.

Given choice is a central tenet of the NDIS, it is important to recognise and have transparent processes in place to justify (to participants and other stakeholders) restrictions on that choice. Restrictions on choice in the NDIS are usually linked to a desire to manage risk, but these objectives are not always clear to participants and other non-Government stakeholders.

One example approaching best practice in terms of transparent policy development in the NDIS is the early stage of the national Quality and Safeguards Framework. The use of quality and safeguards regulations can benefit participants if applied well, but has the potential to restrict choice, and therefore undermine value, if applied too stringently or widely. The Department of Social Services, on behalf of the Council of Australian Governments, ran public consultations about the quality and safeguards risks that it is seeking to address in a national framework, options to manage these risks, and the impacts associated with each option. Importantly, the analysis of impacts acknowledges that all forms of regulation, no matter how well intentioned, come at a cost, and that the scale and distribution of this cost needs to be weighed against the intended benefits of the regulation.

Other restrictions on choice in the NDIS have not been developed in such a transparent way, nor with such an explicit consideration of options to address risk, and the impacts of these options. Notably, NDIS participants are subject to many rules and system constraints that restrict flexibility in the way that they use their plan funds. These restrictions often mean that the reality of choice in the NDIS is much more limited than suggested by many of the creative stories used in vision building seminars. Its application appears rigid and rejects the nuanced arguments that demonstrate genuine value for money both for the participant and the Scheme.

When the application of the NDIS Rules turns 'support for informal supporters' into paid support, the cost increases enormously. It may be more consistent with the vision of the

⁵ For some participants, a companion card would meet this cost. The variable eligibility based on outdated State and Territory funding programs means that many participants who need support to participate in the community are not eligible.

NDIS, that payment for these small incentives and expressions of appreciation be viewed as consistent with a broader reading of S5.2(a) of the NDIS Supports for Participants Rules as additional expenses a participant will face as a result of their disability support needs.

4.2 Assistance to develop an ordinary life included in the community

People who have lived their lives in rationed service centric systems require assistance to develop an ordinary life. 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.

There is no clear item in the Support Catalogue that provides this expert enabling assistance.

During full scheme roll out, LACs assist participants to implement their plans. It is unrealistic however to expect that LACs have the expertise and time to help 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 operationalization through the recent Practice Guidance⁶ does not provide the key to activate self-directed support and put participants in control of their lives. Support Coordination will manage the vast majority of participants into services but will not give them assistance to increase their self-direction and inclusion that is required to make a difference to their life chances. Support coordination needs to be reconceptualised if it is to assist participants to achieve significant and sustained positive outcomes.

4.3 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.

4.4 Encouragement to self-management

⁶ NDIS, (2016) Practice Guidance, Plan Implementation and Monitoring, Guidance for Planners, LACs and Delegates v1.01

4.4.1. Acknowledge self-management in all its forms

The NDIS uses the term with 'self-management' as the gold standard by to measure success in participant choice and control. The NDIA does not recognise the significant choice and control exercised by participants using intermediaries. Experience in the UK and US would suggest that this is not helpful to either the NDIA or participants.

In the US, all participants in self-direction programs are required to use a financial intermediary. In the UK where direct payments has been the main way in which participants gained control over their support, there has been recent acknowledgement of the benefit of using intermediaries giving a significant population group control over their support accompanied by support with the financial and administrative responsibilities.

It is in the interests of the NDIA to acknowledge this for the participants. It is also beneficial for the Scheme to be able to demonstrate a larger proportion of participants achieving a high level of choice and control.

4.4.2. Build 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-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 increased choice and control and ultimately self-management. There is evidence from the UK⁷ that disabled persons user led organisations had a significant impact on building demand and capacity for increased choice and control. 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.

4.5 Development of systems to support self-management

The NDIA provides a range of strategies to support participants to manage their funding but participant feedback suggests they are not yet adequate. Worthy of highlight is the fact that fact sheets, information sessions and workshops provide discouraging information about self-management, presenting it as 'too hard' and do not provide information about intermediaries or plan management providers that could assist participants with the administrative, financial and legal requirements.

⁷ IAC, (2014) Capacity building for people with disability, their families and carers at 90,91

Whilst the NDIA undertakes a risk assessment prior to approving self-management for a participant, it does not identify capacity building desired or required to enable the participant or their nominee to successfully self-manage.

4.5.1. Streamline the administration of self-management

The administration of self-management is perceived to be unnecessarily complicated. Recent online discussion⁸ as well as discussion with self-managing participants and user led Disability Support Organisations (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.

4.5.2. Provide support to self-managing participants

There is no coordinated NDIS approach to enhancing the competence and confidence of participants to self-manage the funding. 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 organisation⁹ 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.

US self-direction programs include support for the responsibilities required as an inherent part of the program. For example, the Cash and Counselling program provides 'counselling' (otherwise known as support brokerage, consulting, flexible case management) to help participants develop the skills necessary to manage their budgets and workers to meet individual support needs. In the UK, participants who want a Direct Payment are directed to peer support and planning and support brokerage services provided by the local authority.

⁸ <https://www.linkedin.com/pulse/sabotaging-ndis-christina-ryan?trk=hp-feed-article-title-publish>

⁹ West Australian Individualised Support Services

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.

Assistance is required to maximise the number of participants who self-manage. Self-management assistance¹⁰ 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 and induction process.

There was widespread agreement 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.

4.5.3. Encourage use of intermediaries

NDIA practice in relation to intermediaries is in the early stage of development with little data on the use of intermediaries. The NDIA acknowledges however that intermediaries will be important in assisting participants to increase their self-direction and is defining the term intermediary widely to include any support that may be helpful for people wanting to increase the direction and control over their supports in more creative and innovative ways.

In the US, a financial intermediary is a requirement for all participants in self-direction programs. In the Cash and Counselling program¹¹, one of the most flexible models of participant direction, early program designers sought to maximise participant choice and control over their services. Designers intended for program participants to fully manage even the financial aspects of their program, including payments to workers, for other goods and services and managing all employer tax, insurance and record keeping responsibilities. However, early program preference studies revealed that a majority of participants preferred a professional service provider to perform financial and administrative services. Empirically, when given the choice, Cash and

¹⁰ 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'.

¹¹ Further information is available at <http://www.rwjf.org/en/library/research/2013/06/cash---counseling.html> accessed 22 March 2017.

Counselling participants chose a financial management service provider to manage all employer related payroll, tax and insurance responsibilities¹².

Most participant direction programs in the US offer participants counselling and financial management support. The primary function of counselling (otherwise known as support brokerage, consulting, flexible case management) is to help participants develop the skills necessary to manage their budgets and workers to meet individual support needs. The financial management services focus on back off support related to service payments, employment compliance and fiscal accountability¹³.

In the UK, leaders in the self-direction movement recently argued for the removal of barriers that prevent participants using intermediaries. They suggested that after 21 years of experience of direct payments, the UK system is close to the upper limit in people who want to manage a direct payment (25%¹⁴), employ their own staff and take on 'the relatively onerous responsibilities of being an employer'.¹⁵ They outlined two other approaches that make it possible for participants to get personalised support without forcing them to become employers. These include enabling people to:

- use their direct payment to purchase support from an organisation that will employ and manage any support staff (this is similar to the shared management approach favoured by many Australian states and territories)
- choose who will provide them with support and then fund this support by contracting directly with the support provider in a way that gives the support provider greater flexibility to operationalize the support and give the person the right to terminate the contract.

Whilst both these approaches are supported in recent UK guidance material, Duffy argues that ill informed bureaucratic obstacles thwart their implementation.

¹² Murphy, M., Selkow, I., & Mahoney, K., (2011) Financial management services in participant direction programs, p3 CLASS Technical Assistance brief Series, The Scan Foundation, accessed http://www.thescanfoundation.org/sites/default/files/TSF_CLASS_TA_Comprehensive.pdf 22 March 2017

¹³ Ibid, p5

¹⁴ Duffy, S., & Watson, C, Individual Service Funds in Dorset Accessed at <http://www.centreforwelfarereform.org/library/type/text/individual-service-funds-ifs-in-dorset.html> 29 march 2017

¹⁵ Duffy, S., et al (2017) Letter on obstacles for personal budgets, Centre for Welfare reform. Accessed at <http://www.centreforwelfarereform.org/library/by-date/letter-on-obstacle-for-personal-budgets.html> 22 March 2017

UK and US experience demonstrates the extent to which participants value the use of intermediaries as a strategy that enables them to have control over key decisions without the administrative responsibilities.

It is an area of NDIA practice that is under-developed but has the capacity extend choice and control for more participants providing them with control over the what, when, where and by whom of support without the administrative responsibilities. 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.

4.5.4. Reframe Support Coordination

Current Practice Guidance prevents the use of Support Coordination for participants who have informal support and makes the assumption that self-managing participants 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.

Support Coordination is one of the possible strategies to 'enable support'. The IAC

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.

4.6 Address the skill deficit in the sector

The skill in using paid support to foster relationships, build informal support and fade out paid support is critical in enabling people with disability to participate without a paid person velcroed to their side. Stancliffe¹⁶ demonstrates the skill set effectively in his study of helping older people with disability¹⁷ to transition to retirement being supported by unpaid relationships in environments of older people. This is not a skill set readily available in the market leading to serious financial implications for the Scheme.

5. Conclusion

¹⁶ Stancliffe et al 2013, Transition to retirement, Policy Bulletin No 2 at <https://sydney.edu.au/health-sciences/cdrp/pdfs/policy-bulletin-2-retirement-2013.pdf>

¹⁷ who had spent their whole lives in day programs and group homes

The benefit of self-management to health and wellbeing of participants is clear irrespective of whether the participant undertakes the legal and financial responsibilities associated with self-management. The NDIA reluctance to equally value self-management using an intermediary is counterproductive because it inhibits the development of an intermediary market that will support self-management and makes it harder for the NDIA to move toward its target of self-managing participants.

Enhanced participant choice and control and self-management are valuable to participants and the Scheme. They represent an opportunity to disrupt the current disability service market creating new markets of participants seeking value for money and an ordinary life using mainstream and community services rather than being reliant on specialist disability services. Relationships and belonging are at the core of an ordinary life and a commitment to these most human needs, together with skilled facilitation will lead to enhanced informal support and hence less need for paid support. From the perspective of the NDIS, these positive participant life outcomes are associated with increased independence, self-management and inclusion, value for money and lower package costs and enhanced Scheme sustainability.

The paper has identified a range of strategies that can support the growth of self-management in an efficient, effective and risk mitigating way. These include increased flexibility of funding, a guide to help participants understand how to direct their support and gain greater control of their lives, systems to support participant self-direction and self-management, continued work in relation to the risk of improper payments and strategies to address critical skill deficits. These will help the NDIA to grow self-management in a sustainable way. The recommendations below identify steps to enhance participant motivation, skill and confidence toward increased self-direction and self-management in a system that assures the NDIA of its integrity.

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