

## PROMOTING SELF-DIRECTION<sup>1</sup> IN THE NDIS

COUNCIL MEMBER: SYLVANA MAHMIC

WRITER: BELINDA EPSTEIN-FRISCH

### 1. Introduction

The NDIS provides a unique opportunity for people with disability in Australia to have the support they need to live the lives they choose. A number of core elements differentiate the NDIS from State and Territory provision. First, eligible individuals are able to identify personal goals and aspirations and receive reasonable and necessary supports to compliment informal, community and mainstream services. Second, the funding is allocated to the participant to support independence and social and economic participation and to enable the exercise of choice and control to the full extent of the participant's capacity. Self-directed funding that gives participants control over major decisions related to the nature and delivery of their support is a critical element in making the legislative aspirations a reality.

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. A significant body of research 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.

The research quoted by the Productivity Commission in Appendix E draws on studies with different management arrangements facilitating self-direction. Differences are related to variations on two critical issues: **who holds the funds** and associated administrative arrangements and **who controls the funds** through planning and managing the package. Some studies reported on direct payment and the majority reported on mechanisms in which a service provider shared control with the individual. Of great interest is the fact that the positive impacts of self-direction are consistent irrespective of whether the individual manages the funding or the responsibilities are shared with a service provider.

In fact, the beneficial impacts of self-direction are reported by the Productivity Commission to extend to the service system. These include reducing the demand for formal services, costing less than other alternatives and partly addressing staffing shortages.

Research demonstrates that people with self-directed support have more active social networks, increased social, economic and community participation and improved wellbeing. These factors are also associated with less dependence on the formal service system. The Productivity Commission argued that there is enough evidence from diverse sources to suggest that self-directed funding is likely to be less costly than alternative service models (Productivity Commission table E.5).

---

<sup>1</sup> This paper deliberately uses the term self-direction rather than self-managed in or to convey a broader application of choice and control as seen in the glossary in Table 1

The Productivity Commission also argued that self-directed funding and personal planning may partly address the shortage of staff because it will draw the so-called 'grey' market of family, friends and neighbours into the pool of people who can provide support to people; it will reduce the number of administrators responsible for contracting and managing frontline workers by shifting that responsibility to people with disability and their families and it will shift away from specialist services to mainstream services (for example, joining a local Scouts group or a gym).

-----

The Independent Advisory Council believes that the NDIS unnecessarily limits the recognition and support for self-direction thereby reducing positive impacts for individuals as well as the NDIS. The Council believes that the NDIS definition of the term self-management is unnecessarily narrow and fails to recognise and support the multiple systems and services mechanisms across Australia that enable people with disability and families to have significant control over the way they manage their supports.

This paper will outline barriers to self-direction drawing on first hand experience of people with disability, families and services in the Hunter as people transition into the NDIS. These barriers include the lack of clarity of language; limitations of plan management provisions of the NDIS, unintentional disincentives to self-management and prevailing attitudes that self-management is *too hard*.

The paper will then outline enablers of self-direction including recognition of State and Territory shared management options, recognition of and support for quality plan implementation support, incentives to retain and strengthen the positive aspects of self-direction and strategies to assist people to self-direct. A proposal for adjustments to the current plan management approach will be outlined to provide clear messages to enable and support people with disability to direct their own support.

The paper will conclude with feedback of NDIA staff to the ideas canvassed in this paper as well as a response to that feedback and the identification of a clear issue for Council advice.

## **2. Experience of Hunter residents moving from the NSW self-managed *Community Participation* program to the NDIS**

The NSW self-managed *Community Participation* program provides day program support for young people with a disability with moderate to high support needs who need an alternative to paid employment or further education in the medium or longer term.

The program operates under a shared management approach where a service provider is the fund holder and participants and their parents are able to negotiate the level of responsibility they want in relation to planning, staffing, support coordination and financial management. The funding from the NSW includes 12% for service and financial administration costs.

Self-managed *Community Participation* has been available in NSW since 2009 and a significant group of the early adopters now undertake all the life planning, staffing and support coordination functions. Many other participants enjoy the control self-managed *Community*

*Participation* gives them over lifestyle decisions but appreciate and want to retain the value added quality plan implementation support from the service in relation to, for example, 'how to develop real freely given relationships'. Others continue to look to the service for assistance in staff recruitment and training, support coordination and the life planning required moving from aspirational goals to real life outcomes.

Those who have moved from self-managed *Community Participation* to the NDIS in the Hunter Trial Site have been disappointed. It appears to the participants, their families and the services that support them that in general, the NDIA only pays for direct support and makes no active provision for aspects of service provision they relied upon in shared management such as:

- Life planning from aspirational goals to the micro steps required to achieve an outcome;
- Capacity to select staff individually;
- Support coordination;
- Professional development of staff.

In theory, an NDIS registered plan management provider could undertake some of these functions as part of its service intermediary role. Given however, that no participants have used a plan management provider, it can be deduced that this avenue of sourcing supports necessary to build a life have not been accessed.

**There is a fear that if the value of life planning, assistance with staffing, and support coordination are not recognized and funded, the functions will not be there in the future.**

Most people with disability and families in the Hunter trial site have not been aware that these are 'services' they need to request. They believe they are asking for the 'self-managed *Community Participation*' under the NDIS and that the professional assistance they have taken for granted will be part of the package. When they realize it is not, they are faced with uncomfortable conversations with service providers who inform them that: if coordination of supports is not written into the plan, the service does not have the money to do it; when staff they have personally selected leave, there is no money to advertise and so people are forced to use agency staff rather than individual selection.

### **Case study**

*The family of a gentleman with autism believed that his 23 hours of direct support per week had been transferred from a NSW self-managed funding program to the NDIS. He remained with the same provider but experienced a most significant change, namely that instead of being able to select his own staff when his staff moved on, he was forced to use allocated agency staff and over a period of months went from having 3 staff to 9 staff. In addition, he was forced to change the times at which he received assistance to fit in with staff timetables.*

### **Case study**

*The mother of a young woman with very high and complex needs found that the flexibility she and her daughter valued so highly has reduced. Previous lifestyle choices such as having a massage and support to attend a concert in Sydney (requiring an overnight stay) are now not permitted. Under state provision, the young woman had a*

*budget determined by her support needs and she was free to use it as appropriate. This has been replaced by the payment of direct support for NDIA approved line items significantly reducing the person centred nature and flexibility of her support and lifestyle.*

*Issues around staffing are also of great concern. The requirement to use the agency staff when her staff leave has been exacerbated by the fact that one highly trained support worker that the family selected and trained is now no longer available to them because she is being used by 'people in greater need'. The mother reported that she feels she has lost the anchor she experienced through the supportive relationship with the service especially the 'sounding out' conversation that she valued. She is not sure where that type of support will come from in the future.*

*Finally, the mother reported that there was no real discussion about plan management. She undertook to self-manage a small part of her daughter's package and the NDIA planner assumed that the Agency would manage the rest.*

Anecdotal evidence suggests that where people have been primed to ask for coordination, they have only been successful where they can argue their needs are complex for which they have received 10 hours per year for this assistance. This provides less assistance than they have been used to.

These case studies reflect a serious reduction in self-direction. The capacity to select one's own staff is central to having the lifestyle of choice; especially for people with cognitive impairment for whom paid support has the capacity to facilitate valued roles and lifestyle. Only staff that truly know the person and are committed to their goals will promote relationships in ways that fade out the role of paid staff. At best, agency staff will provide paid friendship.

### **3. Barriers to self-direction**

#### **Confusion of language**

The term 'self-management' is not used consistently across Australia and this is causing confusion for people with disability, families, service providers and government. The term is not defined in the glossary of the NDIS Quarterly Reports but operationally, it refers to individuals who directly receive all or part of their funding and are responsible for all aspects of implementation and reporting of their NDIS package. Limiting the definition in this way does not represent the intent of self-management as it suggests that individuals who choose to have varying involvement with the administrative processes are not taking control of their lives, their supports and their funding.

The following table lists the terms associated with self-management and defines their current usage within Australia.

Table 1 Terms and definitions associated with individual funding in Australia

Term	Common usage	Use in other contexts
Self-directed support	<p>An approach that gives people with disability greater control over their support and their lives. Often described as self-directed planning, self-directed funding and self-directed support.</p> <p>Self-directed support can be managed through a service provider, a financial intermediary or via a direct payment.</p> <p>Most of the literature on self-directed support refers to arrangements in which a service provider is the fund holder (i.e. shared management)</p>	Consistent meaning across jurisdictions.
Self-managed	<p>Self-managed 'support' is used in NSW to describe arrangements whereby a service provider holds the funds and the participant takes the desired level of responsibility for life planning, recruitment, training and support of staff, and for support coordination.</p> <p>Service provider is the employer.</p>	Self-managed 'funding' is used by NDIS to refer to payment of the entire package directly to the participant (or nominee) who is responsible for all aspects of administration of the package.
Direct payment	States and Territories use this term to refer to an arrangement whereby the payment of the entire package is made directly to the participant (or nominee) who is responsible for all aspects of administration of the package.	NDIS refers to this as self-managed funding.
Shared management	<p>Agreed sharing of funding and service management responsibilities between the person with disability and their family and a disability service provider who holds the funds. The participant takes the desired level of responsibility for micro planning, recruitment, training and support of staff, for support coordination and in some states for employment and payment of staff.</p>	<p>In NSW this is referred to as self-management.</p> <p>Some of these functions are undertaken by a plan management provider under the NDIS</p>
Plan management	NDIS term defined as 'managing the funding for supports in a plan' and includes purchasing the supports, receiving and managing funding from NDIA and acquitting funding provided by NDIA.	No known usage of this term nationally.

## **Limitations of NDIS plan management**

The NDIS (Plan Management) Rules and Operational Guidelines deal with issues of management of funding under the plan.

Information sheets for participants identify plan management options (self-managed, registered plan management provider, the NDIA or a combination) and describe a registered plan management provider as an individual or organisation that manages the funding of support in a participant's plan. The role of a service intermediary is introduced and includes:

- Assisting participants develop skills in this area;
- Negotiating and coordinating the provision of supports;
- Sourcing providers;
- Negotiating method and timing of delivery of supports;
- Negotiating individual requirements as part of the support management.

The service intermediary role can only be undertaken in conjunction with the financial intermediary role.

There are a number of significant limitations of the NDIS plan management framework. Firstly, many people are confused about the concept of plan management. To most people with disability, one's plan is much more than the money. The plan is the document linking aspirations with supports to achieve outcomes and people want to own the plan as a symbol of the ownership of their lives. The term 'plan management' however suggests that the participant's aspirations and lifestyle are being 'managed' and this is contrary to the philosophy that the NDIS provides participants with the opportunity to learn how to take increasing control of their packages and their lives.

Secondly, the Council believes that the assistance anticipated in the service intermediary role is not an optional extra if one is to move from having a paid friend to using paid support in ways that complement and extend informal support. It appears that most NDIS participants are currently funded for direct support but without the infrastructure of a service intermediary role, most participants will not maximise their opportunities.

Thirdly, the service intermediary role as described by the NDIS may be too limited. Under shared management, favoured by many under state and territory provision, the service intermediary provides quality plan implementation support, assisting participants with life planning involved in moving from aspirational goals to implementation of outcomes e.g. having friends, having a job, moving into one's own home, staff recruitment, training and support and support coordination and in some states with employment and payment of staff.

For most participants, these functions are undertaken in a capacity building way that leads to an increased readiness to take responsibility. Some participants however seek ongoing service involvement and choose the shared management option for the authority it affords in choosing lifestyle and ensuring supports are implemented to achieve outcomes in ways consistent with values.

Finally, the fact that the service intermediary role is not identified in the Rules or Operational Guidelines and can only be undertaken in conjunction with the financial intermediary role has

led it to be little understood and hence not utilised. One provider described this linking as a fatal flaw for the service intermediary role.

Table 1.3.1 of the NDIS Quarterly Report to COAG Disability Reform Council (March 2014) demonstrates that the option of using a plan management provider under the NDIS is not understood. Across the trial sites, the majority of plans are agency managed. Only a small proportion of plans are solely self-managed and no participants are using a plan management provider.

State	Agency Managed	Combination	Plan Management Provider	Self-Managed
NSW	68%	30%	0%	2%
SA	83%	12%	0%	5%
TAS	66%	31%	0%	3%
VIC	71%	29%	0%	1%
<b>Total</b>	<b>72%</b>	<b>26%</b>	<b>0%</b>	<b>2%</b>

In summary, the Council believes that under current NDIS Plan management processes, the valued assistance found in state and territory shared management has been lost. This represents a loss of quality plan implementation support critical to building the capacity of people with disability and families to maximise the opportunities enabled under the NDIS and a loss of recognition and valuing of options to attain self-direction.

### **Disincentives to self-manage under the NDIS**

There is no reward to the individual (other than control over their supports) for taking on the additional responsibilities related to self-management. In NSW for example, eligible people receive a package of support based on their assessed need. The size of the package is based on the cost of gaining the required support with a service provider taking 12% for administration. Where a person uses a financial intermediary (at a cost of 5% of their package), the person gains the benefit of being able to use additional hours of support from their package. Where a person uses self-management, further additional hours of support accrue to the individual.

Under the NDIS, this incentive of extra value for money does not accrue to the individual. The Agency argues that people are allocated reasonable and necessary supports and that it would be inequitable to advantage people who take the additional responsibilities of self-management. This reflects a disincentive when compared to current State and Territory service systems.

In addition, the NDIS fee structure does not sufficiently differentiate service offerings such as quality plan implementation support that people value under shared management, offerings such as additional time for life planning, support to recruit/select, train and supervise staff and support coordination. If the fee structure differentiated these offerings, more people would be interested to purchase assistance with self and shared management, making the task easier.

### **The prevailing view that self-direction is too hard**

The uptake of self-directed services in the UK varied enormously, more than could be accounted for by chance. Analysis indicated that differences in the attitudes and support given by local authorities, varying animosity from public sector unions, and variations in voluntary sector advocacy for direct payments significantly affected the adoption of consumer-directed payments (Hasler and Stewart 2004, Rankin 2005, Riddell et al. 2005, Glasby and Littlechild 2009, pp. 47ff, Davey et al. 2007, reported in Glasby 2007)).

This is reflected in a recent Australian study by Rees (2013) where study participants believed it was critical to challenge the attitudes of funding bodies and organisations that place barriers that inhibit the take up of self-management. This means stopping the prevailing message that self-directing / self-managing is *'too hard'* and something to be feared, an attitude that was reflected in 2013 presentations by NDIA staff in the Hunter.

## **4. Enablers of self-direction**

### **Recognition of and support for shared management as an option with which people are familiar**

State and territory systems have used shared management structures over many years. The service is the fund holder and employer of staff and responsibilities for aspects of service management are delegated to people with disability and families reflective of their capacities and wishes at any time. The intermediary roles are highly valued, providing quality plan implementation support crucial in assisting people to increase their capacity to direct their own support. They have provided a training ground for people who want to self-manage their funding.

Other participants want the service provider to retain a role but choose the shared management option because they want to ensure that the support is used to develop the chosen lifestyle in ways that are consistent with family values. Offerings provided through self-management and NDIA managed services do not afford participants this level of choice over management for service delivery.

### **Recognition of and support for quality plan implementation support**

'Good' service provision under shared management offers participants much more than direct support. Services provide quality plan implementation support, helping people to plan, develop skills and orient staff to enable the direct support to go from an outing with a paid friend to facilitation of opportunities to develop relationships, build informal support and fade out paid support. This is not the natural orientation of direct support workers and if direct support is the only aspect of service provision funded, opportunities inherent in individualised support will be missed.

Many people who use disability supports to complement informal support have gained the knowledge and skills to do so from quality plan implementation support provided by skilled and experienced people.



Newer participants who have not had the experience of shared management models may not recognise the need to seek this professional assistance and will then flounder in moving toward their real life goals.

Quality plan implementation support leads to more cost effective support because it leads to the development of informal support that can both improve quality of life (because it leads to an increase in real relationships) and reduce the amount of paid support over time. Quality plan implementation support needs to be recognised and funded by the NDIA as a 'standard' part of service delivery.

### **Retain and strengthen the benefits of state enabled self-directed support**

#### Strengthen the person centred nature of NDIS plans and supports

Many individuals and families consider the reduction in flexibility as a result of having one's lifestyle choices filtered through an NDIS lens a loss. So long as the requirements of value for money and not duplicate the supports available from other systems, the Council believes it is important to provide maximum flexibility in how people use their reasonable and necessary support.

For example, when an adult with disability chooses to use his funding to pay the rent for house sharers who provide significant informal support, Council believes that the Agency should recognise the use as value for money rather than preventing the practice on the general provision that rent is a private expense. The Agency should consider that the particular example is one of an innovative use of support funding - the participant pays his own rent from personal income but uses his reasonable and necessary support to pay (or subsidise) the rent of the house sharers as a strategy to establish a home living with friends who do not have a disability in a way that is cost effective.

For example, when a woman with significant physical disability uses her funding to purchase a massage, Council believes that the Agency should recognise this as a value for money approach to health and wellbeing that reduces muscle tension and the likelihood of decreased mobility. The fact that people without disability pay for a massage from personal income is not the issue.

#### Retain and strengthen capacity for participants to select their own staff

Service providers in the Hunter have argued that the unit cost of service provision is insufficient to enable people to advertise for their own staff. Certainly people moving from shared management in NSW to the NDIS using the same service provider have been prevented from recruiting and selecting their own staff and service providers relate this directly to the unit cost from the NDIA compared to the unit cost from the NSW government.

The capacity to select one's own staff is an aspect of self-direction most valued by participants who are prepared to take considerable time and effort to ensure a good fit with the person assisted. NDIA facilitation of opportunities for participants to be able to select their own staff will provide a very strong incentive to the uptake of self-direction.

### Assist people with disability and families to direct their own support

The move to self-directed support must come from the individual. The NDIA can however set in place strategies under which moves to self-direction are more likely to occur. Some strategies include:

#### Provide clear information to assist people to use self-directed and self-managed options via

- Offering training;
- Developing on line resources;
- Developing a telephone advice line that provides information necessary for the smooth and successful management of a support package e.g. wage rates, insurance, WHS information

#### Build the capacity of individuals

Rees (2013) asked people who were self-managing their packages (i.e. had a direct payment) what type of assistance they believed would be valuable in assisting others think about self-management. They identified factors critical to success including:

- Proactive thinking about what a good life might look like including assistance to develop a vision and strengthen informal support;
- The opportunity to connect with others who are self-managing;
- Having clear information about what self-management entails including from personal, financial and administrative perspectives.

The NDIS needs provide incentives for skill development, particularly for participants using self-managed and self-directed options. The availability of systemic strategies that build capacity of people with disability and families (tier 2) as well as enabling individual participants to have capacity building funds within their package (tier3) would be of value.

#### Facilitate the development of user-led organisations that supports people to self-manage

Glasby and Duffy (2007) reported that where direct payments have been taken up enthusiastically, the biggest successes have often come where there is a user-led Centre for Independent Living to provide advice and peer support for people thinking about such an option and starting to test out whether it is for them. Steps should be taken to encourage the development of user-led, Disability Support Organisations as obvious sources of peer support.

#### Embed supports for people who face multiple disadvantages

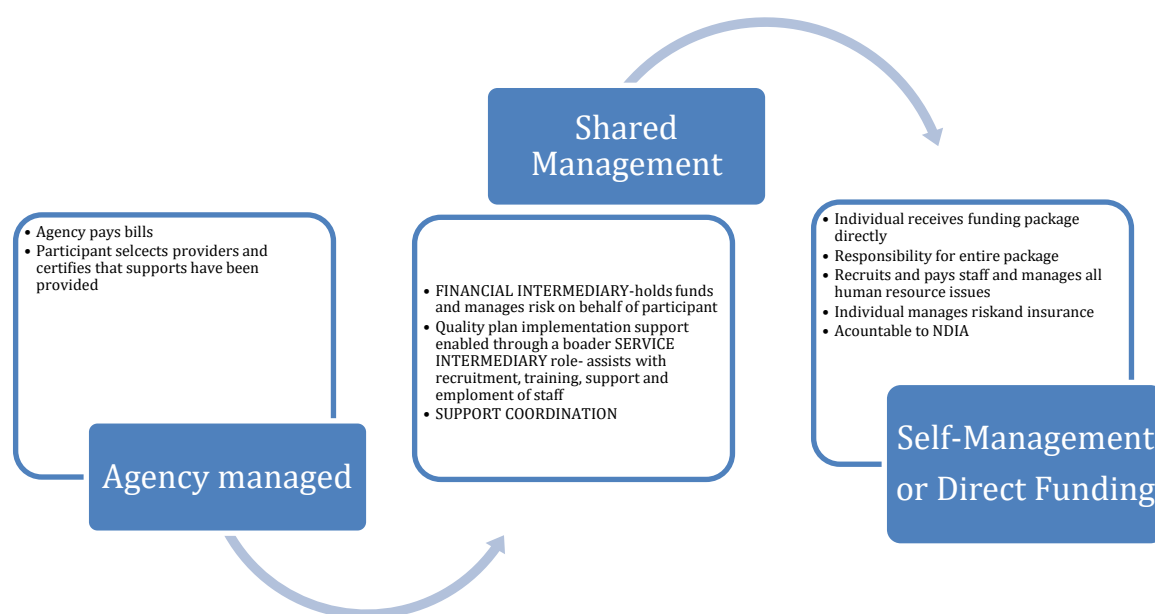
It could be argued that use of shared management is an option that affords increased flexibility and hence accommodates individual circumstances for people of ATSI and CALD heritage and people in rural and remote areas. This is because shared management gives people the opportunity to develop a lifestyle and support that is very individual and hence more closely aligned to their values, cultural practices and lived experience. The challenge however is that few people experiencing multiple disadvantages use self-directed options because they lack the knowledge and skills to negotiate the system.

Additional targeted assistance will be required if people experiencing multiple disadvantages are to have greater uptake of self-directed options. It is anticipated that such steps would

increase participant engagement and satisfaction with the NDIS as well as an increase in the empowerment of participants. Experience in self-directed options could provide a stepping-stone to the use of self-management.

## 5. Alternative framework describing the continuum of self-management

The limitations of the NDIS plan management framework could be overcome by either replacing the role of plan management provider with that of shared management or ensuring that the functions of shared management are fully incorporated in the role of the registered plan management provider. Shared management is a term understood by people with disability, families, service providers and governments across much of Australia and more clearly delineates the roles and responsibilities intended. The use of the term as part of the articulated functions in planned management would be an advantage. Further work to flesh out the continuum of self-management including exact functions and their appropriate fees would be useful.



## **6. Recommendations**

### **1. Develop a glossary to assist people across Australia to discuss the issues around individual funding**

The states have been delivering a variety of individual funding models and have developed their own terminology and definitions. The development of a national glossary is essential and will facilitate the inclusion of valued options from states and territories as well as comparisons between the NDIA experience and international experience.

The Council recommends that the Agency work with state and territory governments to develop a glossary.

- ### **2. Clarify plan management options either to**
- a. Incorporate shared management functions into registered plan management providers, or**
  - b. Replace the concept of registered plan management providers with the concept of shared management**

The role of Plan Management providers has not been understood and the fact that service intermediary role can only be undertaken in conjunction with the financial intermediary role has inhibited its use. In addition, the service intermediary role as currently structured does not appear to provide the depth of assistance provided in shared management options.

Clarification of which way to proceed is a critical decision for Council on this issue. Either way it is essential that any barriers to its utilisation be removed.

### **3. Collect statistics on participants using shared management/plan management providers in the cohort of participants who self direct under the NDIS**

The current NDIS measure of people self-managing their plan is taken as a symbol of the extent to which the NDIS is facilitating choice and control. The level of choice and control anticipated to result from the revision to the responsibilities recommended in (2) means that these participants should also be recognised for the independence and self-direction they will demonstrate.

- ### **4. Strengthen the enablers to self-direction**
- a. Recognise and support quality plan implementation support**

Quality plan implementation support offering skilled advice and facilitation for life planning, staffing, facilitating the development of role and support coordination is a critical part of individualised service provision if direct support is to go from an outing with a paid friend to the facilitation of opportunities to develop relationships, build informal support and fade out paid support.

Council recommends that quality plan implementation support is viewed as an essential element of support and built in individual packages.

- b. Retain and strengthen the state enabled benefits of self directed support including**

**i. Strengthen flexibility**

Council acknowledges the improvement in flexibility that will result from bundling of supports. However, some of the flexibility enabled under state provision has been lost as a result of having one's lifestyle choices filtered through an NDIS lens.

Council recommends a re-examination of the state enabled options that are prohibited under the NDIS (e.g. a personal trainer, a massage, payment of rent for a house sharer) and enable them if they represent value for money.

**ii. Strengthen capacity for participants to select their own staff**

The capacity to select one's staff is an aspect of self-direction most valued by participants. It is considered essential if participants are to develop valued roles and informal support.

Council recommends participants who are not using their support in a grouped environment be enabled to select their own staff.

**iii. Assist people with disability and families to direct their own support**

The move to self-direct one's support must come from the individual but the Agency can establish strategies to maximise the likelihood that participants will want to self-direct.

Council recommends that clear information is provided about self-directed options including challenging the view that self direction and self management is too hard; that resources are devoted to build the capacity of individuals to direct their own support (through allocations in their packages as well as through tier 2 funding and that steps are taken to facilitate the development of user-led organisations, associated with increased uptake of self directed options in the UK.

**5. Implement the recommendations in one trial site**

Council is mindful of the significance of recommendations that alter the infrastructure of the NDIS. In the context of a learning environment, it is considered sound to implement on a small scale and review impacts and outcomes prior to wider implementation.

Council recommends that the recommendations of this report are trialled in one of the total population launch sites.

## **Feedback on the paper from discussion with staff of the NDIA**

Belinda Epstein-Frisch and Joan McKenna Kerr had the opportunity to discuss these issues with a number of NDIA staff to gain feedback on perspectives raised. The staff then provided written feedback summarised as four main points:

- Given the legislation refers to the participant managing the funding for supports, there is no value in reopening the nomenclature debate. All participants self-direct their plans.
- Participants have the same capacity to take control of their lives if they choose to manage the funding for support themselves or they ask the Agency to pay the claims from providers for them (i.e. agency managed funding of supports).
- The concept of shared management used by States and Territories is the same as Plan Management providers under the NDIS.
- The NDIA is undertaking a project to improve plan implementation by:
  - Identifying which participants need support and capacity building to successfully implement their plans, including self-managing supports
  - Improving plan implementation supports available to participants through a broader and clearer role for support coordination that includes developing strategies for participants to achieve their goals
  - Developing resources for participants and staff to improve participants' capacity to implement their plans, including self-managing supports.

## **Response**

This paper has purposefully used the term self-direction instead of self-management in order to promote the broadest possible framework for thinking about ways to enable people to exercise choice and control of their funding, their supports and their lives. Council recognises that under all plan management options, participants are able to choose their service providers but Council believes this is a low threshold for self-direction and it is incumbent on the NDIS to take maximum steps to support participants to increase pathways to extend self-direction.

The significant point that this paper seeks to make is that current NDIS plan management options have led to a reduction in scope for people to direct their own supports. Whilst plan management providers are supposed to fulfil the function of shared management, the fact that no participant in any of the launch sites has used a registered plan management provider and the challenges of plan management outlined in this paper demonstrate that the opportunities for self direction experienced under shared management are being lost.

In addition, Council believes that the Agency has unrealistic expectations of the amount of choice and control participants have when using a service provider. Experience in the Hunter for example documents the fact that the vast majority of services do not enable participants to select their own staff.

People using State and Territory shared management options are able to take responsibility for deciding the what, when, where and by whom of support. Under shared management, people select, orient and direct their staff and train them individually in ways most relevant to the lifestyle of choice. Under these conditions, staff demonstrate a high degree of loyalty and accountability to the person with disability and their family. Traditional services however discourage and prevent the practice of recruitment of staff for individual participants, reducing the potency of relationship so pivotal to facilitating a chosen lifestyle.

Council is very pleased to see that the Agency is embarking on a project that has scope to provide the quality plan implementation support that this paper has argued is pivotal to supporting a good life but which currently missing. Council is interested to contribute to this development.

In conclusion, Council continues to be concerned that opportunities for self-direction are being lost under current NDIS provision and believes that the implementation of the recommendations proposed will go some way to restoring and strengthening all possible avenues to support people in directing their supports and their lives.

### **Recommendation**

Council recommends that concept of 'registered plan management providers' as contained in the NDIS Act, be culturally changed to reflect the roles and responsibilities found in State and territory 'shared management' providers (for example, through the operational guidelines, engagement and other explanatory material).

## References

Carr, S, 2010(*Enabling Risk, ensuring safety: Self directed supports and personal budgets*, SCIE

Duffy, S., (2012) *Designing the NDIS: An international perspective*, Centre for Welfare Reform, at <http://www.scribd.com/doc/127196426/Designing-NDIS>

Fisher, K., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'Aegher, L., & Thompson, D., (2010) *Effectiveness of individual funding approaches for disability support*, Occasional Paper No 29, SPRC

Fisher, K., *Attendant Care Program Direct Funding Pilot Evaluation* (2008) for Dept. of Ageing Disability and Home Care. SPRC Report 11/08

Glasby, J., & Duffy, S.,(2007)*Our health, our care our say: What could the NHS learn from individual budgets and direct payments*, University of Birmingham Joint HSMC and IN Control discussion paper at <http://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2007/Our-care-our-health-our-say.pdf>

Rees, K., Gitana Consulting and Training Services, *It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed/self-managed arrangements*. 21/4/2013 Practical Design Fund

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

Robinson, S, Gendera, S., Fisher, K.,R., Clements, N. and Eastman, C., (2011) *Evaluation of the self directed support pilot second report*, SPRC Report 10/11, prepared for the Dept. of Communities, Disability and Community Care Services Queensland.