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# **Independent Advisory Council Submission to the Productivity Commission Inquiry into NDIS Costs**

**March 2017**

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## Introducing the Independent Advisory Council

Under the *National Disability Insurance Scheme Act 2013* (the NDIS Act), the Independent Advisory Council (IAC) has been established to provide advice to the Board on its own initiative or at the written request of the Board about the way in which the National Disability Insurance Agency:

- performs its functions relating to the National Disability Insurance Scheme
- supports the independence and social and economic participation of people with disability;
- provides reasonable and necessary supports, including early intervention supports, for participants in the Scheme launch;
- enables people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- facilitates the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability;
- promotes the provision of high-quality and innovative supports to people with disability
- raises community awareness of the issues that affect the social and economic participation of people with disability and helps with greater community inclusion of people with disability.

In providing advice, the IAC considers the role of families, carers and other significant persons in the lives of people with disability.

The IAC consists of up to 12 members and a principal member, appointed to reflect the diversity of people with disability.

## Synopsis

This submission focuses on the issue of self-direction and self-management as a market disruptor that has the capacity to enhance Scheme sustainability.

Market disruption is desirable in the disability service sector because current traditional specialist disability service provision is expensive and has not led to positive outcomes for people with disability. In addition, there are shortages of disability support staff in general and workers skilled at providing contemporary enabling support in particular.

The NDIS is itself a promised market disruptor: funding participants to buy support rather than funding services and providing them with the ability to choose clients fundamentally changes the power relationship and paradigm. With the pressures associated with scaling up to 460,000 participants by 2020 however, the foreshadowed paradigm shift has not yet occurred as participants struggle to understand the new opportunities and the NDIA focuses on transitioning participants into the Scheme

Evidence from the 2011 Productivity Commission Report<sup>1</sup> indicates that high expectations and support for participants to take more control over their lives promotes increased capacity and positive outcomes and thereby reduced lifetime costs. This is because self-direction and self-management provide the participant with control over the what, when, where and by whom of support, making it more likely that paid support facilitates lifestyle of choice and complements rather than drives out freely given support by family and friends (informal support).

Increased participant self-direction and self-management can disrupt current patterns of service provision to transform the market to a place where more participants:

- ✓ seek more choice and control
- ✓ choose their staff for the ability to assist them to have a lifestyle of choice
- ✓ use mainstream and community services
- ✓ seek and work toward greater independence, autonomy and citizenship.

Evidence indicates that self-direction and self-management 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. Some participants use a range of new intermediaries to assist them to take control and others undertake all the work themselves (NDIS self-management).

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 services to respond to and welcome one individual than welcome groups of people with disability
- ✓ the emergence of new services or sections of existing services that are responsive to changed demand

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

- ✓ pressure on specialist disability services to provide something different.

Changed participant and provider behaviour will enhance the sustainability of the NDIS as participants with increased independence, self-management 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.

Thus the interests of people with disability and the Scheme are aligned: positive outcomes for participants enhances the sustainability of the Scheme because it:

- ✓ leads to value for money and reduced costs
- ✓ provides incentives to develop informal support
- ✓ encourages participants into mainstream and community services
- ✓ reduces reliance on specialist disability services and
- ✓ leads to increased independence, self reliance and community inclusion.

## Introduction

The fundamental premise of the insurance approach of the NDIS is the recognition that increasing the capacity of participants reduces their long term need for care and support. For people with disability, this represents a unique moment to savour: to understand that the NDIS is genuinely interested to help them increase their capacity to become more independent, more self managing and more included; that their positive outcomes and success promotes the sustainability of the Scheme.

A key question is how to promote increased capacity and positive outcomes and thereby reduce lifetime costs since these were seldom in evidence in the state disability service systems.

The IAC has written extensively<sup>2</sup> on factors that lead to positive outcomes for people with disability. Drawing on evidence from the fields of psychology, education and employment, the IAC identified key enablers of positive outcomes as positive relationships, a sense of belonging, individual autonomy, active involvement in decision-making, active social and economic participation, using one's unique strengths in ways that provide a challenge, and making a contribution.

In addition the IAC has drawn on the many evaluations of approaches to service provision to argue that when participants self-direct their support and self-manage their funds they are more likely to be able to achieve positive outcomes because they have control over the 'what, when, where and by whom' of support, making it more likely that the paid support facilitates the desired lifestyle and compliments rather than drive out freely given support by family and friends (informal support).

The challenge is that in the main, the disability service sector continues to comprise traditional services that are expensive and have not led to positive outcomes. In addition, there are shortages of disability support staff in general and workers skilled at providing contemporary enabling support in particular.

This submission argues that market disruption is required.

The NDIS is itself a promised market disruptor: funding participants to buy support rather than funding services and providing them with the ability to choose clients fundamentally changes the power relationship and paradigm. With the pressures associated with scaling up to 460,000 participants by 2020 however, the foreshadowed paradigm shift has not yet occurred as participants struggle to understand the new opportunities and the NDIA focuses on transitioning participants into the Scheme.

The demand for increased self-direction is in its early stages. Most participants from crisis driven state disability systems do not have a vision or pathway of how to maximise their

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<sup>2</sup> *Reasonable and necessary support across the lifespan: An ordinary life for people with disability (2014), Capacity Building for people with disability (2015), Activating capacity building in the NDIS at surge (2016) Enhancing personal safeguards (2015), Promoting independence (2016), and Enhancing self-direction and self-management (2016)*

independence, self-management and community inclusion. They have learnt to be dependent clients grateful for whatever was on offer.

The appetite for self-direction and self-management has been encouraged however as a result of individualised funding available through states and territories and the opportunities offered by the NDIS. Visioning seminars that showcase the opportunity for an ordinary life encourage people to aspire high. Capacity building, a term with which people were largely unfamiliar 5 years ago is now more widely discussed and over time, the provision of capacity building support will be strengthened by the emerging evidence base. Participants need a guide to show them how to build their capacity and use their reasonable and necessary support to build an ordinary life.

This changed participant behaviour will 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. Some participants use a range of new intermediaries to assist them to take control and others undertake all the work themselves (NDIS self-management).

The time is ripe for increased encouragement and support for participants to direct their own support and manage their budgets to facilitate the market disruption necessary to produce positive outcomes and promote the sustainability of the Scheme.

This submission will define self-direction and self-management and identify what is necessary to enable participants to have control of their lives as a result of control of their budget. The impact on the market and an outline of the enablers and challenges to increasing self-direction and self-management will be discussed. The submission will conclude with observations about the way forward.

## Key concepts defined

### 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 funding is self-directed because other than participants in in-kind services or in areas where a thin market means that there is only one provider, participants can choose their service provider.

### Self-management

The term self-management is **used** by the NDIS to describe a plan management option in which:

*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.*

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.

## Transforming control of the budget into lifestyle of choice

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. NDIS funding gives the participant control of their budget.

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.

Self-directed **support** is the more important ingredient in achieving positive outcomes and giving the participant control over their life. 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 control of the budget into control over life 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 'lifestyle development 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, lifestyle development 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 Local Area Coordinators and Support Coordinators is to ensure that participants develop service agreements that support person centred and self-directed service provision.

## Impact of changed participant behaviour on markets

When participants direct their support and manage their budget, they:

- ✓ seek more choice and control



- ✓ choose staff for their ability to assist them experience their lifestyle of choice
- ✓ use mainstream and community services
- ✓ seek and work toward greater independence, autonomy and citizenship.

They move from dependent clients toward active citizens who have increased independence, self-management and inclusion and as a result require less support over their lifetime.

Support for these ordinary life aspirations however is not readily available from traditional disability services. In addition, there are shortages of disability support staff in general and workers skilled at providing contemporary enabling support in particular. The system is increasingly becoming responsive to the changed demand but with encouragement and assistance, participants and their families will demand a different type of support that can disrupt current patterns of service provision and lead to:

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

## **Enablers of increased self-direction and self-management**

The National Disability Insurance Agency is committed to increasing the rate of self-management among participants and is developing its understanding of the most effective ways to do so. Some of the issues under discussion are outlined below.

### **Recognition of the value and potency of informal support**

Traditional disability service systems thwarted the involvement of families. The expert, service centric approach pushed out the contribution of family and in the context of little support, many handed their family member into state care. The notion of a partnership approach, strengthening the capacity of families to care and recognising the possibility of informal support was yet to come.

Informal support is critical for positive outcomes of participants and for sustainability of the Scheme. Informal support is the assistance that comes from relationships with people who care about (as against care for) a person with disability. The assistance is freely given and may be incidental or planned. For many people with disability, intentional strategies are required to develop, strengthen and sustain informal support.

Informal support enhances positive outcomes for participants because the existence of informal support is a sign of relationships and a step toward belonging. Informal support is important for the NDIS because informal support reduces the need for paid support. It is in the Scheme's interest therefore to invest in the intentional strategies required to develop, strengthen, sustain AND guide, informal support.

Research by Roger Stancliffe<sup>3</sup> (2013) demonstrated what it takes to build and sustain informal support so that people who had led very sheltered lives in grouped services could join community groups and ultimately all support was provided from within the group.

## Capacity building for people with disability and their supporters

The IAC paper *Capacity building for people with disability within the NDIS* provides an overview on evidence-based strategies to increase the capacity of people with disability and their supporters. Capacity building is an important market disruptor that can turn dependent clients into demanding citizens and play a significant role in reshaping the service system.

The **Information Linkages and Capacity Building (ILC)**, described as Tier 2 in the Productivity Commission's 2011 Report, is a tier of capacity building support for all people with disability, not just participants. It is widely believed that the outcomes sought do not match the level of resources provided. The risk for the sustainability of the Scheme is that the lack of capacity building opportunities through the ILC will spill over into increased demand for capacity building as part of reasonable and necessary support, thereby increasing package size. There is also a concern that the lack of widely available capacity building support may ultimately lead to an increase in the number of participants eligible to become participants.

### A skilled facilitator or guide

People who have lived their lives in rationed service centric systems require a guide, 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.

Elsewhere the IAC has described this guide as 'lifestyle development assistance'.

### Reward for initiative

Experience from small programs in states and territories recognises and demonstrates the value of rewarding initiative.

The Community Living Initiative (CLI) of WA and the Supported Living Fund (SLF) of NSW 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 high-cost 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,

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<sup>3</sup> Stancliffe et al 2013, *Transition to retirement*, Policy Bulletin No 2  
at <https://sydney.edu.au>

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.

## Flexible use of funding

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

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. Critically, evidence from state and territory programs of individualised funding demonstrate that flexibility in the use of funding produces value for money leading to an outcome that is more effective in embedding the participant in the community and costing less.

Appendix A and B provide examples of flexible use of funding that provides value for money, significantly reduces package size and contributes to embedding participants in community.

## Peer support

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. However, 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>4</sup> that disabled persons user led organisations had a significant impact on building demand and capacity for self-direction. Peer networks that they auspice also provide a unique location to grow leadership and support local group development. The valuable role of user led organisations has been recognised as one of the priority investment areas in the ILC.

## Multipronged support for self-managing participants

In November 2016, the IAC facilitated a workshop to co-design supports for increased self-management. The workshop was in response to concern that the Agency did not demonstrate sufficient support for self-management. Concerns expressed by self-managing participants related to little focus on self-management in NDIS readiness material, discouragement from planners and LAC partners that self-management was 'too hard', the removal of the float that paid self-managing participants one month in advance, lack of information about intermediaries that could reduce the administration of self-management and restrictions on

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<sup>4</sup> IAC, (2014) Capacity building for people with disability, their families and carers at 90,91

the flexible use of funding that support participants to have an ordinary life and represent value for money for the Agency.

Self-managing participants joined together with key Agency staff and members of the Board in productive discussion about current challenges resulting in a workplan of action supported by all workshop participants. The proposed action canvasses issues of:

- ensuring that NDIS readiness material includes material of self-direction and self-management
- providing support for participants who want to self-manage
- the restoration of the float that paid self-managing participants one month in advance to assist in payment of support
- the provision of information about intermediaries that could assist participants to self-manage.

## Improper use of funds as a perceived challenge

The NDIS self-management is described as a direct payment in literature from the UK. Practitioners of direct payments argue strongly that there is very little fraud among direct payment holder. They have achieved the right to a direct payment through experience and effort and take the responsibility seriously as a mark of their personal integrity. Evaluation of pilot programs have found no instances of misuse of funds<sup>5</sup> and Australian research by the Social Policy Research Centre indicates that by 2010 Australian states and territories had developed mechanisms for monitoring direct payments and had adopted risk mitigation strategies<sup>6</sup>.

Understanding the nature of improper payments is important to responding effectively. There is a continuum of improper use of funds among participants who self-manage with error at one end of the spectrum and deliberate deception or fraud at the other. In an emerging system such as the NDIS, most improper use of funds is a result of errors that occur as a result of lack of policy clarity or communications as to what can be and can't be purchased with reasonable and necessary support. This is especially likely in an environment where that which is allowed in state and territory schemes is broader than that which is allowed in the NDIS. Policy clarification and participant education provide important strategies to mitigate the erroneous use of funds.

Some of the sources of fraudulent use of funds documented in the UK (mainly with older people) include a person falsely claiming they need support, family continuing to receive a direct payment when the person with disability had died and a person controlling the direct payment account not using the money to pay for support for the person with disability and engaging in false accounting to allow money to be misappropriated<sup>7</sup>.

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<sup>5</sup> Victorian Auditor General (2011) *Individualised funding for disability services*, at 3.6

<sup>6</sup> Fisher, K., et al, (2010) *Effectiveness of individual funding approaches for disability support*, Occasional Paper No. 29, Social Policy Research Centre

<sup>7</sup> Audit Commission, (2011) *Protecting the public purse: Fighting fraud against local government*

The UK has a mature system for prevention, detection and responding to the improper use of funds. Guides developed for local authority finance managers<sup>8</sup> emphasise the need to strike an appropriate balance between the need to ensure public money is spent appropriately and the need to promote creative and individual solutions to meet people's support needs. Risk based financial monitoring arrangements have been put in place with guiding principles that:

- the assurance of individual independence and choice balanced with evidence of personal responsibility. It is reasonable to ask people to account for how they have spent their funds in achieving their support plan outcomes
- financial monitoring arrangements should be 'light touch' and proportionate to the level of risk involved
- local authorities can set a local minimum level of expenditure below which receipts are not required
- flexibility within clear boundaries, to spend the resources allocated creatively in ways that reflect the agreed outcomes. The key test of flexibility is the ability to use direct payments in ways other than those identified in the original support plan but which meet the agreed outcomes. Flexibility is described in relation to outcomes, not inputs.

Mitigation strategies discussed in the UK literature include:

- the use of data analytics to identify patterns of fraud and risk factors in large data sets
- the use of risk assessment matrices to assess perceived and actual risks and to determine the support needed to use a direct payment
- monitoring and providing support at a frequency and depth responsive to need and risk
- requiring a separate bank account for social care funds
- providing policy clarity as to what is permissible and what is not
- ensuring participants understand their responsibilities and obligations including educating participants to identify improper payments
- the use of payment cards that offer participants and local authorities more effective and responsive systems for payment.

Payment cards have many advantages for participants including averting unintentional debt and overspend by preventing participants accessing more than the pre-loaded limit. They enable participants to manage their account on line or by telephone and to include an additional card holder to assist with management of the account.

Payment cards are a valuable risk mitigation tool providing local authorities with the ability to monitor account activity, identify account management issues, manage payment adjustments and facilitate data analytics that can identify risk factors and fraud. Payment cards have been shown to improve records by consolidating client's care needs and direct payment expenditure in one place and can reduce the administrative burden and improve budgetary control providing ready evidence available for internal audit.

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<sup>8</sup> CIPFA, (2009) Self directed supports, Direct payments: A guide to local authority finance managers, Chartered institute of public finance and accountancy

In the US self directed system, the requirement for use of financial intermediaries represents a major mitigation strategy that supports participants while assuring compliance with tax and labour laws and ensures fiscal accountability and collection of participant expenditure data<sup>9</sup>.

## The way forward

This submission has argued that self-direction and self-management offer the opportunity to disrupt the current disability market. Self-direction and self-management strengthen the ability of participants to have 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 life outcomes are associated with increased independence, self-management and inclusion, value for money and lower package costs and enhanced Scheme sustainability.

The IAC believes that the Agency should use a broad based strategy to promote self-direction and self-management including:

- showcase the value of increased self-direction and self-management to participants
- encourage the use of intermediaries as a strategy to facilitate self-direction and remove the bureaucracy perceived to be associated with self-management
- provide a skilled guide to assist participants to develop ordinary lives of belonging and contribution
- reward participant and family initiative, especially for using reasonable and necessary support flexibly in ways that provide value for money
- provide assistance to self-managers
- provide peer networks to support participants in the journey.

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<sup>9</sup> Murphy, M., Selkow, & Mahoney, K.,(2011) *Financial management services in participant direction programs* CLASS Technical Assistance Brief Series Accessed at [www.thescanfoundation.org](http://www.thescanfoundation.org) 21 March 2017

## Lexicon

Term	Definition
Direct Payment	Term used in the UK as well as some states and territories to refer to personal budgets paid directly to an individual service user to spend on the support agreed in the plan
Inclusion	The practice of enabling people with disability to be full members of their communities
Informal support	Informal support is the assistance that comes from relationships with people who care about (as against care for) a person with disability. The assistance is freely given and may be incidental or planned. For many people with disability, intentional strategies are required to develop, strengthen and sustain informal support.
Intellectual Disability Reference Group	A Reference Group of the Independent Advisory Council of the NDIS tasked with providing advice on best practice in enabling people with intellectual disability to live ordinary lives in the community
Lifestyle development assistance	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.
Self-direction	A generic term for an approach that gives people with disability greater control over their support <b>and</b> their lives. The concept is often broken into component parts of self-directed planning, self-directed funding and self-directed support.
Self-management	A term used by the NDIS to describe a plan management option in which the Agency allocates the whole or part of the budget direct to the participant or their nominee who is responsible for administration
Shared management	Plan management approach used in WA, Q'ld, NSW and Victoria involving an 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
Value roles	Arising from the Social Role Valorisation Theory (SRV), valued roles describes ordinary social roles that enable a devalued person to be afforded many of the positive expectations and circumstances that people ascribe to the role.

## 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>10</sup> for people requiring 24 hour care.

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<sup>10</sup> Social Policy Research Centre, (2007) *Effectiveness of Supported Living in relation to Shared Accommodation*, at [www.sprc.unsw.edu.au](http://www.sprc.unsw.edu.au)

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.
- 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