
Optimising self-managed funding for people with a long-term disability

Dialogue Summary

April 2015



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Dialogue: The stakeholder dialogue 'Optimising self-managed funding for people with a long-term disability' was held on 5 March 2015 at the Monash Conference Centre, Melbourne, Australia.

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Executive Summary

A day-long stakeholder dialogue was held on 5 March, 2015 to consider the factors which influence the uptake of self-managed funding by people with a long-term disability, and identify barriers and facilitators to the implementation and uptake of self-managed funding. Sixteen people participated.

Discussions noted the following key considerations:

- The term ‘self-managed’ funding is more appropriate for people with long-term disability, particularly those who experience cognitive impairment.
- It should be assumed that all people with a long-term disability have the right to take up self-managed funding.
- Most people with a long-term disability have some capacity to self-manage their funding, and efforts should focus on building this capacity through education and training.
- Although people with a long-term disability may not want to take up self-managed funding the first time it is offered to them, every effort should be made to allow them ample time to consider it and opportunities provided to enable consumers and carers to ask for more information about what is required to participate.
- Self-managed funding should be offered in a timely way but as early as is possible for maximal uptake.
- To date, in the early implementation stages of current models, more people with spinal cord injury (SCI) than people with traumatic brain injury (TBI) have taken up self-managed funding; this is assumed to be a reflection of the additional complexities in the needs of people with TBI.
- To have greater success in the uptake of self-managed funding for people with a traumatic brain injury (TBI), there needs to be considerable thought about making the processes involved appropriate, particularly for those with cognitive and behavioural impairments.
- The capacity of people with a TBI to undertake the tasks associated with self-managed funding needs to be assessed by staff who have appropriate skills and also reasonable expectations of what can be accomplished.
- The relationship of the carers and family members with a person with a TBI needs to be supported through a range of offerings for self-managed funding.
- Funding agencies and service providers need to build trust and be willing to work collaboratively with people with long-term disabilities to ensure that they can consider self-managed funding as a means of empowerment and control.
- Encouraging and actively supporting people in peer support networks to talk to others about what the experience of self-managed funding is like and/or having consumer organisations conduct forums that present real-life experiences were considered next steps to increasing the uptake of self-managed funding.

Background

People with long-term disabilities have become increasingly frustrated with the inadequate support services provided by the disability sector. In particular, people with long-term disabilities want to have support services which meet their needs as well as greater choice and control in the decisions around them. Over the last five years the popularity of “self-directed” funding models has increased significantly. In 2011/12 the Australian Government made a commitment to implement a National Disability Insurance Scheme (NDIS) as advised through an inquiry by the Productivity Commission to have full rollout country wide by 2018. Self-directed funding is being encouraged for the promotion of self-determination and empowerment in people with long-term disabilities and to facilitate their living in the community independently. Self-directed funding can be provided by an individual package held by a provider, by an individual budget held by the person to spend through providers or by direct payments to spend on the open market.

An NTRI Forum was conducted to consider the factors which influence the uptake of self-directed funding by people with a long-term disability and identify barriers and facilitators to the implementation and uptake of self-directed funding.

Two questions were identified for deliberation in a Stakeholder Dialogue:

1. What are the barriers and facilitators to optimal implementation and uptake of self-directed funding in Australia and New Zealand?
2. How can knowledge of barriers and facilitators be used to address these challenges?

A briefing document was developed which synthesised research knowledge from published literature about self-directed funding models for people with a long-term disability:

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Available at: <http://www.ntriforum.org.au/ntri-forums/>

A day-long structured stakeholder dialogue was convened on 5 March, 2015 in Melbourne, Australia. Sixteen people participated in the stakeholder dialogue. Twelve of the participants were from Victoria; three were from other Australian States and Territories and one was from New Zealand. Collectively, the participants represented the following perspectives (with some participants representing multiple perspectives):

- Research, including research leadership,
- Service delivery organisations,
- Clinical practice, and
- Consumer advocacy.

This dialogue summary is directed towards professional service delivery organisations, researchers, consumer advocacy organisations, and other stakeholders with experience and/or expertise in self-directed funding in people with a long-term disability. It presents an

overview of discussions from this stakeholder dialogue, and is designed to be read in conjunction with the briefing document for this NTRI Forum.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened to enable a comprehensive discussion of relevant considerations (including research evidence) about a high-priority clinical issue in order to inform action. The key features of the dialogue were:

1. It addressed an issue that was considered high priority on the basis of one or more of the following criteria:
 - *Overall importance*: prevalence, current impact on patients and / or costs to the healthcare system.
 - *Novelty*: an emerging issue, for example new treatment / technology.
 - *Controversy*: variability in opinion and / or current practice.
 - *Context*: action required within a specified timeframe (for example, policy submission) or other drivers of action present.
2. It focused on different features of the problem, including (where possible) how it affected particular groups
3. It was informed by a pre-circulated briefing document that synthesised research evidence from published literature about effective support strategies in a range of contexts
5. It brought together many parties who would be involved in or affected by future decisions related to the issue
6. It ensured fair representation among clinicians, organisational leaders and other stakeholders relevant to the issue
7. It engaged a facilitator to assist with the deliberations
8. It allowed for frank, off-the-record deliberations, by following the Chatham House rule: “Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”; and
9. It did not aim for consensus.

Participants’ views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue aimed to connect the information from the briefing document with the people who can make change happen, and energise and inspire the participants by bringing them together to address a common challenge. This use of collective problem solving can create outcomes that are not otherwise possible, because it transforms each individual’s knowledge to a collective ‘team knowledge’ that can spark insights and generate action addressing the issue.

Box 2: Data sources

This dialogue summary was prepared based upon two sets of written notes of discussion taken independently by two NTRI Forum staff (audio of stakeholder dialogues is not recorded). These notes were analysed to identify key themes and other information relevant to optimising return to work practices for people with catastrophic injury.

Summary of Deliberations

Opening comments on the topic

- Self-directed funding models have been in existence for several decades, however there is still difficulty with successfully implementing them in the Australian context.
- The factors which contribute to the success of particular self-directed funding models are not widely available or published in a comprehensive manner.
- Many participants did not feel that the term “self-directed” funding was accurate for use in the current forum, particularly for people who have traumatic brain injury with cognitive impairment. The term “self-managed” funding was proposed and received agreement from most participants to be more accurate, hence this terminology will be referred to for the remainder of this document.
- The concept of self-managed funding was acknowledged as being rights-based, i.e. it is a person’s right to be able to take up self-managed funding for empowerment and control.
- Some participants expressed the view that it may take a long period of time for people with a long-term disability to contemplate self-managed funding. Many participants believed consumers may feel scared to change, or believe that there must be a “catch” or “trap” to taking it up. There was also a view that some consumers may not want to manage their own funding because they are happy with their current approach. Participants believed, however, that all consumers should be offered information and encouraged to consider taking up self-managed funding.

Participants identified and discussed some of the factors and issues which should be considered in the implementation of self-managed funding models:

- The current disability support system has been established for many decades. Introducing self-managed funding models into an already established system is difficult and complex.
- The time required to transition from traditional, older funding models to newer self-managed funding models. This is likely to create some problems for some people until there has been sufficient time to establish strong procedures.
- The need for funding agencies and service providers to collaborate with and respect the perspectives of people with a long-term disability when designing self-managed funding models. This takes time and effort and recognises the concerns of consumers, but should contribute to a stronger system in the long-term.
- Clearly communicating what self-managed funding models are. People tend to recognise “brands” of products, so putting a name to the particular self-managed funding model could be useful in promoting awareness and uptake.
- Clearly identifying and advocating for policies that assist the implementation of self-managed funding models. Some policies may not support self-managed funding models as well as others and/or are different across Australian states/territories (e.g., employment and social services policies).
- Outcomes for carers and/or families of people with a long-term disability. Self-managed funding models need to identify and consider their intended consequences for carers and families.

Participants considered that a cultural shift is needed within the field of catastrophic injury to support people to take up self-managed funding. Providing clear resources for both service

providers and people with a catastrophic injury was considered important to encouraging this shift. Steps might include:

- Investigating what is required to get people within the field to think about funding models differently (e.g., recognizing the positive consequences that can result from taking up self-managed funding).
- Increasing the awareness of the concept of self-managed funding. Participants believed that people with a brain injury are often not even aware that self-managed funding exists and/or how they would go about it.
- Provide suitable and appropriate education about self-managed funding so that people with a catastrophic injury are well-prepared to take up the option.

What models currently exist for self-managed funding for people with a catastrophic injury?

A major discussion centred on what models and their features were available in Australia and New Zealand for people with a catastrophic injury for self-managed funding to consider the factors which may influence uptake of self-managed funding. A summary is provided in Table 1.

Table 1 – Current models for self-managed funding for people with a catastrophic injury

Model	Accident Compensation Corporation (ACC) model	Life Time Care and Support (LTCS) model	Individualised Funding -TAC model
National or State level	National (New Zealand)	State (New South Wales)	State (Victoria)
Type of disability	Catastrophic injury (mostly people with SCI)	Catastrophic injury (mostly people with SCI)	Catastrophic injury (mostly people with SCI)
No. of participants (at 5 March 2015)	53	11	31
Which model is it based on?	International models	UK, Attendant Care Program NSW, and TAC model	International models
Implementation stage	Full national roll-out since August 2014 (in 2013 there was an initial pilot)	State wide	State wide
Assessment	Independent (external contractor)	Internal coordinators	Internal coordinators and client self-assessment report of their capacity
Is there an agreement?	Signed agreement	Signed agreement (\$1000 offered for independent legal support assistance)	Signed legal agreement (2 years or less)
How is it administered?	Personal Bank account	Personal Bank account	TAC corporate bank account with client access A debit card with a daily \$200 limit is provided to the client
Criteria for eligibility	<ul style="list-style-type: none"> • Person with a long-term disability must be 18 years or older • Must have a stable support system • An ability to make decisions • No comorbidities, i.e. gambling 	<ul style="list-style-type: none"> • Stable, interested and able to manage their care needs • Must be assessed for “capacity” (person is considered to understand the concept of self-managed funding) 	Not reported

	or drug problems		
Funding	1 year itemised budget provided quarterly	1 year	Yearly budget provided (based on average expenditure and needs/life goals)
Options available under the model	<p>An intermediary which undergoes an assessment to avoid misuse of funds (risk mitigated)</p> <p>Case manager or support worker (available always) through the service provider</p>	<p>Family members can be employed however this is not encouraged and they must be employed by a service provider</p> <p>Case manager or support worker (available always) through the service provider (in-house)</p>	<p>A parent of a child, contracted manager or financial intermediary can “self-manage” on the person’s behalf</p> <p>A plan is not required but available</p> <p>Not open market (do provide a list of eligible providers)</p> <p>Cannot self-employ</p>
Supports types available for funding	<ul style="list-style-type: none"> • Home and community support services including attendant care and day care (formal carers, or can choose a family member that is not employed through an agency, i.e. not considered an employer), day programs • Medical consumables, pharmaceuticals, transport needs, podiatry, equipment \$1000 and under 	<ul style="list-style-type: none"> • Mostly attendant care 	<p>Most support services (there is a list of what can be purchased)</p>
Monitoring	Case by case	Submission of receipts or bank statements (every two weeks or longer if low level of services)	<p>Formal evaluation (3, 6, 9 and 12 months)</p> <p>Review expenditure</p>

What are the barriers and facilitators to optimal implementation and uptake of self-managed funding in Australia and New Zealand?

There was a discussion on the barriers and facilitators to optimal implementation and uptake of self-managed funding, particularly for people with catastrophic injury in Australia and New Zealand. The barriers are grouped into those associated with funding agencies, service providers, people with a catastrophic injury and at the system-level.

Barriers of self-managed funding for people with a catastrophic injury

- *Funding agencies and service providers:*
 - The approach to offering self-managed funding to consumers. While it is assumed that invitations to take up self-managed funding are offered appropriately, there was recognition that this is often not the case. There is no consistency within the sector as to how to engage consumers with catastrophic injury successfully,
 - Uncertainty about how to handle potential saving and stockpiling of funds. Questions about what happens to money which is not spent at the end of the 12 month budget period. For example, if a person spends less than what was itemised/agreed to, remains for funding agencies and service providers,
 - A lack of appropriate resources set up for providing self-managed funding and its long-term sustainability, and
 - That it is resource intensive in terms of staffing.
- *People with a catastrophic injury:*
 - The perceived responsibility associated with self-managed funding – for example, it is not just limited to being able to buy their own supports but also such things as arranging employment contracts, superannuation, and liability,
 - Changing their mindset in terms of saving funds for “a possible emergency” to spending on the supports they need now,
 - Fear that they don't want to make mistakes or will lose their funding if they make bad decisions, and
 - A lack of trust of and respect from the funding agency or service provider.
- *System-level*
 - Resources available in each state differ,
 - Past systems and models in Australia reflect a culture where choice is historically determined, and
 - That some models require an “all or none” commitment to self-managed funding, when some people might be willing to try self-management of some components and gradually sign-up for more responsibility.

Facilitators for encouraging the uptake of self-managed funding for people with long term disability resulting from a catastrophic injury

Most participants agreed that overall it is support from service providers and consumer/advocacy organisations that is needed to encourage uptake of self-managed funding for people with a long-term disability.

- There should be an acknowledgment of a person's right to take up self-managed funding, even if they are cognitively impaired.
- Personal contact – an identified individual to help people out so they do not feel on their own when undertaking self-managed funding.
- Building trust and working collaboratively with the person who is to undertake self-managed funding.
- Asking appropriate questions: For example, how do we help you to do this? What incentives would you like?
- A willingness to be open to consider feedback from the perspective of people with a catastrophic injury.
- Flexibility in the items and kinds of support eligible for self-managed funding.

- Offering a range of options over the continuum of recovery that are supportive of the carer/family relationship.
- Offering a financial incentive to take-up the self-managed funding.
- Enabling people to take up self-managed funding whenever they are ready, including early, late or in periods of high need for support.
- Recognising (with the aim of reducing) concerns about the potential for an increased work load and responsibility for the person's family if they take up self-managed funding.
- Having good infrastructure for monitoring, including regular review and checking progress and a key contact for the person and/or their family to ask questions about the process at any time.
- The person offering self-managed funding needs to have the necessary skills to make an assessment of the person's capacity and consider how they can be supported within their existing capacity or capacity can be further developed.
- Requirement for internal education to manage and support the cultural change required within the funding organisation.
- Support from consumer (advocacy) organisations:
 - To encourage people to share information with one another; and
 - Having forums which are driven by people with a catastrophic injury sharing their experiences of self-managed funding.

The stakeholders discussed the kinds of consumers who had taken up the option of self-managed funding to further help to identify desirable characteristics of a self-managed funding model that was suitable for people with catastrophic injury.

What are the characteristics of early adopters of self-managed funding?

- Personal factors:
 - language (people who speak good English)
 - level of education (experience in utilising technology and having a computer)
 - previously employed,
 - injury severity and/or the person's stage of recovery
 - high capacity and self-efficacy – the ability to make decisions on their own, having a willingness or being highly motivated to take self-management up, and having a supportive informal/family/social network who believe that they can take it up
 - people with unique or unusual support needs requiring individualised solutions
- Environmental or contextual factors:
 - People in regional locations – there are less choices to make due to fewer resources and the culture/attitude so consumers may be less overwhelmed by the perceived complexity of the task
 - Presence of supportive providers
 - those who have the vision, culture, and established supports already in place to offer and provide self-managed funding
 - those willing to share the process of developing the capacity for the person to be independent; they want to make it happen, and they offer support at the participant's pace
 - Time for people to take in the information on self-managed funding when offered and provided to them, and to ask questions

What is the 'ideal' model?

There was some discussion about the principles and characteristics of an ideal model.

i. Overarching principles

- Every person with a long-term disability has a right to a meaningful life as defined by the individual (Funding models should be person-centred).
- The person with a long-term disability has the right to self-determination.
- The person with a long-term disability has the right to make choices about how to manage their own care and be an active partner in the design and delivery of their care and support.

ii. Eligibility principles

- Judgment of the person's capacity to self-manage funds which takes into account a self-assessment component (including legal advice).
- An assumption that every person has some capacity; where it is deemed that the person is not capable of making all decisions themselves, the funding agency/provider should make every effort to train, educate and support the person to make choices to build their capacity over time.

iii. Assessment

- Assessment of new clients should identify disability-related needs.

iv. System for funds management

- i. Systems need to be flexible but robust and transparent and able to be used by participants with capacity issues.
- ii. There needs to be internal adoption of the approach to self-managed funding by funding agencies and service providers, including having policies and procedures that support coordinators to identify and develop the person's capacity on an ongoing basis.
- iii. The self-managed funding model should reflect a continuum of opportunities to manage care (that is, not be 'in' or 'out' of the funding model for all care and support).
- iv. Systems to monitor risks involved for people with a long-term disability in relation to:
 - *The quality and types of services*
 - a. Management through providers to ensure minimum standards are met was raised as an issue, although often this is reliant on state-based quality standards which may not be enforceable.
 - b. Having systems that enable people with a disability to employ carers directly (including family members).
 - c. Ensuring people are fully informed about providers and services available to them.
 - d. Good information sharing between funding agencies and service providers to ensure integrated and coordinated services.
 - e. Appropriate services should involve an educational component for people with a long-term disability.
 - *Appropriateness of goals*
 - a. Regular reviews should be undertaken by a skilled, knowledgeable professional that recognize individual goals as well as some standard reasonable expectations according to the type and nature of disability and level of care needs.
 - b. People with a long-term disability should be satisfied that the funding model is supporting them to achieve a meaningful life.

Is it possible to assume that all people with a catastrophic injury have the same capabilities?

There was a brief discussion about the differences in requirements for people with a traumatic brain injury (TBI) and people with a spinal cord injury (SCI) in terms of how their capacity to self-manage is measured, and how the potential for self-management can be maximised.

It was agreed by most participants that although the process of offering self-management is identical for both people with TBI and SCI, their needs, supports and experiences are very different. For people with TBI, family members usually have a big involvement in their care particularly where there are cognitive and behavioural impairments. This needs consideration when developing and implementing self-managed funding models to accommodate and be supportive of all participants. For example, education about self-managed funding to people with TBI who have a behavioural impairment such as anxiety will need to be performed face-to-face with a representative rather than in group settings to be most effective. People with TBI may also have cognitive impairments—for example a lack of insight or risk perception--therefore a highly trusting relationship needs to be built and established by funding agencies and service providers for uptake of self-managed funding to be considered. There will be further considerations that will need to be taken into account based on the person's cognitive and behavioural impairments.

Next steps

Final deliberations considered what the next steps could be in increasing the uptake of self-managed funding for the catastrophically injured and resulted in the following key points:

- Developing the self-managed funding models in a different way to make them more appropriate and appealing to the target group:
 - Offering other alternatives than only taking up self-managed funding or not. For example, allowing people to choose or trial parts of the care package or support services they would like to self-manage.
 - Have it on checklists for assessment - “Has the client been offered the self-managed funding option?”
 - If people say no when offered self-management, providers should explore how it could be made possible; what education, training, support is required?
 - Funding agencies and service providers should play a role in encouraging and promoting the philosophy of trialing a variety of self-managed funding options with clients, including:
 - Adopting the starting position that every new client can and will self-manage some elements or all of their package (the “default” option), unless they clearly don’t want to.
 - Exploring why people say “yes” and “no”: to consider the factors that lead to a “no” and see what would be required to make self-managed funding possible for a person.
- Building expectations of adoption of an early approach across the system:
 - Promoting options for self-managed funding across other information/communication channels.
 - Educating people with a long-term disability (and their carers/family), embedding information about SM options into sessions not directly related (increasing their awareness) and using different websites to impart relevant knowledge.
- Developing a strategic approach to inform people with a catastrophic injury about self-managed funding models:
 - The way and type of information presented to a person with a TBI should be appropriate:
 - Self-managed funding is not a standalone entity which sits outside of their recovery. It is also often framed as “this is a good thing for you”. However, what needs to occur is for organisations to tell people that self-management involves taking control of part of their life and it may assist in their recovery, enabling them to develop skills such as those related to return to work.
 - A flyer or a 1-page factsheet should be developed and provided to consumers, carers and their families.
 - Revise the language in information provided; recognize that not all people with a catastrophic injury may be ready to discuss the self-management option at the same time. It should also be in Plain English and easily translated into other languages.
 - Self-managed funding will not necessarily change what is received for consumers’ support needs; they may have a change in their role but

- they will still have a case manager to consult/liaise with and may even have more money to spend.
- Employ peer support networks –
 - Service providers should have a peer support liaison person employed to talk with people about taking up the self-managed funding option. The intent would be to increase trust and the relationship with the service provider.
 - Systems to support discussion and promote understanding (not relying on their own ability to understand long written or contractual documents).
 - Peer to peer discussions not just through funding agencies like TAC, but in other organisation's forums.
 - Education provided by carer organisations to inform carers that there is an option to self-manage funding and that they should consider giving it a go. They may also want to facilitate peer to peer support and/or communications.
 - Provide opportunities for clients to hear about other clients' experiences in face-face setting.

Future research considerations

The following were mentioned by participants as potential future research questions and areas for further exploration:

- Improve the approach to self-managed funding to be more person-centred/focused.
- Identify informal carer/family outcomes for self-managed funding.
- Set up systems to enable detailed analyses of (best practice) self-managed funding models.
- Increased sharing of self-managed funding evaluations across jurisdictions/countries (for example with New Zealand).
- Compile findings of multiple pilots – investigate trends and challenges.
- Invest in longitudinal studies. This could include exploring administrative data from people with catastrophic injury over time in respect of outcomes or comparing data on outcomes from people who have taken up self-managed funding with people who have chosen not to participate.
- Explore the assessment of capacity in people with traumatic brain injury and cognitive impairments - how do you assess capacity to self-manage? How do you create capacity?
- How do Australian institutional frameworks support moves towards self-managed funding? (e.g. taxation, industrial relations laws, legislation, and disability insurance policies)

Other issues identified

Box 3: Other issues

When convening leaders to discuss a high-priority issue, a range of other issues can be identified with limited or no direct relevance to the aims of the day. At the commencement of each stakeholder dialogue, participants are advised that there will be limited time to explore issues outside of these aims. These issues are acknowledged through their listing in a 'parking lot,' which can potentially be revisited at another time either within or outside of the Forum process. This section lists all such issues.

- A valid tool for informal assessment to ensure risk safeguarding and that family members have the skills needed to use and maintain the funding on behalf of the person with a disability.
- Considerations for indigenous, remotely located people to achieve self-managed funding.



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