Submission made by Julia Farr Association

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The Julia Farr Association makes this submission to the Productivity Commission's inquiry into Disability Care and Support. Our submission includes commentary on specific questions identified in the Disability Care and Support Issues Paper, May 2010.

1.0 INTRODUCTION

The Julia Farr Association and its predecessor organisations have been involved with the disability community and older persons for over 130 years. The Julia Farr Association is an independent, non-government entity based in South Australia that fosters innovation, shares useful information, and promotes policy and practice that support vulnerable people to access the good things in life. We are not a service provider – we deliver research, evaluation and information services that are anchored upon the stories shared by people living with disability and other people in their lives. As such, we feel we are in a good position to offer comment and analysis without vested interest.

The Julia Farr Association believes that the present inquiry is urgent in the current environment. It is widely understood that people living with disability are poorly-supported in Australia, in terms of dearth of choice and the experience of exclusion. There is increasing demand for services due to changes in Australia's population and demography. Further, there is national commitment to "ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities"[1] through the ratification of the UN Convention on the Rights of Persons with Disabilities by Australia in July 2008.

In considering our submission, we have elected to attempt to answer all of the questions posed by the Productivity Commission. We assume that there are clear reasons why you have framed those particular questions, and so we have done our best to respond using the same structure.

Over and above the content of this submission, we refer the Productivity Commission to the Julia Farr Association 2010 publication, 'Model of Citizenhood Support: Discussion paper', and recommend its use as a contextual framework for thinking about the type of supports people might need to move into an ordinary valued life. We also refer the Productivity Commission to our other publications that cover a range of issues relevant to the Productivity Commission's inquiry. We also refer the Productivity Commission to our website www.juliafarr.org.au, the blogsite http://juliafarrrobbi.blogspot.com and to the website www.incontrol.org.au

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[1] United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 4, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

2.0 REPSONSE TO CONSULTATION QUESTIONS

2.1 The overarching goal and government's role

2.1.1 Why should government act?

The Australian Government has commenced investigating ways to ensure the principles underpinning the UN Convention on the Rights of Persons with Disabilities (hereinafter referred to as the 'UNCRPD') are incorporated into policies and programs that support people living with disability, such as the development of the National Disability Strategy. However, people's right to personhood and *citizenhood*[2] is not currently happening for people living with disability.

The Julia Farr Association has identified through extensive consultation with the disability community[3] that people living with disability continue to experience difficulties accessing and actively participating within their local community. Some of the barriers include:

- *People not having choice and control in their lives*
  - Of the 420 people who answered the Julia Farr Association 2010 **tellus** survey[4] question "Did you choose where to live?", 28% stated that they did not have a choice;
- *People not having choice about the supports they receive*
  - Of the 316 people who answered the Julia Farr Association 2010 **tellus** survey[4] question "Did you choose who provides you with your personal support?", 51% stated that they did not have a choice;
- *People not being able to readily access premises within their community*
  - "Examples of the range of barriers people living with disability experience include toilets being inaccessible, toilets being used for storage, service counters being too high, narrow doorways and corridors, uneven car park surfaces, a lack of accessible signage, and no ramps provided or ramps having insufficient gradients"[5];

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[2] ***"Citizenhood refers to an active lifestyle that has the prospect of fulfilment for the person concerned. Such a lifestyle is one where, as part of a personally defined set of lifestyle choices, the person is in and part of their local community, contributing and growing through involvement in meaningful valued activities, and participating in a network of relationships characterised by acceptance, belonging and love" (Williams 2010, Model of citizenhood support: Discussion paper, Julia Farr Association, p. 3).***

[3] Our qualitative and quantitative research with the disability community has included feedback from: Over 700 attendees at across the previous three ***Loop*** conference programs, which take topics out to country areas in South Australia; Around 800 participants in our ***tellus*** survey in 2008 and currently over 500 participants in the new 2010 version (the survey is still open); People involved in a range of specific surveys conducted on topics of interest, including people's experiences using access taxis and accessing services from their local General Practitioner; Participants attending a range of JFA-hosted workshops on topics including personal choice and control, building networks, personal planning and action, and community development.

[4] Information about the ***tellus*** survey can be found at: http://www.surveymonkey.com/s/JFA_Living_with_Disability_Survey.

[5] Fidock, A & Williams, R 2010, *tellus survey report 3: Accessibility*, Julia Farr Association, Unley, South Australia, p. 9.

- *People not being able to readily access transport when required*
    - Of the 416 people who answered the Julia Farr Association 2010 **tellus** survey[4] question "Is it easy for you to use public transport from where you live?", 46% stated that it was not easy for them to use public transport for reasons including different modes of transport not being readily available or physically accessible, and people not being able to access transport without support from others.

The barriers people living with disability continue to experience highlight that current arrangements are showing no sign of closing the gap.

2.2 What should a new system aspire to achieve?

2.2.1 Are there tradeoffs between the aspirations for a new scheme?

No. Choice, personal authority, safeguards, active citizenhood, capacity building, and cost-effectiveness are not mutually exclusive goals.

The real key is the right balance of dedicated funding, mainstream access, and welcoming communities to ensure that people's rights under the UNCRPD are fully upheld.

2.2.2 What other reasons are there for a new approach to a disability care and support scheme? What are the implications of these objectives for the design of the scheme?

The advent of Individualised Funding (also variously known as Self-Directed Funding, Personalised Budgets, and several others) in various jurisdictions including the United Kingdom, Canada, Scandinavia, United States and various Australian States[6], gives vulnerable people control over the decisions about how best to use the public funds allocated to them. This control can have "a positive impact on quality of life, as reflected in areas such as making choices, achieving goals, participating in the community, and growing relationships"[7].

It is clear from the evaluation of Individualised Funding initiatives in various jurisdictions that when people begin to exercise control of resources within the context of an empowering personal vision, some remarkable positive changes can result[8].

The key features of Individualised Funding can include:

- Genuine control over the funds;
- Equitable system for sharing out the funds, the Resource Allocation System (RAS);

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[6] ***The 2009 report titled " Funding and service options for people with disabilities", by Lesley Chenoweth and Natalie Clements, Griffiths University, Queensland, provides an overview of the range of approaches that exist across jurisdictions where there has been a strong move towards providing people living with disability with direct funding.***

[7] Williams, R 2007, *Individualised funding. A summary review of its nature and impact, and key elements for success*, Julia Farr Association, Unley, South Australia, p. 19.

[8] Leadbeater, C, Bartlett, J & Gallagher, N 2008, *Making it personal*, Demos, London, UK, <http://www.demos.co.uk/files/Demos_PPS_web_A.pdf?1240939425>.

- Support with planning, including the options to navigate into mainstream community opportunities;
- Support with brokerage;
- Support to manage the arrangements;
- Community development.

The Julia Farr Association 2007 publication, 'Individualised Funding. A summary review of its nature and impact, and key elements for success'[7], provides more detail about the key features of Individualised Funding.

2.2.3 *What are the specific design implications of the UN Convention?*

The UNCRPD could be regarded as upholding two main types of status:

1) ***The status of personhood***
   This relates to the person's status as an individual, in terms of identity, uniqueness, value, potential, and dignity. Any service/support must be delivered in a way that honours, upholds, and advances a person's *personhood*;

2) ***The status of citizenhood***
   This relates to the person's connection with the wider community, in terms of place, membership, participation and contribution. Any service/support must be delivered in a way that honours, upholds, and advances a person's *citizenhood*.

Arising from the above, the design implications, indeed the design *principles* that a national scheme must be anchored upon are:

1) ***Entitlement to a Fair Go***
   People living with disability should access the same opportunities as other Australians for a good life, including decent housing, a decent education, the opportunity to work, good healthcare, enough money to live on, and to be visible, active and valued at the core of our communities.

   There are many aspects to a good life that we are likely to share a common interest in, and there will be other aspects of a good life that are more unique to each of us based on our individuality.

   As such, if a person has a degree of function support needs that need to be met in order to secure this far go, the person should be entitled to that support.

2) ***Front-Foot Investment***
   Disability support funding is there to assist the person to move towards a good life, characterised by the ordinary valued opportunities available to all Australians. Given that the funding comes from our taxes, which are an investment in the common good, it is important that public funds are used to support people towards that sense of good. It is not there to maintain a lifestyle of passive service recipiency. Key to this is that funds are allocated

proactively, so that people are able to get on the front-foot in their lives.

3) ***Control***
It is important the person has genuine control over how to spend their allocation of disability support funding, to choose (i.e. ‘self-direct’) arrangements that will feel right to him her/him.

4) ***Capacity***
It is important to assume every person has capacity to make choices about how s/he would like to be supported towards a good life. People are usually the experts on their own circumstances.

5) ***Having an ordinary, valued personal vision***
Any mechanism for disability support funding needs to ensure that there are resources available to assist a person envisage a good life for her/himself. This is particularly important to people who may have experienced years of passive service recipiency and whose personal horizons of what is possible may have diminished compared to non-disabled people.

6) ***Flexibility***
Each of us has an individual journey through life. It therefore follows that if a person is receiving funding assistance, there needs to be full flexibility in how the funding can be spent.

7) ***Community Connectedness***
Any mechanism for disability support funding needs to ensure that there are resources available to assist a person to navigate into community life, and that the wider community is growing its capacity to be welcoming and inclusive.

8) ***Accessible***
All aspects of the funding mechanism are designed to be accessible and easy to use.

9) ***Ownership***
The scheme’s beneficiaries should be extensively represented in the formal governance arrangements, so that the design, delivery and direction of the scheme are accountable to, and influenced by, the scheme’s beneficiaries.

2.2.4 *<u>What weight should be given to each of the various objectives? How should the various objectives be traded-off against one another if they conflict?</u>*

Delivering on the UNCRPD should be the overarching context, with all practical issues addressed within this context. If this ultimately demands higher levels of public funding, then that must happen.

2.3 Key design elements of a new scheme

2.3.1 *<u>Are there other design aspects of a scheme that are important? How are they important and how should they be incorporated into a scheme?</u>*

A key element will be the way that a person's functional support needs are understood and quantified, and then translated into a funding allocation (a personalised budget). This can happen through a mechanism called a Resource Allocation System (RAS), based on:

1. Simple co-operated assessment;
2. Assessment scores logically connected via a price point mechanism to a quantified personalised budget, developed through robust population-based analysis of support needs, corresponding levels of support; and outcomes;
3. Safeguarding mechanisms that don't override personal authority;
4. Resources available for personal/family capacity-building, to envisage valued personhood and citizenhood, to plan to move intentionally towards that;
5. Resources available for community capacity-building and accountability, to ensure an accessible, welcoming, and inclusive community.

2.4 Who should be eligible?

2.4.1 *<u>Is need the appropriate basis for eligibility?</u>*

Yes, the degree of functional support need is the appropriate basis for eligibility, as opposed to diagnosis or age. In the United Kingdom, there tends to be a single common approach to 'adult social care' that covers people living with disability, people who are ageing, people living with enduring mental illness and people living with other chronic, disabling health conditions.

To fail to adopt a similar approach in Australia would likely mean that some people will fall through very large cracks.

There is no reason therefore why the scheme cannot include people living with organic, progressive, neurological conditions such as dementia. Dementia is a disabling condition in terms of functional support needs.

2.4.2 *What groups have the highest needs or have been most disadvantaged by current arrangements?*

The group with the highest need and/or disadvantage is likely to comprise people living with an impairment that brings greater degrees of vulnerability, and who also have a lack of social capital in their lives, and who live in areas of poorer infrastructure, and who have longer experience of passive service recipiency in blunt, depersonalised, separated service settings.

2.4.3 *How does need overlap with core activity limitations or other criteria for identifying the severity of disability?*

The notion of need can be expressed in a number of ways, and this can include core activity limitations and formal diagnostic criteria. Our strong preference is for need to be understood in terms of those areas of life where a person needs functional support to uphold her/his personhood and to move into a lifestyle characterised by active citizenhood. We refer you to section 2.6.12 *How should people's needs be assessed?,* which highlights areas of functional support used in a number of United Kingdom jurisdictions to effectively allocate support funding.

2.4.4 *Is 'severe or profound' disability an appropriate criterion for the need for support?*

If the scheme uses a price-point Resource Allocation System (RAS), which matches degrees of functional support need with degrees of support funding, then the criterion of 'severe or profound' is unnecessary. It will also avoid the drama of some people being just within the criterion and others being just outside the criterion yet with relatively similar functional support needs.

2.4.5 *To what extent should other facets of a person's life: their location, access to services, family circumstances and any disadvantages affect eligibility?*

It does not affect eligibility as such, but affects size of the personalised budget that is made available. An increasing number of the jurisdictions are applying a 'social capital' factor to the extent of funding available, and co-contributions based on personal income/wealth are also a feature.

By contrast, it is our understanding that Sweden does not apply such filters.

Just as staff are offered additional incentives to work in rural and remote locations, so should eligible beneficiaries also be able to access additional funding if they live in rural and remote locations.

2.4.6 *How should carers' needs be factored into eligibility?*

Carers' needs should be assessed separately to those of the person they support. There are good examples in other jurisdictions where a 'trigger question' in the assessment process for the people living with disability then initiates a separate assessment process for carers.

2.4.7 *What other factors might be used as a basis for eligibility?*

Refer to 2.4.1, 2.4.2, 2.4.3, 2.4.4, 2.4.5 and 2.4.6.

Also, looking at a typical assessment tool used in a jurisdiction overseas, the factors that are assessed to determine the extent of functional support need include:

- Complex needs and risks (which in turn triggers a more detailed assessment where warranted, typically after the indicative funds have been determined);
- Meeting personal needs;
- Meals and nutrition;
- Work, learning and leisure;
- Making important decisions about life;
- Being part of the local community;
- Essential family/caring role (ie where the person living with disability is caring for someone else);
- Available social support;
- Family carer and social support (this assesses the sustainability of any informal supports in the person's life, and where requested it triggers a separate assessment for the support needs of any family members providing a carer role to the person).

2.4.8 *How do you ensure that eligibility processes are consistent, fair and transparent?*

By developing a clear, detailed understanding of the extent to which differing degrees of impairment/circumstances impact on the exercise of personhood and citizenhood.

A nationally consistent assessment mechanism can still include weighting factors to take account of critical issues that not every person living with disability is experiencing, such as dearth of social capital, and rurality of residence.

2.4.9 *What about natural ageing?*

2.4.9.1 *How should the scheme address disability associated with natural ageing, and why?*

The scheme should address people living with age-related disability no differently from other people living with disability, because the affects of physical/sensory/cognitive impairment are the same issue, regardless of their cause. In other words, the key consideration is the degree of functional support need, not its specific cause.

2.4.9.2 *What implications would the resulting eligibility criteria have for people outside the system?*

That would depend on why they are outside the system, and whether their role is as consumer or funder.

2.4.10 *Comprehensive versus narrow coverage*

2.4.10.1 *What are the implications of adopting more or less generous eligibility criteria on fairness, adequacy of services, costs and incentives, and how could these be addressed?*

Comprehensive is preferable. The Accident Compensation Corporation (ACC) Mechanism in New Zealand is ample demonstration of how a scheme with narrow coverage creates two classes of people living with disability, depending on whether they got their disability as a result of an accident.

2.4.10.2 *Should the scheme apply to new cases of disability or to all people with existing disabilities?*

Should apply to all people with existing disabilities (refer above ACC example).

2.4.10.3 *To what extent should eligibility include people experiencing short-term (7 to 12 months) compared with people whose disability (and associated needs) is expected to last for many years?*

Depends on the extent to which the person is distanced from expressions of personhood and citizenhood and on the extent to which their circumstances are covered by other payments.

2.4.10.4 *How often should eligibility be re-assessed?*

At least annually. Also, any active stakeholder (e.g. person, family member, government officer) should be able to call for a re-assessment at any time if it is believed that the person’s circumstances no longer match the level of funding made available.

2.4.11 *Should eligibility take account of people’s income or assets?*

2.4.11.1 *Should means or asset tests affect eligibility for the scheme, the amount or type of services funded by the scheme, and the size of any co-payments? If tests were appropriate, what income or asset thresholds might apply?*

This will depend on how the finances of the scheme are structured.

This isn’t a matter of ‘should’. It is a matter of determining which of the following is preferable:

- That a social insurance model does not ask for co-contributions (example Sweden) which means that everyone is assured of a level of cover, including those citizens of significant personal private means who could be regarded as being able to pay their own costs ("it's not fair – I didn't pay taxes just so that rich family can access the same disability support funding as a poor family – they should pay their own way so that the public funds can go further");
- That a social insurance model does ask for co-contributions (example UK) which means that some people may feel they are being asset-stripped through no fault of their own ("it's not fair - I've acquired a disability and now I'm having to lose the value of my accumulated wealth including my house – what was the point of pursuing the great Australian dream in the first place if the government is going to take most of it off me - what will I be able to leave for my kids?")

2.4.11.2 *What would be the impact of means testing?*

Means-testing would typically result in the following:

- Some people might self-select out of the system to avoid the perceived intrusion/indignity of means-testing, especially people who have means that would dramatically alter the amount of disability funding available to them;
- Means-testing will create dissatisfaction and discontent among those system participants who believe it has unfairly reflected their circumstances. This will likely to lead to other activity, such as appeals;
- Means-testing will consume time and resources within the system, because someone will need to administer the means-test and make a determination, and handle the appeals process;
- Because of the time involved, including any appeals process, means-testing may lengthen the time it takes to allocate funding to people, and this may not be helpful to people living with disability who need certainty quickly so that they can put arrangements in place;
- Means-testing will reduce the total amount of disability support funding required for the system, because there will be lower allocations across the population. However, if co-payments were to be a feature of the scheme, there may be simpler methods for collecting these (refer later in this submission).

2.5 Who makes the decisions?

2.5.1 *How can people with disability and their carers have more decision-making-power in a national disability scheme? How would the success or failure of new approaches be tested?*

Based on our view that a NDIS is the right way to go, as long as it is an entitlement-based model of Individualised Funding, we believe that this will bring greater decision-making power to people living with disability.

Individualised Funding, also known as Self-Directed Funding, is a disability funding methodology in growing use in a number of jurisdictions. For example, in the United Kingdom it is anticipated that 30% of all recipients of adult social care (people living with disability, people receiving mental health support, older persons etc) will be in receipt of a personalised budget by 2011.

Julia Farr Association asserts that this methodology, if designed and implemented in line with its best practice principles, gives people living with disability authentic control over how their personalised budget is spent.

Via a government case worker, the approach involves the person completing a simple self-assessment (we can submit examples if required) which translates on a price point basis to an indicative quantum of disability support funding, which can be called a personalised budget. The person then directs how that personalised budget is spent. This decision-making power means that the person can build support arrangements that are more likely to be tailored to the person's own circumstances.

In terms of tests of success, this approach and its variants have been implemented and evaluated within and across a number of jurisdictions, and the findings signal improved outcomes across a range of lifestyle indicators, and at no greater overall cost than the more traditional arrangements where government support funding is transacted via service provider contracts.

Because of the existing body of evidence, we believe that this approach has demonstrated that people can be given authentic control over how their disability support funding is spent on their behalf, and without increased financial risk, reputation risk, or quality assurance risk, to the public funder. For more information refer to question 2.5.3.

2.5.2 <u>What should be the decision-making powers of government and service providers?</u>

Government decision-making powers

Continuing our assumption that a NDIS is an entitlement-based model of best practice Individualised Funding, the decision-making powers of government would typically be as follows (not necessarily exhaustive):

1. Determining the overall pool of funding available for distribution within the scheme;
2. Determining the methodology for attracting revenue to meet current and future demand;
3. Determining the relationship between the increments of assessed need and the increments of support funding;
4. Determining the constraints on how a person may spend funds is framed in the context of their personalised budget. Our view of a best practice approach in developing a personalised budget would be the following constraints:

    a. Nothing illegal
    b. Nothing related to gambling, alcohol or other specific items that might be deemed to be contributory factors to disability or further disadvantage
    c. Nothing that, to a reasonable person, cannot be demonstrably linked to the types of vulnerability that the person lives with;
5. Calling for a review of a person's circumstances (relevant to the funding) if it is believed those circumstances may have changed;
6. Defining a trigger mechanism whereby higher risk is identified;
7. Commissioning a co-design approach to the structure of the scheme, including pathway, governance and evaluation.

Service provider decision-making powers

Continuing our assumption that a NDIS is an entitlement-based model of best practice Individualised Funding, this will reduce the incidence of block service contracts where service providers typically run the decisions around distribution and gate-keeping, as well as on the individual plans of those persons accessing their services.

Instead, the focus of the service provider's decision-making process will be on how it might best respond to an invitation to provide support by a person, based on that person's goals. At a strategic level, service providers will need to decide what range of supports they might offer, and how they might introduce, or otherwise evolve, highly personalised approaches in their organisations. This will include decisions around business processes and organisational competences.

There is no role for service providers to decide how a person might wish to spend their personalised budget as that control rests with the person. However, a person may choose to seek guidance from a trusted service provider (or indeed any other stakeholder of the person's choosing) about how funds might best be spent in line with the person's preferences.

2.5.3 *What have been the experiences overseas and in Australia with individualised funding, including their impacts on outcomes and costs? What lessons do these experiences provide for adopting this approach as an element in a national disability scheme?*

For a summary of the experiences, we refer you to:

- Williams, R 2007, *Individualised funding: A summary review of its nature and impact, and key elements for success*, Julia Farr Association, Unley, South Australia;
- Chenoweth, L & Clements, N 2009, *Final report: Funding and service options for people with disabilities*, Griffiths University, Queensland;
- Fisher, KR, Gleeson, R, Edwards, R, Purcal, C, Sitek, T, Dinning, B, Laragy, C, D'Aegher, L & Thompson, D 2010, *Occasional paper no. 29: Effectiveness of individual funding approaches for disability support*, Department of Families,

Housing, Community Services and Indigenous Affairs, Australian Government, Canberra.

In addition we note the following findings regarding outcomes and costs:

- "When professional power is shifted, gradually and carefully, to people and their freely chosen allies, lives do generally improve, and cost do not increase"[9];
- "By giving consumers the flexibility and independence to spend their money as they best see fit, (Individualised funding) encourages the evolution of long-term care services that are responsible to consumer needs rather than to government regulations"[10];
- "…all the available evidence suggests that (Individualised funding) lead to greater user satisfaction, to greater continuity of care, to fewer unmet needs and to a more cost-effective use of scarce public resources"[11];
- Better health and well-being
  (**47 per cent** reported improvements in their general health and well-being - 5 per cent reporting it had got worse)[8];
- Spending time with people you like
  (**55 per cent** reported spending more time with people they liked - 3 per cent stating things had got worse)[8];
- Improved quality of life
  (**77 per cent** said their quality of life had improved - 1 per cent reporting things had got worse)[8];
- Taking part in community life
  (**63 per cent** said they took part in and contributed to their communities more - 2 per cent saying things got worse)[8];
- Feeling safer and more secure at home
  (**29 per cent** reported improvements in how safe they felt at home - 1 per cent reported things had got worse)[8];
- Choice and control
  (**72 per cent** said they had more choice and control over their lives - 1 per cent stating things had got worse)[8];
- Personal dignity
  (**59 per cent** said they felt their lives had more dignity - no one said it got worse)[8];
- Economic well-being
  (**36 per cent** estimated their economic well-being had improved - 5 per cent reporting it had got worse)[8].

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[9] Conroy, J, Fullerton, A, Brown, M & Garrow, G 2002, *Outcomes of the Robert Woods Johnson Foundation's national initiative on self determination for persons with developmental disabilities: Final report on three years of research and analysis*, Centre for Outcome Analysis, Narberth PA, p. v.

[10] Polivka, L & Salmon, J 2001, *Consumer directed care: An ethical, empirical and practical guide for state policymakers,* Florida Policy Exchange Center on Aging, Tampa FL, p. 20.

[11] Glasby, J & Duffy, S 2007, *Our health, our care, our say – what could the NHS learn from individualised budgets and direct payments*, Univerity of Birmingham HSMC and In Control UK, Birmingham, England, p. 2.

These findings show that the availability of personalised budgets in line with Individualised Funding/Self-Directed Funding lead to significant improvements. So the question shifts from 'If?' to 'How best?' Having read the range of findings across a number of jurisdictions, we have formed a clear view about the necessary ingredients for best practice Individualised Funding.

These may be considered in two ways: process and content.

Lessons about 'process'

A best practice approach to Individualised Funding keeps things simple and accessible for the person, and ensures the person has authentic control over how their personalised budget is directed.

Currently known best practice elements include:

- A co-design approach to the development of the system and its evaluation, so that its authoring draws on the experiences of people who will be using the system;
- A simple, accessible assessment that a person can play a central role in. There is no evidence to suggest that a longer, more complicated assessment mechanism will lead to a better match of funding resources with people's support needs, and we note that an increasing number of jurisdictions in the United Kingdom are using very simple self-assessment tools, cross-checked by a government case worker, to distribute sums of public funds across populations of people needing personal support. We also believe that it is intuitive that a short, accessible assessment tool will produce dollar savings because it won't demand the same degree of professional worker costs that a more complex, professional-only tool would demand. This would mean that those savings could be used to deliver more direct supports;
- A Resource Allocation System (RAS) that on a population basis handles data about levels of support need, matches that to corresponding levels of 'cost of disability' funding, and is engineered to reflect public policy priorities where they exist, such as areas of particular concern, considerations of social capital, circumstances for co-contribution etc;
- A redefined role for the government 'gate-keeping' caseworker, who undertakes three roles:
    - Information, assessment tool cross-check, and advice to the person about their indicative funding allocation
    - Consideration, including in most cases sign-off, of the person's plan for how to spend their personalised budget
    - Determination of impact of the support arrangements on the person's circumstances;

  (Note the above redefinition can be expected to deliver significant resource savings, because the drivers for decision-making are resolved at a system level. This means that those released resources can be used to assist people with planning,

with navigating into community, and with individual/family/community capacity-building.)
- Use of a 'Risk Enablement Panel'[12] to assist consideration of safeguards to help ensure success for those people with the highest degrees of vulnerability.

Lessons about 'Content'

Based on our examination of the various iterations of Individualised/Self-Directed Funding, we have identified a number of other considerations necessary to support a person towards a good life in their local community. We have published this analysis as a 'Model of Citizenhood Support'[13].

In summary, the model can be taken to assert that best practice disability funding/support is dependent on attention to the following variables:

- The person's experience and capacity in terms of their own Personhood;
- The nature of the relationship between the person and the formal agencies in her/his life;
- The extent of access to Support Information;
- The extent of access to both dedicated and mainstream material resources;
- The extent of fellowship and connection in the person's daily life.

This summary hides a large amount of detail and we would be happy to make a more detailed presentation to the Productivity Commission on the model and its applicability to the design of a disability funding and support framework.

2.5.4 *Should individualised funding include the capacity to save some of the annual payment for future purchases of services or borrow from future payments to pay for current services?*

Flexibility is a key principle if people are going to get the most out of their personalised budget, because things can change – the world doesn't stay still just because someone made a plan.

Therefore the Individualised Funding arrangements should include the capacity to manage the ebb and flow you describe, on the understanding that over a given timeframe (typically a year) the total expenditure does not exceed the total amount of personalised budget.

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[12] The purpose of a Risk Enablement Panel is ***"to provide a forum for full and frank discussion and resolution of serious concerns relating to the management of identified risks highlighted in an individual's Support Plan. When there is a significant or perceived substantial risk, it will provide a forum for a shared decision making process where the outcome will lead to the Support Plan being agreed as ensuring that the individual will be enabled by the support described to remain healthy, safe and well, and where the local authority will be seen to have discharged its legal duty of care",*** In Control n.d., *Risk enablement panel*, p. 3, <www.in-control.org.uk/DocumentDownload.axd?documentresourceid=1246

[13] Williams, R 2010, *Model of citizenhood support: Discussion paper*, Julia Farr Association, Unley, South Australia,

2.5.5 *How should the national disability scheme support people's decision-making under individualised funding, taking account of the spectrum of disability – both in terms of the nature and severity of disability? Should all people be able to access individualised funding, and if not, what guidelines would be appropriate?*

In terms of support for decision-making, the typical approach within the In Control movement covers the following:

1. That the assumption of capacity applies, in which case practical supports should be available (if required) to assist the person with their decision-making. There are good examples of legislation-based supported decision-making "designed to remove policy barriers to people with impaired decision making capacity accessing IF options"[14], for example the NIDUS service in British Columbia. There is also a new supported decision-making initiative in South Australia, involving a partnership between the Office of the Public Advocate and the Julia Farr group;
2. Where there are significant capacity issues, or where the person does not wish to take a central role in the decision-making process, a trusted other from the person's network is nominated by that person. The trusted other is expected to make decisions in the person's best interests, and where 'best interest' is interpreted as the decision that the person would make themselves if they were in the process;
3. Where there are significant capacity issues, and there is not a nominated trusted other wishing to undertake the role, a third party is appointed. The third party is expected to make decisions in the person's best interests, and where 'best interest' is interpreted as the decision that the person would make themselves if they were in the process.

In terms of whether all people should be able to access Individualised Funding, then yes, because it is a methodology for the distribution of public funds and isn't restricted to those people who wish to manage their own support arrangements or who have particular degrees of cognition. All people living with disability should be able to access a personalised budget based on their functional support needs, and to receive assistance with decision-making about how that funding might best be directed in support of the person's choices and in the context of an ordinary valued life.

2.5.6 *What are the risks of individualised funding and how can they be managed? What guidelines would be appropriate? How would any accountability measures be designed so as not to be burdensome for those using and overseeing the funding?*

There is no evidence that Individualised Funding presents any greater risk than the currently dominant paradigms for funding. Evidence elsewhere shows no increased financial risk, and in some cases there are significant savings.

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[14] Chenoweth, L & Clements, N 2009, *Final report: Funding and service options for people with disabilities*, Griffiths University, Queensland, p. 24.

There is no evidence of significant quality-of-life risk with the trend data being favourable across a range of lifestyle dimensions.

There is no evidence of systemic misuse of funds by recipients. Noting that many recipients may not even choose to have direct involvement in the technical management of funds and associated purchases, those who do can have their practice guided via typical controls, for example staged release of funds, periodic reporting, and on-demand viewing of budget activity by government officers.

It is important to note that the vast majority of recipients will be sensible and prudent about how their personalised budget is directed, and the accountability mechanisms should reflect this, with a more detailed parallel track of tighter control for those exceptional situations where there are legitimate, evidence-based concerns about a recipient's history in relation to financial decisions.

According to Chenoweth and Clements (2009, p. 21), the establishment and subsequent approval of a person's individual plan as part of the allocation of Individualised Funding provides important accountability mechanism as it ensures:

> "that public tax dollars are being spent effectively/efficiently, thus reducing the need for expensive and external monitoring and accreditation schemes. When the government approves the plan (developed by the person with a disability and his/her chosen supporters and advisors) the individual enters into a contractual agreement with government concerning the expenditure of the allocated funding"[15]

In terms of guidelines and accountability measures, because of the volume of the questions that the Productivity Commission has put into this submission's process, we do not have the resources to provide a more detailed answer regarding guidelines and accountability measures, but would be happy to prepare a supplementary submission on the best practice considerations on the issue of guidelines and accountability and make representation to the Productivity Commission on a mutually suitable date.

2.5.7 <u>Should people be able to treat funding as ordinary income and do what they like with it? Should primary carers or other family members be able to pay themselves for providing care?</u>

Regarding the first question, it is important that the funding is directed in ways that have demonstrable direct or indirect practical benefit for the functional support issues that were identified in the assessment. This can happen in some very imaginative and creative ways, so flexibility is the key.

There are limits, and these might typically be around spending that is contributory to incidence of disability or the deepening of disadvantage. Examples are alcohol, gambling etc.

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[15] Chenoweth, L & Clements, N 2009, *Final report: Funding and service options for people with disabilities*, Griffiths University, Queensland, p. 21.

Personalised budgets typically get spent on hands-on support (including mainstream personal support services like housecleaning and the like) aka ‘staff’, and also on materials, adaptations, memberships and other opportunities, aka ‘stuff’. It is important that there is wide flexibility in respect of ‘staff’ and ‘stuff’ so that a person can organise her/his budget in a highly personalised way. People with similar support needs will not necessarily choose similar solutions.

In terms of ‘treat funding as ordinary income’, the Individualised Funding so allocated should not be subject to tax.

Regarding the second question, the issue of “primary carers or other family members be able to pay themselves for providing care” can seem a complicated one but eminently navigable.

For example, in most instances, it is not a question of a family member “paying themselves for providing care” because it is the person living with disability who has the personal budget and it is the person living with disability who makes the decision about who to pay and for what. In which case, a person living with disability should have the flexibility to employ known people in his/her network, including family members, to provide support. This is not unusual in small businesses, where the proprietor might employ family members, friends and acquaintances in the business.

Some jurisdictions have determined that family members living at the same address cannot be paid for hands-on support. Presumably this is because their support is deemed as a natural extension of the co-habituating familial relationship and therefore part of the person’s social capital. However, a separate carer assessment mechanism should be able to provide additional resource to the family member so that they can, to the extent of their willingness to do so, maintain the primary supporter role. Again though, one can equally argue that there are many family-based small businesses in Australia where family members live and work together. Instead of a black-and-white criterion of address, the defining considerations might include:

- What is the person’s preference?
- What hands-on support arrangements might best support the sustainability of typical family relationships?
- What hands-on support arrangements might be the best match with the person’s functional support needs, in the context of an ordinary valued life?
- What equipment, adaptations, mainstream services etc, might help reduce the reliance on hands-on support, regardless of where that support might come?

There may be instances where a primary carer/family member is also the nominated decision-maker about the use of the personalised budget and puts into the plan that they be paid for providing hands-on support. As per the methodology mentioned elsewhere in this submission, a government case worker would be signing off the plan, and this presents an important opportunity to examine the wisdom of such an arrangement and whether it reflects the beneficiary’s best interests and best value. In other words, for a person to seek to pay themselves out of a family member's Individualised Funding, that would need to be endorsed by a third party, such as a government case worker.

2.5.8 How would individualised funding work in rural and remote areas where service availability is poorer?

There is no reason for the methodology to change because someone lives in a rural/remote area where service availability is deemed poor.

Instead, it should be an appropriate test of the methodology's settings and capacity regarding the following:

- Genuine flexibility about how the funding can be used;
- Resourced assistance with planning support, particularly around building creative solutions based on particular methodologies of enquiry;
- Resourced assistance to build personal networks, and to navigate into existing and new community opportunities.

Cost pressures relating to rural and remote settings should also be factored into the Resource Allocation System (RAS) and associated algorithms, so that a person living with disability who resides in a rural area will be eligible for a quantum of supporting funding that has had regard for the person's rural setting.

2.5.9 Who would be responsible for monitoring individualised funding?

It depends what the Productivity Commission means when asking this question.

For example,

- The person who is the recipient (or their nominated other) would have a stake in monitoring the Individualised Funding because of an understandable interest in getting best possible value
- A third party entity could provide a monitoring and reporting service on behalf of the person who is the recipient. This might include a service provider agency if the person has asked – that their personalised budget be managed by a trusted service provider (this is sometimes called an Individualised Service Package)
- The public funder would have a stake in monitoring Individualised Funding because of an understandable interest in getting best possible value
- A third party entity could provide a monitoring and reporting service on behalf of the public funder.

The bottom line is that both the funder and the recipient will have mutual expectations of accountability. It then becomes a matter of how the monitoring and accountability arrangements are constructed in a way that is both the most meaningful and the least intrusive.

2.5.10 *What would be the impacts of individualised funding on service providers and do these impacts matter?*

Good outcomes for a person are more likely to come when the support arrangements reflect a person's personal circumstances, goals and choices. Therefore this means that service providers interested in delivering good outcomes for people (which one might hopefully assume is somehow expressed in the organisation's constructional objects) will have a corresponding interest in providing the capacity for people to have tailored, personalised support arrangements. Such providers will likely enjoy a positive impact from Individualised Funding because they will be offering what people want.

Service providers who are wedded to static business models based on block-funded, congregate services, are more likely to struggle unless they are prepared to change. In any industry of human endeavour, organisations that don't offer what their customers want tend to go out of business, and this is regarded as the natural order of things.

It might reasonably be argued that service providers have been trained into (and therefore locked into) the provision of static business models based on block-funded, congregate services, because of the ways that governments have chosen to contract services over the past few decades and beyond. In which case, it might therefore be argued that government has a responsibility to make transition funding available for service provider agencies to build capacity. This is supported by Fisher et al. (2010, p. vii) who states that "governments have put mechanisms in place such as base funding and transition assistance for service providers"[16] in acknowledgement of the difficulties service providers may face when transitioning to Individualised Funding arrangements. However, if transition funding is provided, it needs to be thoughtful in its execution, and definitely time-framed.

Also, even though service provider agencies have received block funding, there has always been the capacity for a so-minded agency to find ways to personalise what they offer. So it is eminently reasonable to expect a service provider agency to contribute their own commitment, enthusiasm and active endeavour to the transition and not be driven solely by the availability of any transition funds.

Agencies that do not deeply feel a commitment to personalised supports probably should not have a role in the new sector arrangements, because their practice is likely to be wholly out of step with the UNCRPD.

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[16] *Fisher, KR, Gleeson, R, Edwards, R, Purcal, C, Sitek, T, Dinning, B, Laragy, C, D'Aegher, L & Thompson, D 2010,* Occasional paper no. 29: Effectiveness of individual funding approaches for disability support*, Department of Families, Housing, Community Services and Indigenous Affairs, Australian Government, Canberra, p. vii.*

2.5.11 *Are there ways other than individualised funding that empower people with disabilities and their families?*

There are other ways, but this includes as a necessary ingredient the opportunity for people to self-direct through Individualised Funding. We again refer to the Julia Farr Association 'Model of Citizenhood Support', and note that there are good examples of initiatives in one or more of the following domains that have contributed to people finding empowerment:

- Defining and moving into a person's sense of her/his own Personhood;
- Re-framing on a rights basis the relationship between the person and the formal agencies in her/his life;
- Access to Support Information;
- Access to mainstream resources (buildings, transport, education, employment etc) and dedicated resources (eg a personalised budget through Individualised Funding);
- Access to opportunities for fellowship and connection typical of community life.

2.6 The Nature of services

2.6.1 *Are there any services not provided now that should be part of a national disability scheme?*

Because of our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, then the control that people have over how the funding may be directed, albeit within the parameters we have described elsewhere in this submission, means that a wider range of services and support arrangements become included that are not currently there.

The danger of naming services that should be included (whether they are currently there or not) is that it becomes a prescriptive list and can sub-consciously (or consciously if the formal parameters are set to narrowly) close off the consideration of other creative solutions that might work better for a person.

2.6.2 *What are the most important services, their costs, their likely demand and who would be the predominant users?*

Again, because of our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, this question becomes less relevant, because the most important services will emerge as part of people's purchase preferences and at a cost that reflects the marketplace, government regulatory markers, and the degree of freely-given community assistance.

Notwithstanding, it is perhaps reasonable to assume that the most important services are those that give people the greatest platform to live an ordinary valued life. In which case, one can imagine this including (in no particular order), but not be limited to:

- Assistive technology, including personal equipment and access (without which there is a greater reliance on hands-on personal support and a heavily restricted choice of accommodation);
- Personal support (without which it is hard to engage with other aspects of the day);
- Supplementary costs of transport (without which it is hard to engage with community);
- Supplementary costs of accessing employment opportunities (without which it is hard to have enough money to live on and access the choices available to most Australians);
- Early investment support, aka early intervention (which builds a person's capacity through 'front-foot', strengths-based approaches). There are many examples of the successes of work in early investment, and we can supply further details on this as required.

Note that in pursuit of the above, it is important that other supports/services are available to the person, such as:

- Assistance with personal, vision-based planning;
- Assistance with *hosting*, from social enterprises that offer various types of hosting, for example,
  - fiscal intermediary work and accountability reporting
  - employment of staff.

2.6.3 <u>How should service providers be monitored and regulated with respect to quality outcomes and cost effectiveness?</u>

We again emphasise our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding. In such circumstances, the service provider is directly in a customer relationship with the person who holds a personalised budget. In which case, the impact on the lifestyle of the person, and their perception of this and the cost of achieving it, will be central considerations. This can be supplemented by industry-wide expectations on certain key outcomes, and audited by an independent audit mechanism (there are examples in other jurisdictions of agencies that can provide this 'social audit').

Our view is that the following markers could apply:

Rights-based Markers

The UNCRPD is the appropriate context. Within which, we offer the example (from our own value base at Julia Farr Association) of three key rights-based markers which could be set as metrics:

1. *Personal Authority* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's right to make decisions;
2. *Active Citizenhood* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person in an active, valued role in the life of the wider community. This would include using, and being immersed in, the range of facilities and opportunities available to all citizens, such as transport, workplaces, recreational spaces etc, and not separate special facilities and opportunities just for and with people living with disability;
3. *Capacity-building* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's capacity to grow into their own personhood and citizenhood.

Citizenhood-Support markers

We offer the five domains within the 'Model of Citizenhood Support' as suitable outcome-based markers for the ways that agencies assist people:

1. *Personhood* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's sense of her/his own personhood and a vision for her/his life;
2. *Partnership* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds a sense of partnership between the person and the formal agency;
3. *Supported Information* – to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's access to good information that assists the person's choice-making;
4. *Access to Material Resources* - to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's access to, and use of,
    a. *Dedicated resources designed to assist a person living with disability*
    b. *Mainstream resources designed for use by all citizens, such as transport, public buildings and spaces, education, health services etc*;
5. *Fellowship and Connection* - to what extent has the service agency delivered its supports in a way that demonstrably advances and upholds the person's access to opportunities to connect with, and enjoy fellowship with, a wide range of other citizens (ie not just other people living with disability) in their local community.

Lifestyle-accomplishment markers

We refer you to lifestyle measurement mechanisms such as the *Q50™* that offer a framework for measuring lifestyle advancement.

2.6.4 *How would services be structured to increase the likelihood of participation in work and the community?*

The issue here again is the way that the funding is made available.

Consider the following flow. It may appear simplistic, but we prefer the term ‘fundamental’:

1) Person living with disability is allocated a personalised budget based on functional support needs, and which they can now direct towards the personalised arrangements they seek;
2) Person, with assistance where required, builds a personal vision of an ordinary valued life which includes participation in work and community;
3) Person, with assistance where required, approaches possible sources of assistance, for example service providers, and invites those agencies to describe how they might support that person into work and community;
4) Service agencies with a deeply-felt commitment to personalised supports and genuine lifestyle outcomes in line with UNCRPD, then design support arrangements. As for any tendering process, this in turn might reveal organisational capacity issues that the agency can then attend to;
5) Person, with assistance where required, may also choose to directly navigate to mainstream resources in community and employment.

In these ways, we believe that the overall arrangements for disability support will evolve to include capacity and outcomes in respect of work and community.

One can expect a similar evolution to happen in other aspects of a person’s preferred lifestyle on the basis of the same approach.

2.6.5 *Should all services be free or should there be a scope for co-payments? To which services and/or people might co-payment be applied? How would the size of co-payments be determined?*

This depends on a society’s traditions and its degree of tolerance. Sweden does not seek co-payments, whereas many jurisdictions within the United Kingdom do seek co-payments.

In the United Kingdom, there is no distinction about which services attract co-payments, because the extent of co-contribution is established at the assessment stage, by examining the person’s financial circumstances. This then determines the amount of public funding that is available to the person. Therefore, a person with access to significant personal means will be allocated a smaller sum of disability support funding compared to a person with lesser means. It then follows that the person with greater personal means will add their own contribution in order to purchase services of equivalent dollar value to those purchased by a person with lesser means entirely from their personalised budget.

So the bigger question is about how many dollars are involved in delivering a fair go to *all* Australians living with disability, and how many of these dollars might be exacted from a taxation mechanism and how many might be exacted from people through co-payments.

2.6.6 *What should be the relative roles of specialist compared with mainstream services?*

A fair go at an ordinary valued life means that people's experience should be anchored on mainstream services in the heart of their communities. The role of specialist services should be seen as a *supplement* to mainstream services, not as an *alternative*.

2.6.7 *What needs should not be met (for example, needs that would have existed in the absence of a disability)?*

If the scheme's funding distribution is anchored on a Resource Allocation System comprising a charted relationship between functional support need and a price-point resource allocation, then the assessment tool should be designed to pick up those issues of functional support that are required to ensure the person gets a fair go at an ordinary valued life compared to other Australians. Given that the comparison is with the regular Australian population, this approach should exclude perceived needs that are not related to the functional support issues created by the person's disability.

2.6.8 *To what extent, if any, should people be able to cash-out the benefits from a basic/service/appliance/aid (for example, a wheelchair that met assessed need) and use it as a part payment in purchasing a premium service (a more advanced wheelchair)?*

In again emphasising our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, a person should indeed be able to cash out from a basic service and put it towards a premium service if that is what makes most sense to that person's perspective and circumstances. This is part and parcel of the flexibility and range of choice that comes from having a personalised budget.

2.6.9 *How are service needs likely to change over time and how should that be accounted for in designing a long-term care system?*

In again emphasising our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, and on the assumption that this is implemented coherently, the service needs are likely to change over time as personalised budget holders (people living with disability) reclaim their personal horizons of an ordinary valued life, achieve greater access to freely given assistance from people in their growing personal networks, and make sensible purchases.

We note also that as technological advances continue to be made, we might expect to see people living with disability investing a significant portion of their Individualised Funding into personal equipment and other assistive technology so that they have less reliance on hands-on personal support.

As personalised budget holders achieve more local, sustainable arrangements for their essential personal supports, we can expect to see an increasing interest in directing funds towards initiatives that connect people into active roles in community life. This might include specific individualised initiatives that assist a person into mainstream employment or recreation, and community-collective initiatives such as *time-banking* where people living with disability are active members of a community initiative to contribute time to neighbours and neighbourhoods, and to access corresponding time from neighbours and neighbourhoods for personal assistance.

In such ways, we can hope to see people self-directing their Individualised Funding in ways that, instead of keeping the person in a cycle of reactive and passive service recipiency, present the person as an active member, contributor, and *investor* in her/his local community.

2.6.10 What are the challenges for delivering expanded services in remote and rural Australia, including for specific communities, such as Indigenous Australians, whose needs may vary?

Individualised (Self-Directed) Funding provides people with the means to come up with local innovative solutions which meet, and can be tailored to, their circumstances. As such, this methodology is well-suited to the challenge of rural and remote living.

Assuming this, the first challenge is to calculate what might be considered a fair rural/remote loading when assessing a person's personal support needs, so that their personalised budget takes fair account of the additional costs of living with disability in a rural or remote setting.

The second challenge is to ensure that there is parallel mainstream investment into those rural and remote communities that assist community members to connect in fellowship. This might include transportation, infrastructure and community trade/recreation amenities. With such capacity in place in a rural/remote setting, there is a stronger framework for a person living with disability to connect into community life.

2.6.11 How could innovation be encouraged?

In again emphasising our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, innovation is encouraged by ensuring that there is maximum flexibility in how a person might self-direct the support funds allocated to her/him.

Typically such flexibility is established by setting the following boundaries:

- Support funds cannot be spent on anything illegal;
- Support funds cannot be spent on anything that might contribute to a disabling condition or which might contribute to furthering a cycle of disadvantage;
- Support funding must be spent in a way that will directly or indirectly bring practical benefit to the functional support needs that a person has (which can also be read as a direct or indirect positive impact on the consequences of the person's disability).

With these parameters in place, a person has good flexibility in how her/his support funds might be spent, and this is likely to generate innovative solutions, while at the same time avoiding public funds being spent in ways that might be regarded as un acceptable to most people.

Put another way, innovation is more likely to occur when people have an opportunity to imagine a good life and the means to move toward this goal.

Given that many people living with disability have experienced years of passive service recipiency which will have, among other things, dramatically diminished some people's personal horizons of what is possible in their lives, innovation can be encouraged by ensuring there is investment in specific capacity-building around personal visions, where people living with disability, and the family members in their lives, are supported to re-connect with the vision of an ordinary valued life and how to move intentionally towards it.

Conversely, if there is greater restriction on how people can use their funds, and if there is no investment in people's capacity to imagine and move towards an ordinary valued life, then we can expect much less innovation to emerge, and the greater portion of funding will likely be spent in ways that reflect passive recipiency rather than active citizenhood. In terms of all our hopes for thriving Australian communities of the future, such restriction would be a disaster, and would exacerbate (and realise) the concerns that people have about the shrinking, ageing workforce and how this could result in poorer and more congregate services for our most vulnerable citizens.

2.6.12 How should people's needs be assessed?

2.6.12.1 How should the long-term care and support needs of individuals be assessed?

People's needs should be assessed within the context of what constitutes an ordinary valued life, and the extent to which the person's circumstances distance that person from that ordinary valued life.

Therefore there are three main considerations:

1) Assessing the critical degree of functional support so that funding can be allocated;

2) Determining the person's vision of an ordinary valued life (in the context of UNCRPD), and the areas the person most needs assistance with to move intentionally towards this vision;
3) For people with the greatest complexity in their circumstances, a deeper investigation of the circumstances and history of their disadvantage, as a first step to developing a pro-active multi-layered response that assists the person away from disadvantage and towards a more valued lifestyle.

Assessing the critical degree of functional support so that funding can be allocated

The key question here is *how much information do we need to gather in order to work out how much funding a person is eligible for?* There are several tools being developed in Australia that aim to provide a comprehensive assessment of the consequences of living with disability. However, if such tools become the primary device for assessing a person's functional support needs for the purpose of a funding allocation, then such tools are heavily over-engineered.

This is evidenced by the growing number of Local Authorities in the United Kingdom who are assessing functional support needs for funding by using a simple tool comprising relatively few questions (excluding means-testing questions to assess the degree of co-payments). We note there is no evidence to suggest that such tools are inadequate for the purpose of distributing funds and managing an overall funding pool, and that an increasing amount of United Kingdom public funds are being distributed using these brief assessment tools.

Importantly, these assessment tools are designed so that the person living with disability, and/or the significant other who is centrally involved in that person's life, can directly participate in the administration of these tools, because they are designed to be a self-assessment tool. This of course does not mean that the completed material goes unchallenged, and it is the role of the government officer to sit alongside the person and to explore the answers, checking and testing along the way, to ensure that the assessment score is a fair reflection of the person's situation.

We can supply you with sample Local Authority details as required, and we also note that the United Kingdom tools, particularly those facilitated by In Control, are available on an 'open source' basis, in support of developing a community of best practice.

There may be a role for the more complex assessment tools such as ICAN (University of Sydney) and D-START (University of Adelaide) in assisting with the understanding of the circumstances of people with very complex disability. However, we consider such tools to be over-engineered for the purpose of funding allocation, and by their nature are hard to administer by anyone other than a professional, which is immediately excluding of the person.

Such tools are proprietary, and so there are likely to be costs associated with their use, which again may be unnecessary costs given the task at hand and the tried-and-tested open source material that is available elsewhere.

Determining the person's vision of an ordinary valued life

It is important that people are assessed for assistance in ways that reflects ordinary valued life and the personal choices of the person. For this to happen, the notion of assessment might better be termed *'getting to know you'* because it is not safe to assume that people with common circumstances will therefore have common visions and therefore seek common solutions.

It is important therefore that a national disability funding and support scheme operates in a way that is anchored on the principle that people are treated as individuals and not as collections of diagnoses/symptoms to which a prescription of tasks are applied. This is important if we are to make an authentic attempt to dismantle the commodification of vulnerable people that has happened in human services[17].

As part of the overall scheme, resources need to be available to each person living with disability to explore what an ordinary valued life means to her/him, how this translates to a personal vision, and how the person might move intentionally towards this vision.

For people with the greatest complexity in their circumstances, a deeper investigation of the circumstances and history of their disadvantage

This typically might involve the careful and thoughtful use of more detailed tools of enquiry, for those people with deeper and more complex circumstances of vulnerability. Such mechanisms need to be used sparingly however, because:

- They are likely to be overly intrusive, especially for those where the tool is not warranted. This is of particular importance when we consider that people living with disability are already over assessed and under supported;
- The cost benefit of over-analysing a person's circumstances does not add to the good stewardship of public funds. Funds are better applied to support than to administration;
- They are likely to be time-consuming;
- They are likely to be expensive, in terms of any proprietary costs and/or costs of administration/training.

2.6.12.2 What are the appropriate features of assessment tools?

Focusing on the primary function of assessment, which is to determine the extent of public funds that might be allocated to a person, and again

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[17] Williams, R 2008, 'On being a can of beans', in *link disability magazine*, Vol. 17, Iss. 4, p. 21.

emphasising our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of Individualised (or Self-Directed) Funding, we refer the Productivity Commission to the elements of those relatively simple assessment tools in use in the United Kingdom.

By way of example, we note that the United Kingdom's Hartlepool Borough Council operates a self-assessment tool with the following elements, each of which involves one multiple choice response:

- Complex needs and risks (which in turn triggers a more detailed assessment where warranted, typically after the indicative funds have been determined);
- Meeting personal needs;
- Meals and nutrition;
- Work, learning and leisure;
- Making important decisions about life;
- Being part of the local community;
- Essential family/caring role (ie where the person living with disability is caring for someone else);
- Available social support;
- Family carer and social support (this assesses the sustainability of any informal supports in the person's life, and where requested it triggers a separate assessment for the support needs of any family members providing a carer role to the person).

Note that the tool operates within the context of the funding envelope. The size of the envelope, and the functional support needs that the funding is designed to respond to, will determine the specific metrics within the assessment tool.

In terms of any evidence of benchmarking of different assessment tools (which we were asked about by the Commissioners at the public hearing in Adelaide on 16 June 2010), we offer the following thoughts:

- Other jurisdictions have moved to a shorter, co-operated assessment tool for the purpose of allocating funds. The approach intrinsically involves the person living with disability, is simple, is not time-consuming, and has upheld the overarching budget parameters.

- There is no benchmarking evidence that we have found that suggest that a longer, professionally-driven assessment tool delivers better results in terms of the above. There may still be a separate important role for a more comprehensive assessment tool for understanding the circumstances of that smaller number of people with the highest and most complex degrees of vulnerability.

We can provide more information on this as required.

2.6.12.3 *Should assessment gauge both eligibility and the extent of need in the one set of instruments, or should the assessments be distinct?*

On the assumption that an easy-to-use, open-source instrument is used as described above, and within the context of a Resource Allocation System (RAS) described elsewhere in this submission, you only need one set of instruments, because eligibility thresholds are part-and-parcel of the price point mechanism linking degree of functional support needs with magnitude of dollar funding (which in some case would equate to zero dollars).

2.6.12.4 *Should a nationally consistent tool be used (and what process would be used to achieve consistency quickly)?*

If the goals of the scheme include equity and portability, then the tool should be nationally consistent. A staged rollout of the tool, including prior to the national scheme being formally introduced, will help achieve consistency as soon as possible.

A Resource Allocation System (RAS) has the capacity to attend to jurisdictional differences and to address regional and remote circumstances.

There will need to be investment in the capacity-building of the stakeholders involved, to help ensure that there is a consistent approach. For government officers in a 'gate-keeping' role, this need not be overly expensive as it is essentially about the communication of the principles that lie behind the tool, and a process of calibration across populations of staff.

2.6.12.5 *What are the risks associated with different approaches and how can these be minimized?*

As alluded to elsewhere in this document, the risks (or considerations) are:

- Ensuring that the person living with disability is upheld as a valued human being at the centre of the process;
- Ensuring that the person living with disability can directly participate in the assessment of their circumstances;
- Ensuring that the assessment tool is crafted in the context of an ordinary valued life, not in the context of an objectified, diagnostic enquiry;
- Ensuring that the assessment tool is not over-engineered for purpose, wasting time and administration resources.

Our responses to the previous questions contain ideas that we believe will help minimise the risks.

There are a number of imagined risks with Individualised (Self-Directed) Funding and a discussion of these is included in the Julia Farr Association 2007 publication, 'Individualised Funding. A summary review of its nature and impact, and key elements for success'[7].

2.6.12.6 *Who should use the assessment tools (GPs, specialist disability staff, specialists)? Who should employ or engage the assessors?*

The main tool, to assess the extent of a person's indicative personalised budget, should be designed so that it can be used by a person living with disability and/or the significant other (eg family member) centrally involved in that person's life if the person is particularly vulnerable regarding decision-making. This process is facilitated by a government officer who will use the completed instrument to determine the extent of funds that might be available.

2.6.12.7 *How would the accuracy of assessments and the performance of assessors be gauged?*

A calibration process would take place at the outset, so that there is a consistent connection between degrees of functional support needs and degrees of funding subsequently available.

Thereafter, we would recommend a regular audit process where a random sample of assessments are reviewed and cross-referenced to check for issues of performance against calibration.

In parallel, we would recommend a regular review of the charted relationship between degrees of functional support needs (as scored via the main assessment tool) and the degrees of allocated funds (this relationship being the essence of the Resource Allocation System) and with particular regard to any appeals/complaints received from people concerned about the result in their case.

2.6.12.8 *On what basis should beneficiaries be reassessed? How should assessment processes take account of changes in life circumstances?*

The emerging practice in the United Kingdom (where there is a 2011 target of 30% of all vulnerable people accessing a personalised budget through these types of mechanisms), is that the assessment establishes the degree of public funding for the year ahead, and then there is a routine reassessment in 12 months.

However, we have also been advised that any stakeholder (such as the person, a significant other, a government officer) can call for a reassessment at any time for any reason. This is particularly helpful where people's circumstances have changed, and might result in either an increase or a decrease in the allocated funds.

2.6.12.9 How would data from assessment be used? (for example, should it be available to a range of service providers?)

There is no reason for the data from the main assessment to be made available to potential service providers, because not all people will necessarily go to a service provider as a first resort.

This is because the assessment produces an indicative quantum of public funds available to the person to then consider how it might be directed to create a set of personalised supports that best suit the person's circumstances. As such, it is up to the person concerned what s/he then chooses to share in a conversation with the provider agency. Obviously, the more the person feels able to share about what's important to her/him, the more likely it is that the provider agency/agencies (if that's who the person has decided to approach) might come up with a proposal that matches the person's preferences.

2.6.13 Service coordination and linkages with mainstream services

2.6.13.1 What are the obstacles to a cohesive package of disability services, where do the problems most arise, and how can they be fixed? What processes might be needed to fix them?

If the goal is a set of supports that are the best match with a person's circumstances and in the context of an ordinary valued life, then the most typical problems are:

- A system coordination mechanism that is focused on rationing and gate-keeping;
- A system that views people as commodities;
- A system where the majority of funds are transacted between government and service providers based on imperfect population-based estimates, resulting in the pre-purchase of services before the intended consumer has even showed up and been asked what s/he wants;
- A system that limits the use of funds to the purchase of traditional disability support services, characterised by congregation, separation and depersonalisation;
- A system that does not measure genuine lifestyle outcomes as reported by the person and in keeping with the UNCRPD;
- A system that does not invest in people's capacity to envisage an ordinary valued life for themselves;
- A system that places all the key decision-making about a person away from that person;
- A system that does not invest on the front-foot in people's lives, so that they remain distanced from an ordinary valued life and are not supported to build capacity;
- A system that does not value the person living with disability as most likely the best expert on their personal circumstances and what might help;

- A system that does not invest in community navigation so that people can be assisted to connect into ordinary community life;
- A system that does not invest in community capacity-building so that our communities are more welcoming and inclusive in their habits;
- A system that in its design
    - Reflects anxiety about people's vulnerability and overstates the notion of *safety* at the expense of the notion of *safeguards*
    - Can restrict people's access to ordinary opportunities through routine arrangements. "For example:
        - *Environmental restraint*, where the setting reduces or removes the choices that a person has;
        - *Routines restraint*, where the service setting runs daily living routines that reduce or remove the choices that a person has."[18]

We submit that these issues can be fixed by introducing an entitlements-based model of Individualised (Self-Directed) Funding, including the elements described elsewhere in this submission.

We are very happy to provide further detail as required.

2.6.13.2 What role would mainstream services play in any national disability scheme (such as coordination and facilitating access)?

There are a number of roles within the system that could be performed by a range of 'mainstream' entities.

The roles include:

- Assistance with assessment (assuming this is mandated by the public funder and subject to calibration);
- Assistance with planning;
- Assistance with brokerage;
- Assistance with service coordination, including hosting;
- Assistance with fund management and accountability.

Mainstream entities can include any entity that believes it can add value for a person living with disability by performing one or more of these roles. Such entities should include consumer-directed entities and these should be facilitated to emerge where none exist in a particular jurisdiction. There is reported evidence that people are particularly satisfied with their arrangements

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[18] Julia Farr Association 2010, 'Safeguards and restrictive practices: Literature review and considerations' (yet to be published), Julia Farr Association, Unley, South Australia, p. 3.

when they have been assisted to arrive at those arrangements by entities comprising people with similar experiences of disability[19].

2.6.13.3 *How do you prevent cost shifting between services inside and outside of the scheme?*

By determining at the outset the extent of the demography that the scheme is designed to cater for. Part of the problem with our current arrangements is that there are far too many interfaces between the governments of commonwealth, states and territories, and there are far too many between the different service systems for older people, people living with disability, people living with enduring mental illness, people with chronic disabling health conditions, and so on. All of these interfaces, and the boundaries upon which they are built, have the notion of cost-clarification, cost-shifting, and cost-avoidance at the core of most of the transactions.

Based on the successful changes to adult social care in the United Kingdom, (as evidenced by the United Kingdom government's commitment to a target that 30% of all vulnerable adults have a personalised budget by 2011) where people access a common assessment and funding mechanism based on functional support needs and regardless of the cause of those needs (be it disability, ageing, enduring mental illness, chronic health conditions), it is our view that cost-shifting is most likely to be minimised and avoided if there is one common 'national social assurance' scheme that is designed around functional support needs and not other less relevant aspects of people's circumstances.

2.6.13.4 *Where services remain outside a long-term care and support scheme, how can service delivery be best coordinated?*

This question becomes redundant if the national disability support scheme is an entitlements-based model of Individualised (or Self-Directed) Funding, including the best practice elements described in various places in this submission, because anything constitutes a 'service' as long as it is not illegal or somehow contributing to the incidence of disability or disadvantage.

2.6.13.5 *Should income support and disability service provision be coordinated as part of a package, and if so, who would do that and how? What conflicts or synergies could arise between a national disability scheme and income support?*

On the assumption that the funding for disability support and income support ultimately come from the same source, namely taxation, then both components represent financial assistance to help bridge the gap to an ordinary valued life.

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[19] Williams, R 2007, *Individualised funding. A summary review of its nature and impact, and key elements for success,* Julia Farr Association, Unley, South Australia.

Income support essentially bridges the gap for people who have no other source of income with which to cover the essentials of daily living.

Disability support essentially bridges the gap for people whose personal disabling circumstances demand funding assistance to ‘level the playing field’ so that people can go about their daily lives and access the same opportunities - transport, community facilities etc – on the same basis as other citizens.

Conflicts are most likely to emerge if:

- The relationship between to the two types of funding are not properly understood and charted;
- Access to the two different types of funding involves people having to tell their story more than once and having to endure a double burden of bureaucracy;
- The two systems work to manifestly different values and principles about people, personal authority, citizenhood, and capacity-building;
- Either or both systems exclude people living with disability in the governance of the arrangements.

2.6.13.6 *How could the capacity for people to move between services – both intra and interstate – be made easier?*

This issue is easily resolved if the national disability support scheme is an entitlements-based model of Individualised (or Self-Directed) Funding, including the best practice elements described in various places in this submission. This is because it is based on a personal transaction between a person living with disability and the funding authority, resulting in the person being allocated a personalised budget for the person to direct how s/he thinks best fits her/his circumstances.

Such an arrangement gives full portability so that people can move interstate with the assurance that their entitlement won’t change (save for the impact of any loadings for rural and remote settings).

Also, where a person is using their personalised budget to purchase services from a service provider, that person has much more freedom to move between services, and service providers, when compared with current arrangements where people are often ‘locked in’ to service models because the service agency deems that it cannot run the service viably if a person leaves (for example a shared living ‘group home’ arrangement).

2.6.14 *How should insurance arrangements for catastrophic injury link in with a disability scheme?*

2.6.14.1 *How should disability associated with catastrophic injuries be addressed?*

On the same basis as for other people, and as per the elements described in this submission. The Accident Compensation Corporation (ACC) operates a mechanism that provides funding support to people who have acquired a disability as a result of an accident, and this includes catastrophic injury. The scheme gives people in such circumstances much greater assurance of funding support quickly and easily, without the drama and uncertainty and time-consumption associated with having to wait for a litigious 'blame-establishing' process to take place.

The main issue is that people who have a disability through other ways, including being born with a disability, have had to access their support funding through separate public funding mechanisms. People with similar functional support needs might get differing amounts of support funding based on the cause of their disability, and this is manifestly troublesome and unfair.

We therefore recommend that there be a single national scheme that focuses on functional support need and not how that need came about.

Note that there is nothing to stop the taxation revenue for the national scheme being supplemented by insurance premiums to cover the incidence and prevalence of disability due, for example, to road traffic accidents. The cost of keeping a vehicle on the road in NZ includes an ACC levy for precisely this purpose, and this is in addition to the ACC premium that is collected from all employers and employees.

Interestingly, we note that NZ has a growing number of people living with disability accessing personalised budgets. We refer you to the work of Manawanui-in-Charge - http://www.incharge.org.nz/

2.6.14.2 *What are the benefits and costs of alternative approaches, including any effects on service provision for those covered by existing systems?*

We refer you to the following points.

- "An NDIS would also drive efficiency and best practice across the disability sector. Services would be person centred and individualised funding choices would create a market place for services"[20].

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[20] July 2009, *The plan for a National Disability Insurance Scheme,* p. 2, <http://www.ndis.org.au/downloads/NDIS-The%20Plan%20(LR).pdf>.

- A national disability support scheme would stop the shuffling and fragmentation that exists between commonwealth and state governments.
- Early intervention would reduce long-term costs.

2.6.14.3 How would any coherent Australia-wide approach be achieved given that catastrophic insurance is a state and territory matter? How would a national disability scheme be structured if jurisdictions followed different approaches to accident insurance?

Given the benefits outlined elsewhere in this submission, it is our view that it is eminently possible for the state- and territory-based catastrophic insurance arrangements to be structured into the national scheme we favour.

If different jurisdictions were, disappointingly, to fail to agree on a common approach that brings benefits in terms of outcomes, costs, and sits well within the rights framework established by the UNCRPD, then a national disability scheme would presumably have to exclude those people whose disability has come about through catastrophic injury.

This would be deeply troubling, because it would create cost-shifting and cost-avoiding interface issues that would consume valuable resources, and where people with similar functional support needs might receive differing amounts of funding support, and endure differing amounts of time to access that funding, depending on how their disability came about. We therefore ask that you do not allow such fragmentation to happen.

2.6.14.4 Are there lessons from existing injury insurance systems in Australia and New Zealand for a national disability scheme – regardless of whether those systems are incorporated into a national scheme?

Refer earlier response above.

2.6.14.5 What rights should remain, if any, for common law actions if no-fault arrangements were introduced?

No-fault arrangements should cover the practical consequences of a disability.

Common law actions should still be available for people to pursue where they believe there has been significant and enduring loss of opportunity over and above the level of living supported by no-fault funding.

2.6.14.6 If governments introduced broader no-fault catastrophic injury schemes, what would be the appropriate premium income sources?

As described earlier in this submission, two funding sources we have named include general taxation (including in the form of a named levy) and vehicle registration/insurance where a disability support element is collected by the registration/insurance agency and passed to the national scheme.

2.6.14.7 *If catastrophic injury is bundled with the national disability scheme, how would this be achieved without disrupting existing coherent systems for providing care to people experiencing catastrophic injuries?*

In terms of impact on the person living with disability, there is less likely to be drama if the insurance-based funding the person currently receives affords the same personalisation and flexibility as we recommend for a national disability scheme. In terms of the funder (the insurance company) there would need to be a negotiation so that the funding and coordination passes to the national disability scheme, or so that the insurance-based funding remains in place for that person, and is supplemented by the national disability scheme if the person is receiving less through the insurer than other people with similar functional support needs who are in the national disability scheme. This is necessary to establish fairness in the new system.

2.7 How much is needed?

2.7.1 *What does an entitlement entail?*

An entitlement should cover the additional costs of living with disability, and which might manifest themselves in a number of ways. Again referring to the structure of assessment tools in other jurisdictions, and on the assumption that those assessment tools have been designed to assess the degree of need in a range of essential lifestyle areas, the entitlement should cover at least the following:

- Support with particularly complex needs and risks (which in turn triggers a more detailed assessment where warranted, typically after the indicative funds have been determined);
- Practical assistance with the personal/household tasks of daily life;
- Assistance with meals and nutrition;
- Assistance with accessing work, learning and leisure;
- Assistance with making important decisions about life;
- Assistance to take active roles in and be part of the local community;
- Assistance to undertake essential family/caring role, such as caring for, or parenting, others;
- (Through a separate process) assistance to the person providing the main informal support to a person living with disability.

2.7.1.1 *What is the magnitude of funding needed for a national disability scheme?*

At the time of this submission, we at Julia Farr Association do not have access to information about the total numbers regarding incidence and prevalence in Australia of disability from all causes. Nor do we have access to information around current costs of disability support, segmented on a percentile basis against degrees of support needs. Nor, finally, do we have access to information about any quantified deficit between need currently funded and need not currently funded (on the assumption that the difference is a reasonable measure of the additional funding required to 'level the playing field' with non-disabled people).

The task of quantifying the magnitude of funding will require careful consideration. We are mindful of approaches that have been taken in other jurisdictions such as the United Kingdom to quantify and chart the relationship between functional support need and quantum of support funding, together with the context in which such analysis needs to operate.

We would be very happy to meet with the Productivity Commission to discuss such an approach in more detail.

Note that the magnitude of funding needed for a national disability scheme will be affected by the following highly important considerations:

- The extent to which communities have been rendered more accessible and welcoming in terms of
  - Public transport
  - Community facilities relating to education
  - Community facilities relating to commercial activities
  - Community facilities relating to leisure and recreation
  - Community facilities relating to democracy, local decision-making fellowship and association;
- The extent to which people living with disability are assisted to grow their economic independence, particularly through accessing mainstream employment and thereby earning a fair wage.

The extent of investment and success in these two areas (which would be in line with Australia's obligations under the UNCRPD) would significantly impact on the amount of funds required for a national disability support scheme.

2.7.1.2 How should unmet demand be measured and what is its size in value and person terms? Where are unmet demands greatest?

Refer answer to previous question.

2.7.1.3 What are the future levels of unmet demand associated with the current system, and with what implications for future funding?

Refer answer to previous question.

2.7.1.4 What are the practical implications of an 'entitlement-based system' for the design of a scheme, its sustainability and for budget management by governments? How could cost be contained?

Refer answer to previous question.

2.8 Financing Options

Over and above the relevant material we have provided in other parts of this submission, it is hard for us to attend to most of the Finance Options questions because we don't have access to detailed information about the financing and taxation mechanisms currently operating.

2.8.1 The form of financing

We would need more information about the various forms of financing you consider being options, before we can answer.

But if this question includes the way in which the funding is distributed to people living with disability, our strong recommendation is that the funding is allocated directly to the person living with disability, to be directed by that person in line with their preferences and personal vision.

2.8.2 The sources of funding

Sources of funding we have identified include:

- Funds collected through general taxation, including the option of framing it as a social insurance levy that covers the costs of meeting people's functional support needs as a result of disability, ageing, enduring mental illness, or chronic disabling health conditions;
- Funds collected through insurance/registration mechanism relating to use of road vehicles;
  (We note here that funds could similarly be collected through the registration/insurance processes for other activities that might represent an increased risk of injury leading to disablement, such as organised sports)
- Funds currently collected through employer/employee contributions in respect of workplace injury.

2.8.3 Funding consolidation?

2.8.3.1 What would be the best way of financing a national disability scheme and why? What are the strengths and weaknesses of alternative financing arrangements, including 'pay-as-you-go' and funds that take account of future liabilities?

Refer above.

2.8.3.2 To what extent would a national disability scheme draw from funds currently collected through general revenue? Would it replace some existing funding sources or consolidate them?

Refer above.

2.8.3.3 *What are the equity and efficiency implications of different models? Who would be the 'tax' collector?*

Equity

We take 'equity' to mean equity of access, or fairness. Given the problems within the existing funding mechanism, where the degree of funding assistance a person can access is heavily influenced by where in Australia the person lives, it is important that a national model provides equity of access based on a common assessment of people's functional support needs, and with fair consideration for any other factors that are relevant, for example the additional cost pressures of living in rural or remote areas.

Efficiency

We take 'efficiency' to mean the way that the funds are collected and distributed, with a view to minimising wasted effort. As mentioned elsewhere in this submission, the collection of funds through means-tested co-payments at point of entry to the system may not prove particularly efficient for the reasons set out elsewhere.

It makes sense to make the most of existing efficient fund collection systems, if they are deemed to exist. For example, in New Zealand, employees pay their accident compensation premium levy via their employers through the existing 'pay as you go' system, and motorists pay an accident compensation premium as part of their regular vehicle insurance premiums.

Collecting the tax

Depending on the source components of the funding model, the collector of the taxes could include the ATO, employers, and insurers, which is similar to what happens in New Zealand, with that collected revenue then transferred to the Accident Compensation Corporation (ACC) to run their scheme.

2.8.3.4 *How would costs overruns be managed by different approaches (for instance, using a cash reserve or using the treasury to lend money in times of need)?*

The available evidence from the United Kingdom suggests that cost overruns become less likely as successive iterations of the Resource Allocation System resolve the detail of the relationship between increments of functional support need and corresponding increments of support funding.

That said, as with any business/system planning, it makes sense to include a degree of contingency in the budget (and therefore the revenue generation) to cover for unexpected variations in demand or cost of supply.

2.8.3.5 *What would happen if the fund value exceeded the value of future liabilities (provide dividends to government, serve as a buffer)?*

A buffer is certainly one option, but we would recommend that any fund surplus be viewed as a source of investment in the following:

- Community capacity-building, so that our communities become more welcoming and inclusive in their habits;
- Capacity-building of professionals as they move through their core training, so that mainstream professional services – such as healthcare practitioners, building industry professionals, education professionals, and so on – emerge into their professional lives with good orientation and capacity in respect of the needs of Australians living with disability;
- Investment in innovative ideas, as generated by people living with disability and local communities. Such investment could produce highly significant social dividends in terms of the overall wellbeing of our communities. If required, we can provide the Commission with some excellent examples of this in other jurisdictions.

A dividend to government would not be popular, and would seem counter-intuitive given the extent of disadvantage that vulnerable Australians experience. In other words, there will always be something that a national disability scheme could invest such surpluses in, to grow capacity. Such investment could in turn deliver further surpluses, as more and more of the available funds are invested in 'front-foot' ways.

2.8.3.6 *How would exposure to varying investment returns affect the sustainability and prudential management of a future fund?*

The Julia Farr Association, and its sister agency the Julia Farr MS McLeod Benevolent Fund, are both self-funded entities and we rely on the returns from our investment portfolios to fund our work. We are entirely exposed to varying funding returns.

In response, we have designed investment management arrangements that have helped ensure we can undertake our core work even during the very difficult times.

Even though we are financially tiny compared to the potential size of a national disability scheme, the principles (and the consequences) are the same. If required, we would be happy to talk in more detail about our approach.

2.8.3.7 *How could a financing method take into account future demographic pressures? Would it be desirable to do so?*

Any scheme where one has to have regard for future costs means that one has to assess incidence and prevalence, including that caused by demographic changes. Therefore it is desirable to make estimates of future demographic changes and to include this in the financial methodology for calculating the total dollar value of the scheme.

2.8.3.8 Should there be private funding contributions to a national disability scheme? How much? Through what means?

'How much' will depend on how much the scheme is able to attract from the general taxation mechanism. The size of any shortfall will determine the amount that needs to be sought from other sources.

It's not clear from the question whether 'private funding contributions' means individual contributions from participants through a co-payment mechanism, or whether it refers to contributions from private insurance as for health, or whether it refers to contributions from employers.

Co-payments from participants

As set out earlier in this submission, this isn't a matter of 'should'. It is a matter of determining which of the following is preferable:

1) That a social insurance model does not ask for co-contributions (example Sweden) which means that everyone is assured of a level of cover, including those citizens of significant personal private means who could be regarded as being able to pay their own costs ("it's not fair – I didn't pay taxes just so that a rich family can access the same disability support funding as a poor family – they should pay their own way so that the public funds can go further");
2) That a social insurance model does ask for co-contributions (example United Kingdom) which means that some people may feel they are being asset-stripped through no fault of their own ("it's not fair - I've acquired a disability and now I'm having to lose the value of my accumulated wealth including my house – what was the point of pursuing the great Australian dream in the first place if the government is going to take most of it off me - what will I be able to leave for my kids?").

Private insurance

If this were envisaged to operate the same way as the Medicare arrangements, where people who have means beyond a certain level are expected to take private health insurance or otherwise pay a Medicare surcharge levy, then there is no reason why such a mechanism could not operate in terms of national disability insurance, because people will be familiar with the mechanism. If co-payments were expected from people, then this might be a simpler way to proceed than a more complicated means-testing mechanism at point of entry to the system.

Contributions from employers

In New Zealand, accident insurance levies are collected via employers. Some of this is an employee contribution from pay, while some is an employer contribution. Given that some people acquire disability through their involvement with employing organisations, an employers' social insurance levy is an option.

2.8.3.9 *How could a national disability scheme be used to leverage greater community contributions to the care and support of people with disabilities and their families?*

Refer answers earlier in this submission.

2.8.3.10 *Who would be the funds manager? What should be the investment strategy?*

Funds manager

Taking the example of a not-for-profit grant-making trust, the imperatives are to protect the capital base while also generating enough income to then distribute to the intended beneficiaries.

The approach of one such trust in South Australia is to set the coordinates of an investment strategy, with careful consideration of risk and return issues. These settings are then passed to an external investment funds manager to run the investment portfolio. Typically this arrangement is made because the trustees are not necessarily specialists in investment funds management.

Therefore, if there is to be an Australia Disability Support Authority, the question is whether the investment management portfolio is built into the skill set of the organisation or whether it is outsourced. The choice would be determined by the cost-benefits in each case.

Investment strategy

Again taking the above example, the imperatives are to protect the capital base while also generating enough income to then distribute to the intended beneficiaries. Within this, the primary consideration will be which strategic elements will most reliably deliver the highest quantum of revenue with which to fund the scheme. The better the performance, the more assistance is then available for people living with disability.

Importantly, there will need to be ethical considerations in the investment of funds. We recommend a statement of ethics that sets the boundaries for investment, and which ensures that funds are not invested in enterprises whose products or services may be deemed to contribute to the incidence of disability, or to otherwise deepen the degree of disadvantage that people living with disability currently experience.

2.8.3.11 <u>How could a financing method be structured to create the maximum incentives for getting the best outcomes for people with disabilities and their families, increasing efficiency and in achieving early intervention?</u>

Funds in

Given that some people acquire their disability through sub-optimal workplace practices, and assuming that one financing scenario sees employers making levy contributions to the national disability insurance scheme, then a scale of discounted premiums could be crafted as an incentive for employers who design their workplaces to minimise the incidence of disabling workplace injuries.

Funds Out

The best possible incentive is to allocate the funding directly to people living with disability so that they may direct that funding allocation towards a personalised set of support arrangements that best match their particular circumstances.

We note the outcomes reported elsewhere, where people who have Self-Directed Funding through a personalised budget have generated better outcomes at same or lesser cost. This is because the beneficiary, who bears the consequences of any productivity gains or losses, has the greatest incentive for making sensible decisions that make the funding stretch as far as possible over products, services and supports that are most meaningful to that person.

As soon as you design a funding mechanism that places other people in the decision-making process (such as brokers, service providers etc), that incentive is diluted.

Therefore the financing method for ‘funds out’ should involve a direct allocation to the person, together with high quality supported information, and planning assistance where required, so that the funds are used in ways that are manifestly efficient and focused on the ‘front-foot’ in people’s lives, including early intervention (which we prefer to term, ‘early investment’).

2.8.3.12 <u>Should the funds manager/collector be the body that oversees the national disability scheme more generally?</u>

Not necessarily. Refer earlier answer relating to the funds manager and investment strategy.

2.8.3.13 <u>What lessons are there from overseas approaches for appropriate financing methods?</u>

Refer answers earlier in this submission.

2.9 Workforce Issues

First, the extent of demand for workforce needs to be considered in the context of what people critically need to live a decent live. Often, demand for workforce is created because we have failed to find alternative, often more appropriate solutions, to the issues people are living with. Examples include:

1) Access
   - the more we can achieve universal accessibility in the building, spaces and transportation in our communities, the less pressure there is likely to be for personal hands-on assistance;
2) Personal equipment and assistive technology
   - the more that a person can access personal equipment and assistive technology to facilitate daily life at home and on the move, the less pressure there is likely to be for personal hands-on assistance;
3) Welcoming communities
   - the more that our communities grow their capacity to value diversity, and as a consequence to be welcoming and inclusive in their habits, the less pressure there is likely to be for personal hands-on assistance.

Given the concerns about demographic changes in Australia, where relatively speaking there might be a shrinking population of workers and a growing population of people needing personal assistance, it makes very good sense to attend to the above three areas, as they could have a highly significant impact on workforce demand.

2.9.1 <u>How can workers be attracted to the industry? What role should government play in this process?</u>

Only when our society properly value people living with disability will other people (the potential workers) then value the idea of working in the ‘industry’. Government has a role in this process, by investing in a reframing of the work and its communication to potential workers.

This includes government’s leadership in ensuring that any and all training opportunities relating to the ‘industry’ are (in their heart, in their mind and in their action) advancing and upholding the obligations of the UNCRPD.

2.9.2 *What type of skills and workers are required?*

This question warrants an answer the size of a PhD thesis.

In short, the types of skills and workers required will be those that people living with disability seek, and which are likely to have the biggest positive impact toward a good valued life.

This will also include workers with a deeply felt value base about the dignity and authority of a person living with disability, and the desire to support that person into an ordinary valued life.

2.9.3 *What role should government play in upgrading the skills and training opportunities available to workers?*

The broader question here is about the role that government plays in developing the overall marketplace within which people living with disability are directing their funding allocations.

During transition

As we've mentioned elsewhere in this submission, we believe there is a role for government to assist service providers to move through a transition to the new arrangements. Such funding should primarily be directed to those service agencies that have a demonstrable commitment to upholding and advancing people's rights as set out in the UNCRPD, and a corresponding demonstrable commitment to developing highly personalised supports. In which case, a significant portion of such transition funding would be directed to the development of agency staff.

Ongoing #1

If government wants to assure that there is a defined level of competence across all sector staff in relation to values and practice, then it is entirely possible that government might set aside funding to ensure that all sector staff have accessed a given menu of training opportunities.

However, this assumes that government can correctly predict what each and every person living with disability might seek from the support staff involved in their lives. This is a precarious assumption.

One possibility might be for Government to identify the values-based and practice-based habits that are desirable in all sector staff, set aside funding for this purpose and then leave it to the person living with disability, or the person/agency (which could include a service provider) so nominated by that person, to access those funds for particular staff.

Ongoing #2

It is particularly important that government have regard for the skills of persons working in mainstream services, such as health, education, transport, construction, and so on. One of the reasons why people living with disability find themselves directed into separate support systems, with all the associated cost implications to the public purse, is because of insufficient capacity in our wider communities. This cannot continue, because it is manifestly unfair and contravenes Australia's obligations under the UNCRPD.

There is therefore an important, indeed profound, opportunity for Australia, whether through the proposed new scheme or parallel effort, to address the competence and confidence issues of a range of occupations such as teaching, health and allied health professions, building industry professions, and so on. If government invests in the capacity-building of such people, then it is growing the capacity of our communities to be properly welcoming and inclusive of people living with disability, which in turn can be expected to reduce demand for funding within a national disability support scheme.

2.9.4 <u>How can a scheme be implemented so that extra funding results in more and/or better services rather than paying more for the same services?</u>

In again emphasising our main condition that a national disability scheme is, in its design and implementation, an entitlements-based model of best practice Individualised (or Self-Directed) Funding, the elements that we have described elsewhere in this submission will help ensure that extra funding results in more and better services, and this has been reflected in the evaluation evidence collected elsewhere[8].

2.9.5 <u>What transition arrangements if any, are required?</u>

Transition for people living with disability

There will need to be investment in the capacity of people living with disability to reconnect with the personal vision of an ordinary valued life, and what this means in terms of how they might direct their personalised budget. A significant portion of this may need to continue beyond transition so that people new to the system each year have the chance to make this connection and build capacity.

Transition for service provider agencies

Many service agencies may operate on a not-for-profit basis and may have limited reserves to self-fund any transition. With these agencies in mind, transition arrangements should include a transition fund to assist those agencies to transition to models of individualised, personalised supports. Larger, better endowed agencies might reasonably be expected to self-fund the greater part of the transition journey.

2.9.6 <u>How long would it take to build up the required workforce?</u>

This cannot be estimated, especially in the absence of the investment we have signalled at the start of this section on workforce issues.

2.9.7 <u>Are there particular skill bottlenecks that need immediate attention?</u>

The value base with which workers approach their work, so that the cornerstone of the relationship between helper and helped is based on promoting and upholding the disabled person's personal authority.

The leadership capacity of the agencies that employ workers, so that all of the decisions agencies make are in the context of assisting people into an inclusive valued life, and not the context of agency sustainability.

2.9.8 <u>What role could volunteers and workers in mainstream services play?</u>

Volunteers - informal

In line with the deeply-felt values that might underlie a new national disability scheme, the concept of a 'volunteer' may need to be reframed. For all of us, there are likely to be people in our lives – family, friends, acquaintances, neighbours, workmates, club co-members, local tradespeople – who might from time to time volunteer their free time to assist us with something. Such transactions, such favours, such neighbourliness, are an essential ingredient for the wellbeing of our communities. Such gestures reflect the sense of goodwill that we at Julia Farr Association believe is hardwired into us all. This goodwill just needs to be tapped more intentionally when it comes to people living with disability whose current lifestyles, characterised as they often are by passive service recipiency and dearth of personal networks, don't generate sufficient opportunity for such assistance to happen naturally.

Such activity is important in the life of a person living with disability, because otherwise we are assuming that it is okay for people living with disability to only have paid personnel, 'rented strangers', in their lives. It is therefore essential that a national disability scheme pays careful regard for this and ensures that it has made sufficient provision inside and outside the scheme for such activities to naturally emerge.

Volunteers – formal

For all sorts of reasons, people wish to volunteer their time to be of service in some way. There is a role for such activity in disability support, on two main conditions:

1) That the deeply-felt values underpinning the motive of the volunteer come not from a sense of charity, or pathos, but from a sense of fairness, of the desire to see social justice prevail;
2) That the relationship between the volunteer and the recipient is firmly anchored on a sense of balance in the relationship, where both parties are active and treated with respect and worth, and where the volunteer is not operating in a way that places the balance of power with the volunteer and away from the recipient.

Put another, way, if volunteer effort is conceived, initiated and coordinated in ways that reinforce traditional notions of charity and that reinforce the person living with disability as a passive recipient of service from others and in ways determined by those others, then that voluntary effort is profoundly counter-productive to the person's interests and the obligations of the UNCRPD.

Workers in mainstream services

Given the obligations and expectations established by the rights within the UNCRPD, any worker in any mainstream service can be expected to undertake their work in ways that are respectful, welcoming and inclusive of people living with disability. This would apply to health staff, staff working in hospitality, staff working in public transport, staff working in retail, and so on. Basically, every citizen has a role to play in ensuring our communities are welcoming and inclusive. Please refer to point made earlier in this submission about training opportunities for workers.

2.9.9 What is the appropriate level of training required before commencing work in the industry? Should any existing certification requirements be altered to reduce obstacles to people working in the disability sector?

We recommend caution before any mandatory level of training is asserted before entry to the industry, because this might exclude potential workers that the person living with disability might wish to engage from her/his personal network or neighbourhood.

2.9.10 What role is there for national accreditation?

We cannot answer this question as it's not clear what the national accreditation is meant to relate to.

2.9.11 What scope is there for productivity and efficiency gains in the sector?

As demonstrated in other jurisdictions, there is enormous scope for productivity and efficiency gains in the sector when the funding arrangements reflect best-practice Individualised Funding[8] [11].

2.10 Governance and Infrastructure

2.10.1 Who should do what in a national disability scheme (probity and accountability, data collection, financing, planning, gate-keeper, claims management), and how would these functions be organised?

2.10.1.1 *Should government departments or an independent statutory body administer the scheme?*

2.10.1.2 *To what extent could one agency act as the fund holder and overall decision maker (the role performed by the Transport Accident Commission in Victoria for people affected by catastrophic motor vehicle injury)?*

2.10.1.3 *What is the scope of outsourcing various functions of a national disability scheme (for example, claims and risk management by private insurers)?*

Government departments or independent statutory body

There should be a single standalone agency that runs the main components of the scheme. These components could include at least the following:

1) Overall governance (whose membership would include people living with disability);
2) Design, calibration, maintenance and evolution of the Resource Allocation System (RAS);
3) Data collection;
4) System planning;
5) Fund distribution coordination (otherwise known as gate-keeping and claims management, terms that we suggest you avoid).

Roles that *might* be conducted by separate agencies in support of the scheme include:

- Funds collection;
- Investment management;
- Evaluation (depending on its character).

Roles that *must* be conducted by separate agencies include:

- Independent advocacy;
- Evaluation (depending on its character);
- Significant complaints, of the magnitude that typically find their way to an entity/individual providing an ombudsman role.

One agency for funds and decisions

We don't think it will help coherence or efficiency for different types of disability funding and distribution to be held by different types of agencies. In New Zealand, even though accident insurance funds are collected from a variety of sources, including motor users to cover for consequences of motor accidents, the funds are consolidated into the work of one agency, the Accident Compensation Corporation.

Outsourcing of claims and risk management

Our view is that it would be unwise to outsource claim management to insurance companies. While such agencies may profess competencies in relation to claims management, it is far less likely that such agencies will have capacity in relation to the ethos of the scheme, and the social context of disability that the scheme is designed to alleviate.

Insurance agencies are in danger of applying a reductionist approach based on material considerations; the proper attention to the issues in the lives of people living with disability requires much more than such an approach.

The same is true in terms of risk management. The prevailing ethos of insurance companies is to minimise payouts so that there is a maximum return to shareholders. This is entirely out-of-step with the aims of the scheme.

2.10.2 *Would the new management structure replace, either wholly or partially, the existing systems? How would the various actors in a national disability scheme engage with each other to ensure a coherent system (governments, service providers, departments)? If existing schemes remain, how will the new scheme interact and communicate with these schemes?*

We apply two conditions when considering this question:

- That a National Disability Insurance Scheme, in its design and implementation, reflects an entitlement-based, best-practice model of Individualised (Self-Directed) Funding. This means that the funding agency directly transacts with the person living with disability, via an accessible assessment process that leads to a funding allocation (personalised budget);
- That the above mentioned funding agency is a national standalone agency that runs the main components of the scheme.

In which case, these arrangements would replace the existing mechanisms.

As such, this would also minimise the interface issues for various actors.

For state and territory governments, the new arrangements would mean they could then better focus on the capacity of all of government's mainstream services - in education, transport and so on - to be welcoming and inclusive of people living with disability.

The primary interface for service providers would be with individual people living with disability, who hold a personalised budget and are in an authentic role of customer.

2.10.3 *What kind of information gathering system about outcomes, costs and individual records should be developed, how would it be run, and how long would it take to develop? How would privacy concerns be managed?*

Privacy

For anyone to access publicly-funded services, there will be personal information involved so that funding can be determined for the person. Such information should be cared for in line with Australia's legislative framework relating to privacy.

Individual circumstances

Because of the multiple entry points into existing systems, and because of the extent of professional involvement in the topic of disability, people living with disability have been particularly susceptible to extensive and repeated enquiry into their circumstances. One might hope that the multiple entry points can be resolved through the structure of a single standalone national entity.

However there is still the issue of intrusion. In Australia there are several tools in production or use that attempt to take a comprehensive view of a person's circumstances. Our view is that such tools, for the vast majority of people living with disability, are over-engineered and unacceptably intrusive. Once such information is collected, it then presents issues of how it is safely stored, who can access it, and for what purpose. We therefore urge caution about the amount of data that needs to be collected. There are other jurisdictions that have demonstrated that support funding can be successfully allocated, without undue risk to overall budget, through the collection of a much less volume of data, and in ways that deliver great potency without unduly compromising the person's privacy.

If required, we would be very happy to provide examples of such approaches to the Productivity Commission.

Outcomes

Outcomes appear to have been elusive in the disability support sector, as they often are in other areas of human services. Often other measures are used as proxies, and such measures are often output measures (for example how many day places, respite hours, accommodation places etc), process measures (for example how plans are written, how complaints are managed etc), or even input measures (for example what qualifications in what types of staff).

Unfortunately none of these measures tend to come close to being a useful measure of the impact of that support in people's lives.

Therefore, it is of critical importance that the national scheme considers an authentic outcomes measurement framework that captures the degree of impact of disability funding in people's lives.

One such example is the Q50™ framework, which is the subject of a separate submission by the license holder.

Individual records

The individual record should largely confine itself to three classes of information:

1. *The Circumstances*
   Information that assisted the determination of the amount of funding that was allocated to the person as a personalised budget;
2. *The Plan*
   Information about how the personalised budget was spent;
3. *The Impact*
   Information about the measured impact on the person's lifestyle, and in the context of an ordinary, valued life and the rights as set out in the UNCRPD.

2.10.4 What sort of public reporting would be necessary to ensure the accountability and transparency of a new scheme?

Based on the previous answer, public reporting could include the following, population-based information:

1) The extent of functional support needs, together with an analysis of the factors leading people in such circumstances to present themselves to the scheme for assistance;
2) The ways in which people are directing supports in pursuit of an ordinary valued life, with an analysis of which approaches appear to have had the most potent impact;
3) The degree of impact that the funding has had, measured in terms of lifestyle outcomes.

Together with:

4) Information about the overall funding pool, the contributory sources, investment performance, and extent of use of funds for population-based initiatives such as community capacity-building;
5) Customer satisfaction data, and the extent of feedback-based improvements to the scheme.

2.10.5 How can we reduce the need for form-filling and unnecessary re-assessment?

As reported elsewhere in this submission, the main contributory factors would be:

- ***A single, standalone agency***
  - so that multiple entry points, and therefore multiple storey-telling and assessment, are removed;
- ***A simple assessment tool***
  - so that form-filling, and the associated intrusion, is minimised;
- ***Default annual assessment***
  - so that government accountability expectations are met, but using the same

simple self-assessment mechanism that will not feel burdensome, because it is as much about 'checking-in' as anything else, and because it is about functional support needs. It will not require people to keep proving they live with Down Syndrome, Cerebral Palsy, etc;

- ***On-demand re-assessment***
  - so that necessary reassessment happens quickly for people, including at their instigation, when their circumstances change.

2.10.6 <u>How might coordination achieve cost savings for governments through buying power, shared investments in systems or in other ways?</u>

By definition, a standalone entity for the scheme should deliver the efficiencies of single shared systems because they will be within the one agency. This should therefore deliver efficiencies for state and territory governments who, although no longer receiving that portion of taxation that they allocated for disability support funding, equally are avoiding the costs of local disability support funding systems.

Again, as set out elsewhere in this submission, a single standalone agency distributing funds to individual people, has demonstrably delivered cost savings in other jurisdictions because of the personal incentives that directly come to the person living with disability.

2.10.7 <u>How would the costs and service quality standards be oversighted and 'red tape' burdens avoided?</u>

Service quality standards

The most important contextual point we can make is that people living with disability are citizens first and foremost, and as such belong at the core of our communities.

This means that service quality standards must have proper regard for the rights of people living with disability to live active, inclusive lives with their community, and to promote and uphold this citizenhood in the design and commissioning of disability services.

We believe that the UNCRPD should underpin service quality standards to ensure that the supports provided to people living with disability are meeting Australia's obligations under the UNCRPD.

There needs to be a strong movement away from the quality measurement of organisational processes and systems to "person-centred quality assurance based on responsiveness to the person serviced rather than compliance with process"[21].

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[21] Chenoweth, L & Clements, N 2009, *Final report: Funding and service options for people with disabilities,* Griffiths University, Queensland, p. 25.

2.10.8 *What measures should be in place to address adverse unintended outcomes (such as inappropriate claims in personalised funding accounts)?*

The important principle here is that the vast majority of participants are not going to wantonly break the rules. So the accountability mechanisms should reflect that.

One can look at the practice elements in other domains where funding is being awarded and where outcomes need to be monitored.

For example, the Julia Farr M S McLeod Benevolent Fund makes grant awards every year. Our practice is this:

1. *We only sign-off a grant award when we are satisfied that it is within our rules*
   Applying this approach to a national disability scheme, the government officer would not sign off the funding for a person's support plan until s/he is satisfied that the plan contains nothing that is illegal, or that is likely to contribute to further social disadvantage etc;
2. *We only sign-off a grant award when we are satisfied that there is a clear set of outcomes in mind, which can be measured*
   Applying this approach to a national disability scheme, the government officer would not sign off the funding for a person's support plan until s/he is satisfied that the plan's elements have a clear link (directly or indirectly) to the needs that were identified in the assessment and that this will produce measurable benefits to the person;
3. *We release funding in stages, typically quarterly in advance, to manage our exposure to any misuse of funds*
   Applying this approach to a national disability scheme, the payments schedule would ensure that funding is available in good time to pay for the arrangements (for example, in advance weekly, monthly, quarterly, or as required) , but it isn't released all in one go;
4. *We only release further scheduled payments once we have received feedback on how previous released funds have been used*
   Applying this approach to a national disability scheme, scheduled payments would be released once the government officer has information about how the arrangements are going. It is important that this is not burdensome to the person living with disability and their family. We can give examples of options which are minimally burdensome to the person/entity and which help ensure that funds are being used as expected;
5. *We put in place supplementary reporting arrangements for any grant recipients where there may be capacity issues*
   Applying this approach to a national disability scheme, there may be a very small number of individuals, with specific histories, where the accountability schedule carries some supplementary features, or where the funds are necessarily transacted through a third party with capacity.

We think that the above suggestions can help ensure that funds are not being misused or poorly managed, with a focus on measurable lifestyle outcomes, and without unnecessary burdensome bureaucracy on the vast majority of recipients.

2.10.9 *How would stakeholders be given a 'say' in a national disability scheme? (for example, through an advisory board and formal consultations). Who should be represented?*

Again assuming that our main condition is in place, that a NDIS is an entitlement-based model of best practice Individualised Funding, then people living with disability should be at the heart of the decision-making about how their personalised budget is directed. This is how stakeholders would have a say at the grassroots of the scheme.

In terms of overall governance of the scheme, our view (based on the principle of "nothing about us without us") is that the membership of the body of governance for the scheme should include people living with disability. This should not be limited to advisory functions but should extend to authentic participation in the formal leadership of the scheme, including the range of decisions that any board of directors might be expected to consider.

2.10.10 *What arrangements should be in place for:*

- *Making complaints (for example, a disability ombudsman; complaints devolved to service providers or a centralised complaints arrangement process)*
- *Reaching determinations in any dispute (for example, internal departmental arrangements, independent boards, courts or tribunals, or a process involving a number of layers)?*

As signalled elsewhere in this submission, there needs to be a separate pathway from the main agency, in respect of significant complaints. Typically this would include the duties of an ombudsman, so that complaints may be properly adjudicated, including the use of independent panels to resolve complex disputes.

There also needs to be a third pathway in respect of independent advocacy.

2.10.11 *What would be the appropriate dispute resolution processes?*

Again assuming that our main condition is in place, that a NDIS is an entitlement-based model of best-practice Individualised Funding, then the dispute resolution process should focus on the following (listed in no particular order, and not necessarily an exhaustive list):

- Resolution that is anchored on furthering the person's journey into an ordinary, valued life, on a rights basis in line with the UNCRPD;
- Resolution that is anchored on the express wishes of the person in relation to how that ordinary, valued life is pursued. Where those wishes are in question, resolution

should be anchored on the perceived best interests of the person, as might be expressed by that person if s/he had the capacity to do so, and not on the expressed interests of another party involved in the person's life;

- Resolution that does not use the notion of 'safety' to justify arrangements that stop the person accessing ordinary life choices, and which instead use the notion of 'safeguards';
- Resolution that focuses on building capacity and sustainability, not on keeping the person in a cycle of dependency and disadvantage.

2.10.12 How would people find out about what they were entitled to (online, one-stop shops, service providers)?

There are good examples in other jurisdictions of how online technology is being used to connect people with information about the scheme and how funds can be used. This can include standard website content (eg www.incontrol.org.au; www.in-control.org.uk), and interactive content (eg www.shop4support.org.uk).

We believe there is plenty of opportunity to develop very strong online platforms, and would be interested in assisting this to happen, given our current role and activities.

It is important to be mindful that many people living with disability might not be able to easily access online content, for all sorts of reasons including poor access design, no broadband capacity at the person's home, not owning a PC/laptop, etc.

It is important to think about how government might invest to ensure that all people living with disability are assisted to engage online, and to ensure that material is available in a variety of formats as alternatives to online.

The information available should critically include the following (not necessarily an exhaustive list):

- Information about what a self-directed budget means, and the ways people can direct;
- Information about the values of an ordinary life and the roles within;
- Information about how to develop a personal vision;
- Information about how to plan;
- Information about who can help with planning;
- Information about how people don't just have to rely on the services that currently exist, and can develop something themselves;
- Information about who can help with putting the plan into action and organising things;
- Information about capacity-building opportunities.

2.10.13 When and how would a national disability scheme be evaluated?

Ongoing evaluation arrangements should operate, anchored on metrics such as:

- Measured changes in lifestyle, and what it cost to achieve these;

- Stakeholder satisfaction;
- The effect on outcomes and cost, of the different variables that people might choose (or which reflect their circumstances), e.g.
    - Method of self-direction (typically ranging from Direct Payments to Individualised Service Packages)
    - Urban vs rural vs remote
    - Capacity-building opportunities that were accessed along the way, including building a personal vision
    - Service models selected
    - Quality/quantity of information available
    - Extent of use of agencies that assist with planning, coordination, and service-hosting
    - Etc.

2.10.14 <u>What is the role of research and innovation in a national disability scheme? How could it be promoted, and who would do it?</u>

Just as evaluation harvests the learning from this initiative, so research can harvest learning from outside the parameters of the evaluation.

It will be critically important that Australia joins an international ‘community of interest’ on this topic, to exchange ideas and experience and findings (for example, like open source software communities of interest).

In terms of promoting the research within Australia, we suggest that a community of interest be developed (perhaps not unlike the one currently facilitated at In Control Australia).

In terms of who could do the research, our preference would be that this be done by agencies whose overriding consideration is ‘social profit’, and not ‘financial profit’.

Social profit means that the agency does not exist for financial profit (return to shareholders) but for something else. Commonly called ‘not-for-profit’, we call this ‘social profit’.

We are a social profit agency with an interest in research and evaluation, and with a credible history of engaging with people living with disability. Therefore we believe we could have a role in research and evaluation, and there will be other organisations in Australia who similarly have a social profit motive, and with a background in research.

2.10.15 *What are the lessons from existing state and territory arrangements for effective governance of a national disability scheme?*

We offer the following thoughts.

Insufficient involvement of people living with disability in the governance arrangements

There are many problems that can be named in the design and delivery of state and territory disability support arrangements. We believe that these issues can usually be traced back to a relative absence of people living with disability in the formal governance of those state and territory disability support arrangements (over and above any advisory roles).

Insufficient vision

We also believe that a state or territory will be more likely to struggle with its disability support arrangements if it has not articulated a clear vision for the impact of disability support in people's lives (and of course that vision needs to have been developed alongside people living with disability).

Majority of funds are invested 'on the back foot'

This means that most funds appear to be spent in a way that responds to crisis and which manages how things currently are. We believe that the majority of funds available should be spent 'on the front-foot'. This involves early investment, strengths-based approaches, and focusing on a positive future (rather than on managing a difficult present).

Interface black hole

Too much resource and energy and outcomes lost on managing artificial interfaces between governments of commonwealth, states and territories, with people being shifted around the system (or lost in the gaps therein) because of budget considerations.

Disability the 13th priority on a list of 12

Insufficient appreciation of how disability considerations need to be woven into every aspect of public and community services, from transport to education to recreation and so on. It might be talked about, and listed on action plans, but it is not necessarily a *deeply-felt value* and as such does not produce a crucial mass of support from those involved so that there is real change.

2.10.16 *Implementation issues*

2.10.16.1 *What is the realistic time plan and sequence of initiatives for implementing a national disability scheme?*

A phased rollout of the arrangements could start next week if the inclination was there (refer last bullet of previous answer). We can direct you to good examples in other jurisdictions of how Individualised (Self-Directed) Funding has been rolled out.

It is entirely possible, and indeed vitally important, for Australia to make the decision to introduce an Individualised Funding approach (aka Self-Directed Funding) so that more and more people are able to have a personalised budget (this is happening in the United Kingdom across a large number of local jurisdictions and without the backdrop of the matter of a national entitlements scheme).

This early move would be particularly important, given the mechanics of the financial modelling for a taxation-based national scheme may take a little longer to resolve.

2.10.16.2 *Are there some aspects that can be implemented early (for example, some service expansion, support to a target group, key infrastructure)?*

Refer above – COAG could resolve that all Australians living with disability will have access to a personalised self-directed budget by a given date, with robust percentage milestones along the way.

2.10.16.3 *What are the priorities for immediate development?*

The introduction of a game-changing methodology for personalised budgets, including a first version price point Resource Allocation System (RAS), a simplified self- assessment mechanism, and overall a process that places the person at the centre of decision-making.

The Julia Farr Association can assist with the detailed articulation of these mechanisms.

These are priorities because the current system is a profoundly disempowering experience for people; it does nothing to lift people out of cycles of disadvantage and it damages Australia's overall productivity and human capital. At the level of human rights, our current systems are offensive.

2.10.16.4 *How will stakeholders be engaged during implementation, including their inputs into a scheme and in raising awareness of how to use a new scheme?*

The voice of people living with disability needs to be included throughout implementation, and with people living with disability formally involved in the governance arrangements.

A System Design and Implementation Group, involving a range of representative stakeholders (most importantly, people living with disability), could undertake the detailed design work and establish an ongoing communications profile to provide updates and test ideas with the disability community and beyond.

The group's work might include the following (not necessarily an exhaustive list):

- Chart the relationship between current demand and current cost of response – this is the first step in establishing a Resource Allocation Mechanism;
- Add to this an analysis of the predicted future demand, and the cost pressures that one might predict from Australia's economic profile and workforce trends;
- Assess the dollar cost of the gap between current response costs and the response needed to authentically move out of cycles of disadvantage and dependency;
- Design and cost a system of planning supports, so that people living with disability are able to get assistance as required with planning, brokerage and hosting;
- Design and cost the administration and evaluation;
- Assess the cost to assist service providers with transition to personalised supports;
- Design and cost an independent advocacy mechanism;
- Based on the previous bullets, resolve an indicative dollar value to fund the mechanism, which is then passed to a separate finance group (see below) to chart this against the current disability support revenue from all sources;
- Design/adopt and test a simplified assessment tool;
- Translate public policy priorities into assessment weightings within the tool;
- Design and test the parameters for self-direction;
- Design and run an implementation schedule, including phased roll-out;
- Design and run communications/consultation mechanisms.

A separate Financing Group, with specialist expertise and again including people living with disability, could undertake the detailed financial modelling, in particular the revenue structure for the new scheme.

2.10.16.5 *Would there be a grandfathering of any existing benefits?*

Given the relatively low level of benefits currently enjoyed by people living with disability, it is easy to imagine that the vast majority of people will fare better in the new mechanism. Where some beneficiaries are currently being over-serviced in terms of dollar cost, then a change is implied, and not necessarily with any extended 'grandfathering' unless there are exceptional circumstances.

Similarly, while there should be transition funding to assist those service provider agencies who have an authentic interest in rights-based, personalised support and who have insufficient reserves of their own to reasonably undertake business re-orientation, such transition funding should have a fixed term and not be seen as a 'grandfathering' arrangement for 'heritage' services that do not advance people into ordinary valued lives.

2.10.16.6 *How would governments plan together for the orderly implementation of a national disability scheme?*

This should happen as per any bi-partisan, collaborative approach, involving:

- Alignment of strategic parameters and timelines;
- Shared approach to policy development;
- Shared approach to legislative and regulatory alignment with new arrangements;
- Shared approach to state/territory/federal capacity-building so that all government regulations, policies, services and practices promote and uphold the UNCRPD;
- Shared approach to community capacity-building so that our communities, in all respects, are welcoming and inclusive of people living with disability.

2.10.16.7 *What are the options if some jurisdictions do not cooperate on key issues?*

Where those key issues in some way contradict the obligations created by the UNCRPD (and it is hard to imagine an issue that doesn't have an element that relates back to UNCRPD), the co-operating jurisdictions will need to assert the cooperation of the other jurisdiction(s) in line with those obligations, and to find a solution, if necessary a rights-based 'third path'.

2.11 Appraising costs, risks and benefits

2.11.1 Costs and risks

2.11.1.1 How much do various services cost (for example, attendant care, accommodation, day centres), and what pressures are on these costs?

Because of the varying parameters around Australia for what each of these services constitutes, together with the varying histories around Australia of funding support and service costs, this is a very large question that should be referred to an appropriately constituted group to work through in detail. We have suggested such a group be part of the design and implementation arrangements – see answer to earlier question.

2.11.1.2 What cost methodologies (and data sources) are appropriate? What are the strengths and weaknesses of alternative costing approaches?

Refer previous answer.

2.11.1.3 How should unmet needs be measured?

Over and above the existing mechanisms in states and territories for recording unmet need (typically described as 'waiting lists'), the concept of unmet need requires a context. One can only properly assess whether something is unmet if it is compared to a benchmark for the need that should be met. Our view is that such a benchmark should not be couched in terms of dependency, but in terms of an ordinary valued life.

Therefore, to understand and measure unmet need, Australia first needs to have a clear, explicit and integrated understanding of the elements that comprise an ordinary valued life, and an associated system of metrics that can chart the degree of any shortfall in a particular person's circumstance.

The Julia Farr Association can assist the Productivity Commission to explore one such contextual model.

2.11.1.4 What are reasonable assumptions about future incidence and prevalence?

The reasonable assumptions are that:

- People will live longer, and therefore be more likely to require personal assistance at some point because of age-related disabling circumstances;
- Trends in population lifestyle and health suggest that more and more people might move into situations of dependency because of health issues;
- Continuing advances in technology mean that people will more likely survive pre-natal trauma, peri-natal trauma, road traffic accidents and other events

causing severe injury, but with less capacity and to the extent where varying degrees of personal assistance are required;

- The ratio of *people seeking to personally help* to *people seeking personal help* will become less favourable because of the changing demography within Australia;
- The above points will not be significantly offset by advances in technology that reduce the impact of, or remove the incidence of, certain types of disabling conditions.

2.11.1.5 <u>What would be reasonable assumptions about future cost pressures arising from labour shortages and other factors?</u>

If typical market forces apply to the disability support industry, then we might reasonably assume that:

- Increasing scarcity of labour will mean that the price of labour will go up;
- The 'non-glamorous' nature of disability support, when compared to competing industries, may further exacerbate labour shortages and labour price pressure;
- The increasing competition for personal/community donations, together with potential changes in habits of gift-giving as people work to ensure their own future and that of their children is more adequately covered, might mean that established service provider agencies will have less 'non-contract' resources with which to attract labour and offset other costs of providing services;
- People emerging into the workforce now are expected to experience a much larger number of jobs/occupations in their career than their forebears. This might mean that there is a higher turnover of labour in industries like disability support, which in turn will generate cost pressures in terms of recruitment, induction and training.

2.11.1.6 <u>What is the scope for productivity increases to reduce costs or increase service quality?</u>

In an environment of Individualised (Self-Directed) Funding, evidence elsewhere suggest that there are stronger lifestyle outcomes (which one can reasonably infer to be 'productivity increases') without further costs pressures, and in some cases actual savings. The reasons for this include (not necessarily an exhaustive list):

- ***Stop buying the wrong things***
  People stop buying services that weren't a good fit for their circumstances in the first place, but which had been pre-purchased via block contracts between government and service providers;
- ***Sharper customer focus from service agencies***
  When people have clear and explicit purchasing power through a personalised budget, it changes the behaviour of service provider agencies (this has been reported elsewhere);

- ***Use of unpaid, freely-given supports***
  People have a tendency to build in freely-given supports into their arrangements; by accessing the good will in their personal networks. This is because of an understandable commitment to getting best value for money (because any sub-optimal arrangements will be felt most sorely by the person living with disability). This does not mean that people become reckless or exploitative. It simply means that there might be aspects of a person's daily support that do not demand a professional skill set and which instead are often the things that people do for each other as good neighbours and friends;
- ***Greater use of mainstream resources and opportunities***
  Again because of the best-value-for-money principle, people have tendency to make greater exploration into what mainstream supports and opportunities exist within the community;
- ***Greater use of equipment, aids and adaptations***
  Again because of the best-value-for-money principle, people have a tendency to explore the use of equipment, aids and adaptations, on the basis that such items might pay for themselves over and over because they reduce the person's reliance on hands-on support for certain aspects of daily living.

Note that none of these are necessarily 'givens'. The availability of a personalised budget, by itself, does not guarantee the above will happen. The new arrangements will need to ensure that people can access, as required, assistance to imagine and reclaim the right to an ordinary valued life, to conceive of what this might mean in practical terms, and how freely given neighbourhood supports and opportunities might be a feature. Such assistance also needs to include high quality 'supported information', so that people can make an informed choice on a range of matters, including the cost-benefit opportunities of certain aids, equipment and adaptations.

As stated elsewhere in this submission, it is important that government attends to the broader issue of community capacity-building. The more that our communities are accessible, welcoming and inclusive, the more likely it is that a person living with disability will be able to access opportunities and supports that would otherwise have to be paid for through disability support funding.

2.11.1.7 <u>What would be the efficiency costs of the financing method associated with a new scheme and how does that affect the choice of method?</u>

There are already efficiency costs present in the marketplace because of the predominance of large service provider agencies operating particular congregate models of care. In which case, a move to a marketplace of personalised budgets will help attend to those efficiency costs in service providers who are currently wedded to particular models of support.

In general, efficiency costs can be attended to by the way the incentives operate in the new system.

For example, if a NDIS was arranged so that people were assessed and then their allocated funding was not in each person's control to self-direct, but instead was allocated to a formal broker to orchestrate a plan and purchase services, than this will introduce efficiency costs.

Similarly, if a person is given access to their allocated funding but can only spend it on nominated service agencies on a 'provider panel' this will introduce efficiency costs because the market will not include alternatives to named formal service providers which means that there will be fewer reasons for a service provider to maximise its efforts to add best value at best price.

Both of these scenarios operate in the current funding environment. If they are facilitated in the new funding environment, then we are less likely to see significant changes in the impact of services in people's lives, even if there is more dedicated funding circulating within the system.

To reduce the risk of such efficiency costs, it is critical that the new arrangements include every participant receiving a personalised budget that they can direct towards the arrangements that are best for her/him.

Note that the efficiency cost issue also apply to the way people's support needs are assessed. If the prescribed assessment tools (and the subsequent activities that might be collectively termed as 'brokerage') can only be administered by professionals with particular skills sets, then this 'closed shop' will create efficiency costs and will also be over-engineered (and therefore wasteful) for many people entering the system seeking assistance.

Therefore we recommend that a simple self-assessment tool, supplemented by thoughtful, empathetic enquiry from the government officer responsible for confirming an individual's funding allocation, will help avoid the emergence of efficiency costs in this part of the framework.

2.11.1.8 <u>How would uncertainty be modelled and what implications, if any, does uncertainty have for the design of the scheme and for risk management?</u>

Uncertainty could be modelled by making some assumptions of, and allowances for, margins of error in the following elements of the scheme (not necessarily an exhaustive list):

- Estimates of incidence and prevalence of disabling conditions;
- Estimates of average costs of response to each level of functional support need;
- Estimates of cost to deliver the gate-keeping role;

- Estimates of cost to provide individual assistance with visioning, planning, navigation and orchestration;
- Estimates of cost of risk assurance arrangements for people with the greatest levels of vulnerability.

In each case, the best-estimate can be modelled to have a percentage margin of error, say 10%, and then this can be quantified across the named variables.

This margin can then be built as a contingency into the overall funding of the scheme. Where the margin of error does not eventuate, any such contingency funds can be invested in capacity-building.

Note that the idea of the need for more risk management arrangements can be seductive, especially in a new scheme that has national coverage. However, we would urge that such arrangements be balanced to reflect the risk circumstances of the majority of people living with disability rather than the drama of the few.

2.11.1.9 How could the reliability of cost modelling be assessed?

Inevitably, the scheme's model can be expected to evolve as it progresses, in the light of experience, so that cost modelling becomes more sensitive to people's true circumstances. In which case, an ongoing mechanism for review and evaluation, especially incorporating elements of action research, should be a natural feature of the arrangements.

This must include the ongoing harvesting of data about people's circumstances, the corresponding support arrangements, and the measured outcomes.

In the case of individuals, this can include the option to review a person's circumstances at any time, to make sure the match of functional support needs and funding are right. Each time that happens, the wisdom can be used to evolve the overall calibration of the scheme.

2.11.1.10 To what extent could a new scheme produce cost savings (or other offsets) and what design of the scheme would be likely to maximise these without limiting service delivery?

We refer you to our answers earlier in this section.

Cost savings have been documented in other jurisdictions (eg Worcestershire, United Kingdom). The extent of such savings in Australia will in part depend on the history of funding in each state and territory. If funding has been particularly poor, then the benefit is less likely to be in terms of a cost saving and more likely to be in terms of stronger personal outcomes.

To maximise the possibility of costs savings, while also contributing to stronger outcomes (whether through 'service delivery' or other self-directed elements), the following should be regarded as important features of the scheme's design, because they feature in various accounts of best-practice Self-Directed Funding. This list is not necessarily exhaustive:

- A person's funding allocation within the new scheme comes to the person as a personalised budget, and fully portable;
- A person has authentic control over how that budget may be spent;
- The rules for how to spend the budget are minimal, focusing on eliminating the risk of illegal practice, and practice that might deepen disability or disadvantage;
- There are a range of options that the person can choose from, for how their budget is managed in line with her/his wishes;
- There are resources available to assist those who need it with visioning, planning, navigating and orchestration;
- There is parallel investment in community capacity-building so that people have better access to mainstream opportunities within accessible and welcoming communities;
- There is parallel investment in government service capacity-building, so that people have better access to mainstream public services, including transport and education.

2.11.2 <u>Benefits</u>

2.11.2.1 <u>What are the benefits from a new disability care and support scheme? Which are most important? Who would benefit most from a new scheme? Where would additional resources be best spent? What level of funding maximises the gains from a new scheme?</u>

We hope that we have effectively covered this elsewhere in our submission. In summary, based on our assumption that the scheme in its design and implementation is an entitlements-based, best-practice model of Individualised (Self-Directed) Funding, some of the benefits include (not necessarily an exhaustive list):

- Upholding and advancing the rights of people living with disability;
- Fully portable funding that a person can use to direct towards personalised support arrangements that are best tailored to her/his personal circumstances;
- Likelihood of a better match between a person's functional support needs and the available funding;
- Equity of approach, so that people with similar circumstances access similar funding regardless of where they live in Australia;
- Because of their access to a personalised, self-directed budget, people living with disability become active participants in local economies, including stimulating local employment and other enterprise;
- Sharper customer-focused relationship between service agencies and the people who come to them for assistance;

- Increased likelihood that a person is being supported into a personal network of family, friends, acquaintances and neighbours, within which there emerge the availability of freely-given support and the natural safeguards that come with visibility and association;
- Increased likelihood that a person is accessing mainstream facilities and opportunities within community, again bringing the possibility of freely-given support and natural safeguards;
- More efficient, because artificially created interfaces between commonwealth, state and territory bureaucracies could be reduced or removed, together with artificially created service exclusions based on diagnostic criteria or age.

2.11.2.2 *How could the benefits of various scheme options be qualitatively or quantitatively assessed?*

This will depend on the scheme options under consideration, and the extent of helpful evidence from elsewhere where such options are in place.

Whatever options are under consideration, it is important that they are quantitatively and qualitatively assessed against the obligations within the UNCRPD, and on the corresponding impact on the measurable elements of a person's personhood and citizenhood.

The Julia Farr Association can assist with this.

2.11.2.3 *What criteria should be used to assess the merits of different models of disability care and support? Are there existing studies that provide lessons on how to undertake rigorous assessment of options in this area?*

As above.

2.11.2.4 *Can you foresee any possible unintended consequences from the introduction of a disability care and support scheme?*

This will depend on the design and implementation of the scheme, and how the incentives have been established.

Our main concerns would be that the scheme, in its design and practice and incentives:

- Does not have the advancement of people living with disability as its primary motive;
- Has a primary focus on agency sustainability (variously expressed as service standards, workforce development, and so on) that ends up retaining existing service patterns and which, however unintentionally, keep people living with disability in patterns of passive service recipiency that exclude people from an authentic valued life in the wider community;

- Does not invest in the capacity-building of people living with disability and the significant others involved in their lives;
- Does not invest in transition assistance for community support agencies that demonstrate a deeply felt commitment to personalised supports but don't have sufficient reserves to navigate the transition to the new market settings;
- Reinforces the community's belief that disability support happens separate to mainstream community life and that the solution to the experiences of exclusion is simply about money.

2.11.2.5 <u>What could be done to avoid or reduce the impact of any unintended consequences?</u>

The scheme should be designed to reflect the best-practice features of Individualised Funding, because the available studies show a distinct trend towards good outcomes both in terms of lifestyle and costs, and without any significant unintended consequences.

Refer previous answers for the detail of these best-practice features.

3.0 CONCLUSION

In this submission we have attempted to address the full range of issues that the Productivity Commission has expressed an interest in. We have undertaken this by framing answers in response to the 100+ questions posed by the Productivity Commission.

As emphasised in a number of places throughout this submission, the main condition of our support for a National Disability Insurance Scheme is that the Scheme, in its design and implementation, is an entitlement-based, best-practice Individualised (Self-Directed) Funding model. This is important because we believe such a model will:

- Deliver authentic control to the person living with disability, and increase that person's chances of moving out of cycles of disadvantage and towards an ordinary valued life. This is in line with the obligations established by the UNCRPD;

- Establish the right incentives, because purchases will be driven by people living with disability, who have the greatest stake in the effectiveness of those purchases;

- Shape more responsive and personalised service provision;

- Removes artificial, unhelpful criteria and interfaces. This will produce obvious savings, and will represent a much more accessible and respectful approach for people living with disability;

- Contribute to broader capacity-building so that our communities are more welcoming and inclusive of people living with disability;

- Mark a historic shift from a ‘passive recipiency’ model to an ‘active citizenhood’ model. As such it will stop the commodification of vulnerable people and instead uphold every citizen in Australia as having worth, potential and the right to a decent life.

We would be very happy to provide further assistance as required to the Productivity Commission.

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Appendix 1

Content

A - Julia Farr Association Initiatives
B – Julia Farr Association Publications
C – Julia Farr Association Submissions

A - List of Julia Farr Association initiatives

JFY Youth Group

A growing group of young adults living with disability who meet at Julia Farr Association and provide information and advice to Julia Farr Association and other agencies on relevant policy issues based on their lived experience.

Youth mentorship initiative

A new initiative that matches mainstream school-aged students living with disability with young adults living with disability, in a mentee-mentor relationship.

The Loop

This is an annual conference that takes a themed conversation around South Australia, on the basis that many people living in country areas find it very difficult to attend conferences in metropolitan areas because of issues of mobility, cost, infrastructure, or support. It has been very successful and connects us with several hundred voices.

Supported decision-making

A new initiative that is exploring ways to support vulnerable people to retain control of their own decisions, without recourse to substitute decision-making such as formal guardianship.

Access alert

A new initiative that involves respectful, direct action on issues of poor access.

Word Up

An initiative that involves respectful, direct action on issues of discriminatory language/signage relating to disability.

JFY Parents Forum

A growing group of parents of children living with disability who meet at Julia Farr Association and provide information and advice to Julia Farr Association and other agencies on relevant policy issues based on their lived experience.

Social landlord best practice

This is an initiative to discover the best practice elements of the relationship between housing landlords and tenants living with disability, including the ethical and moral considerations.

JFA Art Exhibition

A well-established initiative that showcases visual art and artists.

Parking Not

A new initiative that involves respectful, direct action on issues of misuse of accessible car-parking.

Tell Us

A lifestyle survey designed to ask the questions that other surveys and censuses might miss. Using the Q50™ framework. we put questions such as, '*Have you met anyone new in the last six months?* and *'Did you choose where you live?'*.

We ran the first survey in South Australia two years ago. The second version of the survey is currently running, and it has been extended to a national audience.

B – Julia Farr Association Publications

Number	Published	Title
01	2007	Individualised Funding. A summary review of its nature and impact, and key elements for success
02	2008	Individualised Funding – general considerations on implementation
03	2008	Why is it so hard to speak up and be heard? Views from the Loop Conference 2007
04	2008	JFA Briefing Paper – Development of the 2009 Survey of Disability, Ageing and Carers
05	2008	Tell Us report 1 – Disability Funding – Where should it go?
06	2009	JFA Briefing Paper – Resources Available For People Living With Disability When Seeking Employment
07	2009	Tell Us report 2 – Having Choice and Control
08	2009	Getting A Good Life: Taking Control of what's possible – Views from the Loop Conference 2008
09	2009	JFA Briefing Paper – Family members causing harm to their loved ones living with disability
10	2010	Tell Us report 3 – Accessibility
11	2010	Research Paper – The experiences of people living with disability accessing primary healthcare – Challenges and Considerations
12	2010	Going to your local gym: Some ideas for people living with disability
13	2010	Model of citizenhood support: Discussion paper

C – Julia Farr Association Submissions

Number	Date	Topic	Recipient
01	July 2008	Inquiry into Better Support for Carers	The Australian Government House of Representatives Standing Committee on Family, Community, Housing and Youth
02	July 2008	Review of the Health and Community Services Complaints Act	State Government HCSC Act Review Reference Group
03	August 2008	Development of the 2009 Survey of Disability, Ageing and Carers	Australian Bureau of Statistics
04	December 2008	A National Disability Strategy for Australia	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
05	February 2009	Inquiry into the investment of Commonwealth and State funds in public passenger transport, infrastructure and service	Australian Government Senate Standing Committee on Rural and Regional Affairs and Transport
06	June 2009	World Wide Web Consortium Accessibility consultation	Authoring Tool Accessibility Guidelines Working Group
07	June 2009	National Human Rights Consultation	Independent Committee, supported by a Secretariat in the Attorney- General's Department
08	July 2009	Harmonisation of Disability Parking Permit Schemes in Australia	Department of Families, Housing, Community Services and Indigenous Affairs
09	August 2009	Greater fairness and equity in the taxation of Special Disability Trusts	Australian Government Treasury
10	May 2010	Planning options and services for people ageing with disability	Australian Government Senate Community Affairs Reference Committee
11	June 2010	Family Violence Inquiry	Australian Law Reform Commission
12	June 2010	Verbal submission at public hearing regarding the Disability Care and Support inquiry	Productivity Commission
13	June 2010	Revision of the National Standards for Disability Services	National Quality Framework Project Team
14	July 2010	Matters related to the General Election of 20 March 2010	State Government Select Committee on Matters related to the General Election of 20 March 2010
15	July 2010	Breaking the cycle of disadvantage	Australian Social Inclusion Board
16	July 2010	Caring for Older Australians	Productivity Commission
17	August 2010	Australia's Initial Report under the Convention on the Rights of Persons with Disabilities	Australian Government Attorney-General's Department
18	August 2010	Draft Health and Community Services Charter of Rights	South Australia Health and Community Services Complaints Commissioner