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Submission made by
Julia Farr Association

Productivity Commission Draft Report
- Caring for Older Australians

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TABLE OF CONTENTS

1.0 INTRODUCTION – summarising our previous recommendations

On the 30 July 2010 the Julia Farr Association forwarded a submission to the Productivity Commission's inquiry into Caring for Older Australians (Appendix A) which included the following recommendations:

R1. *Ensure public policy, planning and commissioning of supports uphold the place of people living with disability as valued citizens at the core of our communities*

We recommended that public policy, planning and commissioning of supports uphold the place of older Australians and people ageing with disability as valued citizens at the core of our communities.

R2 – *Establish new common funding mechanisms for commissioning personal supports*

We recommended that separate funding mechanisms for people living with disability and older people be replaced by a common funding mechanism that assures practical support to all Australians with significant personal support needs.

R3 - *Introduce Individualised (Self-Directed) Funding*

We recommended that best practice Individualised Funding methodology be introduced widely as the dominant paradigm for the practical commissioning of supports for older people.

R4 – *Establish Person-Centred Planning arrangements*

We recommended that authentic, person-centred planning and support methodologies be widely introduced as the dominant paradigm for developing supports for older Australians.

Further to our previous submission we now provide commentary on the Productivity Commission Draft Report – Caring for Older Australians and its focus on supporting older Australians, including people ageing with disability, "to remain independent and in control of how and where they live their lives, continue to be connected and relevant to their families and communities, and be able to exercise some measure of choice if they require care"[1].

2.0 GOOD THINGS ABOUT THE DRAFT REPORT

2.1 Framework for assessing aged care

The Julia Farr Association believes that *Draft Recommendation 4.1* provides a strong foundation upon which changes to the aged care system will enable older Australians to have greater choice and access to supports that address their individual needs and circumstances. We particularly support the focus on:

- Promoting the independence and social inclusion of older Australians;

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[1] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. XXI.

- People having access to person-centred supports that are responsive to their needs as they change;

- People having choice and control over the support they receive;

- People having ready access to information to assist them in identifying what supports are available and responsive to their needs;

- Supporting people who provide informal supports "to assist them to continue performing this role"[2].

2.2 Establishment of an Australian Seniors Gateway Agency

The introduction of a single and national Australian Seniors Gateway Agency as recommended in *Draft Recommendation 8.1*, would assist in simplifying processes and reduce the duplication of information through providing a single entry point for "information, assessment, care coordination and carer referral services"[3].

2.2.1 Access to Supported Information

We are particularly encouraged by the importance the draft report has placed on providing accessible and easy to understand information "at a level which is specific to the needs of individual older people"[4]. *Draft Recommendation 9.1* also emphasises the importance on providing accessible information and assessment services that are culturally appropriate.

As highlighted in our previous submission, we assert that the design and provision of supported information is key to ensuring future support arrangements for older Australians are responsive to the needs and circumstances of older Australians.

This is our definition of *Supported Information*:

"*Supported Information refers to the resourcing of information so that it is accessible and understandable, and soundly relates to the person's best interests (as typically articulated by the person) and in any case incorporating citizenhood, protection of human rights, and upholding the person's potential*"[5].

Given that older Australians, including people ageing with disability, may vary widely in their capacity to engage with a set of written words, for example because of cognitive issues, other disability, and cultural background, the provision of supported information is crucial to enable people to make informed choices and "to assess risk, to test ideas, and to grow capacity"[6].

Importantly for professionals (and others) who are formally involved in the lives of older Australians, the way information is explained to a person can critically affect their understanding of that information, and may not always serve the person well.

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2 Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. 84
3 Ibid, p. 242.
4 Ibid, p. 227.
5 Williams, R 2010, *Model of citizenhood support: Discussion paper,* Julia Farr Association, Unley, South Australia, p. 6.
6 Williams, R 2010, *Model of citizenhood support: Discussion paper,* Julia Farr Association, Unley, South Australia, p. 6.

For example, this issue has been reported in other jurisdictions in relation to the take-up of Individualised Funding[7].

Therefore, to assist older Australians and their families, careful attention needs to be given to how information is made available to a person, and how that person, if required, can be assisted to understand that information and translate it into a personal decision that moves the person towards, or keeps the person in, a lifestyle characterised by personhood and citizenhood.

R5 – *Provision of 'Supported Information'*

> The Julia Farr Association recommends that staff formally involved in the proposed arrangements are trained and orientated to have an active commitment to the delivery of *Supported Information.*

2.2.2 National Aged Care Needs Assessment Instrument

We support the use of a national single assessment instrument to identify "an individual's entitlement to basic support, personal care and specialised care, and carer support"[8] as this will create consistency in assessments and ensure people do not have to go through multiple assessments for receipt of supports.

3.0 HOW THE DRAFT REPORT CAN BE FURTHER STRENGTHENED

The Julia Farr Association also believes that the draft report needs to have a strong emphasis on ensuring older Australians, and people ageing with disability, are supported to have authentic opportunity to:

- Remain living in their own homes for as long as possible;

- Remain connected with community life;

- Build personalised supports through Individualised (Self-directed) Funding.

- Be supported within their community in ways that draw on access to, or creation of, natural informal support arrangements that in turn reduce the chances that their assets are stripped through co-contributions to formal support arrangements. We feel this is a particularly important point as it seems profoundly wrong that older Australians are directed to, and have to make part payment for, support arrangements (including residential care) that may not be the best match for their circumstances and hopes.

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[7] Phillips, B & Schneider, B 2004, *Changing to consumer-directed care: The implementation of the cash and counselling demonstration in Florida,* Office of Disability, Ageing and Long-Term Care Policy, US Department of Health and Human Services, Washington, DC.
[8] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. 243.

3.1 Living in your own home

"Part of making a home of one's own is to integrate one's home life with one's web of relationships and one's lifestyle"[9].

A key focus of aged care support should be to ensure that people have the choice and opportunity to remain living in their own home. The importance of this is reinforced in the draft report where it states that "[t]here is a strong and increasing preference for ageing at home"[10].

To support older Australians to live in their own homes for longer, the proposed Australian Seniors Gateway Agency (*Draft Recommendation 8.1*) needs to provide detailed information and guidance on the full range of methodologies and supports that can assist the person to stay at home and retain a strong sense of belonging in their local community.

This could and should mean that away-from-home aged care supports (ie residential aged care) should only be considered as a very last resort. We would further argue that an absence of a local, naturally occurring support network should not automatically mean that a frail older person should be admitted to residential care. This is because there are ways that people can be supported to retain, and build, connections in their lives. This is covered in the next section.

The Julia Farr Association can, if required, provide examples of methodologies that assist older people to remain living in their own homes. We also refer the Productivity Commission to research conducted in Sweden[11] and the United Kingdom[12], demonstrating that older people regularly visited in their homes can result in increased longevity and quality of life.

> ### R6 – *Provision of information and guidance on ways older Australians can remain living in their own homes*
>
> The Julia Farr Association recommends that the proposed Australian Seniors Gateway Agency provide older Australians with information and guidance on ways in which they can remain living in their own homes.

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[9] Kendrick, M 2008, 'How genuinely supportive person, agencies and systems can enable people to have real homes of their own', *Crucial Times,* issue 40, p. 15.

[10] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. 225.

[11] Hellstrőm, Y, Andersson & M, Hallberg, IR 2004, 'Quality of life among older people in Sweden receiving help from informal and/or formal helpers at home or in special accommodation', in *Health and Social Care in the Community,* vol. 12, iss. 6, pp. 504-516.

[12] Elkan, R, Kendrick, D, Dewey, M, Hewitt, M, Robinson, J, Blair, M, Williams, D & Brummell, K 2001, 'Effectiveness of home based support for older people: systematic review and meta-analysis', in *BMJ 2001; 323:719.*

3.2 Being connected with community

The draft report highlights that older Australians generally want to "continue to be connected and relevant to their families and communities"[13]. One key way to ensure that older people are supported to remain connected with their community is to assess the extent that this occurs.

The focus of the base assessment described in the draft report would be to assess "an older person's core functions such as their ability to undertake instrumental activities of daily living (IADLs), activities of daily living (ADLs), their care settings and level of informal carer support"[14].

In addition to these assessment domains, there needs to be a focus on assessing the connections older people have within their community. This is important as "if we are to truly reduce the drama of ageing for people, and uphold an older person's capacity, and right, to remain in valued roles in their local community, we need to consider how that person can be assisted to retain and grow natural connections with other people in the local community"[15].

The Resource Allocation System (RAS), increasingly used as a locally tailored framework in the United Kingdom for allocation of personalised funding to older adults, reinforces the importance of connections with community life and also aligns with the areas already highlighted in the draft report. The key headings used enable people to describe their individual needs and circumstances through self-assessment questionnaires and focus on:

- Making decisions and having choice;
- Developing and keeping relationships and involvement in activities;
- Daily living tasks;
- Personal care;
- Eating and drinking;
- Physical health and well-being;
- Mental health and emotional well-being;
- Staying safe;
- Additional information
    - Falls
    - Continuing health care assessment
    - 'Safeguarding adults' issues
    - Fire and rescue home safety check
    - Choices that cause concern

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[13] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. XXI.
[14] Ibid, p. 235.
[15] Julia Farr Association 2010 submission to Caring for Older Australians Inquiry (Appendix A, p. 8).

- 'Carer' needs[16].

We live our lives as part of groups - neighbourhoods, communities, clubs, work teams, and so on. Membership of such groups brings a great deal of connection and fellowship into people's lives.

We believe it is of critical importance that older Australians are supported to maintain and indeed further develop the connections and fellowships in their lives. Not only does this reduce the risk of loneliness and isolation, it also increases the active presence of naturally occurring safeguards that can keep people at home and part of the community.

We therefore assert that 'community connection and fellowship' be an integral part of assessment.

> ### R7 – *Inclusion of community connections as part of the assessment instrument*
>
> The Julia Farr Association recommends the assessment of the needs of older Australians occur in the context of supporting people to stay actively connected to community life.

3.2.1 Circles of Support

Arrangements that emphasise the intentional development of trusting and freely given networks in people's lives can support older Australians and their families to achieve their life goals and participate as active citizens in the life of their local community.

Circles of Support is one such initiative that focuses on the importance of establishing freely given relationships and connections within the community.

> A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help[17].

The Community Resource Unit (based in Brisbane) dedicated one of its CRUcial Times issues to people's accounts and experiences with 'Circles of Support' - http://www.cru.org.au/crutimes/CT38/CT38Mar07.pdf.

Also, the Circles model was implemented in South Australia[18] and is now a valued feature within the landscape of disability support.

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[16] *Cumbria Support Assessment*, UK – This resource is available in the Julia Farr Association's library. We would be happy to provide more information if required.
[17] Circle Networks 2008, 'Circles of Support', p. 1, <http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115>.
[18] Further information on the Circles Initiative in South Australia - http://www.clp-sa.org.au/content/circles-initiative

Given that many older people, and people ageing with disability, are currently living lifestyles characterised by a dearth of opportunities to meet new people in ordinary ways, and given that many family members who actively support a vulnerable family member often also forego opportunities to connect (which includes the opportunity to introduce new people into the life of their loved one), we believe it critically important that older Australians at very high risk of loneliness and isolation have the option to access supports such as Circles . The methodology has proven its capacity to bring new people into the lives of the central person, and strengthen connections into community life.

There are good examples available of frail older people being systematically supported to build fellowship and connection resulting in a mix of formal and informal support that has kept the person at home and connected to their community for the remainder of their life. We can refer the Productivity commission to such examples if required. Such methodologies should be a genuine option within funding arrangements.

> ***R8*** – *Provision of information and guidance (including funded assistance) on ways older Australians can maintain and develop personal and community networks, via methodologies such as Circles*
>
> The Julia Farr Association recommends that the proposed Australian Seniors Gateway Agency provide information and active guidance on ways older Australians can maintain and develop personal networks (and thereby connections into community life) via methodologies such as Circles.

3.3 Building personalised supports through Individualised Funding

Draft Recommendation 8.2 highlights the importance of replacing "the current system of discrete care packages with a single integrated, and flexible, system of care provision" and approving "a range of care services to individuals on an entitlement basis, based on assessed need"[19]. This recommendation also highlights that people should have the opportunity to choose from approved providers of support.

Although we support providing services based on assessed need, we believe that if people are only provided a menu of options covering supports that are currently available, this does not offer them authentic control over how they spend their entitlements. This is because such a menu will not necessarily include more creative, personalised options that may not exist at that moment in time but which could be created as part of the personal planning process.

As highlighted in our previous submission (see Appendix A), we believe introducing Individualised (Self-directed) Funding will ensure people have genuine choice and control over the types of supports they need through directing how funding should be spent.

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[19] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. 257.

We acknowledge the Productivity Commission has concerns about establishing "a fully 'cashed out' system, where individuals receive a subsidy via cash or cheque and can determine to expend it in full in any way they see fit"[20] including the possible abuse of funds by carers, and people's underestimating the amount needed to spend on supports.

As demonstrated in our previous submission, Individualised (Self-directed) Funding brings flexibility about the way that funding is used without necessarily compromising reasonable expectations around accountability for public funding, and can lead to highly creative, value-added solutions. Notably, the Individualised Funding methodology is inclusive of people who do not wish to manage their own arrangements, or who have diminished capacity, because people can choose a variety of ways for how the funding allocation is managed on their behalf[21].

Also another benefit of Individualised (Self-directed) Funding is increased efficient use of resources. In research conducted in the United Kingdom in 2008 it has been demonstrated that "[s]elf-directed services, combined with personal budgets, create a new operating system for social care that lowers costs, raises quality, improves productivity, offers greater choice, reconnects people to their social networks and helps to generate social capital"[22].

There are plenty of good examples that we can refer the Productivity Commission to, where Individualised (Self-directed) Funding has resulted in strong positive outcomes for older people, and without elevated fiscal risk.

3.4 Co-contributions and personal assets

The Productivity Commission's parallel inquiry into Disability Care and Support highlights that after the pension age, to ensure fairness, people living with disability should also be subject to co-contribution arrangements in regards to the support they receive regardless of whether they continue with the proposed National Disability Insurance Scheme or move to aged care. The Productivity Commission states that "[i]n most instances, the caps and means tests applying to those co-contributions would mean people who acquire a disability early in their life would not have to pay anything" and a person who acquires their disability closer to the pension age and has accumulated assets "like any other aged person, would be expected to contribute to their aged care"[23].

We acknowledge the consideration of equitable access to funded aged care, based on capacity to make co-contributions. However, we believe this needs to occur in the context of a policy/industry bias for supporting people to stay in their own homes and remain connected within their community, and in ways that do not result in

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[20] Productivity Commission 2010, *Caring for older Australians*, Draft Inquiry Report, Commonwealth of Australia, Canberra, p. 253.
[21] More information about Self-Directed funding can be found at: www.in-control.org.au.
[22] 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, p. 36.
[23] Productivity Commission 2011, Productivity Commission Draft Report, Disability Care and Support, Vol. 1, p. 3.19.

unnecessary asset stripping. For example, it is entirely conceivable and achievable for a frail older person to successfully remain at home through an intentional, safeguarded mix of formal (paid) and informal (unpaid) supports, where the overall cost is at a level that does not result in the stripping of the person's assets through co-contributions.

4.0 THE MERITS OF INTRODUCING A COMPULSORY INSURANCE SCHEME

As set out in our original submission, the Julia Farr Association believes that the funding mechanisms for the provision of support funding for older Australians and people living with disability should be the same.

We note the Productivity Commission's draft report sees no value in shifting to an insurance model over and above the current taxpayer-funded arrangements.

Our view is that the proposed National Disability Insurance Scheme (NDIS) is not best labelled as insurance, because it contains features that are not typical within the insurance industry. Instead, we believe it should be named the National Disability *Assurance* Scheme because, in essence, the scheme is designed to give assurance of funding support to eligible persons regardless of where they live, and that such funding support is taxpayer funded.

In this way we believe that the current tax-funded aged care funding arrangements and the proposed tax-funded disability funding arrangements will have more in common than not. Given that the two target populations present with comparable circumstances and support considerations, we believe there is room to remove artificial and unhelpful funding interfaces by creating one common funding mechanism.

As we set out in our previous submission, there are a number of key reasons for this:

- The introduction of a compulsory 'insurance' (we prefer 'assurance') scheme would address the current difficulties faced at the interface between disability and aged care funding and services, through ensuring that the funding source is the same for aged care as is being proposed for disability supports in the parallel inquiry by the Productivity Commission into Disability Care and Support. People would not have to deal with the operations of two funding and supports systems and continue to have authentic control and choice over the supports they received as their needs and circumstances change.

- The assistance people living with disability and older people require is the same. This includes needing:
  - o Help at home;
  - o Help with personal care;
  - o Help to access the community (use of transport, access to public buildings and amenities);
  - o Help with decision-making;

o Help with connections and fellowship.

Therefore, the introduction of a compulsory insurance scheme would reduce the duplication of services and the potential for 'cost shifting' between sectors, and address the fact that currently "[t]here is considerable overlap between the two systems in terms of the types of services delivered and the eligibility of clients"[24].

The introduction of a compulsory insurance scheme can provide equitable tax-funded assurance of assistance to people based on their functional support needs and not their age or 'diagnosis'. Such an approach can provide built-in continuity, and indeed can provide a dignified and affirming mechanism to deliver supports to all Australians living with significantly greater vulnerability regardless of its cause.

There is growing practice elsewhere of a common approach to the functional support needs of adults without artificial boundaries of diagnosis or age. One example is the United Kingdom, where the widespread introduction of personalised budgets in adult social care is anchored in common mechanisms for people living with disability, older people, and other vulnerable citizens. To illustrate, we refer the Productivity Commission to Worcestershire County Council's common approach to direct payments (http://www.worcestershire.gov.uk/cms/health-and-social-care/direct-payments/are-you-eligible.aspx) and their common approach to support planning and provision (http://www.worcestershire.gov.uk/cms/health-and-social-care/choice-and-control/about-choice-and-control.aspx).

We therefore reassert the following recommendation highlighted in our previous submission (Appendix A).

R9 – *Establish new common funding mechanisms for commissioning personal supports*

The Julia Farr Association recommends that separate funding mechanisms for people living with disability and older people be replaced by a common funding mechanism that assures practical support to all Australians with significant personal support needs.

5.0 CONCLUSION

The Julia Farr Association asserts that attending to the issues highlighted in this submission, and the resulting recommendations, will provide older Australians, including people ageing with disability, with increased access to supports that are responsive to their individual needs and circumstances.

As required, and to the best of our resources, we welcome the opportunity to make further contribution to the work of the Productivity Commission on this important issue.

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[24] Bigby, C 2008, 'Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability', *Journal of Intellectual and Developmental Disability,* Vol. 33, No. 1, pp. 76-86, p. 81.

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APPENDIX A

JULIA FARR ASSOCIATION SUBMISSION

- **PRODUCTIVITY COMMISSION'S INQUIRY INTO CARING FOR OLDER AUSTRALIANS (30 July 2010)**

Submission made by Julia Farr Association

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TABLE OF CONTENTS

The Julia Farr Association makes this submission to the Productivity Commission's inquiry into Caring for Older Australians. Our submission includes commentary on specific matters identified in the Inquiry into Aged Care Terms of Reference:

"Develop regulatory and funding options for residential and community aged care (including services currently delivered under the Home and Community Care program for older people) that:

o *ensure access (in terms of availability and affordability) to an appropriate standard of aged care for all older people in need, with particular attention given to the means of achieving this in special needs groups...*

o *support independence, social participation and social inclusion, including examination of policy, services and infrastructure that support older people remaining in their own homes for longer, participating in the community, and which reduce pressure on the aged care system...*

o *allow smooth transition for consumers between different types and levels of aged care, and between aged, primary, acute, sub-acute, disability services and palliative care services as need determines"[25].*

1.0 PURPOSE

The purpose of our submission is to highlight ways in which older Australians, including people ageing with disability[26], can gain access to supports that meet their individual needs and circumstances as they age.

2.0 SUMMARY OF RECOMMENDATIONS

The Julia Farr Association submits the following recommendations.

R1 – *Ensure public policy, planning and commissioning of supports uphold the place of older people as valued citizens at the core of our communities*

The Julia Farr Association recommends that public policy, planning and commissioning of supports uphold the place of older Australians and people ageing with disability as valued citizens at the core of our communities.

We refer the Productivity Commission to the Julia Farr Association 2010 publication '*Model of Citizenhood Support*'[27] which sets out a framework for support that will lead people to *citizenhood*[28].

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[25] Productivity Commission 2010, *Caring for older Australians: Terms of reference*, p. 1, <http://www.pc.gov.au/projects/inquiry/aged-care/terms-of-reference>.

[26] *Note that throughout this document we interchange the terms 'people living with disability' and 'people ageing with disability', and in using these terms we acknowledge and support the benefits that family members can also gain from the arrangements we argue for.*

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

[28] "*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, p. 3)

***R2** – Establish new common funding mechanisms for commissioning personal supports*

The Julia Farr Association recommends that separate funding mechanisms for people living with disability and older people be replaced by a common funding mechanism that assures practical support to all Australians with significant personal support needs.

***R3** – Introduce Individualised (Self-Directed) Funding*

The Julia Farr Association recommends that best practice Individualised Funding methodology be widely introduced as the dominant paradigm for the practical commissioning of supports for older people.

***R4** – Establish Person-Centred Planning arrangements*

The Julia Farr Association recommends that authentic, person-centred planning and support methodologies be widely introduced as the dominant paradigm for developing supports for older Australians.

3.0 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 timely in the current environment. There is increasing demand for services due to Australia's ageing population. There is currently a focus on investigating ways to improve access to planning options and services for people ageing with disability by the Australian Government's Senate Community Affairs References Committee[29]. Further, there is international emphasis on ensuring that "services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs"[30] through the UN Convention on the Rights of Persons With Disabilities and Optional Protocol ratified by the Australian Government in July 2008.

The present inquiry provides the opportunity to assess ways in which supports provided to older people can further reflect the rights and needs of people ageing with disability.

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[29] Inquiry into Planning Options and Services for People Ageing with a Disability, Terms of Reference, http://www.aph.gov.au/senate/committee/clac_ctte/planning_options_people_ageing_with_disability/tor.htm.
[30] United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 14, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

4.0 CITIZENS FIRST AND FOREMOST

What older people and people ageing with disability have in common is they experience increased vulnerability and can enter, and become trapped in, cycles of disadvantage when they are unable to access the supports they need, maintain personal authority in their lives, and actively participate within their community.

Mindful of these circumstances, we believe the most important contextual point we can make is that older Australians, including people ageing with disability, are citizens first and foremost, and as such belong at the core of our communities.

This means that commissioning arrangements must ensure that people have genuine opportunities to have and retain choice and control in their lives, remain active and included in their local community, and are supported in ways that assert and uphold their status as valued citizens.

By way of example, we refer the Productivity Commission to the Swedish welfare system which, according to Lilja et al. (2003, p. 130) "states that people with disabilities should have the same opportunities and the same obligations as everyone else in society and be offered equal resources, regardless of where they live"[31].

Further, this means that Australia's public policy settings must have proper regard for the inherent status of older people, and to promote and uphold this citizenhood[4] in the design and commissioning of support services.

R1 – *Ensure public policy, planning and commissioning of supports uphold the place of older people as valued citizens at the core of our communities*

> The Julia Farr Association recommends that public policy, planning and commissioning of supports uphold the place of older Australians and people ageing with disability as valued citizens at the core of our communities.

> We refer the Productivity Commission to the Julia Farr Association 2010 publication '*Model of Citizenhood Support*'[3] which sets out a framework for support that will lead people to *citizenhood*.

4.1 Framework for Citizenhood Support

The five domains in the *Framework for Citizenhood Support* set out in the '*Model of Citizenhood Support*' publication provide a good context for ensuring that public policy settings have proper regard for the inherent status of older people. The five domains are covered below:

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[31] Lilja, M, Månsson, I, Jahlenius, L & Sacco-Peterson, M 2003, 'Disability policy in Sweden. Policies concerning assistive technology and home modification services', in *Journal of Disability Policy Studies,* vol. 14, no. 3, pp. 130-135, p. 130.

4.1.1 Carrying a personal vision

A rich active life has to be anchored on self-belief. Many people in situations of greater vulnerability have had their self-belief diminished by their experiences of capacity change, loss, service recipiency, poverty and social isolation, and this can lead to deeper cycles of disadvantage and dependency.

Therefore, if we are to evolve proactive support arrangements for older Australians, this demands that the person is the central architect in her/his personal vision. This vision is about the articulation, affirmation and realisation of a preferred lifestyle, reflecting the person's individuality, strengths, ordinary life goals, and opportunity to participate as an active citizen in the life of the local community.

The first steps here, especially for an older person with heightened vulnerability due to changes in personal capacity or life circumstances, are to support the person to reclaim/maintain a sense of positive personhood and to access opportunities to grow/adapt her/his capacity to see herself/himself as an individual of worth and an active valued member of the wider community.

To illustrate, we refer the Productivity Commissioner to research conducted by Yale University and Miami University which demonstrated that people having a positive attitude towards ageing can result in them living longer[32].

4.1.2 Asserting a *citizenhood-based* approach to service systems

A power imbalance can exist in the relationship between the *helper* and the *helped* in formal support systems where older persons do not have choice and control about the supports they receive. This can create dependency, passivity, restriction, even abuse, neglect and oppression, all of which establish, maintain and deepen cycles of disadvantage.

To break out of this, formal support systems need to be redesigned so that the essence of the relationship between *helper* and *helped* is one of collaboration, and where the *helped* is constantly affirmed as the architect of her/his own life. At the Julia Farr Association, we refer to this as a *citizenhood-based approach to service systems*.

There are a number of ways that formal support systems can move towards this *citizenhood-based* approach, including but not limited to the following:

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[32] Levy, BR, Slade, MD, Kunkel, SR, Kasl, SV 2002, 'Longevity increased by positive self-perceptions of aging', in *Journal of Personality and Social Psychology*, vol. 83, no. 2, pp. 261-270.

- Public funders demanding evidence of this approach from any support agency seeking to be formally involved in the lives of vulnerable older people;
- Ensuring that all new system architecture is designed in partnership with the intended recipients, in this case older Australians. This practice of *co-design* can help ensure that the public funder systems and support agency systems are built in ways that are more meaningful and helpful to the intended recipients, and establishes a sense of ownership consistent with the principle of *citizenhood-support*;
- Stronger recruitment practice to enrol staff with a *citizenhood-support* value base (noting that such candidates do not exclusively reside in the human services industry);
- Stronger staff induction and training, to build practice in line with the principle of *citizenhood-support*;
- Leadership development, so that we build leadership capacity across support agencies for older persons, in support of the principle of *citizenhood-support*. Note that this includes addressing the issue, as identified by the Julia Farr Association, of ego-based leadership and how to build leadership beyond ego.

4.1.3 Access to supported information

This third domain in the *Framework for Citizenhood Support* focuses on older Australians having access to good person-centred information that is easy to use and ensures they are well informed. There can be no doubt that a lack of access to information can keep older people in cycles of disadvantage. People need information to make choices, to assess risk, to test ideas, and to grow/adapt capacity. Good information makes it more possible for the older person to make an informed choice.

However, it's not just the mere *presence* of relevant information that can help break cycles of disadvantage. For many people, the information also needs to be accessible, given that older people may vary widely in their capacity to engage with a set of written words, for example because of cognitive issues, other disability, and cultural background.

Similarly, the way that information is explained to a person can critically affect their understanding of that information. For example, the way professional staff give information can critically affect the way the intended beneficiaries understand, and act on, the information. This issue has been reported for example in other jurisdictions in relation to the take-up of Individualised Funding[33].

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[33] Phillips, B & Schneider, B 2004, *Changing to consumer-directed care: The implementation of the cash and counselling demonstration in Florida,* Office of Disability, Ageing and Long-Term Care Policy, US Department of Health and Human Services, Washington, DC.

Therefore, to assist older people to break out of cycles of disadvantage, careful attention needs to be given to how information is made available to a person, and how that person, if required, can be assisted to understand that information and translate it into a personal decision that keeps the person in a lifestyle characterised by choice and citizenhood.

We call this *Supported Information*, and this refers to the resourcing of information so that it is accessible and understandable, and soundly relates to the person's best interests (as typically articulated by the person) and in any case incorporating citizenhood, protection of human rights, and upholding the person's potential and capacity.

We assert that the design and provision of *Supported Information* is key to future formal support systems for older Australians.

This in turn underscores the importance of clarifying the differing roles of different agencies (eg government agencies, service organisations, advocacy agencies, and other community groups) in the delivery of information to vulnerable people, and how that information is delivered.

4.1.4 Access to material resources

People need to be able to access material resources that enable and reflect active citizenhood, so that older persons remain at the core of our communities as valued citizens. These material resources include funded assistance and mainstream community resources.

There are many, many examples of how this can come about. Access to material resources can include, but is not limited to, the following:

- The older person (or a nominated trusted other in the person's life) becoming the central decision-maker in how to spend any public funds allocated to that person (this is variously called Individualised Funding, Self-Directed funding, Consumer-Managed Funding, Cash and Counselling, Personalised Budgets etc);
- Accessible public transport, buildings and public spaces so that older Australians can remain visible and connected in their local communities;
- Employment choices free from assumptions about age of retirement;
- Opportunities to contribute to community that are free from assumptions about age and diminished capacity.

4.1.5 Fellowship and connection

The provision of material resources is an important element in supporting older Australians, but by itself does not necessarily deliver older people into a good life.

Funding and other material resources do not ensure older people's active membership of the local community, and older people with access to material resources can still be isolated, excluded and lonely.

Society is built on ideas of interdependency and association. Through such association, rich and trusting relationships emerge that help sustain and grow us on life's journey. Therefore, if we are to truly reduce the drama of ageing for people, and uphold an older person's capacity, and right, to remain in valued roles in their local community, we need to consider how that person can be assisted to retain and grow natural connections with other people in the local community.

This demands that the formal agencies involved in the life of an older person ensure that the support arrangements consistently create proactive opportunities for that person to move into fellowship and connection with other people in the local community. We believe that living at an older age is likely to be a much more positive experience when an older person has others in her/his life who hold the person in good regard and are mindful of the person's welfare. This needs to be above and beyond the involvement of any paid support persons in the older person's daily life.

This calls upon a range of intentional techniques that can help create sustainable opportunities for an older person to move into, or remain in, fellowship and connection with other people in their local community. Such circumstances make it more likely that natural relationships are nurtured and sustained, together with a sense of belonging.

Intentional techniques include, but are not limited to, the following:
• Circles;
• Asset-Based Community Development;
• Time-banking;
• Community Navigation.

To illustrate, we refer the Productivity Commissioner to research conducted in Sweden[34] and the United Kingdom[35] which demonstrated that older people being regularly visited in their homes can result in increased longevity and quality of life.

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[34] Hellstrőm, Y, Andersson & M, Hallberg, IR 2004, 'Quality of life among older people in Sweden receiving help from informal and/or formal helpers at home or in special accommodation', in *Health and Social Care in the Community*, vol. 12, iss. 6, pp. 504-516.

[35] Elkan, R, Kendrick, D, Dewey, M, Hewitt, M, Robinson, J, Blair, M, Williams, D & Brummell, K 2001, 'Effectiveness of home based support for older people: systematic review and meta-analysis', in *BMJ 2001; 323:719*.

5.0 INCREASING DEMAND FOR SERVICES THAT SUPPORT PEOPLE AGEING WITH DISABILITY

In 2003, 3.9 million Australians were living with disability (20% of the population), of whom around 1.2 million were living with a severe or profound limitation (6.3% of the population)[36]. Of those living with a severe or profound limitation, nearly 561,000 (over 45%) were aged 65 years or over[37].

These statistics highlight the extent of the need for support for people ageing with disability. It is expected that (assuming normal patterns of longevity) the number of people living with severe or profound disability aged 65 years and over will increase significantly, to over 1.45 million by 2030 (over 63% of all people living with severe or profound limitation)[13].

Another factor that will contribute to an increased demand for services and support options for people ageing with disability, is the impact of ageing on their families (if there are family members actively involved in that person's life, which is not the case for every person living with disability) or other informal supports (also known as unpaid carers[38]). In 2003, a total of nearly 454,000 people aged 65 and over provided informal assistance to people living with disability, with 113,200 being identified as a 'primary carer'[39]. It is expected that with Australia's growing ageing population "an increasing number of unpaid carers will require aged care services themselves and will no longer be able to act as carers"[40].

The expected increase in age of people living with disability and their informal or unpaid supports provides a considerable challenge for the provision of responsive supports.

6.0 THE CONCERNS AND BARRIERS PEOPLE LIVING WITH DISABILITY EXPERIENCE AS THEY AGE

6.1 The concerns people living with disability have

The Julia Farr Association has evidenced through its own research a range of issues and concerns people living with disability have about growing old and accessing the supports they need in the future.

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[36] AIHW 2009, *Australia's welfare 2009,* Cat. No. AUS 117, AIHW, Canberra.

[37] AIHW 2009, *Australia's welfare 2009,* Cat. No. AUS 117, AIHW, Canberra - *Table A4.2: Trends and projections in the number of people with disability, 1981–2030 ('000s).*

[38] *A carer is defined by the Survey of Disability, Ageing and Carers as someone who provides informal and ongoing support. A primary carer is defined as a person who provides the most informal assistance (AIHW 2009).*

[39] Senate Community Affairs Committee Secretariat 2007, 'Chapter 5. The ageing/disability interface' in *The senate standing committee on community affairs: Funding and operations of the commonwealth state/territory disability agreement,* pp. 103-122, <http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/c05.pdf>*.*

[40] Ibid p. 121.

The main research device we used was our ***Tellus*©** disability survey[41], a current survey that by July 2010 attracted over 470 respondents. These respondents provided us with valuable information about their experiences living with disability.

From the results, we draw your attention to the following table.

***Tellus*© survey question: What things worry you about getting older with a disability?**
The major concerns identified by survey respondents about ageing and living with a disability were: • The reliance on support from ageing parents and not having family support later in life (over 15%); • Losing independence (over 13%); • Needing more support and not being able to access it (over 7%); • Not having the freedom of choice and control about the supports they need and want (over 4%).

6.2 People living with disability experience difficulty accessing supports relating to ageing

Currently, as far as people living with disability are concerned, public funding for personal support is organised mainly into two separate streams – one for people aged less than 65 years, and one for older people aged over 65 years. This presents at least three significant problems:

• Arbitrary age-based eligibility to access aged care services;

• Difficulties at the interface between disability and aged care funding and services;

• Problem of capacity within disability and aged care services to support people ageing with disability.

Each of these is now explained and evidenced in more detail.

6.2.1 Arbitrary aged-based eligibility to access aged care services

According to Ellison et al. (2009, p. 2), the "[c]riteria for community based aged care support were developed based on understanding the lifespan development of

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

a typical Australian"[42].   However, people living with disability do not necessarily age in a 'typical' way. Findings suggest that people can experience ageing earlier "as a consequence of living with a disability or due to shorter than average life expectancy"[43].   This can result in people living with disability not having equal access to the supports they need as they age. This impinges on their rights to access, on an equal basis as others, "services open or provided to the public"[44] as defined in the UN Disability Convention.

6.2.2 Difficulties at the interface between disability and aged care funding and services

Evidence suggests that it can be difficult determining whether an individual's support needs are related to living with disability or the typical ageing process[45]. This is because "[p]eople with a disability who are ageing are not a homogenous group and there is no single factor such as age, the age disability is acquired or the type of acquired disability which will reliably indicate their needs as they age"[46].   This lack of uniformity creates challenges for the disability and aged care sectors when identifying which sector is best equipped to support the needs of people ageing with disability.   This uncertainty is further compounded by the fact that "[t]here is considerable overlap between the two systems in terms of the types of services delivered and the eligibility of clients"[47]. This can result in 'cost shifting' between the sectors, where it is viewed the other sector is responsible for, or more capable of, supporting the needs of people ageing with disability. However, this does not address the fact that the support needs people have because of disability do not disappear as they age, highlighting the importance of the need for a continuous, seamless approach without the encumbrance of the requirements of two separate systems.

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[42] Ellison, C, Chapman, L, Pascoe, E & Patmore, A 2009, *Avoiding institutional outcomes for older adults living with disability: the use of community based aged care supports*, Flinders University of South Australia, Adelaide, p. 2.

[43] Senate Community Affairs Committee Secretariat 2007, 'Chapter 5. The ageing/disability interface' in *The senate standing committee on community affairs: Funding and operations of the commonwealth state/territory disability agreement,* pp. 103-122, <http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/c05.pdf>, p. 103.

[44] United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, viewed 11 May 2010, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>, p. 9.

[45] Ellison, C, Chapman, L, Pascoe, E & Patmore, A 2009, *Avoiding institutional outcomes for older adults living with disability: the use of community based aged care supports*, Flinders University of South Australia, Adelaide.

[46] Senate Community Affairs Committee Secretariat 2007, 'Chapter 5. The ageing/disability interface' in *The senate standing committee on community affairs: Funding and operations of the commonwealth state/territory disability agreement,* pp. 103-122, <http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/c05.pdf>, p. 106.

[47] Bigby, C 2008, 'Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability', *Journal of Intellectual and Developmental Disability,* Vol. 33, No. 1, pp. 76-86, p. 81.

6.2.3 Problem of capacity within disability and aged care services to support people ageing with disability

According to the Senate Community Affairs Committee Secretariat (2007, p. 103), "[w]hile disability services and aged care services can often provide similar types of services to clients, disability services are generally not well equipped to manage the conditions and symptoms of ageing, and aged care services are generally not able to meet the specific support needs of people with disability"[48].

This can result in people ageing with disability not receiving the most appropriate supports they require.

6.2.4 The potential to remove the disability / age care interface problems by establishing a consolidated 'personal support' funding mechanism

Given the interface and capacity problems described above, it appears to us that the current separation of aged care and disability funding is distinctly unhelpful to people ageing with disability, because there is no life moment where a person suddenly becomes more 'old' than 'disabled'. Similarly, it is artificial and contrived to think of someone suddenly becoming more 'disabled' than 'old'.

Therefore we assert that the current separate funding mechanisms for people living with disability and older persons be replaced by a common funding mechanism that provides the assurance of practical supports to people based on their functional support needs and not their age or 'diagnosis'. Such an approach provides built-in continuity, and indeed can provide a dignified and affirming mechanism to deliver supports to all Australians living with significantly greater vulnerability regardless of its cause.

There is growing practice elsewhere of a common approach to the functional support needs of adults without artificial boundaries of diagnosis or age. One example is the United Kingdom, where the widespread introduction of personalised budgets in adult social care is anchored in common mechanisms for people living with disability, older people, and other vulnerable citizens. To illustrate, we refer the Productivity Commission to Worcestershire County Council's common approach to direct payments (http://www.worcestershire.gov.uk/cms/health-and-social-care/direct-payments/are-you-eligible.aspx) and their common approach to support planning and provision (http://www.worcestershire.gov.uk/cms/health-and-social-care/choice-and-control/about-choice-and-control.aspx).

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[48] Senate Community Affairs Committee Secretariat 2007, 'Chapter 5. The ageing/disability interface' in *The senate standing committee on community affairs: Funding and operations of the commonwealth state/territory disability agreement,* pp. 103-122, <http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/c05.pdf>, p. 103.

Other jurisdictions have explored the potential of a common approach, for example Ireland[49].

> ### R2 – *Establish new common funding mechanisms for commissioning personal supports*
>
> The Julia Farr Association recommends that separate funding mechanisms for people living with disability and older people be replaced by a common funding mechanism that assures practical support to all Australians with significant personal support needs.

7.0 SUCCESSFUL INTERVENTIONS TO ASSIST PEOPLE AS THEY AGE

The Julia Farr Association's *Tellus©* disability survey[17] asked people what they thought would assist them as they got older. A range of key suggestions provided by survey respondents reinforced that they wanted to have:

- Ownership of their life;
- Control of the supports they receive;
- Choices;
- Individualised Funding;
- Support to plan for the future;
- Person-centred planning;
- More money and funding;
- More information to assist with planning for the future;
- More support to respond to increasing needs.

7.1 The potential of Individualised (Self-Directed) Funding

These reported preferences are similar to the benefits reported in those jurisdictions that have introduced Individualised Funding, a methodology that gives the beneficiary a central role in how their allocation of public funding is used to create highly personalised supports[50].

Individualised Funding (also variously known as Self-Directed Funding, Personal Budgets, and several others) gives people the control over the types of support they require and who should provide this support. This control can have "a positive impact

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[49] National Disability Authority & National Council on Ageing and Older People 2006, *Ageing and disability: A discussion paper*
<http://www.nda.ie/cntmgmtnew.nsf/0/FBE570D7C6D435C28025710D004594B9/$File/NDAAgeingandDisabilityDiscussionPaper.pdf>.

[50] 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

on quality of life, as reflected in areas such as making choices, achieving goals, participating in the community, and growing relationships"[51].

The essence of Individualised Funding is that instead of having an allocation of service, the older person gets a personal allocation of public funding relating to support needs, and can choose and direct how the funding should be spent to best respond to their circumstances. This brings flexibility about the way that funding is used without necessarily compromising reasonable expectations around accountability for public funding, and can lead to highly creative, value-added solutions. Notably, the Individualised Funding methodology is inclusive of people who do not wish to manage their own arrangements, or who have diminished capacity, because people can choose a variety of ways for how the allocation is managed on their behalf[52].

Another benefit is increased efficient use of resources. In research conducted in the United Kingdom in 2008 it has been demonstrated that "[s]elf-directed services, combined with personal budgets, create a new operating system for social care that lowers costs, raises quality, improves productivity, offers greater choice, reconnects people to their social networks and helps to generate social capital"[53].

Given the continuing concerns regarding levels of public funding to support older people there is great merit therefore in considering a methodology that delivers both lifestyle *and* economic benefits.

R3 - *Introduce Individualised (Self-Directed) Funding*

The Julia Farr Association recommends that best practice Individualised Funding methodology be introduced widely as the dominant paradigm for the practical commissioning of supports for older people.

7.1.1 Individualised Funding and the National Disability Insurance Scheme

There is growing interest and dialogue in Australia regarding the introduction of a National Disability Insurance Scheme through its inclusion in the terms of reference of the Productivity Commission's current inquiry into Disability Care and Support. A National Disability Insurance Scheme would provide "cover to Australians as and when they need it, [and] would be funded by all taxpayers through general revenue or an extension of the Medicare insurance levy"[54].

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[51] 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.

[52] More information about Self-Directed funding can be found at: www.in-control.org.au or http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=37&cc=GB

[53] 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, p. 36.

[54] *NDIS: The plan for a national disability insurance scheme,* http://www.ndis.org.au/downloads/NDIS-The%20Plan%20(LR).pdf, p. 1.

We believe that a National Social Assurance Scheme, if designed to serve all vulnerable Australians, and if implemented using best practice features of Individualised Funding, would provide critical capacity for older people to access highly personalised support arrangements that uphold their dignity and place at the core of our communities.

7.2 The potential of Person-Centred Planning

Person-centred planning is an ongoing process that enables "older people to have much greater control and say over what they need and want in order to be full active citizens wherever they live, whoever they live with, and however they live"[55]. There is a focus on assisting people to identify their aspirations and needs in the context not only of what is currently available but of what might be possible[56]. This includes the affirming assumption that every person has potential, and regardless of issues of age or disability, can be supported to access or maintain active, inclusive lifestyles.

The use of person-centred planning, with its emphasis on self determination and shared action, would not only increase the chances that a strong plan emerges for the person, but also that the subsequent support arrangements include freely given community supports and fellowship that go far beyond just paid services. This is of critical importance if we are to avoid the assumption that older Australians with heightened vulnerability have lives characterised by paid support services and little else.

R4 – *Establish Person-Centred Planning arrangements*

The Julia Farr Association recommends that authentic, person-centred planning and support methodologies be widely introduced as the dominant paradigm for developing supports for older Australians.

8.0 CONCLUSION

The Julia Farr Association asserts that attending to the issues highlighted in this submission, and the resulting recommendations, will provide older Australians, including people ageing with disability, with increased access to supports that are responsive to their individual needs and circumstances.

As required, and to the best of our resources, we are available to make further contribution to the work of the Productivity Commission on this important issue.

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[55] Bowers, H, Bailey, G, Sanderson, H, Easterbrook, L & Macadam, A 2007, *Person centred thinking with older people: Practicalities and possibilities,* Helen Sanderson Associates, Cheshire, UK, p. 5, <http://www.helensandersonassociates.co.uk/media/12222/full%20book.%20practicalities%20and%20possibilities.pdf>.
[56] More information on Person-centred Planning can be found at:
http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm.