



**Submission made by Julia Farr
Association**

**Planning options and services for
people ageing with disability**

ABN: 16 464 890 778

104 Greenhill Road Unley SA 5061

PO Box 701 Unley Business Centre SA 5061

t: (08) 8373 8333 f: (08) 8373 8373

e: admin@juliafarr.org.au w: www.juliafarr.org.au

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*Submission made by Julia Farr Association:
Planning options and services for people ageing with disability*

Authors

Robbi Williams
Alicia Fidock

Julia Farr Association
PO Box 701
Unley Business Centre
South Australia 5061
Ph: (08) 8373 8333
www.juliefarr.org.au

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The Julia Farr Association makes this submission to the Senate Community Affairs References Committee's inquiry into planning options and services for people ageing with disability.

1.0 PURPOSE

The purpose of our submission is to highlight ways in which people living with disability¹ can gain access to planning and funding options that ensure they are supported in ways 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 people living with disability as valued citizens at the core of our communities*

We recommend that public policy, planning and commissioning of supports uphold the place of people living with disability as valued citizens at the core of our communities, and no longer commission congregate support arrangements that separate people from their communities.

R2. *Introduce Individualised (Self-Directed) Funding*

We recommend that the Individualised Funding methodology be widely introduced as the dominant paradigm for the commissioning of planning and support services for people ageing with disability.

R3. *Establish Person-Centred Planning arrangements*

We recommend that authentic, person-centred planning and support methodologies be widely introduced as the dominant paradigm for developing plans and supports for people ageing with disability.

R4. *Establish new common funding mechanisms for commissioning personal supports*

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

¹ *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.*

3.0 INTRODUCTION

The Julia Farr Association and its predecessor organisations have been involved with the disability community for 130 years. The organisation holds that the following values should inform policy development in this area:

- **Personal authority** – where people living with disability have and exercise control over the decisions in their lives;
- **Social inclusion** – where people living with disability are included as active citizens in the life of the wider community;
- **Capacity-building** – where people living with disability, through access to experiences and support, are growing their capacity to enjoy active lives of choice. This also includes the wider community growing its capacity to be inclusive and supportive of people living with disability.

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 people living with disability 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, family members and other supporters. 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 into planning options and services for people ageing with disability is timely in the current environment. There is a strong focus on exploring ways to improve the responsiveness of aged care services through the current Productivity Commission's Inquiry into Caring for Older Australians². 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"³ 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 services and planning options can further reflect the rights and needs of people ageing with disability.

4.0 CITIZENS FIRST AND FOREMOST

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.

² Productivity Commission Inquiry into Caring for Older Australians, Terms of Reference, <<http://www.pc.gov.au/projects/inquiry/aged-care/terms-of-reference>>.

³ 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>>.

This means that Australia's public policy settings must have proper regard for the inherent status of people living with disability, and to promote and uphold this citizenship in the design and commissioning of support services.

Further, this means that commissioning arrangements must ensure that people living with disability have genuine opportunity to access, and maintain, presence within the local community, and to enjoy active participation in mainstream community life alongside non-disabled people.

To provide for anything less would mean that our public policy settings are undermining the right of people living with disability to a decent, valued life.

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 recommend that public policy, planning and commissioning of supports uphold the place of people living with disability as valued citizens at the core of our communities, and no longer commission congregate support arrangements that separate people from their communities and non-disabled people.

5.0 INCREASING DEMAND FOR SERVICES AND PLANNING OPTIONS THAT SUPPORT PEOPLE AGEING WITH DISABILITY

In 2003, 3.9 million Australians were living with disability (20% of the population), of which around 1.2 million were living with a severe or profound limitation (6.3% of the population)⁴. Of those living with a severe or profound limitation, nearly 561,000 (over 45%) were aged 65 years or over⁵.

These statistics highlights the extent of the need for support and planning options 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)⁵.

Another factor that will contribute to an increased demand for services and planning 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 carers⁶). In 2003, a total of nearly 454,000 people aged 65 and over provided informal assistance to

⁴ AIHW 2009, *Australia's welfare 2009*, Cat. No. AUS 117, AIHW, Canberra.

⁵ 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)*.

⁶ ***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).***

people living with disability, with 113,200 being identified as a primary carer⁷. 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"⁸.

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

6.0 CONCERNS PEOPLE LIVING WITH DISABILITY HAVE ABOUT GETTING OLDER AND WHAT THEY THINK WOULD ASSIST TO PLAN FOR THE FUTURE

6.1 The concerns people have

The Julia Farr Association has identified 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.

The main research device we used was our **Tellus**© disability survey⁹ conducted in April 2010 and involving 180 respondents. They provided us with valuable information about their experiences living with disability.

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

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 when parents die;
- Not having the freedom of choice and control about the supports they need;
- Needing more support and not being able to access it.

⁷ 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>.

⁸ 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. 121.

⁹ Information about the **tellus** survey can be found at: http://www.surveymonkey.com/s/JFA_Living_with_Disability_Survey.

Tellus© survey question: What could help lessen these worries?

(This question refers to worries people have about getting older and living with a disability)

Tellus © survey question: What could help you plan for the future, as you get 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 funding;
- More information to assist with planning for the future.

6.2 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 build supports¹⁰.

Individualised Funding (also variously known as Self-Directed Funding, Personal Budgets, and several others) gives people living with disability the control over the types of support they require and who should provide this support. 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”¹¹.

¹⁰ 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

¹¹ 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.

The essence of Individualised Funding is that instead of having an allocation of service, the 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 with cognitive impairment, because people can choose a variety of ways for how the allocation is managed on their behalf¹².

The Julia Farr Association believe that such benefits demonstrate how Individualised Funding can provide people ageing with disability with “continued quality of life as they and their carers age”¹³ which is a key focus of the terms of reference of this inquiry.

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”¹⁴.

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

R2 – Introduce Individualised (Self-Directed) Funding

We recommend that the Individualised Funding methodology be widely introduced as the dominant paradigm for the commissioning of planning and support services for people ageing with disability.

6.2.1 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 Support¹⁵. A National Disability Insurance Scheme would provide “cover to Australians as and when they need it, [and] would

¹² 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>

¹³ 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, p. 1.

¹⁴ 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.

¹⁵ More information on the Productivity Commission’s inquiry into Disability Care and Support can be found at: <http://www.pc.gov.au/projects/inquiry/disability-support>.

be funded by all taxpayers through general revenue or an extension of the Medicare insurance levy¹⁶. More information in the National Disability Insurance Scheme can be found at: www.ndis.org.au.

We believe that a National Disability Insurance Scheme, if implemented using best practice features of Individualised Funding would provide critical capacity for people living with disability to plan for their lifestyle options as they age.

6.3 The potential of Person-Centred Planning

Person-centred planning is an ongoing process that gives people living with disability the central role in determining what they want to do now and in the future. There is a focus on assisting people living with disability to identify their aspirations and needs in the context not only of what is currently available but of what might be possible¹⁷. 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 people living with disability have lives characterised by paid support services and little else.

R3 – Establish Person-Centred Planning arrangements

We recommend that authentic, person-centred planning and support methodologies be widely introduced as the dominant paradigm for developing plans and supports for people ageing with disability.

7.0 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:

¹⁶ *NDIS: The plan for a national disability insurance scheme*, [http://www.ndis.org.au/downloads/NDIS-The%20Plan%20\(LR\).pdf](http://www.ndis.org.au/downloads/NDIS-The%20Plan%20(LR).pdf), p. 1.

¹⁷ More information on Person-centred Planning can be found at: http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm.

- 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 in more detail.

7.1 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 a typical Australian”¹⁸. However, people living with disability do not necessarily age in a ‘typical’ way as findings suggest that people can experience ageing earlier “as a consequence of living with a disability or due to shorter than average life expectancy”¹⁹. This can result in people living with disability not having equal access to the supports they need as they age. This impedes on their rights to access, on an equal basis as others, “services open or provided to the public”²⁰ as defined in the UN Disability Convention.

7.2 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 process²¹. 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”²². 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

¹⁸ 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.

¹⁹ 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.

²⁰ 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.

²¹ 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.

²² 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.

services delivered and the eligibility of clients”²³. 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 a continuous approach without the encumbrance of the requirements of two separate systems.

7.3 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”²⁴.

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

7.4 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’. What people living with disability and older people have in common is the experience of increased vulnerability that fairly demands the availability of practical and personal supports so that the person can maintain personal authority in her/his life, and remain as active and included as possible in her/his local community.

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 Australian’s living with significantly greater vulnerability regardless of its cause.

²³ 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.

²⁴ 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.

R4 – Establish new common funding mechanisms for commissioning personal supports

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

8.0 CONCLUSION

The Julia Farr Association asserts that attending to the issues highlighted in this submission, and the resulting recommendations, will provide people ageing with disability with increased access to planning and funding options that ensure they are supported in ways that meet their individual needs and circumstances.

For further information about this submission, please contact:

Robbi Williams
Chief Executive Officer
Julia Farr Association
Ph: 08 8373 8333
Email: admin@juliafarr.org.au.