SUPPLEMENTARY SUBMISSION
by the 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

TABLE OF CONTENTS

1.0 INTRODUCTION – summarising our previous recommendations

On the 28 May 2010 the Julia Farr Association forwarded a submission to the Senate Community Affairs References Committee's inquiry into planning options and services for people ageing with disability (see 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 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.

Further to the above previous submission we now provide supplementary commentary on a specific matter identified in the new terms of reference referred to the Committee by the Senate on 30 September 2010:

> *(d) Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I/we can no longer care?'*

2.0 INCREASED VULNERABILITY OF FAMILIES LIVING WITH DISABILITY

Families typically care about each other. This is reinforced by longstanding informal supports provided by families to loved ones living with disability. The stakes are intensified when families experience increased vulnerability in their lives and raised anxieties about the future.

The vulnerabilities that people living with disability and their families experience can be understood in the context of two principal concepts - *Personhood* and *Citizenhood*.

2.1 Personhood

This is our definition of Personhood:

A person's status as an individual, in terms of identity, uniqueness, value, potential, and dignity.

Support planning, and the options therein, must uphold the person's essential personhood. The United Nations Convention on the Rights of Persons with Disabilities (hereinafter referred to as the 'UNCRPD') ratified by the Australian Government in July 2008, highlights the importance of respecting the inherent dignity of people living with disability and ensuring "the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities"[1]. This includes attaining the highest standard of health, education, work and, "an adequate standard of living for themselves and their families, including adequate food, clothing and housing"[2].

Families need certainty that these essential supports are readily available to their loved ones living with disability to ensure their personhood is upheld and safeguarded.

However, the current service system does not provide this guarantee due to factors such as:

- People, and the families supporting them, not having the freedom of choice and control about the supports they require or receive[3];
- People, and the families supporting them, having poor access to information and advice[4];
- People, and the families supporting them, not having the financial capacity to access the supports they need. This is because people living with disability "on the one hand, often have fewer financial resources than other members of society, while on the other hand may have to bear additional costs due to their disability"[5].
- Conventional, programmatic service arrangements place the power with the 'helper' rather than the 'helped'[4];
- Inaccessibility of public transport and mainstream community amenities[6].

---

[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] Ibid, p. 20.

[3] Our qualitative and quantitative research with the disability community has included feedback from over 540 participants in our 2010 ***tellus*** survey (the survey is still open) - Information about the ***tellus*** survey can be found at: http://www.surveymonkey.com/s/JFA_Living_with_Disability_Survey.

[4] Williams, R 2007, *Why is it so hard to speak up and be heard? Views for the loop conference 2007,* Julia Farr Association, Unley, South Australia.

[5] Australian Institute of Health and Welfare 2009, *Australia's welfare 2009*. Australian Institute of Health and Welfare, Canberra, ACT, p. 155.

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

Therefore, people living with disability, and the families supporting them, need to have choice and control about the supports they receive, and have access to appropriate information, services and funding mechanisms within the community to ensure their fundamental rights and needs are promoted and upheld.

2.2 Citizenhood

This is our definition of Citizenhood:

> *"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"*[7].

Over and above the essential supports for *personhood*, we are all citizens and belong as active members of our local communities.

Family anxieties about the future can often be linked to the absence of others in their family member's life who care about that person and can look out for them as they travel through life. The Julia Farr Association has identified through our **tellus**© disability survey[3], that family members are increasingly concerned about the future welfare of their loved one living with disability when family supports are no longer available.

We refer the Community Affairs References Committee to the Julia Farr Association 2010 publication '*Model of Citizenhood Support: Discussion Paper*'[8] which provides a good contextual framework for thinking about, and planning for, the types of supports that would be most helpful to people living with disability. The framework includes:

1. Advancing and upholding personhood;
2. Reframing the relationship between people who are vulnerable and the formal agencies involved in their lives;
3. Access to supported information;
4. Access to material resources;
5. Development of fellowship and connection.

R5: *In addition to our previous four recommendations, the Julia Farr Association recommends:*

Using the 'Model of Citizenhood Support' as contextual framework for establishing supports that enable people living with disability and their families to plan for the future.

---

[7] Williams, R 2010, *Model of citizenhood support: Discussion paper,* Julia Farr Association, Unley, South Australia, p. 3.

[8] Ibid.

3.0 MODEL OF CITIZENHOOD SUPPORT

The five domains for *Citizenhood Support* can help guide the planning of supports for people living with disability as they age, especially through establishing "intentional set of arrangements that help ensure people with greater degrees of vulnerability are supported to achieve the activities and status of citizenhood in keeping with each person's lifestyle choices"[7]. We believe this will give people living with disability, and the families involved in their lives, greater hope and certainty about the future

As a demonstration of the utility of the Model of Citizenhood Support, we have applied it to the remainder of this submission, to generate a plan for system reform as it relates to the planning and support options for people living with disability as they age.

Each of the next five sections relates to each of the five domains of the Model.

3.1 Domain 1 - Advancing and upholding personhood

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 people living with disability and the families actively involved in their lives, 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.

Many people living with disability, and many family members actively involved in their lives, do not currently have a strong sense of what might be possible in terms of an ordinary valued life. This might be because of a person's current capacity, or because of their horizon-limiting experiences as recipients of formal services, or through repeated frustration trying to access fair and reasonable support. It is harder to move towards an ordinary valued life if you don't believe such a life is possible.

Therefore the first step here is to support the person to claim/reclaim/maintain a sense of positive personhood and to access opportunities to grow her/his capacity to see herself/himself as an individual of worth and an active valued member of the wider community. This is a critical element when planning the support options for people living with disability as they age, and can be reflected in an approach called *authentic person-centred planning.*

3.1.1 Authentic Person-Centred Planning

Person-centred planning essentially relates to the way that a plan is developed so that is anchored on a particular person's character, circumstance, and vision.

Importantly, Person-centred planning is "built on the values of inclusion and looks at what support a person needs to be included and involved in their community"[9].

The use of the word 'authentic' signals the importance of making sure that the planning is genuinely person-centred. Unfortunately, much planning is done in people's lives that carries the badge of person-centred but which in fact is not, because it operates within the context of the services that are currently available.

As highlighted in our previous submission (see Appendix A), the establishment of authentic person-centred planning arrangements provides people living with disability and the family members active in their lives, with the opportunity to think about what they want now and in the future, articulate this, and work towards realising these goals.

Research demonstrates that person-centred planning has a positive influence on the life experiences of people living with disability and their families with "benefits in the areas of:

- community involvement
- contact with friends
- contact with family
- choice"[10].

The benefits of person-centred planning advancing and upholding the personhood of people living with disability and their families, further reinforces our previous submission's recommendation to establish person-centred planning arrangements (see ***R3*** on page one of this submission).

3.2 Domain 2 - Reframing the relationship between people who are vulnerable and the formal agencies involved in their lives

A power imbalance can exist in the relationship between the *helper* and the *helped* in formal support systems where people living with disability 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 person being '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*.

---

[9] Inclusive Solutions n.d., *Person Centred Planning*, viewed 6 July 2010, p. 1, <http://www.inclusive-solutions.com/word/pcp.doc>.

[10] Robertson et al. 2005, *The impact of person centred planning*, Institute for Health Research, Lancaster University, Lancaster, UK, p. iii, <http://www.lancs.ac.uk/staff/emersone/FASSWeb/Robertson_05_PCP_FinalReport.pdf>.

At a whole-system level, this can be advanced through an approach called 'co-design'.

3.2.1 Co-design Approach

The practice of co-design essentially relates to design work where the intended beneficiaries have had an active central involvement. In human services, this can help ensure that the resulting design of formal support systems is more meaningful, responsive and helpful to the intended recipients, and can establish a sense of ownership consistent with the principle of *citizenhood-support*.

For example, when the need emerged to reform mental health services in Wellington New Zealand, the reform approach included principles of co-design. People living with mental illness, family members, General Practitioners and other community stakeholders had the opportunity to contribute to the development of the new system. This included the opportunity for people to move away from specialist mental health services back to the support of their local GP. The scheme, called the Wellington Mental Health Liaison Service, and each personal solution within it, was constructed in collaboration with the intended beneficiaries[11].

For a general illustration of the concept, we refer you to this video on You Tube - http://www.youtube.com/watch?v=HWgJlwTDIRQ.

R6: *The Julia Farr Association recommends:*

Using a co-design approach within formal support systems to ensure people living with disability and their families have a genuine stake in support arrangements.

3.3 Domain 3 - Access to supported information

This third domain in the *Framework for Citizenhood Support* focuses on people living with disability, and the family members actively involved in their lives, having access to good information. 'Good' information is likely to be relevant to the person, and helpful to an informed choice. There can be no doubt that a lack of access to information can keep people in cycles of disadvantage. Everyone needs good information to make choices, to assess risk, to test ideas, and to grow/adapt capacity.

However, it's not just the mere *presence* of relevant information that can help people to plan for the future. For many people, the information also needs to be accessible, given that people living 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.

---

[11] O'Malley, C, McGeorge P, & Kelly A 2000, *Programme evaluation: Primary and secondary care mental health liaison programme*, Wellington Independent Practice Association, Capital Coast Health, Mental Health Consumer Union (Funded by the Mental Health Commission), New Zealand.

Similarly, the way that information is explained to a person can critically affect their understanding of that information. For example, the way professional staff provide 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[12].

Therefore, to assist people living with disability 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.

We call this *Supported Information*, referring 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.

R7: *The Julia Farr Association recommends:*

The establishment of arrangements for the provision of high quality 'Supported Information' to help ensure that future formal support systems are responsive to the informed choices of people living with disability and the family members actively involved in their lives.

In addition to this recommendation, which emphasises the importance of availability of good information, there is a companion issue on how the person is supported to make a decision with that information. Many Australians who are vulnerable, including people living with significant degrees of disability, are at risk of having their personal authority given over to a substitute decision-maker, for example though the appointment of a formal guardian. Given the importance of personal authority, and its critical role in planning for the future, we believe that this should not be given away from a person who is vulnerable if alternatives are available. One such alternative is *supported decision-making.*

3.3.1 Supported decision-making

Supported decision-making is an approach where people are supported to make informed decisions without having to have a formal substitute decision-maker involved. It is a companion idea to the 'Supported Information' assertion above because it includes communicating and providing information that is accessible and easy to understand[13].

---

[12] 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.

[13] The Open Society Mental Health Initiative 2005, 'Alternatives to guardianship: Supported decision making', viewed 7 July 2010, p. 1, <http://www.osmhi.org/index.php?page=266>.

Research on supported decision-making has identified that "[s]imple, appropriate language, accessible information and suitable decision-making environments"[14] were essential in supporting people to make decisions and take control.

R8: *The Julia Farr Association recommends:*

The establishment of Supported Decision-Making arrangements across Australia, to maximise the potential for people living with significant degrees of disability to retain their personal authority and to exercise this authority in the planning of future supports as they age.

3.4 Domain 4 - Access to material resources

People living with disability, and the family members actively involved in their lives, "need to be able to access material resources that enable and reflect active citizenhood, that are reasonable in terms of 'levelling the playing field' and achieving a fair go"[15].

Importantly, access to material resources includes the wide range of amenities that are available to all citizens. Among other things this includes access to public transport, public buildings, open spaces, and venues for work and recreation. It will be much easier to assist people ageing with disability to plan for the future if our mainstream community resources are accessible and welcoming. This imperative has been consolidated by the United Nations Convention on the Rights of Persons with Disabilities which states that people living with disability have the right to have "access, on an equal basis with others, to the physical environment, to transportation..., and to other facilities and services open or provided to the public"[16].

R9: *The Julia Farr Association recommends:*

Specific planning and support options for people ageing with disability occur within the context of Australia-wide community capacity-building, so that public transport and the full range of community amenities are genuinely accessible to, and welcoming of, all citizens.

In addition, there are important considerations in relation to material resources specific to people ageing with disability. If we are to uphold the personal authority of people living with disability, then such material resources are best made available as indicative personal budgets (ie dollars) as opposed to indicative allocations of units (e.g. respite hours, program places etc). This is important because it gives the person much greater flexibility to create and craft the support arrangements that have the best possible match with that person's circumstances and preferences.

---

[14] Edge, J 2001, *Findings: Demonstrating control of decisions by adults with learning difficulties who have high support needs*, Joseph Rowntree Foundation, p. 2, <http://www.jrf.org.uk/sites/files/jrf/021.pdf>.

[15] Williams, R 2010, *Model of citizenhood support: Discussion paper,* Julia Farr Association, Unley, South Australia, p. 7.

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

In considering the availability of funds in this way, there are two main elements we now comment on further. The first is the methodology as it relates to public funds to support a person living with disability, which we term Individualised (Self-Directed) Funding, and the second is a methodology for accumulating private funds to support a person living with disability – our example is a Registered Disability Savings Plan.

3.4.1 Individualised (Self-Directed) Funding

Individualised (Self-Directed) Funding arrangements that are fair and equitable can provide people living with disability, and the family members actively involved in their lives, with the necessary material resources to intentionally move towards a life of choice driven by personhood and citizenhood.

We note the increasing availability of Individualised (Self-Directed) Funding across a number of jurisdictions in Australia and overseas, and its potency in people's lives without compromising the public purse[17].

As recommended in our previous submission (see Appendix A), we assert that Individualised (Self-Directed) Funding arrangements be established as they provide people living with disability with central control over the types of supports they received and who should provide this support (see ***R2*** on page one of this submission).

3.4.2 Registered Disability Savings Plan

The Registered Disability Savings Plan, established in Canada, is another innovative funding arrangement that assists people living with disability and the family members actively involved in their lives to put money aside to plan for their future.

The Registered Disability Savings Plan enables family members, friends and any other concerned parties, to financially contribute to the plan. There are additional benefits with the Canadian government also contributing to the plan. There are no unhelpful restrictions on when the funds can be used and for what purpose. Given the concerns that many family members have about the future for their loved one living with disability, this mechanism is an important additional way for people to help ensure they "have the financial resources needed to access the services and opportunities that will provide [their loved one] with a good life"[18].

More information on the Registered Disability Savings Plan can be found at: http://www.rdsp.com/sections/what.html.

---

[17] 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

[18] Kuntz, T n.d., *The registered disability savings plan. BC edition*, Plan, Vancouver, British Columbia, www.plan.ca, p. 1.

R10: *The Julia Farr Association recommends:*

The introduction of new innovative funding mechanisms, such as the Registered Disability Savings Plan, to support people living with disability and the family members actively involved in their lives to strengthen the financial resources available to support people as they age with disability.

3.5 Domain 5 - Development of fellowship and connection

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. However, people living with disability, and the family members actively involved in their lives, encounter barriers to establishing such freely given relationships. This is often due to increased exposure to social exclusion and isolation[19]. To counter this, there is often great benefit resulting from the *intentional* development of networks in the lives of people who are vulnerable, to increase the amount of fellowship and connection that a person enjoys, so that rich relationships might emerge.

3.5.1 Establishment of intentional networks

Arrangements that emphasise the intentional development of trusting and freely given networks in people's lives can support people living with disability 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[20].

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[21] and is now a valued feature within the landscape of disability support.

Given that many people living 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

---

[19] National People with Disabilities and Carer Council 2009, *Shut out: The experiences of people with disabilities and their families in Australia*, Commonwealth of Australia, Canberra.

[20] Circle Networks 2008, 'Circles of Support', viewed 7 July 2010, p. 1, <http://www.circlesnetwork.org.uk/circles_of_support.htm>.

[21] Further information on the Circles Initiative in South Australia - http://www.clp-sa.org.au/content/circles-initiative

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 there be assistance such as Circles for our most vulnerable citizens living with disability. The methodology has proven its capacity to bring new people into the lives of people living with disability, which in turn will help offer greater assurance for family members that there are others out there who can look out for their loved one once the family members are no longer around.

R11: *The Julia Farr Association recommends:*

> *The establishment of resourced arrangements, for example as a component of Individualised (Self-Directed) Funding, that facilitate the intentional development of sustainable, freely given networks of regard and support in the lives of people ageing with disability.*

4.0 BUILDING ORDINARINESS IN PEOPLE'S LIVES

The *Model of Citizenhood Support* can also help to build ordinariness in the lives of people living with disability and their families through focusing on ensuring people experience:

- Ordinary valued roles;
- Ordinary relationships;
- Ordinary presence in the community.

This demands significant effort to ensure services and supports within the community "promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability"[22].

This focus would also give families hope about the future when they "can no longer care"[23] through providing them with the necessary supports and mechanisms to help them to plan ahead.

5.0 CONCLUSION

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

The Julia Farr Association would be very happy to make a more detailed presentation to the Senate Community Affairs References Committee on the *Model of Citizenhood*

---

[22] United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 5, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

[23] Senate Commuity Affairs Committee 2010, 'Inquiry into planning options and services for people ageing with a disability. Terms of reference, p. 1, <http://www.aph.gov.au/Senate/committee/clac_ctte/planning_options_people_ageing_with_disability_43/tor.htm>.

Support and its applicability to the design of supports that encourage people living with disability and their families to plan for the future.

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.

APPENDIX A -

Julia Farr Association Submission (submitted 28 May 2010) –

Planning options and services for people ageing with disability

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

Published by
Julia Farr Association
Adelaide, Australia

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.juliafarr.org.au

ISBN 978-0-9807086-0-8

TABLE OF CONTENTS

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 disability[1] 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 Australians[2]. 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 citizenhood 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 over[5].

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 carers[6]). 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 carer[7]. 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 survey[9] 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 supports[10].

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 behalf[12].

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 Support[15]. 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 levy"[16]. 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 possible[17]. 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, 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 process[21]. 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.