Submission made by Julia Farr Association

National Carer Strategy

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1.0 INTRODUCTION

The Julia Farr Association makes this submission to the Australian Government's consultation on the development of the National Carer Strategy.

The Julia Farr Association and its predecessor organisations have been involved with the disability community 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 people living with disability to access the good things in life. We are not a conventional 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 consultation on the development of the National Carer Strategy is necessary to respond to the increased stresses and challenges experienced by family units where a member lives with disability. The Julia Farr Association has identified through our **tellus**© disability survey[1], that 82% of family member respondents reported that providing unpaid personal supports definitely had an impact on their lifestyle leading to stressful experiences.

This consultation is also timely in the current environment. There is national emphasis on responding to the social and economic barriers people living with disability and other vulnerable citizens experience with the Productivity Commission's inquiry into Disability Care and Support and the Australian Social Inclusion Board's research investigating breaking cycles of disadvantage. There is also commitment to "improving life for Australians with disability, their families and carers"[2] through the National Disability Strategy. Further, there is international acknowledgement of the social disadvantage that people living with disability experience, and emphasis through the UN Convention on the Rights of Persons with Disabilities ratified by the Australian Government in July 2008, that measures are put in place to ensure that people living with disability can fully participate and be included within their society[3].

The development of the National Carer Strategy provides the opportunity to assess ways in which the services and experiences provided within our community can further reflect the rights and needs of family units where a member lives with disability.

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[1] 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.

[2] '2010-2020 National disability strategy: An initiative of the Council of Australian Governments', p. 8, <http://www.billshorten.com.au/uploads/billshorten/National_Disability_Strategy.pdf>.

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

2.0 QUESTION 1: Do you think the Strategy as outlined in this discussion paper sets the right direction to meet the vision and aim to better support carers?

Recommendations from the Julia Farr Association

R1 – That the **Vision** of the National Carer Strategy should be:

The family/friend unit thrives in a welcoming and supportive community, supported where necessary by a flexible and responsive service system.

R2 – A lower order (yet none-the-less crucial) vision is:

Family and friends are supported in the range of caring roles so they can maintain their health and wellbeing and take part in all aspects of life in Australia, including work, community and family life.

2.1 Discussion

The Julia Farr Association believes that the vision, goals and aims are broadly in the right direction. However, this is tempered by the following comments.

While it is clear that the needs of those who care for people living with disability in an unpaid capacity have not been met well for many years and so are deserving of focus, two cautions are issued. Firstly, the discussion paper states on page 5 that the national approach is to 'place carers at the centre of government policy'. This submission posits that families are a unit of interconnected parts, and that each part is more likely to do well when the needs of the whole unit and the needs of each of the parts are met well.

A focus on carers to the exclusion of a complimentary focus on the needs of the people they care for has a high likelihood of the carer's needs trumping the needs of the friend or family member with a disability. This is currently seen in many respite services, where it is the needs of the carer that are primarily met, that is, the need for a break. Anything, including minding people living with disability by taking them to parks and coffee shops will meet the need for the carer, but with a cost borne by the person living with disability with regard to wasted potential and opportunities for development. This is explored further in Question 3.

The corollary of this is that the Overall Vision should be: *that the family/friend unit thrives in a welcoming and supportive community, supported where necessary by a flexible and responsive service system.* A secondary (and lower level) vision relates to the family members/friends who care for the person living with disability, and would be similar to that stated in the discussion paper: *Family and friends are supported in the range of caring roles so they can maintain their health and wellbeing and take part in all aspects of life in Australia, including work, community and family life*.

The second caution is a language issue. It is acknowledged that the term 'carer' is used in the legislation, however this term is highly imprecise. Paid workers have also adopted this term, and this leads to confusion about who is the subject of the discussion. Further, this term implies that the primary sets of tasks are ‘caring for’ someone, which implies that people living with disability are in the dependent caree role and therefore are burdens. This submission uses the term ‘family/friends’ to refer to those who love, like, share, include, advocate, enable, teach, guide, inspire, witness, and are more free of vested interest than those paid by the service system.

In light of these cautions, the Julia Farr Association has proposed an alternative vision where the focus is on the family unit, not only the ‘carers’, and where the context is a resilient family/friend unit and a welcoming community supported where necessary by paid services. It is within this vision that the specific needs of families/friends should be met.

3.0 QUESTION 2: Do you agree with the five goals outlined in this discussion paper?

While positive comments are made about all of the goals, the Julia Farr Association also raises concerns and recommendations about Goals 1, 3 and 4 in Question 3.

3.1 Goal 1: Better recognition for carers

The list of outcomes that this goal is intended to achieve, as outlined on page 8 of the discussion paper, are very positive. They appear to be based on the following positive and helpful assumptions, with which the Julia Farr Association agrees:

i. That the family/friend unit can be crucial to enabling the person living with disability to remain at home, to be part of the fabric of community life, to grow and develop and to be perceived positively by the wider community;

ii. That family members/friends also have needs for a decent life;

iii. That family members/friends bring knowledge about the person that is of a longer duration and of a deeper nature than the vast majority of paid workers;

iv. That family members/friends bring a set of skills and expertise in terms of what might work best for the dependent family member.

One of the strengths of these assumptions is that they lead to a high likelihood of the person living with disability staying in the home and/or community as would be expected for any person without a disability.

The list of achievements on page 8 of the discussion paper also refers to family members/friends being in the role of ‘partners’ – this is a crucial intention, and is explored further on page 7 of our submission.

3.2 Goal 2: Better support to help carers work

This goal recognises that the work role is very important not only for family income and to meet the costs associated with disability but also for self esteem and social networks. An intended achievement listed on page 8 of the Discussion Paper also refers to the provision of income support. This is an important recognition that for many families and people living with disability, the family culture and the needs of the person are such that outside work has not been pursued as an option. It is vital that income support be of a sufficient level, as the combination of high costs and low income with resulting financial disadvantage exacerbates other things with which the family/friend is dealing.

Notwithstanding the importance if income support, the Julia Farr Association strongly supports the idea that all family members in support roles should not have to forego work opportunities. The Julia Farr Association notes that agencies elsewhere have demonstrated that family/friends in informal support roles can still successfully hold down an outside work role. A good example of such an agency is Onandago Community Living in Syracuse, New York State.

3.3 Goal 3: Better information and support for carers, and Goal 4: Better education and training for carers

Having information and education is recognised by the Julia Farr Association to be effective ways to meet needs.

What is key for family members and friends is to have access to social, physical and economic resources *and* to have high expectations about what is possible in the life of the person living with disability. Information and education are a means to this goal. The Julia Farr Association sees this as the preferred higher order goal and explores this further in Question 3.

Therefore, a key issue here is deciding what information/education/training might be of most assistance to people in informal support roles, and in what context. This deliberation would extend to the questions that are formed in research on the needs of family/friends in support roles.

We refer the reader to the Julia Farr Assocation **tellus** survey initiative that researches the experiences of people living with disability and their family supporters in the context of choice and an ordinary valued life.

3.4 Goal 5: Better health and wellbeing for carers

Our view is that health and wellbeing are less a strategic goal in itself, and more the result of the other goals. As such, we recommend that this theme be reframed as a framework to measure the impact of the strategy.

We do not believe that initiatives under this element, such as training in coping strategies, are sustainable in the long term as they focus on people coping with the status quo rather than advancing their own circumstances and those of the person(s) they are supporting.

4.0 QUESTION 3: Tell us if you have any suggestions about how the goals could be improved?

4.1 Goal 1: Better Recognition for carers

Recommendations from the Julia Farr Association

R3 – That the current Goal 1 be changed to:

Greater consciousness and understanding of the capacities, needs and roles of family members/friends and their natural authority in meeting the needs of the dependent family member.

R4 – That the achievements for Goal 1 be changed to:

I. *The resilience of the family unit or friend unit is strengthened;*

II. *Health and community care professionals and government officers are conscious of the capacities, needs and roles of family members/friends;*

III. *Health and community care professionals and government officers are conscious of the natural authority of family members/friends;*

IV. *Health and community care professionals and government officers work to foster this authority and engage in equal, ethical and empowering partnerships in co-designing what will meet the needs of the family unit.*

4.1.1 Discussion

The term 'recognised and acknowledged' is of great concern. It is not defined anywhere in the discussion paper nor in the legislation and could, albeit unwittingly, lead to the needs of the family member/friend being seen as more pressing and having greater priority than the needs of the person living with disability.

This is not a naïve or unfounded concern. One of the common perceptions of people living with disability is that they are burdens. This relates to perceptions of people as eternal children, incompetent, nuisances, sick, a drain on society and families, gifts from God, atonement for past sins, and better off dead. This has been referred to as the 'othering'[4] of people living with disability and is clearly a denial of their personhood, citizenship and rights.

Related to this dynamic is the perception that family members and friends who care for and look out for a person living with disability must be a saint or a hero. Thus the model of tragedy is enacted, whereby the person living with disability is the cause of all stresses within the family unit, and the family members or friends bear great costs for looking after them. This has been perpetuated in public demands such as for more respite as captured by various documentaries that have demonised people living with disability.

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[4] Goggin, G & Newell, C 2005, *Disability in Australia: Exposing a social apartheid*, University of New South Wales Press, Sydney, NSW.

One of the stated achievements of this goal refers to partnership. Natural authority lies with the family unit in terms of the key decisions that affect the family member living with disability. This should be part of the goal in itself, not just a desirable achievement. The nature of the relationship between the human service and the family member/friend is crucial to the achievement of citizenship, community inclusion and strengthened community capacity.

There are forces which shift power from families/friends to the service system and therefore make partnerships less likely to happen.

For example, the traditional service arrangement is where the power resides totally within the human service system, and it is the service provider whose expertise is recognised, and who makes the majority of the key decisions in the life of the person living with disability: which school will be attended, which service will provide support after leaving school, who the person lives with, how they spend their time etc. It is they who hold the information about the private domain of the family and the person living with disability. This relationship with the service provider can be one of the sources of great stress for many family members/friends. This relationship is played out through the forms of communication, the nature of the information that is shared, the way that decisions get made, the extent of consultation, and the extent of delegated decision making. Self management of funds and self governance at a service or individual level continues to be available for only a minority of individual arrangements.

These circumstances make it harder to establish authentic partnership and co-design, without which there is less chance that a person will be supported in a way that upholds the right to an ordinary valued life for them and their family members.

We have heard the view that societal values in Australia are reflected in the expectation of many families. The argument goes that we live lives that reflect individualism and materialism. These two value sets contribute to an expectation that the ‘State will provide’ (so that ‘I’ can live my own life and earn money to gather material possessions). Anecdotal evidence from older experienced parents is that there is a significant wave of younger parents who despite having worked for regular schooling for their children, now expect that services will provide what is basically a minding service so that the parents can continue working.

Further, it is not uncommon for families/friends to expect that when things get to breaking point or on the death of the parent, then the service system becomes not only the substitute parent but also that the vulnerable person’s community life is replaced by a ‘service life’.

This is not intended to be a harsh judgment on parents. It is a view we have heard put forward in our society and these values have shaped the expectations of parents. It is a comment on the lack of timely and relevant support for families that meet needs in the short term and with a clear eye on the long term. It is a comment on our communities that express ‘we don’t want people who are different’, which makes the parenting in favour of community inclusion that much more difficult. The service system reinforces these expectations by implicitly and explicitly saying ‘we are the experts’, ‘we have the answers’, ‘we are the answers’ and becomes an unquestioned source of assistance for people living with disability. This places a particular burden on professionals who, armed with a longstanding bias towards a conservative duty of care, have to take charge (and therefore not relinquish control) and attempt to live up to the image of the ‘know-everything hero problem-solver’.

What is important is what *underpins* the current stated goal – there is great value here, so the Julia Farr Association is not suggesting that the underpinnings of the goal be erased. It is instead recommended that the goal read: *‘Greater consciousness and understanding of the capacities, needs and role of family members/friends and their natural authority in meeting the needs of the dependent family member.’*

This would lead to a revision of the achievements with the key outcome being resilience in the family/friend unit, and emphasising the actions of paid workers in the formal human service system. The Julia Farr Association recommends the following achievements:

i. *The resilience of the family unit or friend unit is strengthened;*
ii. *Health and community care professionals and government officers are conscious of the capacities, needs and role of family members/friends;*
iii. *Health and community care professionals and government officers are conscious of the natural authority of family members/friends;*
iv. *Health and community care professionals and government officers work to foster this authority and engage in equal, ethical and empowering partnerships in co-designing what will meet the needs of the family unit.*

4.2 Goal 3: Better information and support for carers, and Goal 4: Better education and training for carers

Recommendation from the Julia Farr Association

R5 – That the current Goals 3 and 4 concerning education and information be changed to the higher order goal:

Increased capacity in family members/friends, reflected in higher expectations of human services and utilising social, financial and information resources towards a positive vision for the person living with disability and the family.

4.2.1 Discussion

As stated in Question 2, information and education are good strategies, however it is vital that the information and education are about the things that really matter, and for that reason it is important to be clear about the purpose of information and education. The Julia Farr Association believes that what is important for family members and friends is to have two key things: access to social, physical and economic resources *and* to have positive expectations about what is possible in the life of the person living with disability.

Social resources are defined as people such as the wider family and friends, colleagues and neighbours who can share in creating a vision of a good life and make it happen. Physical resources are those material things that meet needs such as adapted vehicles and other equipment. Economic resources are those personal funds that any family needs and funds from the Government to meet the additional costs of disability.

It is a minority of family members and friends who have clear expectations about what a good and meaningful life could look like, with high expectations about the service system supporting them in crafting a good and decent life for the person living with disability. Parents are taught to have low expectations about what is possible in the life of their son or daughter. At birth, the phrase 'I am sorry to tell you that your child has a disability' is still very common, thereby imparting negative value on the baby. Similarly, it is still common for parents to be told by professionals that their child will not achieve and that they will be a burden. Early in life children are streamed into a segregated system through schooling and through formal 'respite'. This continues into adulthood where it is far easier to get a group home and a day service than it is to get support to have an ordinary and typical lifestyle such as that enjoyed by others without a disability. Thus the pattern of messages to parents is one of hopelessness. Many families receive no support until they are in crisis, and these situations depict the person living with disability as the cause of the crisis, when the cause could equally be lack of the resources mentioned above or other factors in the family.

Further, it is very difficult for family members/friends to be proactive. Family members/friends live very busy lives just like everyone else, and ordinary stress is exacerbated by disabling societal conditions and difficulties with schools and the adult service system[5]. As a result family members/friends live day-to-day and have little time or energy for planning for key transition points: school to work; young adulthood to adult; leaving home; getting a job; crafting a meaningful week; sustaining lifestyle and support arrangements after the death of a significant loved one.

Information and education that is provided to family members and friends should have the intent of building capacities and expectations to mobilize their own resources and to utilise funded resources in the most potent way such that the family unit does well and the person living with disability has a meaningful life.

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

5.0 QUESTION 4: What should the Australian Government focus on under the goals to better support carers now and into the future?

The Julia Farr Association addresses this section through focusing on what should be used under Goals 1, 3 and 4.

Recommendation from the Julia Farr Association

R6 – *Conceptualise all goals through the notion of Citizenhood and Personhood for the person living with disability, not through a model of Tragedy and Burden.*

5.1 Discussion

The strategies that are implemented under the goals should come from a framework that reflects the following beliefs. These beliefs are listed to temper and to contextualise the discussion paper's emphasis on 'acknowledgement and recognition of Carers', and provide a balance so that the focus remains on the person living with disability, while remaining conscious of the needs of the broader family.

The underpinning beliefs **should not** be:

i. People living with disability are burdens on their families, communities and services;
ii. The cost of this burden is primarily borne by the family;
iii. The main solution for the family is to remove the person living with disability, either through placement into a service or through centre-based respite so that the parents can return to work, study or home duties.

These beliefs polarise the interests of the family member/friend and the person living with disability. The Julia Farr Association puts forward an alternative set of guiding beliefs and principles that lead to a different set of solutions.

The helpful underpinning beliefs **should** be:

i. Families want to care for their own;
ii. Families/friends can be supported to do well as a unit;
iii. Families are likely to do better when they are confident that their loved one's needs are met and that a meaningful, positive and safeguarded future is being crafted. Parents are intimately connected to the experience of disability, and when for example, their loved one is rejected, parents feel this too. Parents also worry about what will happen to their son/daughter when they die. This leads to the next belief;
iv. Planning for lifestyle and support arrangements must start early. The National Carer Strategy should prioritise this, and refer to it not as 'early intervention' but as 'early investment' with a clear emphasis on individual and family capacity-building in the context of an ordinary valued life;
v. The needs of families/friends should never trump the needs of the vulnerable party (the person living with disability);

vi. It should not be assumed that the mere presence of someone living with disability in a family is causing stress: poverty, unemployment, mental illness in parents and siblings that are going through transition points have been found to contribute significant stress to the family unit. Lack of sleep and lack of exercise which could be for a range of reasons, people's low natural resilience, the characteristics of the family members/friends themselves, and the loss of natural social supports will also contribute to stress;

vii. The needs of families where there is someone living with disability are the same as other families: to thrive as a unit and individually;

viii. The additional needs of families where there is someone living with disability includes building resilience to offset the negative societal messages, to have the ability and energy to craft a regular and ordinary life for their loved one, to be respected, to have authority over lifestyle decisions and support arrangements that matter to them;

ix. The medical model has a place at those times when it is important to have a diagnosis and treatment for needs related to the impairment. It has no or low usefulness in shaping what a good life looks like or what support arrangements should look like. The latter requires frameworks that assist family members to address the disabling conditions of society. These disabling conditions include negative perceptions of disability, the impulse of society to reject on the basis of 'otherness' and segregation and congregation of people on the basis of impairment;

x. Human services can help or hinder the pursuit of decent lives for people living with disability. Those services that use a model that is building-based, group-based and activity-based, as are typically found in centre-based services like group homes, day centres and respite services, are more likely to hinder the pursuit of personhood and citizenhood. They also hinder the capacity of communities to welcome all citizens, as they emit messages that 'these people are so burdensome that only paid people can look after them';

xi. Families might seek solutions that are building-based, group-based and activity-based, trusting that these services will offer safety and long term security. Research indicates that such environments are more likely to foster abuse and show that this is misplaced trust[6];

xii. When families/friends ask for a solution that is not likely to be in the best interest of the person living with disability, then it should be assumed that this is not an informed decision or that it comes from a place of exhaustion and desperation. Secondly, it should be a non-negotiable that the person living with disability should not be worse off as a result of meeting the carer's needs;

xiii. Families have learnt to tell the stories that emphasise the negative, and systems reinforce these types of stories as that is the way that people are more likely to get funding. Families start to believe these stories[5].

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[6] 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.

Therefore the principles would include:

i. The meeting of the needs of family members/friends should never be at the expense of the person living with disability. Community and service strategies should benefit *both* parties;

ii. Services that strengthen the family unit and contribute to the community participation and belonging of people living with disability should get priority in funding;

iii. Family members/friends have potential: potential to be more resilient, potential to have high expectations of the service system so that their loved one can have a better community life (not a service life) and potential to draw on their own resources;

iv. Family members/friends will do better when they are supported through access to resources (such as information, social or financial resources) to clarify their vision of a decent life and to negotiate an equal, ethical and empowering partnership with services;

v. Family members/friends will do better when they are connected to other progressive family members and friends.

These underpinning beliefs and principles lead to the following sets of activities under the (reconceptualised) goals.

5.2 Revised Goal Statement 1

Recommendation from the Julia Farr Association re Revised Goal Statement 1

R7 – *Greater consciousness and understanding of the capacities, needs and role of family members/friends and their natural authority in meeting the needs of the dependent family member.*

5.2.1 Implications

a. For the design of human services: this will require a move away from menu-driven traditional forms of services where families have to fit in with what is on offer and where the planning is done in the absence of or with low involvement from the family. It requires:

- A move towards planning that will enable rich and meaningful lives, valued roles and community participation;
- A mechanism in the system, yet separate from existing accommodation, day and respite services, to assist families/friends to engage in short and long term planning;
    - ➢ Person-Centred planning, and approaches such as PATH and MAPS[7], provide family units with the opportunity to think about what they want now and in the future, articulate this, and work towards realising their goals. Person-Centred planning is “built on the values

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[7] Inclusive Solutions n.d., *Person Centred Planning*, <http://www.inclusive-solutions.com/word/pcp.doc>.

of inclusion and looks at what support a person needs to be included and involved in their community”[8].

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”[9];

- Arrangements where there is a bias towards co-design throughout the human service system, so that people living with disability and family members in support roles have a genuine stake in the arrangements;
    - A co-design approach can help ensure that service systems better respond to the needs of family units where a members lives with disability. 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[10].
- Arrangements that emphasise the intentional development of sustainable networks of decision-making support in people’s lives, such as *Circles of Support:*

> 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[11].

- Funding that is tied to a named individual living with disability: individualised funding that includes self management or a fiscal intermediary is one way to achieve this;
- Funding that fosters innovation would be a necessary parallel strategy;

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

[9] 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>.

[10] 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.

[11] Circle Networks 2008, ‘Circles of Support’, p. 1, <http://www.circlesnetwork.org.uk/circles_of_support.htm>.

  - A re-conceptualisation away from ‘respite’ towards family support.

b. For the training of service workers: this will require socialisation away from the worker-as-expert towards training that strengthens the capacity of workers to assist not only by doing practical things but also through the nature of the relationship with the family member/friend and person living with disability.

5.3 Revised Goal Statement (for current Goals 3 and 4)

Recommendation from the Julia Farr Association re Revised Goal Statement (for current Goals 3 and 4)

R8 – *Increased capacity in family members/friends, reflected in higher expectations of human services and utilising social, financial and information resources towards a positive vision for the person living with disability and the family.*

5.3.1 Implications

Capacity-building will be possible through furthering the following content and using the following processes.

a. Regarding the content of capacity building activities, this will require family members/friends to:

  - Understand the limits of traditional forms of services;
  - Explore what is meant by ‘a good life’, ‘imagining a life that is better than what is mostly commonly provided’ and alternatives to traditional forms of services that have features such as being highly individualised, personal, flexible and responsive;
  - Explore alternatives to traditional forms of governance and funding including self-management and self-directed funding;
  - Note that this is very different from topics such as ‘what is autism’, ‘how to manage difficult behaviour’, and ‘safe lifting’, which are largely deficit-oriented.

b. Regarding the processes that are helpful to family members/friends, these include:

  - Examples of where good things have been possible (through information and education);
  - Exposure to progressive families and stories of communities who have successfully welcomed and included people living with disability (through information and education);
  - Attending conferences, both professional conferences as well as family-friendly conferences such as those run by the Julia Farr Association in South Australia, Personalised Lifestyle Assistance in Victoria, Family Advocacy in New South Wales, Community Resource Unit in Queensland and Imagine Better in New Zealand;

- Being connected to progressive, visionary family members;
- Being mentored by progressive, visionary family members or paid professionals;
- Being supported to engage in short and long term planning to ‘imagine better’ through approaches such as person-centred planning.

6.0 CONCLUSION

The Julia Farr Association concludes that a National Carer Strategy could bring significant value to Australians living with disability and family/friends who support them ***if*** it is founded on principles of an ordinary valued life for people living with disability and their families, and where support arrangements for ‘carers’ consistently uphold the person living with disability’s journey into personhood and citizenhood.

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