Submission made by

Julia Farr Association

PARENT’S FORUM

Towards a National Carer Strategy

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The Julia Farr Association Parents Forum would like to take this opportunity to respond to the Australian Government's Discussion Paper titled 'Towards a National Carer Strategy.'

The Parents Forum is hosted by the Julia Farr Association and provides opportunity for parents of school aged children living with disability to share information about how best to ensure that their children get a fair go at high quality inclusive education.

The Forum members work together to identify pathways towards helpful change, not only for their children, but for all children living with disability. For these parents, the Forums are about taking action, social networking and support. It offers opportunity for them to work towards shared vision: for their children to lead valued and inclusive lives with access to the same opportunities as their non-disabled peers and to explore the issues they experience as family members.

The Julia Farr Association's role, within the context of its own value base and knowledge capital, is to help amplify the voice of the Forum about what needs to happen.

Forum members are passionate and highly positive about their role in the lives of their children, and at the same time acknowledge there are challenges. These challenges include system bureaucracy, fragmentation and lack of transparency. They are exacerbated when combined with insufficiencies in funding and other service resources. The result is huge difficulties in accessing appropriate support. This is especially pertinent in terms of limited access to specialists, equipment and family support.

Against this backdrop, the Parents Forum has considered how the Australian Government can support family members in their caring roles now and into the future.

The Parents Forum acknowledges the relevance of the vision, aims and goals in the government's discussion paper on a National Carers Strategy. However, the Parents Forum believes the Strategy blueprint developed so far does not properly address how these objectives will be advanced in real terms; moving from theory to tangible outcomes. Above all, the Parents Forum advocates that any framework or strategy around family members in caring roles must encompass a person-centred, whole family approach.

GOAL ONE: BETTER RECOGNITION FOR CARERS

1. RECOMMENDATION:

Design and Implement a credits system for family carers

The Parents Forum have articulated profound concern for how the system does not reward capacity nor sufficiently plan for future needs. For example, if parents don't use the system when they are managing they risk not being able to access it when they need it the most; at least not without being subjected to intense scrutiny to prove their case of changing circumstances and diminished capacity. The Parents Forum propose an approach that can remove this stress, through the allocation of credits to the family for support hours and services that would otherwise have been provided by a paid support worker. These could then be 'banked' and used at such time when the family or the family member seek additional assistance outside family resources. The easiest type of credit unit is the Australian dollar, in which case this scheme would be a specific type of Individualised (Self-Directed) Funding.

2. RECOMMENDATION:

The introduction of Self-Directed funding for individuals who live with disability and their family Carers

Self-Directed funding is "public funding that is allocated to the individual based on his/her unique strengths and needs and placed under the control of the individual to enable them to live in the community as a full citizen".[1] Implementing self-directed funding for children who live with disability will allow them and their family to identify the nature of support that provides the most beneficial assistance. It would make it possible for those with personal lived expertise, and their family, to plan, arrange and (if they so choose) administer their own support; whether this involves purchasing equipment, support hours, or even shared family time together. The benefit is that such arrangements would be individually tailored to the child's physical, psychological and social health needs and preferences. This arrangement acknowledges that individuals and their family know what is best for their child. It gives them back some control to move forward in life.

3. RECOMMENDATION:

Accountability for waiting lists, limited recognition, limited funding for equipment, services and respite

The parent's forum is requesting improved accountability from the government with respect to how public funds are spent. It is of prime importance to families that they are no longer placed on the bottom of the government's priorities and are instead brought to the forefront for immediate action. Parents are tired of waiting up to three years for equipment and services to assist their caring role. Easy access to independent living equipment like wheelchairs and easy access to specialist therapeutic assistance should be seen as fair and right. People should not have to languish in a long waiting list or made to feel guilty for requesting these needs.

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[1] Dowson and Salisbury, 1999, Individualized Funding: Emerging Policy Issues, viewed 23rd November 2010

GOAL 2. BETTER SUPPORT TO HELP CARERS WORK

4. RECOMMENDATION:

Implementation of thorough screening and matching processes between paid support workers, children living with disability and their family carers

Respite care, perhaps better termed family support, possesses valuable potential to serve an integral function in the lives of those who live with disability and their families. Nonetheless if such services are going to fulfil their objectives effectively by providing supports that match a person's circumstances, there needs to be a thoughtful approach to the matching of agencies and workers with the recipient families. Careful matching would assist in managing delicate issues, and help build trust; rapport and confidence in the working relationship are an essential factor for success. It would also help minimising high staff turnover and be instrumental in the the development of building positive relationships and trust therefore allowing greater opportunity for carers to access work.

The Parents Forum also highlighted concerns around inadequate monitoring and review processes following the establishment of a service contract, ensuring services are meeting needs and remain fit for purpose must occupy as a priority. Parents strongly believe that improved matching, screening and pay for paid support workers would enable family with improved access to paid employment and will alleviate some of the fear parents have around accessing paid support workers.

5. RECOMMENDATION:

The introduction of a Mentorship Program for Carers

The Parents Forum recommends the introduction of a mentorship initiative for family carers to provide mentor support to other family carers seeking to re-enter the workforce. This could involve guidance around balancing their caring responsibilities with their work and personal commitments and to assist carers with improved support and access to relevant resources. Family carers who spend time with another family carer in a mentor role can find this empowering and through a structured relationship can assist with guidance, support and encouragement from a mentor who has first-hand understanding of what the person is experiencing. A similar mentor example is the Julia Farr Youth Mentorship Initiative where young adults living with disability spend time with adolescents also living with disability and assist with capacity building, personal authority and with participative citizenship. Mentors have personal lived experiences of growing up with disability and are a valuable resource to adolescents going through similar circumstances[2].

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[2] For more information please contact Robbi Williams, CEO Julia Farr Association, PO Box 701, Unley Business Centre, 5061, Ph. 83738302, robbiw@juliafarr.org.au

6. RECOMMENDATION:
Education for employers about what is needed to support carers and flexible hours

The Parents Forum recommends that education is provided to employers about the role of a family carer and how an employer can assist employees in their workforce who have family caring responsibilities. Developing a workplace which has an understanding of a person's caring responsibilities and is able to promote a healthy work-life balance is also beneficial to the employer in retaining skilled staff. Flexible work arrangements are important to carers so they are able to successfully combine work and caring duties. A change to work arrangements may occur just once or may be an ongoing change due to a person's changing care responsibilities. The Victorian Equal Opportunity and Human Rights Commission supports this and states that 'evidence shows that flexible work arrangements benefits employers, employees and their families'......with flexible working arrangements including 'hours of work, break times, rosters, overtime, leave arrangements, the scheduling of staff meetings, work travel, location of work and access to other workplace areas'[3].

Employers have a legal responsibility to support parents or carers with requests for flexible working arrangements which is under the National Employment Standards. In addition, the Equal Opportunity Amendment (Family Responsibilities) Act 2008 makes it against the law to discriminate against a person because of their family responsibilities[4].

Further education is required for employers to improve their knowledge on a family carer's rights and how they can manage flexible work arrangements effectively. This could occur through workshops for employers, television and radio commercials and pamphlets.

7. RECOMMENDATION:
Government to be a role model in supporting carers to enter the workforce

The Parents Forum recommend that the government lead the way in supporting carers to enter the workforce and encourage carers to apply for positions within the government and create positions for carers.

8. RECOMMENDATION:
An increase in the number of spaces and facilities for OSHC

The Parents Forum advocates the benefit of increases in the number of spaces available at OSCH (Out of School Care Hours) for children living with disability. Current arrangements are marred by limited spaces and insufficient resource facilities. Broadening the accessibility of

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[3] Victorian Equal Opportunity and Human Rights Commission, 2010 http://www.humanrightscommission.vic.gov.au/index.php?option=com_k2&view=item&layout=item&id=944&Itemid=88&tmpl=component&print=1&page, viewed 25th November 2010

[4] Australian Government Fair Work Ombudsman: What are the 10 NES Entitlements, 2010, http://www.fairwork.gov.au/employment/national-employment-standards/pages/what-are-the-10-nes-entitlements.aspx, viewed 25th November 2010

support services of this nature would allow greater opportunity for family carers to enter, re-enter and/or continue their participation in the paid labour force.

9. RECOMMENDATION:
Introduction of National Superannuation Co-Contribution Scheme for family Carers

The Parents Forum call for the introduction of a National Superannuation Co-contribution Scheme for family carers. They articulate the need for a framework of this nature to acknowledge the value of their unpaid care work and alleviate stresses of poverty in the later decades of life.

10. RECOMMENDATION:
Increasing the Carers Payment and modifying the eligibility Criteria

In alignment with the Working Carers Organization the Parents Forum has articulated the need for the Australian Government to increase all Carer Payments. The time has long since come for these payments to be an accurate reimbursement for the income foregone by the carer because of their family support responsibilities, together with the additional day-to-day expenses associated with their child's disability. A carer's minimum income must be equivalent to the Federal Minimum Wage, and it must be accompanied by an extension of the income test. The Parents Forum has told of experiences whereby their children's less common disability/medical conditions are being under- and/or mis-diagnosed. This creates problems of equity of carer's payments. The Parents Forum urgently campaign that entitlements must place greater emphasis upon the practical impact of their children's disability. In turn this would diminish the risk of misrepresentation from the labels/stereotypes associated with whichever their particular medical condition may be. Once more, the Parents Forum have communicated that the eligibility criteria for their payments need to be extended so that in situations where two primary carers both partake in their child's care and work part-time, they can still be eligible for a single Carer Payment[5]. In effect families would not feel compelled to contend with deductions purely because they are trying to balance their lives. After all, two people sharing the caring tasks are involved with just as much work as a sole person undertaking care all of the time.

11. RECOMMENDATION:
Implementation of a National long term savings Scheme functioning similar to RDSP's

The Parents' Forum is strongly in favour of the design and implementation of a National long-term saving scheme similar to Canada's Registered Disability Savings Plan (RDSP). This scheme provides opportunity for family carers and other members of the community to financially contribute to a fund for the beneficiary's future. Eligibility is conferred on those people who live with prolonged and/or severe physical or intellectual disability. It is true that Australia currently endorses special Trust Funds for a small collection of eligible

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[5] Working Carers Gateway, Carer Payment (Child Review), 2007, http://www.workingcarers.org.au/money/754-carerpayment , viewed 30th November 2010

candidates but the primary distinction between these and Canada's RDSP is that in the Canadian model there is a provision for Government to match the funds. The extent of the matching contributions depends upon the recipient family's income but can equate to anywhere from matching dollar for dollar to as much as three government dollars for every one community dollar.

Whilst there is not a cap on the amount that can be deposited in any given year, the total amount pledged over the duration of the account must not surpass $200,000. An account can be opened until the recipient turns 49 and withdrawals must commence by age 60[6]. Initiatives of this nature are adaptable to changing circumstances, and are not complicated to implement and administer. They provide greater assurance for the future financial stability and security of the recipient; a prospect especially important to the outlook of a person living with disability beyond their unpaid family carer's support. Funds can be used in a variety of ways, including supplementary income, home ownership, and general access to the 'good things' in life. Also, if RSDPs were similarly implemented in Australia, it could serve as a powerful incentive for families who live with disability and the wider community to personally invest in people's lives.

12. RECOMMENDATION:
Implementation of Tax Deductions for family Carers

The Parents Forum advocates that the introduction of Tax Deductions for Parents/family carers will help alleviate financial stress. Family carers have to contend with additional expenses whilst not being able to participate in the paid labour force. This is hugely limiting for other needs and preferences a family might reasonably have. The US Congress Committee on Finance[7] is currently examining the issue of tax deductions for family carers. Called Financial Security Accounts for Individuals with Disabilities, they could be critical in assisting family carers to afford the additional care expenses that correspond with their child's needs. They also have potential as planning tools to increase the future financial security for their children living with disability, a mode of saving where contributions up to $2000 dollars are tax deductable[8].

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[6] Department of Families, Housing, Community Services and Indigenous Affairs; International Review of Future Planning Options, 2009, http://www.fahcsia.gov.au/sa/carers/pubs/Documents/international_review/chap3.htm, viewed 18th November 2010

[7] Department of Families, Housing, Community Services and Indigenous Affairs; International Review of Future Planning Options, 2009, http://www.fahcsia.gov.au/sa/carers/pubs/Documents/international_review/chap3.htm, viewed 18th November 2010

[8] Department of Families, Housing, Community Services and Indigenous Affairs; International Review of Future Planning Options, 2009, http://www.fahcsia.gov.au/sa/carers/pubs/Documents/international_review/chap3.htm, viewed 18th November 2010

GOAL 3. BETTER INFORMATION AND SUPPORT FOR CARERS

13. RECOMMENDATION:

An increased number of support groups for parents

It has been recommended that there is an increase in the number of support groups for parents and other family members who support a child living with disability. Parents feel this is a vital way to access information and find out about services, things that have worked or not worked for other families and to just have a good old chat with someone who understands what they are going through. Currently one parent, who lives at Clearview, travels to Elizabeth (approximately 20 kms) due to not being able to find a closer parent's support group. Parents and family members are a great resource to other parents and have a wealth of knowledge to share. Parents also have the opportunity through support groups to make friendships that can help them in times when they need additional support, affirmation of their progress and achievements, or just a hug.

14. RECOMMENDATION:

Helpful services booklet:

Many parents and families who are supporting a child with disability do not have the time or energy to find out about services that might be helpful. The Parents Forum have expressed the difficulty in accessing information, with varying (and conflicting) content depending on who you speak to. Many parents have also given up trying to access services because of lengthy wait-times. The Parent Forum recommends that each council prepares a booklet of services that are available for family members in caring roles and update this annually.

15. RECOMMENDATION:

Information on accessible retreats

Parents would like more information on accessible accommodation and family support (inc. 'respite'), sensibly compiled and well-promoted for easy access when required.

16. RECOMMENDATION:

Carers are regularly consulted by government and agencies about what is best for them

The Parents forum strongly believes that parents/carers know best about their family member and therefore should be consulted at every available opportunity on relevant issues and ideas. Parents and carers are an invaluable source of information, have deep experience, and often have creative approaches on what works best for them.

17. RECOMMENDATION:
Development of an organisation to trade used equipment

Parents have suggested the development of an organisation which can assist with the trading or buying of used equipment to assist with the long waiting lists. Such an organisation could be governed by people living with disability and family carers themselves, who have good understanding of how important a piece of equipment is.

GOAL 4: BETTER EDUCATION AND TRAINING FOR CARERS

18. RECOMMENDATION:
Improved access to higher education providers

Members of the parent's forum have expressed their need for greater access to university and TAFE options. This could be achieved through increased online options for study, to allow for flexibility. Another way is to provide extra financial assistance to family carers who are studying to assist with the cost of child care or for paid support staff. It is also recommended that the government allocate extra funding for additional family support, enabling carers with greater opportunities to access education and training opportunities to further themselves and their families.

GOAL 5. BETTER HEALTH AND WELLBEING FOR CARERS

19. RECOMMENDATION:
Independent Review into performance of key agencies involved in the distribution of public funding for services to families that have a family member living with disability

Given the limits on public funding for children living with disability, the Parents Forum believes it is vital that funds are spent as efficiently and effectively as possible. This means that those service agencies involved need to strive for good practice in accounting for doing the best possible job with the funds available.

For example the South Australian non-government organisation Novita Childrens Services plays a significant role in providing essential therapy, equipment and family support to children living with disability.[9] However, individual Parent Forum members have expressed

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[9] Novita Children's Services, November 2010, http://www.novita.org.au/Content.aspx?p=28, viewed 1st December 2010

concern that Novita is not adequately meeting the needs of their children. Subsequently, members of the forum recommend that a process of independent reviews be undertaken for organisations involved in the coordination of equipment and services. The review might include aspects such as; equipment waiting list times, efficiency measures and quality of outcomes.

20. RECOMMENDATION:

Access to exercise that assists to strengthen the family carer

Members of the parent's forum recommend access to exercise at discounted cost. Regular access to exercise such as swimming and yoga would strengthen a family carer's core muscles (which are important when lifting). Exercise would also relieve stress, would assist with supporting a family carer's mental wellbeing recognition and provides opportunity for family carers to develop natural friendships outside of their family roles.

IN CONCLUSION

The Julia Farr Association seeks to 'amplify' the stated views of people living with disability and the family members involved in their lives, where such views are consistent with the values of personal authority, active citizenhood and capacity-building.

In keeping with this, the Julia Farr Association is lodging this submission on behalf of the Julia Farr Parents Forum, and trusts that the recommendations will be given due consideration in the development of a National Carer Strategy. The Parent Forum welcomes further discussion and can be contacted via the Julia Farr Association:

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