Submission No. 768
(Inq into better support for carers)

Aoc 15/7/08

family ADVOCACY

Submission by Family Advocacy

Inquiry into Better Support for Carers

Conducted by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

July 2008

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Background to Family Advocacy

Family Advocacy is a community based, state-wide independent advocacy agency which promotes and defends the interests, rights and needs of children and adults who have developmental disability in NSW.

The work Family Advocacy undertakes falls into four main areas, as follows:

- systemic advocacy;
- advocacy and leadership development with families;
- advocacy related advice and support;
- the provision of information which furthers the interests and rights of individuals with disability.

Family Advocacy's staff and committee comprises a majority of people who themselves are family members of people with developmental disability. The issues of support to people with disability are very familiar to Family Advocacy and many of the concerns raised by 'carers' in the lead-up to the recent Federal election are shared ones.

This submission focuses on the role parents or family members of people with disability perform, which in keeping with the language of the Inquiry, will be called 'caring'. It will attempt to argue that many of the issues facing carers today stem from the lack of an adequate disability support system and that if Governments, both Federal and State, got the support system right for people with disability, the flow on effect to carers would be significant and would reduce the need for the current focus on carers.

Family Advocacy is concerned at the amount of funding that is being deflected from the disability service system into programs for carers, as often the benefit is aimed at the carer alone, is short lived and creates a demand for more of the same. This is opposed to providing support which is long term, benefits the person with disability equally, and builds on, rather than replaces, naturally occurring supports. *The Disability Services Act, 1986*, places the needs of the person with disability at the forefront of the disability services system and this pre-eminence is currently in jeopardy.

Family Advocacy also feels great frustration at yet another Inquiry into an area where a significant volume of evidence already exists as to what is needed. Family Advocacy believes the extent of the problem is well known as is what is needed to rectify it. What is missing is the commitment from Government to take the necessary steps needed to implement the many recommendations that have already been made as a result of previous Inquiries, Discussion Papers, and Reports etc.

Overview

Recent times have seen a strengthening of the 'carers' lobby which is long overdue and completely understandable. Families supporting a family member with disability have been neglected by Government of all persuasions over many years. Unpaid family carers are the backbone of the support system for people with disability. Carers love their family member with disability and want what is best for them at all times. Carers also get worn down by the constancy of their caring role and the lack of adequate support for themselves and their sons and daughters. This can lead otherwise caring and loving parents to demand and accept support that is not in the best interest of their family member and that simply provides them, the carers, with a break. This is understandable but not desirable.

Caring impacts on[1]:

- Mental health – higher rates of poor mental health and vitality and higher rates of depression;
- Physical health – poorer physical health;
- Employment – inability to work or reduced capacity to work due to caring responsibilities;
- Finances – greater financial hardship due to reduced employment or the inability to gain employment compounded by the additional costs associated with caring for a person with disability;
- Relationships and support networks – an increased incidence of breakdown in these areas;
- Support services – many carers currently do not access the support system. If they do, respite is the support most commonly accessed.

Two main factors come into play and often compete with each other when dealing with the issue of caring:

1. Carers need support to minimise the impact of the caring role on the areas highlighted above, to enable them to care adequately for themselves as well as for the person in their care.
2. People with disability need adequate support services to assist them function as fully and as independently as possible while with their families and to then enable them to establish their own lives out of the family home when it is normative for them to do so.

Competing interests

Family Advocacy has great concerns that the current focus on the needs of carers undermines what should be a focus on the rights, needs and interests of people with disability.

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[1] Australian Institute of Family Studies, Research Report No. 16, 2008, *The Nature and Impact of Caring for Family Members with a Disability in Australia,* pages xiii - xiv

Carers have a much greater capacity, regardless of their caring responsibilities, to attract attention to their 'plight'. The language of 'burden' feeds into society's unconscious beliefs and assumptions about how difficult it must be to care for a person with disability.

> *"A deeply disturbing issue for people with disability concerns the way in which caring, loving family members will feel that they are forced to characterise a family member with a disability in extremely negative terms by the processes used to make funding applications. I cannot guess at the harm that this does to private family relationships, but I have seen more than enough tears and heartache to know that this is often a source of pain and regret. As traumatic as this process is for those intimately involved, the impact can reach much further. When people with disability are described as burdensome, difficult or even dangerous by those closest to them, these labels are then far more likely to be believed by those who hear about it. Whatever the reason, whatever the benefit to be gained from describing people in this way, there is a terrible price to be paid. A reputation thus constructed will remain with a person with disability forever, and can be used as justification for poor service practice, unnecessary restrictions, neglect, or even abuse.*
>
> *All of us who share a concern about the lives of people with disability need urgently to be aware of the dangers of indulging in 'burden' talk. We need to stop doing it now, and we need to appeal to others to stop. We need to examine critically who benefits from speaking about people with disability in this way. We should have a coherent position to stop the confusion that exists about this in the rest of the community. If we do indeed value people with disability, we need to talk as though we do.*[2]*"*

This situation is derailing the hard won victories of the 1980's, during which time people with disability and their advocates fought for and succeeding in bringing to light the desperate need for recognition of the rights and needs of people with disability. There is now the risk that the voice of carers will drown out and usurp the voice of people with disability in an environment of competing for limited resources.

Recommendation 1
The rights, needs and interests of the person with disability remain the pre-eminent focus of the disability support system within Australia.

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[2] Lee, B. 2007. *The Community: Heroes and Villains.* Paper presented at the Family Advocacy Conference, The Odyssey...a journey of enrichment and possibility.

Unmet need

> *"The disability service system is neither a short term nor crisis care system, yet it operates as if it were. The time for a well planned, appropriately resourced, efficient quality care system with the rights and aspirations of people with disability at its centre is long overdue.[3]"*

Such were the sentiments of the then NSW Community Services Commission in 2000. Eight years on, little has changed.

Unmet need for supported accommodation has come up time and time again, in most States of Australia and is one of the fundamental causes of stress and concern for carers irrespective of their age.

> *"Permanent supported accommodation stands out as the area of greatest need for disability services in NSW. Other areas of unmet need cannot be effectively addressed unless demand for accommodation services is substantially reduced.*
>
> *A relatively small but significant number of people with disability now live in unsustainable care arrangements that place them and their carers at risk. There is currently a substantial under-supply of permanent supported accommodation for these people. This unmet need for accommodation, places extreme pressure on families, service providers and coordinating agencies.[4]"*

Family Advocacy believes that the current NSW Government's response to this unmet need being rolled out under *Stronger Together* will fall short of providing the type of support that will bring about the best outcomes for people with disability. Providing a roof over someone's head is simply not enough. Family Advocacy supports the concept of 'supported living', as it is a much more holistic approach which takes a broader view on what it takes to support someone well.

Supported living can be described as...
"...a person with a disability who requires long-term, publicly funded, organized assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own.[5]"

Recommendation 2

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[3] NSW Community Services Commission 2000 - *Inquiry into Residential and Support Services for People with Disability Part 2 - Unmet need.* Page 36

[4] NSW Standing Committee on Social Issues - *A Matter of Priority, Report on Disability Services, Second Report,* December 2000, Executive Summary. Page xi

[5] John O'Brien, 1993, *Supported Living: What's the difference?* Page 1

Family Advocacy refers the Standing Committee to the Supported Living website – www.supportedliving.org.au

Family-Governed/Self managed responses

People with disability who have lived within the family home for most or all of their life, should be assisted to move into a home of their own, having a choice of living alone or with a person of their own choosing, *before* they have to deal with the loss of a parent and/or primary carer. These two situations happening simultaneously must be avoided at all costs.

Receiving 'something' is not always better than having 'nothing'. Carers also want an assurance of 'quality of care' and 'quality of life' for their son or daughter. This will not come from a service response alone. People who know and care about the person with disability must be enabled to play a significant role in the person's life regardless of what form the support service takes. Formal services must complement and not subsume informal supports. Informal supports must be encouraged, supported and sustained by the service system and not be seen as a threat or a nuisance to be tolerated or ignored.

Recommendation 3

Individual funding packages, family-governed and/or self-managed supported living arrangements become an option within the policy and funding landscape of the disability support system.

Carer Capacity

Within the disability service system, 'carer capacity' has been used as a benchmark for the level of support provided as well as when looking at criteria for who is eligible for Government funded support. Family Advocacy contests that 'carer capacity', should not be seen as the only measure of whether care should continue within the family home. Carers may be able to continue to care, but to expect that they will do so until such time as they become incapacitated or die is completely unacceptable. The individual needs and preferences of the person with disability and their family must take precedence. It should be recognised as reasonable for young adults reaching a certain age to be assisted to leave home and establish lives of their own, with the necessary supports provided.

Recommendation 4

Federal and State Governments move away from using 'carer capacity' as the pre-determining factor in eligibility criteria for support services and move towards eligibility based on preference and social norms.

Expectations

Inquiries of this nature act to raise the expectation that once identified issues of concern for families and carers will be dealt with. Many carers have continued their caring role well beyond a time that should be expected of them simply because they have lived long enough to have seen their needs and the needs of their sons and daughters with disability recognised and ignored, all too often.

This cycle of raised expectation and disappointment and dashed hopes must stop. It could only be increasing the level of depression and poor mental health for carers.

Recommendation 5
Federal and State Governments stop 'inquiring', and take action.

Catherine Hogan
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Family Advocacy