

Submission No. 663
(Inq into better support for carers)
AOC 10/7/08

SUBMISSION

TO: The Secretary, House Standing Committee on Family, Housing, Community and Youth
FROM: Frank Francis, CEO Sunnyfield
SUBJECT: Submission: *Inquiry into better support for carers*
DATE: 4 July 2008

Dear Secretary of the Committee,

On behalf of Sunnyfield, I thank the Minister, The Hon Jenny Macklin MP, for initiating *the 'Inquiry into better support for carers'* and for providing the opportunity for Sunnyfield to contribute.

Sunnyfield was started in October 1951 by six (6) women who met to discuss the possibility of forming an organisation to provide programs for their children, who had an intellectual disability. Now, under the governance of a Board of Directors elected by parents and family members of people with a disability, Sunnyfield provides over 1,400 services each year in a range of locations from Campbelltown to Tamworth NSW. For more information about Sunnyfield please go to our website www.sunnyfield.org.au.

Addressing each of the Committee's terms of reference in turn:

1. The role and contribution of carers in society and how this should be recognised

Sunnyfield endorses recent reports by the Australian Institute of Health and Welfare, the Australian Institute of Family Studies and Carers Australia of findings as consistent with its own experience, that:

- Over 50% of carers of people with a severe/profound disability are volunteers operating in the family home
- By 2010 the number of these carers will diminish
- These carers are subject to an inequitable cost in terms of the impact on their physical, emotional, relational (ie, broken marriages) financial and employment wellbeing.

During its lifetime, Sunnyfield has welcomed the evolution from next to nothing of Government support for people with an intellectual disability in the community. Until more recently, family members and other

carers were excluded from direct support. We submit that the role and contribution of carers in society is best recognised by Government funding and support to ameliorate the costs of that support. As the kind of support recommended below will lead to more effective and better quality support by carers, this will provide a win/win/win solution for people with a disability, carers and the community.

2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and retain employment.

The barriers for parents of children with a developmental disability such as “intellectual disability” begin to be erected at the birth of the child. Usually the parents are without prior experience or practical help, yet they have to learn how to cope with a unique pattern of emerging multiple disabilities and how to progress through successive developmental milestones. This process is typically compounded by situational barriers such as social isolation, breakdown of marriage as they knew it and sheer exhaustion. The capacity to plan for the person’s life care is often an early casualty.

Thus the barriers to economic participation (joining the paid workforce) form early. These are often manifest as:

- Lack of social competencies required for entry level positions
- Difficulty in giving priority to workplace commitments over those to their sons and daughters
- Limited respite provided by many external agencies (bounded by school hours, opening hours for day services, etc), preventing participation for an 8-hour working day.
- Frustration in negotiating the complexities of services by Government departments, across Departmental and Commonwealth/State boundaries.

3. The practical measures required to better support carers, including key priorities for action

The most important measure that can support and empower parents, families, and other volunteer carers to support people with a disability is supported planning through the family and person centred planning approach. The key features would be:

- Competent, accredited facilitators of quality plans
- Third party providers (not government agencies)
- Accredited plan facilitation agency chosen by the carer

- Planning and support available to family from birth of child
- Role to facilitate planning and implementation of plans to address whole of life situations.
- With support of person with a disability and carers, facilitates participation of therapists, teachers, government agencies, NGOs, medical/paramedicals in planning as needed.
- Plan for person with a disability may include referral to agencies, therapists, etc.
- Funding to support the Person/Family Centred Planning approach would be proportional to the level of need of the person with a disability and the assessed level of disadvantage of the family/carers.
- Agreed plan to be actioned (within budget) with timelines, accountability.
- Empowerment of people with a disability and their carers to take charge of their lives.

While early intervention is a key time to institute the planning process, other events where preparatory planning is crucial also involve transitions:

- Transition to pre-school and school
- Transition from school to post school options (including employment)
- Transition of the person with a disability to retirement
- Transition of the primary carers from the caring role

Sunnyfield has observed that the generation of people with an intellectual disability born in the 1950s will be the first in our society to survive to reach an "old age" and outlive their parents in any numbers. This is also a situation for which Government does not have a precedent. In planning for the family;

- Focus on the person will be imperative to improve the quality of support and promote connections to the natural supports in their local community

4. Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future

Sunnyfield recommends that the needs of carers, especially primary carers and their family members, be addressed through the person and family centred planning approach described above. Specifically any plan

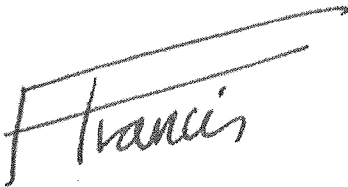
for a person with a disability and their family would be structured to provide for relevant carers and family members and include (according to set criteria being met):

- Provision for respite (time away)
- Wellness programs/check ups
- Counselling/medical reviews as needed
- Opportunities for carer skill development, vocational skill development, work experience and planning skill development.

I thank the Committee for inviting submissions to address this extremely important problem, which has a significant impact on our community.

If Sunnyfield can assist the Committee further, please do not hesitate to contact me via the contact points below.

Yours faithfully

A handwritten signature in black ink that reads "Francis". The signature is written in a cursive style with a long horizontal stroke above the name.

Frank Francis

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