

July 2, 2008

Committee Secretariat
Carer Support Senate Enquiry
House of Representatives
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Sir / Madam

Attached please find AFFORD's submission in relation to better support for Carers.

It is hoped that our comments will assist your enquiry and we wish you every success in providing recommendations for more positive outcomes for Carers.

Yours sincerely

Shirley Crowe

**Executive Manager** Client Services

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Australian Foundation for Disability ABN: 99 000 112 729

Head Office:

12 Marieanne Place Minchinbury 2770

T: 02 8805 3700

F: 02 9677 2499

E: info@afford.com.au W: www.afford.com.au



# SUBMISSION TO PARLIAMENTARY ENQUIRY INTO BETTER SUPPORT FOR CARERS

Organisation:

AFFORD - Australian Foundation for Disability

**Contact Details:** 

Shirley Crowe - Executive Manager Client Services

12 Marianne Place, Minchinbury NSW 2770

Telephone:

(02) 8805 3765

Fax:

(02) 9675 4709

Email:

shirley.crowe@afford.com.au

## Background

AFFORD created a Carer Support Coordinator Position July 2007 in response to the recognised need that AFFORD's families and carers required additional supports.

AFFORD does not receive funding for the Carer Support Program, which is modelled on the Carer Compass, developed by the Kings Fund in the UK, following on a Carer Impact Study carried out in England in 1997. (See the attached brochure, and Reference to a recently published report undertaken in Australia "The nature and impact of caring for family Members with a disability in Australia" (2008) ISBN 978-1-921414-02-2. ISSN 1447-1469(Print) 1477-1477 (Online).

### **Organisational Scope**

The Australian Foundation for Disability, (AFFORD) was originally established in 1951, as The Poliomyelitis and Physically Handicapped Society following a severe outbreak of poliomyelitis. In 1953 the "Cherrywood After Care Hospital" was established at Turramurra as a Rehabilitation Home. By 1967 the Salk vaccine had effectively eliminated the incidence of poliomyelitis in Australia.

In 1968 the organisation moved into offering multi diagnostic services and changed its name to better reflect the services being offered. The Foundation for Disabled was born out of needs presented by the community. It was within this time Cherrywood Village at Llandilo was officially opened by His Excellency the Governor of NSW, Sir Roden Cutler.

As the organisation continued to grow and expand the name has moved along with it, for today (as from July 2001) it is known as Australian Foundation for Disability, operating as AFFORD.

Since 1952, AFFORD has been providing Care and Services for people with disability. Services and individualised programs are designed to teach the skills needed to strengthen Social, Domestic and Vocational abilities.

Currently over 1,000 people with disability are using the Services available through AFFORD at our Accommodation Services – Cherrywood Village and Community Living, Day Programs, Respite, Employment facilities, Open Employment and Training Resource Centre.

## **Role and Contribution**

AFFORD services are aligned with a "Person Centred – Family Focused" approach.

Many families who access AFFORD Services care for people with a dual diagnosis – intellectual disability combined with mental health issues. Many of these clients also develop early dementia. AFFORD has a significant number of families from a CALD background so therefore the added challenge of language and lack knowledge of systems and services.

Within AFFORD's Carer Support Program, a high priority is placed on validating the carer role and providing the training and education to develop the skills of our carers. AFFORD is making this submission to draw the Senate Enquiry to the model of support being provided through partnerships with other organisations as well as highlighting unmet Carer needs.

# Barriers to social and economic participation for carers, with a particular focus on helping carers to find and / or retain employment

Many AFFORD employees are carers themselves, so AFFORD's policies and procedures are being developed to support these staff. AFFORD's Carer Support Coordinator is also able to support employees who self refer using the Carer Referral Forms.

AFFORD has an Employee Assistance Program that also assists in supporting staff who might be challenged in their working role by family / carer responsibilities. AFFORD would like to encourage more employers, especially those that work in Human Service organisations, to look at providing a strategic framework of support for their staff who may be family carers. AFFORD believes that many carers seeking employment, might choose caring organisations in which to work, to utilise their family caring skills.

# Strategy

AFFORD provides Traineeships for people to train on the job in Disability Studies, and this could also include carers wanting to join the workforce. If an incentive was offered, many employers might be encouraged to provide these opportunities to carers.

Through Education and Training of Carers AFFORD offers a "Carer Ladder of Learning". AFFORD would recommend that TAFE or another RTO with ongoing funding might be able to offer a Certificate III or IV in Family Carer Skills to create opportunities for carers to gain knowledge of effective caring. They could then use these skills within their caring role as well as gain qualifications that will create a pathway to employment.

# Strategies to assist carers to access the same range of opportunities and choices as the wider community

Since the inception of the AFFORD Carer Support Program, Carers have provided valuable feedback and suggestions as to how they feel they could be supported.

- 1. Reduced TAFE fees and resource costs for carers, so they can access personal interest courses to revitalise themselves, and assist them to sustain themselves in their caring role or gain qualifications to assist them to volunteer or work.
- 2. Respite and Support to work or study as well as flexible course material coverage (attendance requirements/on line opportunities).
- Increased carer allowance and carer payments to better bridge the costs of caring, including fees for service. Carers often have increased costs as they have to make up shortfalls to assist people on pensions acquire services as well as caring for other family members.
- 4. Ongoing funding to train carers in their caring roles ie manual handling, understanding the person they care for (grief and impact of grief for carer and care recipient) and impact on the whole family.
- 5. Having a strategic framework of support, rather than just doing it haphazardly. Some areas of Sydney are more disadvantaged than others, so carers living in these areas are more disadvantaged.

- 6. Extra challenges for CALD and Aboriginal carers:
  - more education so that they understand they fit the criteria of a carer.
  - Funding to make education & training opportunities available in cultural languages, or are culturally appropriate.
  - More funds available to train and support bilingual workers.
- 7. Recurrent funding for organisations to raise awareness of carers of the need to plan and make arrangements for the future for themselves and the person for whom they care.
- 8. Assistance with legal subsidies as it costs money to set up a disability trust and consult to find out the best ways of doing this planning.
- 9. A superannuation plan for carers.
- 10. A reward system for long time carers, and multiple caring roles a long service plan, like other workers are entitled for 10 years etc. There has been a bonus, but that is being challenged by the current government and this doesn't provide additional assistance for more than one caring role.
- 11. A Holiday fund system for carers very few carers get to have a holiday as there is usually not enough money, and the respite has been used up during the year to survive.
- 12. More promotion in schools about Young Carers and the availability of supports to assist families who have someone with a disability, including mobility allowances.

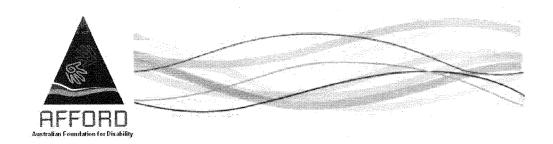
### Summary

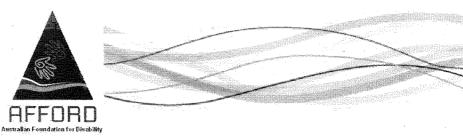
The demand on health, welfare and disability services continues to increase at an alarming rate. Carers provide a huge resource to the community both from a financial and human perspective in alleviating some of this demand. Without the support of Carers the health, welfare and disability system would not survive. It is imperative that the Government finds additional ways to support carers in their caring role.

Shirley Crowe, Manager

Client Services

June 30, 2008





### **Contact Details:**

Patricia Berrutti
Carer Support Coordinator
239 Sackville Street
CANLEY VALE 2166

Tel:

9727 9199 9727 7561

Fax: Mobile:

0437 043 673

Email:

patricia.berrutti@afford .com.au

# Carer Support Program

The AFFORD Carer Support Program provides a strategic framework of support to family carers accessing AFFORD Services

The Carer Support Coordinator works closely with staff to provide a supportive environment for families, whose family member accesses AFFORD Day Programs, Accommodation Services and Business Services.

This strategic framework is based on the Carer Compass, developed in the United Kingdom, after extensive research into carer needs, and the outcome that unless carers are supported in all eight (8) sections of the Compass, they will feel "alone" and unsupported in their caring role.

# CARER COMPASS AND CARER SUPPORT

Carer Compass	What will be Provided	How this will be Provided
Full Information	Resource Department  AFFORD Basic Information Packs  Carer Package Forums - four (4) per year on requested topics  Navigating the Systems  accessing services  meeting your needs	Carer Orientation for families accessing AFFORD Services Workshops to show Carers how to maximise benefits from using resources February 2008 - Planning for the Future Workshops - June / September / November 2008
Recognition and your own health and wellbeing taken into account  being valued and respected	Principles of Coping and Self Care Workshops three (3) times per year Carer Pathway (Carer Needs)	April / August / November 2008 Being developed and trialled in 2008
A Life of their Own Quality services for Carer and the person cared for	Well coordinated services for the person cared for Quality Service for Carer	Ongoing  An organisational focus on the family / carer
Time Off	<ul> <li>Developing an Emergency Care Plan</li> <li>Revitalisation</li> <li>Creating time for the Carer's own life needs</li> <li>Flexible and Emergency Respite</li> </ul>	Ongoing Forums; Social Events; Linking to other carer social opportunities through partnerships Knowledge of Respite opportunities
Emotional Support	Services focussed on Carer     Carer Networks     Counselling     Carer Outreach	Ongoing Information Forums Developing Carer Networks

# CARER **OMPASS**

Carer Compass	What will be Provided	How this will be Provided
Training and Education	Seasons for Growth (Change/Loss and Grief)	Ongoing Practical skills to manage change and associated Loss / Grief
	Eight (8) Stages of Healing	Practical skills to heal impact on family and relationships
	Principles of Coping and Self Care	Effective Coping and Caring
	Workshops to meet Carer needs	
Financial Security	Benefits information	Ongoing
	Clear understanding of costs of services	Workshops
	Support for Carers to access employment or volunteering opportunities	Forums on requested Topics
Having a Voice - being heard and recognised as a valuable member of the team	Advocacy skills to effectively advocate for self and the person cared for	Ongoing Workshops Training

Welcome to AFFORD a commitment to supporting YOU in your caring role