

John

ADG 28/7/08

1 July 2008

The Secretary
H of R Standing Committee on Family, Community, Housing and Youth
Parliament House,
CANBERRA ACT 2600

Dear Secretary,

Inquiry into Better Support for Carers

Attached is my submission to the above Standing Committee inquiry. I believe my background qualifies me to submit some unique solutions to a pressing problem:

- 10 years experience as a Carer;
- I have worked as long term volunteer Welfare Counsellor with the Salvation Army Community Service (and continue to be active in this role);
- Board Member of the Mental Health Community Coalition ACT;
- am active in the Carers' Alliance ACT, the Mental Health Caucus, the Mental Health Foundation and Carers ACT Inc, for who I have also done unpaid consultancy work; and.
- member of the Koolamon Fellowship that accommodates homeless men.

I have also undertaken work in a professional capacity in this area. Disability ACT (an ACT Govt Authority) several years ago appointed me to a Panel to evaluate applications for grants for Innovative Projects to improve quality of life for Carers and people with disabilities.

In the 1970s I oversaw the introduction of, and administered for many years, the States Grants (Home Care) Act, States Grants (Homeless Persons Assistance) Act and the Delivered Meals Subsidy Act. This legislation gave rise to today's HACC program. The question of support for the needy, aged, homeless and their Carers has always been close to my heart.

While drawing on this experience and my work as a Carer and Volunteer with these organisations, I make this submission in a private capacity only, as a caring Carer.

Although addressing predominantly the problems of Mental Health Carers, we share many of the same problems and issues of those caring for people with physical disabilities, and the solutions and principles promoted in this paper apply equally. My paper addresses many of the problems of Carers, poses unique solutions and also deals with the transition back to work when the Carer's role is finished.

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The House of Representatives Standing Committee Family, Community, Housing and Youth

Inquiry into Better Support for Carers

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A More Flexible Support Service for Mental Health Carers – A Decentralised Model

Taking Respite and Support to the Carers

Current Arrangements for support of Mental Health Carers do not fully meet the needs of many of those Carers. The model in use today is large, fairly centralised, moderately bureaucratic and insufficiently flexible to meet many of the day to day needs of Carers.

MH Carers have all the needs of those carers looking after people with physical incapacities plus a whole range of extra requirements. Generally, MH Carers are seen as a Subset of mainstream Carers and seem to inherit the “left overs” of resources. This applies to funding, staffing, support, training and general community acceptance. Some Consumers (Mental Health Sufferers) with physical disabilities pose further problems.

Lack of support is even more apparent for a Sub-subset, Carers for people with Dual Diagnosis (mental health problems and illicit drug use). The principles outlined in this options paper apply equally to Dual Diagnosis Carers who need a whole range of other support which is not canvassed in this paper but needs separate follow up.

Who speaks for the Carers?

MH Carers attending meetings are usually vocal middle-class people well able to deal with meeting protocol. They can make their views known. Seldom are Young Carers, represented at these meetings. Even less often do we encounter any Dual Diagnosis Carers or people from lower social economic groupings who seem to be unaware of the meetings or are overwhelmed by the thought of attending. Often their needs are even more pressing.

Evidence Based Un-met Need

A greater worry is the large number of unidentified Carers, people providing care neither identifying as Carers, nor receiving any help at all. These people view their caring as a normal part of life, of being a wife, husband, sibling or even a friend, and never think of themselves as Carers and are thus isolated without support. I have interviewed many such people in my voluntary and professional work.

Identification and quantification of this substantial group needs to be undertaken so that their needs can be determined. This will need a focussed and funded survey perhaps using General Practitioners and Mental Health workers in a study.

Perception

Mental Health Carers feel that they do not receive the same recognition or support resources as people caring for those with disabilities with more public or emotional appeal eg, Parkinson's Disease, MS, Breast Cancer etc. Similarly, Carers of persons with bowel diseases like Crohns and Ulcerative Colitis agree that Governments and the general public find these subjects to be less than dinner table topics. As a result access to funding to support services for such Carers is patently less available.

Prognosis/Duration

MH Carers can see no end to their caring role, unlike many Carers of people with temporary or life threatening or progressive illnesses that have a tangible sunset in view. The MH Carer sees an endless vista that can often hold more abuse, threat of violence, suicide and the squandering of income by the Consumer. Potential legal morasses, property damage and other uncertainties that living in this environment can generate place more stress on the MH Carer.

Impact on Mental Health Carer

Ask a Mental Health Carer if mental health disorders are "infectious" and you will inevitably receive a resounding "yes". Depression, lethargy and anxiety are common amongst MH Carers and become ingrained with the passage of time. Physical illness disease follows together with an inability to deal with the processes of life due to loss of confidence and drive. In addition, lack of respite services or funds (personal and/or Government) are strictly limiting factors in MH Carers accessing health care, recreation, exercise, even economic and nutritional shopping.

However, these services, including exercise and hobby classes, are usually available to Consumers but not MH Carers. This can cause resentment and emphasises the need for equal support for both Carers and Consumers.

Solutions - Decentralisation

A decentralised support service similar in standard, to the level of services available to Consumers is indicated. MH Carers need visiting case managers/workers, staffed shopfront drop-in centres, accessible training, on call transport and/or Cabcharge facilities and access to medical services, counselling, fitness, nutrition and recreation. Sadly due to absence of these services, many of our MH Carers live in isolation, almost as outcasts, and go on to develop physical and mental illnesses.

Many services are provided by large institutionalised organisations such as Carers ACT, Centrecare, Uniting Care etc. These are very good organisations staffed by good people, but like any large model, they present a degree of bureaucracy and, frequently, are not sufficiently flexible to meet the needs (often in narrow

unpredictable “time windows”) of MH Carers. These providential “time windows” may be created by the arrival of a Consumer’s Case Manager, Peer Support Worker, or hospitalisation etc.

In this day of electronic communications the early prediction of some of these “time windows” and a flexible support service for MH Carers would be invaluable. Co-ordination of support services between Carers and MH Workers remains a pipe dream at present but could be achieved with adequate resolve, resources and application.

Decentralised Drop-in Centres for MH Carers

Many shortcomings in services for MH Carers could be overcome by the provision of staffed suburban drop-in centres.

A Drop-in Centre could include:

- Easily accessible suburban shopfront with ease of parking
- Staffed with Welfare Officer/Counsellor
- Amenities – tea making, TV, private room, seating for small support group/training meetings
- Serving as an informal meeting spot for “off duty” Carers
- Self governing with a Committee of Carers
- Actively promoted support group meetings
- Short course training eg 1 or 2 hours on assertiveness, dealing with depression, medications, self care, advocacy, legal rights, meditation, relaxation etc to be run at frequent intervals with refresher courses to follow
- Contact point for other services
- Information service, brochures etc
- Form filling or completion
- Benefit eligibility interviews

Localised availability of services generates its own demand. Experience of the Dept of Social Security opening over 200 new regional offices saw a massive growth in the client base and people accessing services/benefits. It is believed decentralised Carer Drop-in centres could increase demand and help in identification of the “missing Carers”.

Training

The training courses are important but need to be short, sharp and accessible. Long formal courses such as those run at CIT or other centralised locations over several weeks are often too difficult to attend without respite and transport and are daunting for many MH Carers.

The Decentralised Drop-in Centre is ideal for delivery of such short courses.

Centrelink often penalises people for non-attendance at courses deemed necessary for employment purposes. The opposite approach for Carers could be adopted with an incentive scheme, could encourage them to attend training. Incentives such as a small cash bonus or reward, a couple of theatre tickets, a meal etc would encourage isolated

MH Carers to attend, especially if some respite can be provided. Of course this model also allows quick uptake of services in those providential “time windows”.

Similar courses run separately for young Carers are felt to be of equal importance.

Service Access/Form Filling/ Help/Advocacy for Carers

The biggest hurdle for many MH Carers is lethargy induced by depression and the seemingly endless grind of their role. Dealing with bureaucracy, forms and large Carers’ organisations on the other side of the city is like travelling to Mars or appearing before the High Court. Many MH Carers do without rather than deal with these Mt Everest size obstacles. Decentralised Drop-in Centres could remove these psychological barriers.

Transport

Getting anywhere in a fragile condition and/or time limited period is another large hurdle for MH Carers. “On call” transport or buses or Cabcharge vouchers would be of invaluable assistance in breaking down this service access barrier. Training course attendance would be more appealing too. Carers might be encouraged to take more care of their own health by going to medical appointments with provision of adequate transport. A big saving to government on health costs would result in the long term.

Medical Services

Research shows a substantial number of MH Carers suffer major health (physical and mental) problems. We stress that MH Carers should have equal if not superior access to subsidised, public or bulk billed services similar to those available to Consumers:

- Doctors
- Counsellors, Psychologists and psychiatrists based on the hypothesis that mental illness is “infectious”
- Dietitians
- Physiotherapy
- Dentists
- Fitness trainers etc (this list is not exhaustive)

Respite Care

MH Carers (including young Carers) have identified 3 levels of Respite Care for MH Carers and Consumers. It is important that respite timing coincides for both Consumer and Carer.

- Short term for Young Carers – one night a week, preferably Friday or Saturday to go out with friends, peers, to remain in contact with social groups. Lack of such contact can destroy friendships with people who may be afraid or embarrassed to visit the Young Carer’s home. It also gives the young carer a “life”.
- Holiday Respite – a chance for a weekend or week away at least twice a year with assistance with travel and transport costs – Respite Care for the Consumer must coincide in these cases.

- Local Residential Respite – a chance for the Carer to stay at home while the Consumer has a break in residential accommodation locally or in a holiday setting.

In Canberra there are virtually no beds for male respite apart from three at I'anson House which sometimes are lost to men if a female is admitted.

Male Consumers have been housed at Samaritan House to provide Carer relief. This is a crisis Hostel for Itinerants, many of whom suffer drug, mental health or anti social behaviour. They must vacate the hostel during the day. This venue is totally unsuitable for respite relief but is sometimes a "desperate choice" in absence of any suitable alternative.

The urgent provision of extra respite care beds for Male Consumers is desperately needed. Existing beds for women may be adequate at present.

Respite from Duress

Consumer/Carer relationships may degenerate in periods of illness. Carers can suffer considerable emotional and/or physical abuse. At times rapid relief from these situations is essential. Mental Health Crisis Teams cannot respond for hours if involved in another incident, with only two teams by day and one by night. Carers, Consumers and the Public are at risk. Police response, although compassionate, is sometimes resented by all and can be degrading for the Consumer taken away in a Paddy Wagon when ill. Ambulances would be more appropriate.

More response staff are needed and even better training of police on the lines of the Memphis, Tennessee (USA) model is desirable. A Carer would be more at ease knowing early respite from duress was available.

Legal Aid

Often MH Carers are faced with legal problems sometimes generated by the Consumer or their own inability to deal with things. Easy access to Legal Assistance/Advocacy is important even for minor matters or more substantial things like violence, property damage, wills, Tribunal hearings etc. This is essential as Carers often lack the energy, resources or capacity to initiate action, and will let matters compound through inaction.

Carer's Allowance

The non-means tested Carer's Allowance stands at about \$100 per fortnight. This is totally disproportionate to the work and responsibility involved and the savings to all levels of government: Federal, State and Local. This allowance should be increased to a meaningful amount to offset the work, cost and loss of opportunity that usually faces a Mental Health Carer.

Ease of Application

The Centrelink model for claiming Carer's Allowance or Pension are felt by many to be confronting, with too many forms, interviews and medical appointments etc. Interviews are usually held in open plan offices with applicants being asked extremely personal questions while in an extremely fragile and emotional state. One applicant was recently asked to reveal her father's medical condition, life expectancy and many other delicate matters in respect of her father who died painfully a few weeks later. Support after his death was prompt and sensitive. She felt everyone was listening in.

Eligibility

Eligibility conditions for many of these support services, allowances and respite should be eased and co-payments eliminated where charged. Eligibility should not be predicated on qualifying for a Health Care Card. Importantly, all these services should be accessible through the Decentralised Drop-In Centre. Where these services cannot be provided permanently, they should be offered on a "sessional or visiting" basis. Alternatively, field workers/case managers could take these services to the Mental Health Carer's home.

Centrelink Breaches Burden Carers and Hamper Return to Work

Consumers transferred from Disability Pension to New Start Benefit have trouble coping with the transition. They often fall victim to the Centrelink Breaching regime as they cannot comprehend the rules or have temporary health relapses that make them vulnerable to breaching. According to representatives of several relief agencies providing emergency food services, this breaching system is administered in a harsh manner and falls most harshly on those least able to defend themselves.

Breaching also imposes terrible imposts on agencies, Carers, family and friends of the breached person called on to support the Consumer for at least 10 weeks (8 weeks breach and 2 weeks restoration period).

This stress can lead to a break down of the Consumer's health and can end, sadly, in a resumption of the Carer/Consumer role with all the old economic, emotional and health issues re-established at great expense to governments and the people involved. As a result a proposed return to work is foiled.

The breaching rules need review and a substantial softening of their imposition. More help by way of case management is needed for breached beneficiaries. The current level of case management is totally unrealistic and punitive. Centrelink needs to ensure Consumers do not lose housing, can maintain medications and nutrition etc during penalty periods. The current policies of case management for breached beneficiaries virtually deny a single person any support and this is often the case for families too. Again Carers often have to pick up the pieces again.

Getting Ready to Return to Work

Loss of Carer's allowance

Often due to care, love and support at home the Consumer may reach the stage of being able to live independently. As a result the Carer loses his/her allowance but it does not reduce the cost and time of providing ongoing care and support for the loved one now living in a separate residence.

Carer's support from Centrelink at a gradually reducing level should be ongoing for at least 12 months to ensure the transition to independent living is successful and not a drain on the Carer. This transition would enable the Carer to retrain and prepare to re-enter the workforce.

Some breathing space is required by the Carer to start a rehabilitation process for employment. Respite is needed from the Carer's daily grind of supervising the Consumer's medication, diet, hygiene etc when the Consumer, is allegedly living independently. This could be best achieved by daily case manager visits to the Consumer. This may be a long-term commitment to ensure the success of the "severance." Adequate Consumer support at this point is a form of respite for the Carer whether or not the Carer has received Carer's Allowance. More help in this example for the Consumer improves the chances of a Carer taking up paid work.

Co-Dependency and Rehabilitation of Carer

Undoubtedly a co-dependent relationship develops frequently between Consumer and Carer in long term situations. The Carer can be faced with enormous readjustment problems: emotional, financial, social status, health etc, if no longer needed to provide full time care. At this point a program of support and rehabilitation would greatly benefit Carers enabling them to take their deserved place back in work and society. Carers facing re-entry to the workforce should be placed in the Personal Support Program and be quarantined from the usual reporting and breaching rules of Centrelink.

Other Support for Carers - Brokerage Models

Some emerging Brokerage models for Family, Consumer and Carer support are promising. Funding increases appear to be justified.

Training Support Staff for Carers

A major limiting factor on expansion of support services is the lack of suitable staff. This model really creates an ideal environment for part time work. People may be deterred from applying for work due to lack of qualifications when the only qualifications needed may be communication skills and/or a sense of vocation or caring – abilities found in a majority of the public. Carers and Consumers alike often only need a "friend" to talk to without any socio/psycho babble.

NGOs and Brokerage agencies could be funded to provide short and sharp awareness courses coupled with some "on-the-job training" to prepare applicants for work in this important support field. Again the decentralised Carer Shopfronts would facilitate this training.

General

I have shown this draft and discussed it with a number of Mental Health Carers who strongly support the views and ideas contained in my submission that I hope will be of value to your Committee in its deliberations. It was agreed that the principles in this model would generally apply to Carers of disabled people.

John

1 July 2008