Legislative Assembly Inquiry into Respite Care April 2010

Current Arrangements for respite support of Mental Health Carers and Consumers do not fully meet the needs of many of those people. 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 and consumers. MH Carers have all the needs of those carers looking after people with physical incapacities plus a whole range of extra requirements.

Respite in my mind does not simply mean alternative housing for a short time! (See "**Other Respite Services**")

Carers of Consumers with Dual Diagnosis

Lack of respite support is even more apparent for 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.

The Carers of this group are no lesser people than the general range of carers but do not get support because of the "difficulties" posed by their consumers. These carers need support, not punishment because they are "too hard".

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, amputation etc. Carers of persons with bowel diseases like Crohn's and Ulcerative Colitis agree that Governments and the general public find these subjects to be less than dinner table topics and like MH Carers believe access to respite support services 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.

This emphasizes the need for adequate respite care/support for carers and which in turn means better respite support for consumers.

Timing

To be effective, respite for consumers and carers must occur simultaneously and not in different time slots. Co-ordination of timing is essential across service providers if more than one is involved

Other Respite Services

Respite does not just mean residential "time apart." It can mean short day or evening periods where Care and Consumer can undertake recreational, cultural, educational, or sporting time apart (or

occasionally together). Often such services are available to consumers but seldom to carers. This can cause resentment in carers and add to a festering degeneration in their health and well being.

This list is only suggestive and could embrace many other components.

Some service NGOs such as Carers ACT Inc will offer recreational type (group) activities for carers but due to lack of timely respite care for the consumer it is not possible for the carer to take up the offer. This highlights the need for adequate resources and perhaps some centralised "bank of services". This in no way is intended as a criticism of Carers Act or other NGOs

Decentralised Drop-in Centres

At present there is an Activity Centre for Consumers (the Rainbow at Watson). It is not well attended, we believe due to its remoteness (serviced by only one bus), poor management and the dominance by some assertive consumers. Perhaps consideration could be given to relocating this centre and reviewing its operations, management and activities. There is no equivalent centre for carers.

Centre for Carers

A decentralised respite and for carers is indicated. MH Carers need visiting case managers/workers, staffed "shop" front 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 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 shop front with ease of parking
Staffed with Welfare Officer/Counsellor
Amenities – tea making, TV, private room, seating for small support group/training meetings
As a base for a Peer Support Service
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 or unidentified Carers".

Respite Care – Accommodation Based

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 these Respite Houses supervision must be on a 24 hour basis.

Summary

In looking at respite it is important that we use a wide ranging definition and not simply restrict ourselves to "Residential Care".

General

I present the following submission in my private capacity as a carer and not in any way representing organizations I am involved with but obviously my long exposure through work with Salvation Army as a volunteer counsellor, Vice President of the Mental Health Consumer and Carer Community Coalition and the Koolamon Fellowship for Homeless Men have helped me develop my views.

John Wilkinson
27 April 2010