A·O·C· 10/7/08

Submission No. 678
(Inq into better support for carers)

STANDING COMMITTEE
ON
4 JUL 2008
FAMILY, COMMUNITY,
HOUSING & YOUTH

YNH
SERVICES INC.
Linking Our Community

Neighbourhood House
Adult Education & Training
Centrelink Agency
Tax Help Centre
Community Development

YNH SERVICES INC.
RTO No. 21765
1 HARGRAVE CRT
PO BOX 308
YARRAWONGA VIC 3730

PH **03 5744 3911**
FAX **03 5744 2700**
EMAIL manager@ynhservices.org.au

2nd July 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community Housing and Youth
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Secretary

Attached please find a joint submission from YNH Services Inc and Yarrawonga Mulwala Carers Support group, along with a number of individual submissions from carers.

Yarrawonga Mulwala Carers Support Group was formed in 1998. Members have a wide range of care situations, including frail aged, people with Parkinson's Disease, Alzheimers Disease or diabetes, heart attack and stroke victims, those with acquired brain injury, and those with disabilities. The Group meets regularly, has workshops, information sessions and social activities. Members are linked into services provided locally and regionally. The Group also conducts regular self care sessions where members are introduced to a range of self care activities such as relaxation and massage.

Members of the group met recently to discuss issues surrounding their care situation and how they could be better supported. The attached submission reflects the concerns they raised and discusses possible solutions and has been endorsed by members of the Carers Group (see over).

Yours sincerely

Heather Kelly

Heather Kelly
Coordinator
YNH Services

The attached submission is endorsed by:

Maureen Edwards
2/15 Duffield Street
Yarrawonga
VIC 3730
Ph 03 5743 1597

M. Edwards

Past carer of husband with cancer and adult sibling with Downs Syndrome and Alzheimers disease

Margaret Chandler
19 Orr Street
Yarrawonga
VIC 3730
Ph 03 5743 2830

M Chandler.

Marg is a current carer of her husband who has Parkinson's Disease

Ron Foley
3/33 Coghill Street
Yarrawonga
VIC 3730
Ph 03 5743 2055

R. C. Foley

Ron is a current carer of his wife who has an Acquired Brain Injury

Sylvia Burley
Jackson Street
Yarrawonga
VIC 3730

Sylvia. Burley.
ph. 035744 3061

Sylvia is a past carer of her husband who suffered a stroke

Anne Pearce
33 Gilmore Street
Yarrawonga
VIC 3730
Ph 03 5743 1261

A Pearce.

Anne is a current carer of her adult son who has an Acquired Brain Injury.

SUBMISSION TO THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH'S INQUIRY INTO BETTER SUPPORT FOR CARERS

FROM: YNH SERVICES INC (incorporating Neighbourhood House, Registered Training Organisation and a Centrelink Agency)
&
YARRAWONGA MULWALA CARER SUPPORT GROUP

2ND July 2008

We believe that carers are not adequately supported in the extremely important role that they play across our nation.

According to Carers Victoria, conservative estimates show that carers save our economy $19.3 billion annually. Carers are the major providers of community care services, delivering 74% of all services to people needing care and support. The Home and Community Care (HACC) Program, worth over $1,301 million nationally in 2004-5, meets only a small proportion of this need.

We live in one of the fastest growing rural communities of equivalent size in Australia, with current population of over 6,000 people. During the period 2001 to 2005, population increased by 16.3%. A recent study commissioned by Moira Shire[1] projects future growth to be an average of 3.5% pa. Significantly the predicted growth rate of people over 55years and over 70 years is predicted to be 4.4% and 4.8% pa respectively during the next 25 years. This growth will have significant impact on delivery of services to carers. The services audit undertaken shows that a range of services are currently experiencing demands that exceed their service capacity and anticipate severe gaps in their capacity to respond to local population needs.

Key services experiencing these challenges include residential and aged care facilities, disabled respite care, Home and Community care programs and packages and community transport.

Local services are further challenged by the fact that Yarrawonga (Victoria) is a border town and its close proximity to Mulwala (New South Wales) with a population of just under 2,000 means that many people from Mulwala use services at Yarrawonga.

---

[1] Yarrawonga Growth Management Strategy Stages 2 & 3 Report April 2008. prepared by Coomes Consulting Group for Moira Shire Council

Our carers face many barriers to social and economic participation and have raised the following issues of concern:

Financial hardship

Many of the carers in our group are on low incomes and have no opportunity to accumulate or preserve superannuation or any other savings. They feel extremely financially vulnerable, and see no rosy future. Many of them are ageing carers and are concerned about their own future care.

Carers and those they support often have higher living expenses, such as extra heating and laundry costs, special dietary costs, and other costs relating to disability aids, health care and transport. As one carer said "I am doing a job 24/7, it costs me money, and the government insults me by paying me a mere $100 per fortnight". Another carer said "What about holiday pay – I've earned it?"

Many are extremely concerned about rising prices of food and fuel. Fuel costs are a particular concern for rural carers as they often have to travel hundreds of kilometres to access services.

Carers also expressed concern regarding the costs incurred when the person they have been caring for needs to go into permanent care. The issue of having to pay interest whilst raising money for the bond has caused financial stress and hardship.

Financial stress often affects the health and well being of carers. Many report experiencing anxiety and depression as they are worried about how they can keep coping on a day to day basis, let alone planning for a future.

Carers often sacrifice important life opportunities, particularly for paid work, a career and education. Some carers would like the opportunity to participate in the work place but are denied the opportunity due to inflexible work place practices. Consequently carers often also miss out on important social relationships associated with work, recreation and leisure pursuits, which leaves them feeling very isolated. Paid work not only alleviates their poverty, but provides opportunities for new friendships and a sense of identity outside the care situation. After an extended period of caring, support and retraining is often needed to assist carers to re-enter the work force

Recommendations:

(a) that payments to carers be increased to a level that allows them to have financial security

(b) that a travel allowance be instituted to cover costs of transporting loved ones to regional services

(c) that employers be encouraged to adopt practices that support carers to work if they so choose (eg flexible working hours, carers leave, reduced pay in return for extra paid leave)

This will enable carers to keep up their caring responsibilities, maintain their health and well being and participate in life's activities in a manner that we who are carefree take for granted.

Respite

Many carers are chronically tired and desperately need a break. Even one night of unbroken sleep or a day off can give them renewed energy to just keep going. Carers need extended periods with no caring responsibilities so they can "recharge their batteries", and gain a sense of wellbeing.

Lack of suitable respite facilities is a critical issue in our community. Aged care facilities in Yarrawonga have a small number of beds allocated for respite. Most carers access respite from a range of facilities out of town. This limits their ability to visit their loved one, and has the added burden of transport costs

Failure to obtain government support and funding has resulted in our community currently fundraising to build a respite facility in Yarrawonga. Carers feel angry and let down that they have to " go it alone" and devote precious time and energy to planning for the development of a facility and raising funds – many are already over committed as a result of their caring role.

Carers also express concern regarding the level of funding for respite care. There have been times when agencies indicate that they have used all available funding before the end of the funding period and carers have had to wait till the start of the next funding period to access much needed respite.

Recommendations:

(d) That there be a significant injection of funding to build appropriate respite facilities in rural communities

(e) That consideration be given to developing "multi function' respite facilities in rural communities with small population catchments catering for a range of clients rather than designating facilities to specific target groups

(f) that extra funding be allocated to increase access to respite care

This will enable carers to have regular breaks from caring and assist them to continue in their caring role. It also has the potential to enable smaller communities to have a local respite facility.

Access to Information

Many carers report difficulty accessing appropriate information throughout their caring life. There is a broad range of information available for carers however dissemination of this information is very fragmented – often what carers find out depends on which agency they have been referred to. Many carers report "stumbling on information" which would have been useful to them much earlier on.

Carers often find it difficult to source appropriate funding packages to provide extra support needed. There have been many instances when carers in our support group have provided information to each other on services and resources that are available. Whilst that is a useful outcome of the support group it highlights the need to develop a better system of getting valuable information out to carers, particularly in the early stages. What happens to those carers that are housebound and not linked into many services?

Carers often have difficulty understanding or interpreting information that is available. They may not access a service because they think that they will not be eligible.

Carers expressed a desire for a "one stop shop" which has information about all types of services and resources available and how to find out what may be available in their community. They suggested that it would be useful if an information kit was sent out to all people who apply for a caring payment, with the offer of a follow up visit by a social worker or financial services officer. This would then equip carers to better navigate the maze of information. If carers don't know a service exists how can they ask for information about it?

Recommendations:

(g) that Centrelink adopt an add on function and become a national "One Stop Shop" for information for carers.

(e) that Centrelink develop and send out an information kit to all people who apply for any carer payment or allowance.

This will enable carers to better source services and resources that will support them in their caring role.

Service delivery

Carers are often faced with a range of problems in obtaining the services they require. Often they are not accorded the respect and dignity that they deserve when seeking help and support. After caring for a loved one day in and day out, carers are a valuable source of health information, yet they are often ignored and in some instances belittled when they want to become involved in developing a care plan. Carers often want to be involved and also say that they need to be so that they can provide better care. One carer told me "that the OT insisted on putting a rail at the standard height even though I knew, and told her vigorously, that my wife needed it to be lower – she simply refused to listen to me". The information carers have needs to be listened to and taken into account.

Carers report that lack of coordination between medical staff, allied health and other carer services often results in stress and confusion –having to tell your story over and over again, conflicting information being given, treatments applied that are counter productive, referrals made that are never activated or followed up.

Limited access to rehabilitation services is another source of frustration to carers. There are many carers in Yarrawonga & Mulwala who have to travel out of town so that the person being cared for can have rehabilitation treatment. In some cases the journey home undoes the therapeutic benefit of the treatment.

Access to services in our community is further complicated due to cross border issues. As some services are state funded the Murray River becomes a significant boundary. There are many instances of people living in Mulwala and travelling 100kms to use a service when a comparable service is provided just 3 kms away. How ridiculous, and what an unnecessary burden!

Recommendations

(f) that a review of federal and state funding arrangements for allied health and support services be undertaken to remove border anomalies, to ensure equal access, and to increase the level of services available

(g) that medical and allied health professionals be encouraged to develop a holistic approach to care and take family needs into account.

This will enable carers to gain better access to information and services needed for the care of their loved one, and to feel a valued part of the care team.

Carer Support and Advocacy

Carer Support Groups play an important role in providing support and advocacy for carers. They provide an opportunity for carers to come together to discuss their needs, and to share experiences and information. Workshops and structured information sessions are also offered to assist carers in their caring role. Carer Support Groups also offer a bit of space - time out from the caring role, and recognition of the role of carers and their contribution to the community.

These groups provide important social and emotional support and can help reduce the feelings of isolation often experienced by carers. These groups are extremely under resourced.

Funding needs to be increased for Carer Support Groups such as ours. In fact, this year our group has been unable to obtain funding as it is run under the umbrella of a neighbourhood house and is reliant on volunteers to provide critical support, referral to services and to organise activities. Support group funding is only available to groups that are independent and have their own bank account.

Current members do not have the capacity to take on the role of managing the group – they come for support, not to add to their workload.

There also needs to be recognition of the role of past carers – they have an enormous capacity to give support, to share wisdom and knowledge gained through their own caring experiences. Funding for group respite activities does not allow for past carers.

Recommendation:

That federal funding be allocated to coordinate, resource and support Carer Support Groups, and that this funding include past carers as members.

This will enable carers to receive the support and advocacy that they deserve.

Heather Kelly
Coordinator
YNH Services