

26th June 2008

M/s Annette Ellis,
Committee Chairman,
Inquiry into the Needs of Carers,
Parliament House,
CANBERRA

Dear M/s Ellis,

As the President of Real Living Options Association Inc (a community based lifestyle support service for adults with a disability), a carer myself, I submit these comments for consideration by the Inquiry into the Needs of Carers.

The needs of carers are many and varied however the area of knowledge which our Service is most familiar with is in the area of carers of adult people with a disability who have been carers since the birth of their son/daughter. Most of these carers have been caring for family members for up to 50 years, many for 30 – 40 years. Most carers are women. The impact for many of these individuals is that they have given their whole life to the care of their son/daughter. Some have had to give up employment when their son/daughter left school simply because of the inadequacy of support services for their family member.

In addressing the needs of carers, our Service believes that the needs of carers should not be seen in isolation but consideration should be given to the support required by both the person being cared for and the carer in most cases as separate forms of funding, advice services and funding for support arrangements.

Give the person being cared for a life and many of the needs of the carer are resolved.

The reality is that if the person with a disability is the focus of the support requirements, (e.g. personal care services, community access, accommodation support, recreation and leisure) many of the issues for carer's are resolved. This cannot be overstated as the person who is cared for is entitled to have a life which allows the person with a disability to have their own interests, recreation and leisure and work. As a flow on from the person getting a life, the carer's situation and ability to develop his/her own life improves.

Our Service has seen demonstrated when an individual with a disability enters our Service and is supported to have a life of his/her own, the carer is then able to have time to themselves and begin to pursue a life of their own.

This demonstrates the point I am making about giving the person with a disability a life and the carer also is a beneficiary

The CSTDA is an avenue for the Commonwealth to provide funding for services to support people with a disability to have lives which have opportunities similar to those which are taken for granted by the average member of society.

Carers of adults with a disability in our Service choose one of the following options for their situation.

- Living in the family home
- Living in a unit/granny flat attached to family home
- Living independent of family in home in community e.g. living alone or sharing with others

Whichever option a family may choose for their son/daughter they are funded to receive support which is:

- Flexible and target to the needs of the individual and his/her level of disability
- Is available at a time which is effective for the needs of the person
- allows for involvement in community activities and/or work
- Available in his/her own community
- Can provide advice and support to consider all the available options for home and lifestyle

This support to their family member has been most effective in meeting many of the needs of the parents who are carers.

However, the most critical area is that of parents who are in their 70' and even 80's and trying to plan and prepare for the day when they are not able to be involved with or care for their son/daughter. Historically, this has been a neglected area. The lack of funding to address the needs of these families seems to have been inquired into, a small amount of respite given, but no real commitment by either State or Commonwealth to address this most critical need for lifestyle and accommodation services.

Caring in the area of disability is a birth to death situation for many families, e.g. the birth of a child with a disability to the death of either the parent or family member. How support services are received during this time is crucial to the success, happiness and opportunities of all concerned.

It is common to hear words such as the burden of caring. Consider the impact these statements can have on the person being cared for. No parent wishes to think of their son/daughter as a burden. Not one of us would wish to be considered a burden and each one of us aspires to having a life which provides us with opportunities and happiness. People with a disability are no different. Because of their disability, they have more difficulty in accessing many of the things we take for granted. However when we provide support/assistance, we have seen amazing changes in accomplishments and their lifestyle.

In addressing the needs of carers through this approach, I am trying to demonstrate as we in our Service have observed, the need to consider the issues for caring for an adult with a disability in broader terms than isolating the needs of the carer. Address the caring issues through how support services which are funded to the person being cared for is a realistic and appropriate way of achieving the goal of assisting the carer.

It is my hope that the above comments will be taken into consideration when this Inquiry reports to Government on the issue of the needs of carers.

Yours faithfully

Elsie Butler
 Hon..President,
 Real Living Options Association Inc.