

Submission No. 136

(Inq into better support for carers)

A.O.C. 25/4/08

ROSALIE & TONY

12.06.2008.

COMMITTEE SECRETARY
STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING & YOUTH.
PO BOX 6021,
HOUSE OF REPRESENTATIVES,
PARLIAMENT HOUSE,
CANBERRA. ACT. 2600.

SUBMISSION INTO BETTER SUPPORT FOR CARERS.

We feel that it is in the best interests of this inquiry that there be some definition of:

1. What is a carer?
2. Who is a carer?
3. Care eligibility - why is care required?
4. The different ways of providing care. Is it physical, psychological, financial etc?
5. Care classifications according to need. Is it because of disability, psychiatric disorder, aged care etc?
6. What is the time frame for care required?
7. Are there other options.

"Better Support for Carers" covers a very wide range of circumstances.

Is it defined by those receiving a care payment or care allowance?

Is there some way of categorising care requirements?

Is there some way of establishing an accurate assessment of carers who are,

1. Concerned about their role.
2. Have many problems associated with their role.
3. Need more help.
4. Think the Government can better help Carers.

As carers of a son with Down Syndrome for 31 years who for the past 4 years has had a significant psychiatric illness & who as carers have readily provided information & responses to submissions during that time we find that this format brings little response.

We strongly feel that the best way to obtain information on such a wide ranging subject is a short question multi answer questionnaire - this data, which would not be difficult to obtain through Centrelink if an appropriate care plan questionnaire was developed utilising the points outlined in your Terms of reference.

CARERS.

At present we are,

1. Carers for each other.

We are 65 & 67 years old, recently retired, self funded retirees on a modest budget mostly existing to provide care & support for our son who continues not to attract funding for supported accommodation through the Western Australian Disability Services Commission. We have been applying for 4 years - our needs are considered of significant need but not at crisis point. Because at this stage we have a material asset to compliment our self funding means we are only eligible for The carers allowance for our son. In the near future this asset will be needed for our financial needs.

Caring for each other requires having a vision, planning, time for each other, all that which our peers enjoy for which we have restrictions or very little opportunity.

2. Carers for our son aged 31 with Down syndrome who for 4 years has had a significant psychiatric illness. An illness which reached a peak in January 2007 & has required extensive drug treatment prescribed by a very experienced psychiatrist. Our journey with his intellectual disability has been incredible, which, now combined with the psychiatric illness has been often a heartbreaking nightmare, made more so by his reaction to medications which for many months reduced his functionality by 75%.

We have actively pursued support which we know & feel he needs, however it is mostly not available or if it is the management is complex, non supportive & time consuming.

We know that as parents we are contributing to the detriment of his abilities & illness,

We know & feel that as carers, that the philosophies of community integration & inclusion are too rigid in their application, denying many people with disabilities the support & care they require & unless there is a softening in this stance by Governments & their agencies there will be little improvement Far too much money is spent on promotion of this rather than the basic needs for support & care.

We know many people in similar circumstances to ours, reconciled to existing in their circumstances as there is very little hope of anything else.

3. Carers for our other child, married with a 14 month old child an another expected in 10 days. We naturally want to provide care & support similar to that our peers are able to provide for their children.

4. Carers for 4 aged parents.

Although the paternal parents aged 90 & 88 live in England there are communication & support requirements regularly needed. Unfortunately it has not been possible to visit them as often as we would like due to our care commitments here & often only one of us has been able to go. It has been & is a difficult situation. The maternal parents aged 90 & 88 live an hour away, independently, assisted by a community care package through a ACAP Assessment. They are frail, unable to understand the complex demands of the aged care system & require constant support & assistance.

5. Carers for self needs.

It is extremely difficult to stay balanced & healthy with all of the above commitments.

It is extremely difficult to remain positive & objective, to enjoy retirement together like "ordinary" Australians.

Better Support For Carers

As carers our roles are obvious. We provide CARE, constant care.

We have no idea when that care role will be lessened. We find the care role demanding.

We find the support often fragmented & fractured,

We find that managing the support is time consuming, stressful, requires energy & some extra financial support.

The problems we face are obvious for all those in contact with us, ourselves, each other, our son, our daughter & family, extended family, friends, associates & people involved in other activities we are involved with.

Planning anything, any activity is not simple. It is easier often to "lock" yourself in & be reconciled with an exclusive inequitable lifestyle.

We know & feel the difference in our lives compared to that of our peers.

We experience and feel the problems necessitating this inquiry.

As carers we need help.

We need funding for independent supported accommodation for our son immediately.

We need to support & assist our son through a transitional period leading to independent supported accommodation - a home of his own with others of similar needs requiring support which can be shared & as assessed by an appropriate agency.

We need to support our son in a sustainable home of his own where we can provide support as needed by him - a reversal of what he is now receiving.

We need to have confidence in the above provision to allow us to live & plan our lives as aging retirees.

We need acknowledgement of our concerns & addressing of those concerns to enable us to manage in the short term.

The Government/s & their Agencies can better help carers.

Communication is essential.

Proper funding is imperative.

Giving carers like us a time frame whereby we can see resolution of the situation we are in - the same situation as so many other families with an adult child with a disability.

We have exposed aspects of our life in support of this inquiry in the hope that in doing so it will enable readers to feel & think about our situation which is like so many others needing a positive outcome for the quality of life for the person they care for & themselves.

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

[Insert date here]

12.6.08

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

As a Carer, I feel that my role is

VISIONARY
I AS A 65 YEAR OLD WITH A 30 YEAR OLD SON WITH DOWN SYNDROME & A SIGNIFICANT PSYCHIATRIC ILLNESS & A HEART BEATING RECENTLY'S NON VISIONARY JOURNEY TO MY HUSBAND & MY LIFE IN RETIREMENT FINDS US IN A DAUNTING & HOPELESS POSITION OF CARE & LOVE WITH COMPLICATED SUPPORT REQUIREMENTS
I face the following problems ...

UNABLE TO PLAN FOR OUR LIVES NOW AND IN THE FUTURE. THE SUPPORT WE HAVE IS CONDITIONAL, FRAGMENTED & DEMANDING TAKING A HUGE AMOUNT OF TIME, ENERGY & FINANCES BEYOND THE "NORM" OF AN "ORDINARY" AUSTRALIAN.

I need help with ...

RELOCATING MY SON IMMEDIATELY INTO FUNDED INDEPENDENT SUPPORTED ACCOMMODATION THAT THROUGH A TRANSITIONER / PERIOD CAN PROVIDE SUSTAINABLE SUPPORT A REVERSAL OF NOW

I think the Government can better help Carers by ...

- PLEASE THANK TO ME
- OPENING THE RIGHT PHILOSOPHY OF INCLUSION & COMMUNITY INTEGRATION BY UNDERSTANDING & ACKNOWLEDGING WITH FUNDING SUPPORT REQUIREMENTS - PARTICULARLY FOR PEOPLE WITH INTELLECTUAL DISABILITY.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

[Type or clearly print your name here]

Inquiry into Better Support for Carers

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

ROSALIE