

**House of Representatives
Standing Committee on Family, Community, Housing and Youth
ACT Public Hearing – 26 September 2008
Better Support for Carers Talking Points – Some Thoughts
A.W. and K.D.**

Background

We had previously provided a written submission to the Standing Committee from a carer's perspective and are prepared to respond to questions or expand on any issues raised in that submission.

In our case we have been a parent for 39 years and a carer for some 23 years of a young adult who has been experiencing chronic mental health (anxiety, depression) issues and all that goes with those. These had initially manifested as anti-social and learning problems.

Carer Role

First and foremost we see our primary role to be that of a "parent". In our case we believe the "carer" role is simply part of the broader role of being a parent. We perceive these roles as being intrinsically linked; they are one and the same. Always demanding emotionally, physically and financially. At other times a real challenge and draining especially given that the health issues involve a non-biological family member. This relationship carries special responsibilities for the parent/carer.

Primary Concerns

Our principal concerns are with our ability (or inability) to provide for through life quality care for the person receiving the care.

Support arrangements for those experiencing mental health issues are complex and difficult to access. Government subsidies, accommodation that is safe and secure is extremely limited and difficult to access. Private accommodation is costly and will be increasingly so.

As they stand the support arrangements are seen to be overly complex and dysfunctional. In our case they have been so since 1985 – a period of 23 years.

Of particular concern is the availability and health of the carer. These decline substantially with age. The quality and scope of the care will change over time and will, in part, be determined by the well being and financial security of the carer. At some point it will be removed entirely and responsibilities for providing care will transfer to Government service providers. Not a welcome thought, but a reality of life.

Fundamental Problems

Over the years lack of effective diagnosis and treatment support arrangements in the delivery of mental health services have created major problems for both the person receiving the care and the carer. This is of particular concern in instances of mis-diagnosis where symptoms are diagnosed at the GP level as being the cause.

As a consequence neither the young person experiencing mental health issues nor the carer are able to achieve relief. Recovery is protracted and both the cared and the carers are denied the opportunity of achieving their full potential and enjoying a reasonable lifestyle. Persons directly involved become disillusioned and frustrated. They are unable to contribute to either the broader community or the nation.

The individuals' self esteem and confidence declines and opportunities are wasted. Those in need of care become virtual liabilities to the community and the government of the day, both State and Federal. Invariably, the person experiencing mental health problems is acutely aware of the need for care and the costs involved. This again impacts self esteem and delays recovery. Rehabilitation as a functional member of the community is often delayed.

From our experience these in need of mental health care or rehabilitation support are at a distinct risk of being permanently marginalised in broader community. Some will simply fall through the "gaps" in the system and will tend to be acknowledged as statistics rather than real people in need of care and rehabilitation.

Principle of Human Rights

In a modern society of a developed or developing nation, persons experiencing the trauma of mental health issues, and to a lesser degree those providing family care, should as a general principle be able to live and experience a full and secure productive life within the physical and mental limitations whether they be permanent or transient. This is a normal human right.

Unfortunately, as things stand, we seem to encounter six fundamental impediments to long-term wellness of those being cared for who experience chronic mental health issues. These being the need for:

- early and accurate diagnosis;
- full acceptance by both those being cared and the carers;
- co-ordinated health treatment plans involving primary (GP) medical and mental health professionals (psychologists/psychiatrists), the patient and the carers;
- rehabilitation support programs aimed to achieve either full or part integration into the community and depending on the individual case, employment;
- short and long term financial security; and
- safe independent living accommodation.

Until these issues are acknowledged and form part of the co-ordinated treatment/rehabilitation plan carers will have difficulty in coping, especially in the longer term as they age and their financial assets decline.

Accommodation

In the case of accommodation some carers have been obliged, and have been able, to establish safe independent private arrangements to avoid the need for or use of government subsidised facilities. But with increasing government and maintenance costs there are real risks that family carers will not be able to sustain these arrangements in the medium to longer term. The reality is that as the carers essential financial assets decline over time the maintenance costs are increasing substantially. Things do not augur well either for the aged carers or the person in need of long term care.

Early Diagnosis – the Imperative of Wellness

While we have been in the carer role for over 23 years, the intensity and demands, together with the fear and frustration of not being able to cope, have varied over time. Sometimes the changes have been daily with the person being cared for at risk of self harm. This risk could be minimised substantially through early diagnosis and intervention.

In our case we were initially in denial; we simply put our heads in the sand. It was easier; like the general practitioners (GPs) we were looking at symptoms rather than real causes of the problem. Maybe we were just slow learners and were looking for a magic wand.

At that time mental health issues tended to carry a stigma; they were not openly discussed or acknowledged. This made life more difficult for both those being cared for and those providing the care. Self harm was always a real issue causing extreme stress for the carer.

On reflection it seems that the primary health care provider, the General Practitioner, had little or no experience with mental health issues and did not particularly want to become involved. It was easier to prescribe treatment for the symptom displayed rather than the cause. Real wellness was never achieved. Perhaps we are cynical!!

Today this situation is seen to be changing – but ever so slowly. Unfortunately the support arrangements are convoluted and difficult to access, both by those experiencing mental health issues and the carer.

Demographics and the shortages of doctors, especially at the general primary care level, together with the creation of large centralised regional medical centres simply compound mental health problems, both diagnosis and treatment, prolonging recovery.

Privacy of the patient continues to be a problem for some GPs and specialist health service providers. This causes the patient requiring the treatment and care to remain isolated from and places stress on the family care provider. Continuity of

care is lost and can at times become dysfunctional – perhaps fragmented is a better word.

Conclusion

Clearly, changes need to be made to the existing physical and mental health treatment and support arrangements if those in need of care are to be rehabilitated to be a functional member of the community and able to enjoy a quality of life that we all take for granted.

Co-ordinated and well structured mental health treatment plans will ease stress on and contribute to the wellbeing of both those being cared for and those providing the care.

As a community we need to do better, as do governments both at the State and Federal levels. Mental health presents complex issues for both patients and carers. We should not take things for granted. The risks are far too high. Without family carers the health system as it stands is not sustainable.

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