

SUBMISSION: SENATE AGED CARE INQUIRY

INTRODUCTION

This submission concerns the appropriateness of accommodating and caring for young people in nursing homes. The submission will not address the tragedy and grief associated with acquired brain injury, or the extraordinary courage of those people whose independence is so dramatically and permanently diminished in the face of these life changing injuries. Rather, I wish to focus on what is needed from a bureaucratic perspective to bring about change for such people. The submission is made in a personal capacity and does not reflect the views of the organisation in which I am employed.

My perspective is informed through my friendship with a young person who entered a nursing home at the age of 29. I shared part of my youth and young adulthood with this person – whose life, pre-injury, was that of a leader and high achiever. He was a driven, ambitious and dynamic person, determined to contribute to his community and to make sure he made a difference in whatever he did. We both studied law after finishing school, and I watched my friend's career take shape within a large corporate law firm while I commenced a career in legal policy within the Mental Health Branch of the Victorian Department of Human Services. Much of my work at that time related to legislative and policy reform of a sector which had been grossly neglected by governments for decades. This neglect resulted in gross abuses of human rights which were well documented in the 1993 HREOC *Inquiry into the Human Rights of People with Mental Illness*.

When my friend became inexplicably ill in 1996 while on an overseas posting, I watched in shock as it became clear that there were no options for his ongoing accommodation and care other than in an aged care nursing home. Not only did this seem manifestly inappropriate, but from my professional perspective, it reflected an ongoing abdication of responsibility by state and federal governments which was not dissimilar to the neglect of persons with mental illness during the preceding decades.

Since 1996, I have remained closely connected with my friend's parents, who, together with other carers and friends, have tirelessly fought to bring the issue of YPINH to public attention. I have been continually dismayed by the failures of leadership and commitment which mean that nothing changes for YPINH, and have repeatedly wondered how different the political and bureaucratic response would be if it were the sons or daughters of politicians or senior bureaucrats who were trapped in such an inappropriate environment.

It is by no means an exaggeration to state that these continuing failures have resulted in the deaths of such young people – through a combination of ignorance of their clinical needs and compounded *neglect*. It is almost incomprehensible to think that this can occur in 2004. Addressing it requires a genuine and joint Commonwealth- state commitment which is underpinned by sophisticated policy development, a national strategy for – and ongoing commitment to - change, and the development of monitoring and accountability mechanisms which enable change to be publicly reported and monitored. This has occurred in mental health over the last 15 years, and I consider that aspects of those reforms could be broad models for action on YPINH. While reform in mental health has been, and remains, controversial, the models provide a basic framework which is worthy of consideration.

A POTENTIAL MODEL FOR REFORM

There is no coherent policy governing placement of YPINH at either state or federal level. Despite the numbers of young people in such situations, the Commonwealth and states have, until now, passed responsibility for development of such policy – and provision of funding to support it - between each other. Seen in context, however, many of these young people represent the *most vulnerable* members of our community. YPINH like my friend cannot speak for themselves – profound physical disabilities mean that they are trapped within their disabled bodies, unable to articulate their frustration at the grossly inadequate situation in which they find themselves.

The work of organisations like *Inability Possibility* provides extraordinarily moving evidence that for the vast majority of young people, nursing home care is manifestly inappropriate. This work also articulates the grief and tragedy which confronts carers and friends as they struggle to accept that nursing home environments are currently the only options for the people that they love.

What, then, is required to change the situation for YPINH? From a policy perspective, and given the way in which services for YPINH are currently funded and administered, a joint state-Commonwealth approach would seem critical in order to bring about change. As part of this, the following should be considered as fundamental to development and delivery of different service models for YPINH:

- **a joint Commonwealth/state commitment to bring about change the situation for YPINH.** Without such commitment, the above situation will continue, and genuine reform will be impossible.
- **development of sophisticated joint Commonwealth-state policy developed in consultation with YPINH and their carers, which articulates principles for reform, intended outcomes and methodology for change.** A commitment to change would facilitate development of national policy for change. An example of such a commitment is contained in the 1991 *National Mental Health Policy and Plan* which formed the foundation for reform of mental health services across Australia. Like the situation for YPINH, prior to the development of the *Policy and Plan*, the quality of mental health services for people with serious mental illness was poor, variable across states and there was no coherent policy to guide states in bringing about reform. The *Policy and Plan* reflected a high degree of commitment by responsible Commonwealth and state ministers, outlined key principles to govern reform, and included a plan to bring this about. They were seminal documents, and were followed by two further plans to continue reforms in 1998 and 2003. Such policy development could serve as a framework for development of a national policy and plan for YPINH.
- Development of such policy for YPINH would enable identification of the major barriers to structural reform, ways in which to tackle these problems, define state and Commonwealth responsibilities and break down key tasks and timelines to shape and guide reform activity. The policy should provide for a flexible response to the accommodation and care needs of YPINH, acknowledging that their levels of need depend on the nature and extent of their disability.

- **quantification of the additional funding required by states and Commonwealth to achieve reform and provision of this funding as part of the policy response.** Part of the above policy development must include a commitment to provision of additional recurrent funding for YPINH by states and the Commonwealth. Scoping the extent of the additional funding, how funding can be realigned in the context of changing service models and equitably allocated is an extremely complex task, but again, requires joint commitment to be realised.
- **establishment of a state-Commonwealth standing committee, made up of senior state and federal bureaucrats and representatives of peak groups.** In mental health, a standing committee was established early in the life of the first *National Mental Health Plan*, consisting of state and federal senior bureaucrats and carer and consumer representatives – the National Mental Health Working Group (NMHWG). The group reports to the Australian Health Ministers Advisory Conference, and ultimately to state and federal Health Ministers. The group has served a number of critically important functions: creation of a mechanism for ongoing national dialogue and problem solving on reform, for shaping of key policy documents, for ‘tracking’ of key activities and sharing of innovative approaches to difficult issues. It has also provided enabled increased governmental accountability for delivery of reforms.

Whatever the extent of these reforms, establishment of such a body for YPINH could provide a means to manage the complexities of reform, and of driving change.

CONCLUSION

From a bureaucratic perspective, the current situation for YPINH represents an enormously complex problem which requires innovative capital, structural, administrative and policy reform. The foundation for change must be a state and federal commitment to do things differently, to innovate and to change the quality of life for YPINH. Such a commitment could enable the above to be tackled strategically and effectively, and in doing so, provide YPINH with some of the basic human rights currently denied them.

ERICA GRUNDELL AND RICHARD REILLY