Productivity Commission SUBMISSION Author - Paul G Prendergast (Victoria) Disability Care and Support

Accommodation Shortages

As the ageing parent of an adult daughter with an intellectual disability, our most pressing future need is to set up our daughter in a suitable independent but supported permanent accommodation arrangement before we depart from her life. Yet only a few permanent accommodation places are available and there will never be enough accommodation places without a major overall of the disability sector. I am one of the shrinking pool of aged carer's providing unpaid care that realises he will not be around forever.

This Commission Hearing is very welcome and long overdue. If nothing else the Commission's findings will highlight the huge unmet need for services that can only be provided through a national disability scheme.

My own examination of what services from respite, transport, individual funding, and accommodation available in rural Victoria does not provide me with any sense of comfort or expectation. In relation to accommodation we are not in the financial position to fully fund an arrangement for our daughter with our own limited resources. We have been advised by a disability provider that a shared house with four other similar occupants requiring medium not high level support could cost up to \$120,000 per annum to staff if this includes carer sleepovers. Even should we wish to avail ourselves of respite or short term accommodation we know there are only a few respite or short term residential houses in central Victoria. They are heavily used, with waiting lists, and involve very short term stays only. Plus we have no Government funding to apply towards this option.

We are aware that there are between 1600 and 1700 young Victorians with intellectual disability including acquired brain injury in aged care nursing homes. They are there because there is nowhere else to place them. We are also aware of (and know personally many of them) the large numbers of elderly parents far older than what we are who have older adult disabled children still living at home.

We are aware of the very few permanent accommodation places in existence in rural Victoria and the new places on the drawing board. They are very welcome but will not meet unmet need in even a most basic manner. We are aware under Commonwealth economic stimulus initiatives for 4,500 new housing units only 1% or 45 are set aside for disability housing. This low number is not even tokenism at its most basic. Additional places in central Victoria to be built by not for profit agencies such as Loddon Mallee Housing Services Limited and other providers will not even be the tip of the iceberg of need.

Current Government Initiatives

Both State and the Commonwealth governments have been active in introducing disability support and funding initiatives in recent years. This support is very welcome but always lags behind demand. The Commonwealth Government provided \$100 million to expedite disability housing. In Victoria we are yet to see actual housing built from these funds. The Victorian Government in its 2010

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Budget has increased disability funding including a small number of extra Individual Support Plans but little in the way of accommodation. The Disability Housing Trust, taxation incentives to establish

testamentary and disability trusts are all welcome but for most of us are not applicable as we lack the financial resources to take advantage of the measures.

Quality of Life

Our daughter currently enjoys a good quality of life. This includes an active social life, attendance of a drama group and a dance group and 10 pin bowling. Our daughter has had previous participation in netball and basketball teams. She enjoys singing and dancing and has a large music collection. Whilst not high functioning she is reasonably literate and numerate mainly thanks to continuing day programs and can read and write basic text. Our daughter is part way through a transition Certificate in Education. Our daughter has one sibling who is currently overseas. *Should her parents die we understand she could most probably end up in an aged care home anywhere in Victoria where the first vacancy occurs.* This thought fills us with dread as our daughter's quality of life would evaporate should she be housed far from her friends and activities. Her support network would be gone along with access to her friends and loss of transport options to social activities. Despite her disability my daughter's name was removed from the DHS Disability Support Register (DSR) due we understand to the high level of family support she received.

United Kingdom

In the United Kingdom along with many other European countries entitlement to disability services including housing is a legislated right. My understanding is that in Victoria and in all other Australian states and territories no legislated entitlement exists. In effect it means that state government and government agencies will provide services where finances allow. Even a person with a nominated sum in an Individual Support Package will only receive services if finances and budgetary constraints allow. This difference was highlighted in the ABC Four Corner's Program in February 2010 comparing United Kingdom disability services including housing with that provided in NSW and Victoria.

Author's Background

Paul Prendergast is the ageing parent of a daughter with Down syndrome (aged 24) Paul lives in rural Victoria north of Bendigo. His daughter Kate attends day services in Bendigo from Monday to Friday. The day services are funded by Victorian Dept of Human Services (DHS) under a three year Plan. No other support is provided by DHS. Kate's living arrangements are shared with her mother in Bendigo and also with her father who lives on a small rural property. Paul is retired with health problems and held Certified Practising Accountant (CPA) qualifications.