

Productivity Commission Submission 2010

Disability Care and Support

A Personal Response

I am writing to emphasise the need for adequate housing for Intellectually Disabled people in Bendigo, Victoria. The existing CRU accommodation provides care for people who need constant 24-hour care but the disabled who have some life skills but are not able to care for themselves independently are poorly assimilated. I am the concerned parent of a 51 year old intellectually disabled son who has a disability resulting from damage to the frontal lobe of his brain following a car accident which caused an early birth. This is complicated by severe depression carrying with it with suicidal tendencies - for which he needs constant care and a 2 years ago he was diagnosed with Diabetes - Type 2. At present he lives alone and isolated from his peers in an Office of Housing Unit in a village primarily for the Aged here in Bendigo with some daily care from the Outreach services of DHS and of Golden City Services. He is not able to attend any day services, sporting events or work without the assistance of carers to prepare and prompt him constantly. For his daily core activities of cooking and cleaning he again needs constant prompting and assistance, without which he is not motivated to care for himself. He has very little understanding of abstract concepts such as time and money and this has implications for his ability to reach out and involve himself in the community without a lot of help. Currently, our family provide the major role in his care – organising extra care such as visits to doctor, dentist, podiatrist, optician etc along with access to entertainment, purchasing clothing paying bills etc. As we are now aged and in our seventies our capacity for this support is becoming very limited and rests on one or two people, this means that the future needs of our son is the cause of much anxiety. In the last six months he has gained ten kilograms in weight which will have a dramatic effect on his health should this continue to escalate. In order for his behaviour and ability to cope with daily life on a reasonable basis he needs to be medicated to the extent that his general health is now threatened.

Prior to coming to Bendigo he lived for a period of nearly twenty years in a CRU in Warrnambool which was staffed part time. This situation suited him – it gave him the supervision that he needs to look after himself, the company of other people who also prompted and supported him informally and the essential overview of one facilitating service to deliver consistent care. Sharing with others meant that there were people to go out into the community socially and the chores of shopping, cleaning and other tasks was more acceptable to him when it was shared around. During this time the role of the family was only needed to provide social and personal support where it was needed. After the family moved to Bendigo it was found that he also needed to move and we brought him to Bendigo where the amount of suitable accommodation available for him was vastly reduced. The gap between CRU's which deliver 24 hr care and independent living is not covered adequately here and after eight years of trying the family is becoming increasingly anxious about his future safety and the threat to his ongoing health.

At present his name is down for consideration for group housing which is still materialising, but as he is not considered homeless or in dire threat of harm he is not considered to be in a crisis situation. His ability to continue living as he is at present depends heavily on the support and

coordination of services by myself as his mother and some other family members. These resources are becoming more difficult with each year due to limits of age and health. I believe accommodation resources for disabled people in this region needs to be thoroughly reviewed with consideration given to alternatives to 24hour care such as Cluster or Group housing which would provide independent units with one unit occupied by staff for overall supervision and a resource for occupants as well as more access to other peers than the isolation experienced amongst other adults. Achieving a balance between independence and a safely supported environment is a delicate one, but one which can be achieved - as we have witnessed.

Families carrying this burden of care for their loved ones inevitably find they cannot continue indefinitely, without further assistance as they age their quality of life is immensely threatened. Finding a solution to the adequate care of their disabled person would allow primary carers to experience the relief of seeing their role of daily caring reduced and their right to face the challenges of decreasing health and abilities with equanimity assured. The study mentioned in the Issues paper – Cummins et al (2007) found that ‘... carers had the lowest level of well-being of any group they had studied...’¹ This is no surprise to those involved in constant care of their charges.

My personal recommendations include:

- the development of alternative housing options where clients with a range of abilities – including the aged if this is appropriate - with adequate support to construct meaningful lives for themselves whilst retaining their independence.
- This means more funding options for accommodation for disabled people - such as Cluster or Group Housing with flexible staffing.
- I wholeheartedly support the notion of a National Insurance Disability Scheme which would assure families that their disabled person would be cared for beyond their capability to care for them.
- That the long term essential care and support is available to achieve the desired outcomes for each person over their lifetime and that the quality of life and the choices attached to that concept, that are available to the rest of our society, be available to disabled people.

Dr Noela Foreman
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¹ As quoted in the Productivity Commission Issues Paper titled *Disability Care and Support* May 2010, p10.