

17 May 2005

The Secretary
Senate Community Affairs
Suite S1 59
Parliament House
CANBERRA ACT 2600



Dear Sir/Madam

Submission to Senate Inquiry into Aged Care

This submission relates to term of reference (c):

“the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs such as dementia, mental illness or specific conditions are met under current funding arrangements;”

The submission is made by William James and Marie Edith Clements, based on the accommodation needs of their daughter Karen (date of birth 24-02-1961, aged 44) who is mildly/moderately intellectually disabled with severe, chronic, complex health problems.

Karen was assessed in 1975 by Department of Health as requiring 24 hour supervision. The extent of her health problems is shown in the attached medication chart, Appendix A, the latest in scores of such charts authorised since 1995. Additionally, Karen has developed challenging behaviour since late 2003 and in January 2004 shattered her hip in a fall and is now very restricted in mobility i.e. walking frame and/or wheelchair.

Karen was accommodated from aged 16 for two years in Marsden Hospital School, Westmead, and for the next 15 years in Marsden Rehabilitation Centre (MRC), Parramatta. In the mid/late 1980's conditions began to change at MRC and parents removed her in 1994 for her safety and well being. In 1996, Karen was accommodated in a group home operated by the Handicapped Children's Centre NSW (HCC) and funded under the 300 Supported Places Programme of the State Government.

The level of care provided was not sufficient for Karen's needs – she spent more than 25% of the next eight years at home for mainly remedial care. HCC acknowledged this situation in 2002 (Appendix B) and in July 2004, parents removed her from the

group home at service provider's request. Karen is now being cared for fulltime at home by her parents.

The possibilities for respite and long term care for Karen are as follows:

Respite

Various service providers, other than aged care facilities, offer services in three streams:

- (i) at home assistance/respite;
- (ii) some hours away from home with a carer;
- (iii) overnight service.

Streams (i) and (ii) are not useful for Karen or parents because the latter need to be present to deal with any health, behaviour or mobility issue arising, unless carers are suitably qualified which is normally not the case. Stream (iii) has the same drawback with the added disadvantage of not providing "awake shift" carers with the necessary qualifications and/or knowledge and experience to monitor Karen overnight every two hours at least, for epileptic or diabetic (hypoglycaemic) signs or episodes.

Accommodation

It is parents' understanding that for people with disabilities in the age group 18-60, there is in NSW but one accommodation service capable of providing high level care with medical orientation, located at Wollongong. Karen's claim to a vacancy there, if there was one, would be no better than anyone else's and doubtless there are many in similar or worse situations.

Since 2002, neither service provider nor Department of Ageing, Disability and Home Care (DADHC) have offered Karen suitable or any alternative accommodation. Parents' experience indicates that the high level care needed for Karen as a respite service or for long term care is only available in aged care facilities. This is simply because there are not any available separate facilities for people aged 18-60 with special needs.

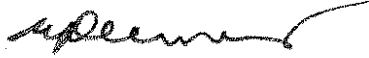
Aged care facility accommodation for Karen, to the best of our knowledge, does not exist other than as a dispensation. Respite or long term care may be provided in certain emergency circumstances at the discretion of the local health care service, who can approve recommendations for such care. Acceptance of the approval depends on bed availability, prior bookings, etc. The number of aged care respite places in the Sutherland Shire, where Karen lives, can be counted on the fingers.

Karen has recently managed to obtain respite for two weeks in each of two aged care facilities, thereby denying those places to aged persons. The level of care was satisfactory, however, Karen and her parents remain equivocal about the service. Karen is at her best, in all respects, when stimulated by social interaction. In these respite situations this has been available to her, less than more, with only some of the staff and aged residents and Karen has been dismayed by exposure to some dementia patients.

The placement of someone like Karen, with a mental age about 3 years old, in an aged care environment, is inappropriate. Nevertheless, there is no alternative. Parents are in mid 70's with failing health and endurance. Sooner or later or in emergency, an aged care facility will be the only place Karen can go. The outcome will be detrimental to those involved and to the aged care service itself. When considered across the population, the prospect is appalling.

Only government action can mitigate this circumstance by direction of funding to the services in need.

Yours faithfully



W J CLEMENTS



M E CLEMENTS

Encl: Appendices A and B