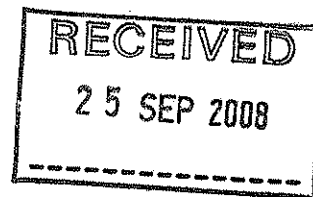


Carers & Parents Support Group

P.O. Box 931
23 Carrier Street
Benalla VIC 3672

Phone: 03) 57 626202
Mobile: 040 9167 037

Email: cspgbenalla@bigpond.com



28th September 2008.

Executive Officer,
Family and Community Development Committee,
Parliament House,
Spring St, East Melbourne, VIC 3002

Dear Sir / Madam,

The members of the Carers & Parents Support Group Inc. wish to make submission to the inquiry into on the provision of supported accommodation for Victorians with a disability and/or mental illness.

The Carers and Parents Support Group provide information, support and advocacy for carers, parents and families of adult children with an Intellectual Disability and dual disabilities from our small office in Benalla. Many of our families live in rural and remote areas of North East Victoria and are bound by the towns of Myrtleford to Numurkah from Ruffy to Mansfield.

1. Our office receives ongoing calls from many distressed and frustrated parents and families of people with a disability regarding the lack of available beds in shared supported accommodation in the Hume Region, in particular Benalla, Wangaratta and Mansfield. Benalla and Wangaratta could easily fill a six bed facility (SSA) tomorrow according to our list of requests for support to find accommodation for local families. Too many sons and daughters aged 45 + years with high support needs are still residing at home with their now aging parents or parent. It is inappropriate and unacceptable that these parents and carers in their 60's and 70's are expected to provide ongoing care for people with high support needs on a day to day basis without any indication that their person will be settled into permanent accommodation soon.
2. The only choice of suitable models of accommodation in the Hume Region is between the general SSA facility of up to six beds or to partner flexible packages (ISP) with at least three interested people with disabilities to cover the 24 hour supervision and care required for a viable accommodation house. However, currently there are no available beds in Benalla or Mansfield therefore there is no choice for local people with disabilities to be able to reside in their area of choice with family close by, attend day programs and employment with their friends and other familiar community supports. The major disadvantage of the second model of accommodation (partnering ISP's) is what happens to the remaining people should one person pull out of the house for whatever reason e.g. incompatibility? The support funding left for two ISP's would not fully cover 24 hour care. There is a real need to investigate a broad range of other models of accommodation as "one size does not fit all". Two models that may address present accommodation issues include lead tenancy in a block of units, and the Key Ring model from England.
3. The quality of care for both people with a disability and mental illness largely depends on where people live and what the ethos and attitude of the agency providing the support. Residential units are in general understaffed, thereby severely limiting the provision of any genuine opportunities for people to trial a range of recreational activities to chose from and pursue in their leisure time with support. Support workers are often not properly trained to deal with people with behaviours of concern, this leads to serious safety issues for both residents and workers. Support workers are underpaid for the important work that they carry out. Parents believe the staff should be well respected as good workers and rewarded with an appropriate wage. Better wages and respect will increase the retention of workers, who deliver best practice service for our people with disabilities.

4. Generally parents experience a negative response when taking the big step to access long term supported accommodation including information, planning and decision making, due to the current situation in the Hume Region - there are no vacancies within both DHS and NGO run CRU's. In Benalla and Mansfield vacancies in SSA rarely become available, if a vacancy comes up then it is quickly filled by people on a higher priority, as many other DHS clients with disabilities are deemed "homeless". Parents and Carers by their very nature do CARE for their families and not wish to relinquish their caring role but are often forced to due to ill health and the need to ensure their person who is disabled and vulnerable will be settled and cared for in the manner chosen before the parents die. It is unacceptable that parents and carers are often placed in patronizing situations and negatively judged when making reasonable requests to register their 40+ year old son /or daughter to be assessed for DSR so they may move out of home and build a life for themselves. Parents who are aging that are left to care for their adult children with disabilities become unwell due to the stress of not knowing what will happen for their son or/ daughter in their future accommodation.

5. Implications for people with disabilities who are not deemed a high priority for SSA mean that they must continue to live at home with ailing parents who are suffering from increased stress and anxiety (not knowing what the future holds for their adult child) leading to severe health problems. Financial capacity of families is also diminished due to the amount of care required, limiting parents' choice to pursue careers or paid employment as their peers. Families of people with disabilities are often forced to rely on Centrelink payments and the welfare system to survive.

6. The current provision of care in supported accommodation needs to be reviewed across the private, government and community sector.

7. Positives of current situation is that some people with lower support needs on ISP's are having their needs met so these carers and parents can rest easier at night knowing their family member as been provided for and is in good hands. Uniting Care Goulburn North East has an excellent record as a NGO supporting people to find appropriate accommodation, however they do not provide direct care.

8. The negatives of the current approach in rural and regional Victoria include:-


- Crisis driven accommodation services
- DSR is a priority list, not a waiting list therefore no capacity to gauge future need and no real future plan for accommodation
- No available SSA beds for people in need
- Rapid onset of ill health of aging parents and carers
- Lack of real recreation activities for people already in SSA
- Better quality of care-increased support and wages for workers
- Negative and judgmental attitudes when families make requests
- More funding for better paid and trained support staff
- Lack of accountability of NGO's invoices to families
- Transport is a huge issue in regional areas due to the expense and tyranny of distances
- Plan B for people who partner with ISP flexible packages should one leave the house
- Nursing homes – what role will they play?

Need for a balance and choice of Accommodation options presented.

This current situation can not continue, not only is it inappropriate and unacceptable for the people with a disability according to the Disability Act 2006, it contravenes the freedoms and rights protected by the Charter of Human Rights and Responsibilities Act 2006 (Vic).

Our Group waits with anticipation to the report and outcomes of this inquiry.

Yours Sincerely,



Sally Martin
Coordinator.