

## **Parliamentary Inquiry into Supported Accommodation for People with a Disability**

### **Presentation by Heather Cooney, Program Manager, Bayview Disability Services MacKillop Family Services**

Bayview Disability Services provides a range of support services for school aged children and young adults who have a moderate to severe disability, and their families. These supports include:

- Flexible Support Packages,
- planning and case management,
- home-based respite and part time care placements with volunteer caregivers, and
- full time placements with volunteer caregivers.

Many of the families we support are keen to keep their children, once they reach adulthood, within the family on a long term basis. Wherever possible, we provide support for them to do this, and indeed, prevention of family breakdown is one of the outcomes we work towards.

A small number wish to plan for their teenage or young adult member to move to another accommodation type. For some, this is because they have found the task of raising their child very challenging, and may be worn out with trying to manage constant challenging behaviour or the demands of high physical care needs. Some feel that after many years of their child's needs dominating family life, it is time to attend to their own needs or the needs of siblings of the child with the disability, the way other parents can when children transition into adulthood. Some recognise that their own health is deteriorating and wish to see their child happily settled in a long term alternative home before they are totally incapacitated. Some of these parents will have made the assessment that Disability-Services funded shared supported accommodation is the most suitable option for meeting their child's daily support needs.

The Disability Act (2006) places a high value on planning, and on providing for individual needs and choices. In practice, we as an agency have found that the current system within Disability Services for allocating places in supported residential accommodation not only does not promote these principles, but actually makes timely planning and choice impossible for families. To gain access to supported accommodation, young people and their parents are forced to reach a crisis situation before they will be considered.

There are not enough supported accommodation facilities available to meet the community need. The pathway into supported accommodation is through the Disability Support Register, a register of current and ongoing need. Without exception in my experience, young people listed as requiring supported accommodation will wait years on the DSR for a suitable vacancy to arise. The first to be considered for any vacancy are those who have been flagged as having priority status. To get priority status requires the young person and/or their family to already be at crisis point. For example, the young person or their family members must be at high risk of, or actually experiencing, harm or emotional or physical breakdown. Some families after years of dedicated care are forced to the crisis point of needing to relinquish care of their young person because they can no longer cope.

I would like to offer 3 examples of situations we have been involved in during the last 12 months:

1. Young man aged 18 had been on the DSR for supported accommodation, with priority status, for over 18 months due to having very high physical and medical care needs and challenging behaviour. His mother had multiple chronic and deteriorating health conditions. The son had become very physically aggressive towards his increasingly frail mother. Despite enormous support going into the home, including specialist behaviour intervention, it was not enough to prevent a crisis situation, and the family becoming so physically and emotionally burnt out that they abandoned their son in a respite facility. It then took months of work to help them recover to the point where they could resume some form of contact with their son. He spent some time moving between respite facilities prior to being placed in long term accommodation, which did not help him develop a sense of security in the face of being abandoned by his family.
2. Young man aged 17 has a dual diagnosis of a mental health condition as well as autism and intellectual disability. His father is a sole parent who struggled to cope when the son's mental illness symptoms were active. Insufficient assessment, treatment and support services for young people with dual diagnoses meant that thorough treatment and adequate respite care were difficult to obtain. This father also reached crisis point and relinquished his son. Moving this lad between respite houses was not helpful for his mental health, and he required very expensive 1:1 support. He was given priority when a temporary vacancy arose, and spent 4 months in two supported accommodation houses before his father felt strong enough to take him home again. Initially this father had been told that there was no provision in the system for a 3 month respite break, it was just luck and circumstance that led to it happening, and was a good outcome for him and his son. He will probably need good long breaks from time to time, but the system doesn't make it easy to plan for this.
3. Teenage boy aged 15 has Lennox Gastaut (uncontrolled) epilepsy and a moderate intellectual disability who became increasingly difficult to manage during his bouts of unpredictable, irrational and physically aggressive outbursts. Private psychologists and BIST have been involved over the years, but it has been difficult to develop successful strategies. The parents' marriage has broken down, and the father has mental health issues. The mother and the boy's younger sister are regularly subjected to emotional and physical assaults by this boy, and considerable psychological impact. About 2 years ago the mother reached crisis point and believed the boy could only be managed in supported accommodation with trained rostered staff. She was told that there was no such accommodation for people under 18 years of age. He was allocated an Individual Support Package which provided funds for intensive in-home support and recruitment of an alternative home-based caregiver. However, because of his very high support needs, we have not been able to attract a volunteer caregiver family to care for him, and the mother and sister remain struggling on. Attendant care agencies struggle to recruit suitable and consistent staff even for brief respite care sessions. There is very inadequate availability of out of home overnight care, which is what the family needs on a regular basis. If this boy could be settled in supported accommodation for teenagers, his mother and sister could have the opportunity to rebuild a positive, supportive relationship with him, rather than the ongoing harmful resentment and anger and mounting psychological damage that dominates their relationship at present.

**Recommendations:**

Bayview Disability Services (MacKillop Family Services) recommends the following in order to more adequately meet community need as we experience it:

1. Increased availability of supported accommodation houses;
2. Supported accommodation availability for young people (12-18) with high support needs who are unable to remain with their families or be placed in alternative family placements;
3. Capacity within the service system for families to plan for, and access in a timely way, supported accommodation for their young people without being forced into crisis;
4. Greater availability for overnight out-of-home respite care, including for extended periods, in order to prevent parents from reaching crisis and relinquishing their children longer term.

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