10th October 2008

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

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Submission to: Inquiry Into Supported Accommodation for Victorians with a Disability or Mental Illness

I have attempted to answer where I have comment.

<table>
<thead>
<tr>
<th>1. What have been your experiences with supported accommodation in Victoria with regard to availability, suitability, and adequacy of care for people with a mental illness or disability?</th>
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<tr>
<td>Availability – I have been fortunate in that for the two times where my son has had to be placed, some form of supported accommodation has been found.</td>
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<td>Suitability – is another matter. My son, who is 25, lives at a SRS. No, it is not a suitable place for him to live.</td>
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<td>• Aged and patients with dementia also live there.</td>
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<td>My son has feelings of isolation and disengagement, is a person, who by nature is more comfortable participating on the fringes – i.e. not being the centre of activity or even participating in the main activity, but being in the company of people who are doing the activity. At the SRS, there are few people of his own age to mix and identify with. And definitely no one to assist with facilitation or engagement.</td>
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<td>Any young person may get impatient with the aged and infirm. A mentally ill person who is given psychotropic drugs may display increased impatience and agitated behaviour as a result of the drugs. This happened to my son. It took it 10 months to convince clinical staff that this level of agitation was unacceptable. During this time he would display enormous impatience and agitation in the lead up to lunch, often pushing past elderly residents. It happened once too often, and he was punched in the face. Incidents like this jeopardize security of tenure.</td>
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<td>My arrangement to enable myself to care for him as best I can, is that I bring him home religiously on a Friday evening after work to enable him to participate in a family and caring environment which he desperately requires to maintain social contact and stave off his “I feel so isolated” (his words) feeling, and take him back on a Sunday evening. His feelings of isolation are exacerbated because he has real difficulty engaging with people. This is not to say that he does not know how to travel on public transport independently. He can and does everyday – using my work as a drop in. There are no suitable resources to assist him to attempt to engage near where he lives, such as in a hall nearby. He has to travel by train to get everywhere, and has got used to this.</td>
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<td>• The timing of when meals are served does not suit a young person.</td>
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<td>Dinner is started at 4:45pm. This is far too early a time for young people. My son is usually out at this time or on his way back from his visit to the city.</td>
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<td>• The meals are unappealing, and geared towards more elderly people.</td>
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We are from an Asian background, and while my son does eat snags, hamburgers and the like, these foods and especially the boiled vegetables, can be very bland to someone who prefers and was brought up on ethnic foods with stronger flavours.

Adequacy of Care

- I see to my son's hygiene at the weekend.

The SRS does not have adequate staff levels to monitor whether my son has washed himself or brushed his teeth. Basically, someone has to supervise this, otherwise it won't get done. I ensure this happens at the weekend.

- I take my son to the dentist every quarter.
- I ensure that he cuts his hand and toe nails, that he shaves and that he has a haircut as appropriate - at the weekend.
- I have to ensure that my son changes his clothes once a week, at the weekend.
- I wash his clothes at home as the SRS uses the worst quality washing powder, which does not clean clothes, and leaves cleaner clothes streaked with undissolved soap powder.
- My son has the habit of walking a lot. He can walk to the point where his feet are bleeding, and he does not notice. He has previously had times twice, and both times I have detected the condition as it is smelly. Once recognized, I have asked him to practice hygiene stringently over the weekend, walk barefooted and not go out in order to give his feet a rest, and this has solved the problem. However, this condition goes undetected in supported accommodation.
- The SRS has one staff in the evening shift from about 6pm at night to 7am in the morning. And during the day the owner and one other staff member is about. To do cleaning, washing of resident's clothes, vacuuming, and seeing to a maximum of 30 residents, each one having difficulty with self-care. Food is prepared by the cook. Some staff have more experience and are more willing to provide feedback/observation with regard to my son's wellbeing. Others do not have the time, skill or are unwilling to provide the barest of feedback. The wellbeing of residents is compromised as staff seek to do their best they can in a legislative framework which allows proprietors total discretion with regard to staffing levels and skills mix.

2. What is your experience of trying to access supported accommodation in terms of information, planning and decision making?

In terms of information

- I was given the government booklet on Supported Residential Accommodation in Victoria. At the time, I did not know what to ask or question about in practical terms of what actually happens practically and physically in terms of
  - How the washing of clothes was organized. Unless my son is specifically instructed to wear a change of clothes, clothes don't go in the wash.
  - What food was prepared, and how meals were organized. Whether there was any flexibility.
  - What arrangements for medical and dental care was organized.
  - How hygiene was monitored.
  - As my son is a psychiatric patient, medication was taken care of with the dosette box system, where the doctors and Case Managers contact/fax the pharmacy to arrange medication.

- Some staff at the SRS have more experience and are more willing to provide feedback/observation with regard to my son's wellbeing. Others do not have the time, skill or are unwilling to provide the barest of feedback. The wellbeing of residents is
compromised as staff seek to do the best they can in a legislative framework which allows proprietors total discretion with regard to staffing levels and skills mix.

In terms of planning

In terms of decision making

3. What other approaches/models should be considered to address supported accommodation funding, planning and delivery?

Supported Accommodation – Opt-In Opt-Out Board

I would welcome the Supported Accommodation model where Board is a separate payment and the resident could choose to Opt-In or Opt-Out of Board.

I have commented on the unsuitability of meals in item 1. Currently, I supply my son with frozen meals for his dinner during the week. And for lunch he drops in to my work or his father’s work to get his meal. We do not give him money as this would be spent on cigarettes. So we currently have to fund double the amount of money for food.

I would also welcome a model where residents are assisted to participate in activities which interest them. My son listens to music (CDs) all the time.

Supported Accommodation on the carer’s property

Most carers do not have the means to purchase accommodation outright for their disabled relative. However, some do have the land to put up a separate granny flat in the back for accommodation, or have some fibro building out the back, which requires repair so that it can be habitable, or can accommodate the relative with some modification their own house so that there is a modicum of privacy and separation. However, currently, there are no government departments where carers can explore this option.

4. What are the implications for individuals who need but cannot get supported accommodation? Is the alternate accommodation that is available adequate and care appropriate?

Some individuals will be taken in by their families. This is a huge burden on carers, especially mothers who are themselves old and frail. Sometimes mothers allow their disabled children back home, only to find their stress levels rocketing with alcohol and drug abuse coming into their homes.

Others will not be taken in, and if they are lucky, will find their way to places like the Sacred Heart Mission, where a manager has the job of selecting who gets a bed for the night. The Sacred Heart Mission will arrange for more permanent accommodation. I participated in an AIM Leadership course where a Complex Needs manager said that these individuals get ripped off. Often paying $200 per week to live under a staircase with only a sheet for privacy.

5. What is your view on the provision of accommodation and care in private, government and community sector managed supported accommodation?

Prior to living at an SRS, my son lived at a Community Care Unit, and prior to that he lived at home. He will be 26 next birthday. My comments here are directed at the CCU experience.

When he lived at home, I managed his pension, and he was comfortable with that. At that stage he did not smoke. When at the Community Care Unit, staff assured me that he would be assisted with a budget to manage his money. In reality and practice, this meant that they focused on getting the rent paid. It was quite some time before I realized that residents are not supervised with the balance of their pension, and that the money was being squandered on cigarettes and other things, and not being used to contribute buy food (CCU had a small budget for that). My
son knows how to use public transport, and indeed, he is considered not ill enough because he has this single capacity which makes him appear more well than what he is, if other clinical and behavioural capacities are not also considered. However, no discussion or education on how to purchase the most appropriate train tickets for a journey. Consequently, he was considered 'well enough' to be moved to an SRS, I had to cope with anger and disappointment at the amount left over for transport, cigarettes and pin money after paying for rent and board. The pension is not sufficient to cover all of these at an SRS, and I supplement all of these items. He now gets a regular 10 cigarettes a day, $5 to spend and a train ticket.

| 6. What are the positives and/or negatives of the current approach to provision of supported accommodation on families and carers? |
| 7. What issues need to be considered in the accessibility and provision of supported accommodation for people from: |
| a. Rural and regional Victoria |
| b. Culturally and linguistically diverse backgrounds |
| c. Indigenous Victorians |
| 8. What other issues do you think need to be considered which have not been addressed by the above questions? |