28th October 2008

To Committee Secretariat
Family and Community Development Committee
Parliament House, Spring Street
East Melbourne, VIC. 3002

To Committee Secretariat,

Please find attached to this letter, Wesley Mission Melbourne’s submission to the Senate Inquiry into the Provision of Supported Accommodation for Victorians with a Mental Illness or Disability.

We would like to thank the Committee for the opportunity to make a submission on this very important area and would be happy to talk to the Commission further if required.

Yours Sincerely,

[Signature]

Poul Bottern
CEO
Wesley Mission Melbourne
Wesley Mission Melbourne

Submission:

To the Victorian Senate Inquiry into

Supported Accommodation
for Victorians with a Disability or Mental Illness

Wesley Mission Melbourne

October 2008
Strictly Confidential
Submission to the Senate Inquiry into the Provision of Supported Accommodation for Victorians with a Mental Illness or Disability

Wesley Mission Melbourne

1) Our organisation

Wesley Mission Melbourne supports people who are disadvantaged to live meaningful lives by delivering effective services and working to create social systems that value and liberate.

Our vision is for a community where all are valued and included. We believe in the possibility of personal and social transformation, and work to empower those who are disadvantaged to participate fully in community life.

The fundamental values underpinning our work are hope, compassion and justice.

Wesley has two specific supported accommodation programs for people with disabilities: Wesley Disability Support Eastern (WDSE) has ten houses, accommodating forty-eight adults long term, while Wesley Disability Support Southern (WDSS) has eight houses accommodating forty one adults long term and a respite facility accommodating up to six people at a time and accessed by up to ninety-five families a year. In order to be equitable the service limits access to respite, notwithstanding that pension entitlements are affected if more than sixty-three days of respite is used per annum.

Wesley also has a thirty bed congregate care facility, Arthur Preston Residential Services (APRS), for people with Huntington’s Disease and other complex progressive neurological disorders and physical disability. It is quite common for people with Huntington’s disease to have a dual diagnosis of mental illness and there would be a number of people with mental health issues living at APRS at any time. However, there are also a number of people with dual disability whose behaviour would be injurious to other residents at APRS and this group notoriously languish in long term mental health facilities or are homeless.

In the Northern Metropolitan region our organisation provides accommodation for low income aged persons with most of those residing there having a mental health issue. Furthermore, people with a mental illness also access other Wesley services such as the Wesley Homelessness Service, or seek support through Lifeline to access short and long-term accommodation.

Wesley believes that access to appropriate and affordable housing is a basic right for all people and that the current level of provision for housing for people with a disability or a mental health issue is inappropriate and insufficient. The current range of options available as a result of policy direction is limited which in turn limits people’s right to exercise choice.

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2) **General comments: scope of the current inquiry**

The current inquiry aims to examine the provision of supported accommodation of individuals with a disability according to the definition laid down in the Disability Act 2006. In restricting examination to this definition, the inquiry fails to appreciate the needs of those persons diagnosed with autism who do not have a disability as defined by the Act. In Southern Metro region there is only one autism specific service limited to provision of resources for children only. No similar organization exists for adults over eighteen years of age. WDSS has contact with families of individuals with autism, seeking advice about accommodation (both long term and respite). At present such inquiries must be referred to DHS's Service Needs Register before the family can access any form of supported accommodation.

Information from Wesley Homelessness Services shows that in relation to public housing, their clients may be referred for access to either Segment #1 or #2 of the waiting list. While Segment #1 is usually for those clients who display significant risk factors such as accommodation breakdown or crisis; Segment #2 is available to people with disabilities whose accommodation may need structural modifications, or those with a mental illness who may require a sensitive allocation. For instance forty percent of those who have been on the Waiting List for 5yrs+ are single adults with a disability. While there is an awareness of the inadequacy of accommodation for people in this area, this has not translated into the development and provision of greater supply. There is a similar lack of accommodation options for people with a mental illness, especially self-harming/suicidal young women who also experience a lack of respite options.

There appears to be limited understanding of the needs of young people with behavioural needs exhibited in relation to autism or Asperger's syndrome, and the accommodation provided is often unsuitable to support these needs. This has been reported as referral to sites where the client's behaviour of shouting and/or ritualistic behaviors may have an adverse effect on others in the near vicinity. Further if there is no acknowledgement of autism as a disabling condition, access to Segment #2 may be compromised.

3) **Current provision: level of need and range of accommodation available**

Wesley believes that the current amount and range of accommodation options is insufficient to meet the existing and future needs.

3a) **Respite accommodation**

For some families, respite is often the only form of accommodation support that they receive. This includes families who would prefer to access permanent supported accommodation for their loved one, but are unable to because of a lack of provision. Wesley has several instances of clients being left in a respite facility as the only option for families when there is either insufficient time for respite available, a limited range of options, or lack of any ongoing more permanent accommodation. This is particularly evident in cases where an elderly sole parent who cares for an
adult child either dies or suffers illness that prevents their continued caring. There have been cases where such a client has been transferred between a range of similar facilities while an alternative permanent accommodation is located. The lack of facility-based respite means that the client, not being accustomed to living away from home, finds the dislocation even more unsettling, while the lack of permanent accommodation limits the availability of an alternative site. Respite should not necessarily be considered as preparation for permanent accommodation, due to the differing dynamics between the two types of support. Living in a respite setting with constantly changing cast of fellow residents with possibly a wide range of individual support needs, does not automatically provide a good foundation for permanent and more settled, accommodation. A family member of a regular Wesley respite user commented that the needs of someone with a profound disability differ markedly from those of someone with a mild disability, yet respite policy does not necessarily recognize this. However for those families who may be seeking permanent accommodation frequent respite may be the only option open to them.

A fifty-year-old man, a regular respite user of WDSS suffered the death of his mother, his primary carer. Due to a lack of resources and planning for such an event, he was shifted between various respite facilities over a period of six months. His final location was nursing home type accommodation sharing a room with four others. WDSS was able to offer one month’s respite in one of their long-term houses due to re-location of another resident. When the vacancy was declared, this resident was referred for consideration through the regional Vacancy Co-ordination system and was subsequently considered appropriate for permanent accommodation. Had this vacancy not been available, even in the short term, the resident may well have still been on the respite merry-go-round.

At a recent meeting with the people and their families who use our respite service, the following issues were raised:

- The current respite allocation is insufficient: where a family receives 2 nights a month, this equates to one full day of respite, once traveling time to and from the respite service has been taken into account;

- One family reported a decrease in the availability of respite in their area because respite places had been taken up by people who were placed in the facility on a permanent basis because of emergencies that resulted in care no longer being available at home. (This was told in relation to one of the outer western Melbourne suburbs);

- Services vary in quality, particularly in relation to safety, health management, cleanliness and how ‘inviting’ or ‘homely’ the facility is. For the families of younger women with a disability, the issue of placing their daughters in accommodation with men, where there is not an active night shift, is of particular concern. In relation to health management, one parent reported having to visit the respite facility each time her daughter needed to be fed because the staff did not feel competent to manage her daughter’s feeding tube – as she said, ‘this isn’t respite’;

- There is competition for places amongst people who are all needy: one mother reported having to collect her daughter during an allotted respite visit because the place was needed by another family with a more severely disabled loved one (ie

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non-verbal and non-ambulant) who would otherwise have to have cancelled their family holiday;

- Inconsistency of staff means that it is hard for the respite users to develop relationships within which they feel that their needs are understood and will be met. There is a sense for families of constantly having to train new staff into the care needs of their loved one;

- Single-parent families who are reliant on a combination of Disability Support Pension and Carers Payment reported that, even if more respite was available, they wouldn’t be able to use it because their level of household income was so low that they couldn’t do anything they wanted to with the extra time they had.

- Families we spoke to in connection with the review didn’t like the concept of in home respite and had a strong preference for facility based respite. As one woman said, if she feels that she can’t put her pyjamas on at 5pm because there’s someone else in the house, then ‘it’s not respite’.

The following case study, provided by one of the families using our respite service, gives a picture of the experience of relying on respite over the life-course. (Names have been changed/omitted to protect privacy).

Sally is the third of four children. She is 33 years old and suffers from Epilepsy and Cerebral Palsy. Sally is totally dependent for all needs. She attends a day care centre on the Peninsula.

Throughout her life Sally has made regular use of Respite Care. We always thought it important to spend holiday time with our other children and to not become so attached to Sally as to be afraid to use respite. We also recognised the advisability of ensuring that Sally was able to cope with a routine away from the family home.

Over the years the availability of respite ebbed and flowed. Initially the only facility (located in the eastern suburbs) capable of accommodating Janine’s high needs was a two hour round trip from where we lived in the western suburbs. Then, on the basis of a chance comment by another parent, we discovered existence of a facility in the western suburbs. Usually respite availability at a facility was quite good in the beginning but deteriorated as its existence became more widely known and therefore the demand for its services increased. The pattern has been repeated many times over the last thirty years and exacerbated, in more recent years, by the tendency for facilities, originally intended for temporary respite only, to be forced to become permanent homes for those unable to find other suitable accommodation. At the time of leaving our home in the western suburbs, there were two facilities able to supply a reasonable amount of respite provided it was booked well in advance and provided it fitted into Day Care Term holiday periods as there was often no care available for 6 or 7 hours during the day. Naturally the two facilities, one at Melton and the other in Sunshine were a considerable distance from our home. Any emergency accommodation was becoming increasingly difficult.

We have found the situation more difficult since our move to the south eastern suburbs. The only suitable facility is a 2 hour, one hundred kilometre round trip (in Carrum Downs). In the relatively short time we have lived in the area the availability at this facility shrunk to 3 or 4 days a quarter booked months in advance.

In July, 2007 our youngest daughter was involved in an accident in the UK and, because of her injuries, was unable to return home. We were extremely frustrated by the situation as it was impossible for one of us to join our daughter in England as the other would not have been able...
to cope with Sally. We began to investigate the possibility of placing Sally in care to enable us to travel to England. Whilst the Carrum Downs facility was a possibility, there had to be a back-up plan, so if Sally became ill or for some reason had to leave the facility, there was another option.

In the end, we were able to find a place for Sally in two different aged care homes, because we were unable to find a single facility with high care vacancy for the whole period we were going to be away. With the co-operation of the day centre, Sally was able to attend day care as normal and the exercise was a success although Sally had a number of severe seizures which required ambulances and visits to Rosebud and Frankston hospitals. When she stabilised she was taken back to the homes and continued on.

3b) Permanent accommodation

While the shift in thinking away from congregate care as the sole or preferred option is applauded, the decision to not fund the development of further shared supported accommodation in the form of CRUs, fails to recognize that there are some clients whose needs are best met with this option, or for whose families this is a preferred option. In many cases families with a family member with profound and significant disabilities want the security of institutionally managed care. In addition ageing carers’ needs and anxieties about their family member’s future may increase with the knowledge that there will be only limited shared supported accommodation in the future when they are no longer able to support their family member. Limiting the options available also negates the family’s right to have a choice in the type of accommodation required for their family member. The extent of the Service Needs Register (waiting list) is testament to this option being favoured by many families. Extensive works needs to be done with families and long term contingency plans developed, long before parents/carers are beyond their ability to cope.

It is fallacious to assume that the policy of supporting community integration for people with disabilities will itself alone translate into practice, and that people with disabilities will have the community supports they need. Concentrated community development and awareness must occur before this is a reality. A range of options for families, needs to be developed to provide some surety that their family member will continue to be supported in the most appropriate way when there are no family members around to do so. The planning process also needs to have a residential component; person centred planning should consider long term residential needs as having equal importance as other wishes and goals. Present planning focuses on what the person wants and therefore can be limited by that person’s experience. It is important that consideration of accommodation options becomes a feature of all planning processes; if it has not become an issue until that point, it is unlikely that families will consider it necessary to be planned for. In addition to long-term needs, there needs to be consideration of the options accessible in the event of an emergency such as the illness of an ageing parent or carer.

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However such an approach does not identify or help to plan for those clients who are not already linked into the service system, and who may be living at home with ageing families, and not attending a day placement.

An example of the community's knowledge of options comes from Wesley’s experience in setting up an in-home respite service. Volunteer support was available quickly, but it took a long time to find families who were prepared to take up the option. This further indicates the need for much community development work to be done to assist families to understand and access such services. Families we talked to regarding options other than out-of-home respite had anxieties about the imposition of having someone in their house, having to instruct carers as to what to do, then finding somewhere/something outside the house to occupy them. It is essential to work with families for them to adapt to the notion of co-dependency necessary for someone else to assume the carer role. While it is an attractive option for some it does not suit everyone’s life-style.

Planning needs to be holistic and forward focused and readily available to all, particularly those who may not be already linked into the service system. The notion of individual choice in person centred planning is supported, but if there are no options, information or inadequate resourcing, then it is a false choice.

Finally, at the family meeting reported in the previous section, the issue of cost of care was raised. The cost of supported accommodation in a CRU currently consumes 75% of an individual’s Disability Support Pension. Families report that this leaves little over for anything else.

3c) Private rental market

People with disabilities accessing the private rental market may find that as their personal needs change the suitability of the rented option is reduced. Wesley has several examples of the difficulties working with private landlords to install shower rails and ramps for someone who is disabled, or a family with a child with a disability and where the landlord won’t allow any modifications to be made. This raises questions about funding and regulation e.g. should we have regulations that operate within the private rental market to make it more accessible for people with disability?

4) System and service design

4a) Assessment of accommodation needs

Discussion on the accommodation issue has highlighted the absence of a systematic assessment tool to give some indication of the level of accommodation support that someone may need. Experience has shown that DHS does not have such a tool. Within Homelessness Services there is a system; the Wide Complexity Assessment tool that all providers use for Intake and Assessment, which is holistic and looks at
person in the context of the “whole of their life”, not just what that service may be able to provide.

Person centred planning approaches look at a person’s goals and dreams but may not necessarily address a person’s support needs into the future. The sixteen life areas of the new Quality Framework may provide some guidance, but attention to the development of an appropriate assessment tool is a high priority.

Wesley is aware of the Support Needs Assessment from Assessments Australia, which has been used in DHS Shared Supported Accommodation, and the Pleasant Creek redevelopment. The tool assesses a client’s physical, social, independent living, behaviour management and safety support requirements at the levels of none, minimal, some, substantial and total. This is then translated into support requirements from low to very high across the variety of domains.

It is recommended that work be undertaken to develop a mechanism to translate support levels into hours of funded support.

A CSO managed CRU in an eastern suburb is home to five ageing ladies, three of whom left Kew RS in 1999. The other two residents are more recent tenants. The ladies’ physical support needs have naturally increased with their age over the past eight years (including one resident who has had a hip replacement), and their full time attendance at a day program is proving tiring and no longer appropriate. As their needs increased the CSO found it necessary to transfer hours from another similarly funded house. While this was appropriate as a short-term measure, illness in the second house means that the “borrowed” hours must be re-allocated back to it. There being no mechanism to calculate hours of support, the CSO must now negotiate with the day centre for reduced hours of attendance and changes to its transport timetable to allow a later start. The suggestion to convert day program funded hours to residential support was unworkable, and the house has been forced to operate at a deficit.

Beach House, a large CSO managed nursing home for people with disabilities, closed in 1997. Prior to its closure DHS staff assessed the residents’ support needs and CRUs that then opened were funded accordingly. This particular population has very high physical support needs, which have increased over the intervening decade. The CSO must now apply every three months for additional funds to support the residents. A difference in regional practices within DHS means that this fund is not available in other regions.

While in the aged care service system there is a continuum of levels of support from retirement villages through hostels to high care nursing homes, there is very little similar in the disability area. Currently there are few alternatives to shared supported accommodation (CRUs), limited facility based respite and a range of community based respite options, and even these latter options are struggling to gain community understanding and acceptance. The community accepts a range of supports to ageing people, yet there is little pressure to duplicate this range within the disability sector.
Furthermore there is little activity from the market in providing supports for people with disabilities as is evident in aged care options.

4b) Role of State government

We have concerns about the dual role of government in the funding and provision of accommodation services to people with disabilities. The government’s multi-faceted role of policy maker, regulator, and purchaser when it is also a provider of services, we believe has lead to some inequities in service delivery, when comparing government provided service delivery and that provided by CSO’s. This disparity is exacerbated by differing funding levels for government and non-government services.

The unit cost (currently $39.55 per hour) supposedly has an 80/20 split between staff costs and administration expenses, however in reality the staff component is more like 90%. The unit cost is the same for all levels and times of service; consequently a middle of week “hour” is funded identical to a Sunday or public holiday hour which can attract penalties from 100% to 175%. In addition agency staffing costs are beyond the capacity of the unit cost, and can often be double what CSOs are able to offer their regular staff. It is hoped that the current costing review will address these inequities.

There appears to be a disparity in hours of staff support provided between CSO and DHS managed houses, where anecdotally CRS staff are often full time in a house with no residents during the day. The different funding levels lead to differences in remuneration levels of staff in CSO managed services compared to those managed by government.

While CSOs are funded per the unit cost system for an agreed level of hours of support, there appears to be no mechanism with DHS to monitor or review the suitability of this level of provision when people’s needs change, either through the ageing process or the advent of further disabling conditions. The move towards the concept of ageing in place for the non-disabled population has community acceptance, and should also guide the provision of accommodation options for people with disabilities.

4c) Federal government

A wide variety of Commonwealth funded support initiatives are available for older Australians and those with disabilities.

The Home and Community Care (HACC) Program is a joint Australian, State and Territory Government initiative. It provides services such as domestic assistance, personal care as well as professional allied health care and nursing services, in order to support older Australians, younger people with a disability and their carers to be more independent at home and in the community and to reduce the potential or inappropriate need for admission to residential care.
The Community Aged Care Package (CACP) program provides a planned and managed package of community care for older people with complex care needs who wish to remain living in their own home. Extended Aged Care at Home (EACH) packages are individually planned and coordinated packages of care, tailored to help frail older Australians to remain living at home. They are funded by the Australian Government to provide for the complex care needs of older people.

Unfortunately this funding is siloed and people living in CRUs in supported accommodation cannot access HACC resources. In addition it has proved difficult to have residents with intellectual disabilities assessed for aged care services, as they are often too young. This ignores the reality that people with disabilities (particularly those with Down’s Syndrome) may age more prematurely than the non-disabled population.

A guiding principle of HACC is that people are best suited to live in their communities and this is what should be pursued. There needs to be greater flexibility in current funding models to allow individuals with a disability who are ageing and residing in a CRU to remain to age in their own home if they wish by being able to access the same funding as their non-disabled peers. The “Principle” and “Model” of HACC should be part of disability policy direction.

This disparity in funding allocation is further highlighted by the following examples of the lack of service co-ordination between agencies both State and Federal, and between agencies within the State.

Staff at an eastern CRU noted that one of the residents, a man with Down's Syndrome; was becoming forgetful, lacking in motivation and showing skill loss. Attempts to have him assessed by the ACAT were unsuccessful because of his age (ACAT has a 60 year age entry). After many attempts he was eventually diagnosed with early stage dementia at CDDHV at Monash Medical Centre. He will continue to be supported in the CRU but his access to mainstream aged care services is limited because he has a disability and is receiving state funding accommodation support.

Homelessness Services provided support to the mother of a young man with cerebral palsy who was having difficulties maintaining accommodation for her and her son. The woman suffered a psychiatric condition and her obsessive-compulsive behaviours had resulted in her losing several rented accommodation sites. Her problem was compounded by the stress of caring for her physically disabled son in inappropriate accommodation. The son became the subject of a child protection order when clearly better co-ordination between the services providing support would have eased the distress and provided positive outcomes for them both. Had there been a holistic approach to the family's issues, crisis-point for both mother and son would not have been reached.

5) Skills development
Of equal importance to the development of new accommodation models is the development of skills within the disability sector to support these models. The current training of workers at certificate IV level addresses only working in CRU and facility-based respite models, and there is only limited attention to supporting people with behaviours of concern; this module often only being taken as an elective.

The difficulties of providing services to people who have a mental illness in addition to their disability is heightened due to lack of staff who have skills in both areas. This lack is evident both within the disability sector and also the wider support community — housing, recreation, welfare and medical services. The medical profession in particular is limited in its ability to assist people to access services due to their inadequate knowledge and practice for people with a dual disability.

Community education and the community’s willingness and capacity to embrace new models of support are also of paramount importance.

6) Recommendations

1. Increase the level of provision
   The size of the Service Needs Register (waiting list) is evidence of supply being far exceeded by demand

2. Increase the range of provision
   Attention needs to be given to the wishes of clients and their families around supported accommodation even when these are different to the current trend towards independent living

3. Ensure the importance of consideration of short-term respite, long-term and emergency accommodation needs within every client’s planning process

4. Ensure that community awareness is factored into the development and implementation of new models of supported accommodation especially community/independent living, also the current range of community based respite options

5. Develop a whole-of-life assessment tool which can be re-applied as people’s needs change
   The assessment process should be used to translate information relating to people’s support needs into a funding model, with capacity for ongoing monitoring and review

6. Improve inter-service co-ordination between agencies and between state authorities (e.g. DHS and Mental Health)

7. Further outsource disability accommodation service provision, except for forensic and high/secure residents, to the community service sector

8. Improve funding levels to CSO’s to ensure adequate and effective staffing levels and to ensure increases in quality of services

9. Enable people living and ageing in CRUs to access HACC funding as others in the community are able to access HACC

10. Develop and implement an up-to-date capability framework related to emerging models of support, and include the capabilities required by those who work in mainstream services who work with people with disabilities