PARLIAMENT OF VICTORIA

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

INQUIRIES INTO SUPPORTED ACCOMMODATION FOR VICTORIANS WITH A DISABILITY AND MENTAL ILLNESS

Submission by:
IAN SPICER AM
MELBOURNE

November 13, 2008
INQUIRIES INTO SUPPORTED ACCOMMODATION FOR VICTORIANS WITH A DISABILITY AND MENTAL ILLNESS

'I HOPE HE DIES BEFORE I DO.'

PREAMBLE

'I hope he dies before I do' was a comment made by an mother who was caring for a child with a significant disability and subsequently used as a title to a 1997 Report to the Commonwealth and State/Territory disability service administrators. It reflected the despair that some family carers of people with disability have as they look to the future but see no clarity on who will carry on the care when they are no longer able to do so.

A decade on and while much has been achieved, this fear is still sadly prominent in the minds of many parents who see no clear prospect of supported accommodation ever being available to their child with disability. Many of these parent carers are unable to plan for the future for as one carer stated 'I can't make provision for the future because I'm still trying to get what I need now'. Others simply hope that the crisis that flows from their death or other inability to continue their caring role will result in some agency or other taking over the task, regardless of how appropriate it may be.

For a small number, quality supported accommodation may be available but that should be the right of all with a disability who require it.

INTRODUCTION

It is noted that the Family and community Development Committee has received references from both Houses of the Victorian Parliament requesting it to inquire into supported accommodation for people with disability and mental illness. It is
also noted that the Terms of reference of both references are similar and that the Committee will undertake both the inquiries simultaneously.

The committee is required to report by June 30, 2009.

The importance of this inquiry to people with disability and their family carers cannot be overestimated and it is pleasing that both Houses have recognised this through these references. This is reinforced by the fact that research continues to disclose in Victoria that both demand and need for supported accommodation exceeds supply in terms of numbers and in the variety of options that are available.

This submission will be in three sections with the first seeking to make a short comment on the Victorian State Disability Plan 2002–2012.

The second part will deal, in general terms, with the issues of:

- The importance and role of alternative supported accommodation for people with disability and their carer families;
- Policy of "crisis management";
- Models of supported accommodation; and
- Access to information on supported accommodation options.

The third part of the submission will respond to the question raised in the Discussion Paper based on the experience of seeking to accommodate an adult child with an intellectual disability.

The submission will conclude with some recommendations.

BACKGROUND

I make this submission on a personal basis as a parent of an adult daughter who, since birth, has had a severe intellectual disability. My adult daughter is now thirty years of age and has been cared for during that time at home. She requires constant supervision and assistance with many living tasks and could only continue to live in a supported environment.

She has day activity placement funded through the Department of Human Services and is also in receipt of a "Support and Choice" package designed to develop, over time, some independent living skills.
I should also point out that I am seventy years of age, with my wife only slightly younger and have a limited time in which to be able to continue providing her care. This submission, therefore, is informed by the reality that we, like so many others with whom we have contact, see no alternative option that will continue to provide accommodation and a caring role to her when we can no longer provide it.

This submission, however, is also informed through my involvement in the disability sector. I have, for example, held the positions of Chair of the Australian government’s National Disability Advisory Council for ten years and Chairman of VATMI Industries, which is one of the largest disability employment businesses operating throughout Victoria. I am also a member of NADRASCA and Winaccom Inc., both of which are involved with the provision of supported accommodation. I am also a member of the Board of the Australian Institute of Health and Welfare, which is the body responsible for the collection, analysis, and publication of national disability data.

As stated earlier, this submission is made in my personal capacity and I make no representations on behalf of any of these organisations.

In drafting this submission, however, I have dealt with the issue of supported accommodation from the point of a person with an intellectual disability or other impaired function that will remain with them for the remainder of their lives and render the continuing need for some level of support.

**PART 1**
**VICTORIAN STATE DISABILITY PLAN 2002 – 2012**

In September 2002, the Victorian Government published its State Disability Plan for the next decade. It was an ambitious Plan and set out, perhaps for the first time, a number of important principles and goals. These principles were to be used to guide the development of government policy and programs for people with disability and the Plan set out the areas that were to be considered as a matter of priority.

Two of the areas identified in the Plan, while not prominent, were ‘Individualised Planning’ and ‘More choice about Housing’.

As a statement of principle, most would agree that its goals and objectives are excellent and provides an appropriate context for planning for the decade ahead. The concerns, however, are that its implementation is totally dependent on available funds and does not provide measurable targets assessed against identified unmet need. While the subsequent Implementation Plans identify a
great deal of activity in a range of areas, there is no basis on which any assessment can be made about whether it is making a difference to the lives of people with disability or their carers in the field of supported accommodation. Neither does the Plan make central enough the delivery of supported accommodation or the rights and roles of family carers.

All available information suggests that there are hundreds of people with disability who are on the needs register awaiting accommodation and possibly an equal or greater number who have not registered as they believe it is a waste of time.

The State Disability Plan also lists other important goals, including developing strategic partnerships and in better targeting disability supports. All these issues suggest that the Government needs to lift the implementation of the Plan to a top priority, adequately fund it and set targets for improvement that are measured against the identified unmet need.

PART 2

• SUPPORTED ACCOMMODATION AND PEOPLE WITH DISABILITY

Most families who have a child or other family member with disability would wish to care for that person for as long as they are able and for long as it was in the interests of that person and the family. Of course, there are some disabilities that may be so profound or which raise issues of personal and community safety, that specialist supported accommodation is needed and welcomed by families. In most circumstances, however, while family care would be the preferred option it must be able to come to an end when it is in the interests of the person with disability and their family. Consequently, it should be recognised that family care is not limitless and there is a time when alternative supported accommodation is required.

The greatest concern with all carer families is that there is no clear plan for the succession of the caring function when it is no longer appropriate or possible for it to be undertaken by that family. If a clear process of transition was available then families would embrace the caring role with great enthusiasm in the knowledge that they could “retire” from the responsibility and with the confidence that an appropriate level of care would continue to be provided.

It is my belief that the public policy response to the provision of supported accommodation for people with disability should be driven, at the outset, by recognition that people with disabilities and their families should experience the same basic human rights as other individuals and families.
All children have the right to grow through their formative years with the support of a family or other caring adult. While this not always satisfactorily achieved, the community recognises it as a right and seeks to meet that obligation. In addition, when that child grows, it has the option, at some stage, to choose to move out of the parent’s home and live independently or with friends. This is often part of the development and maturing of the young person. They then have the opportunity to choose and experience a range of options for later in life. Again, these are recognised by the community as a right for young people and are supported by public policy options such as ‘first home-buyer’ grants and other facilitative programs.

On the other hand, the rights of a child with disability are only partially recognised and supported. Government programs designed to assist in meeting the additional costs that arise from the disability are one positive response. However, when that young person reaches an age when they might expect to seek accommodation outside the family home there is, in reality, no option available to them should they need both support and accommodation. In fact, the opposite is the case as many public policy responses are designed to keep that person living with their parent-carer for as long as possible. These policy responses can include carer payments and allowances, the provision of respite and assistance from state and local government. While families welcome and need this assistance, the reality is that there is no other option offered to the person with disability. Consequently, this lack of choice for the person with disability results in them experiencing fewer rights than those without disability.

In addition, a person without a disability has the right to decide with whom they wish to live or whether they wish to live alone. Currently, many funded supported accommodation options do not really give that option of choice to people with disability as any placements that may become available are offered to urgent cases who often believe that it is on a “take it or leave it” basis. In that case, the need for an accommodation placement simply overrides the rights of the person with disability or their carers.

It is interesting to note that these issues are recognised in the State Disability Plan 2002 – 2012. For example, the opening comment under the heading “More choice about Housing” reads as follows:

"The Government believes that, as much as possible, people with disability should be able to choose where they live, with whom and in what type of housing – just like most other members of the community".
This embraces a high ideal and appears to provide a commitment to uphold the
rights of people with disability in the same way as others. Sadly, however, the
reality is that government will only recognise the rights of people with disability
to the extent that they are prepared to make the resources available. The stated
ideal, of course, is contingent upon someone making a judgement on the
qualification “as much as possible” and the availability of funding would be a
critical consideration. One might be excused from concluding that if the funds
are not provided by a government, the rights of citizens with disability are either
not recognised or simply disappear!

In a modern democracy such as Victoria, that champions equal opportunity and
values human rights, such a situation should not be tolerated.

There is also a significant challenge to the human rights of the parents and other
family members with a caring role. The public policy responses of promoting
ongoing care “at home” and without any conclusion (other than death or
incapacity) often means that parents have had to forgo employment (and the
ability to contribute to their superannuation) as well as significantly limiting the
care that can be provided to other children and family members. It also restricts
their own level of community and social participation.

These pressures can often lead to family breakdown with significant ongoing
social and other cost to the community.

It is my view that families ought to be able to look forward to a time when their
role as the provider of “in home” supported accommodation can come to an end
and have the ability then to look forward to resuming their rights and pleasures
of older age.

In this respect, a distinction needs to be drawn between care for people with long
disability and care for the aged. If someone is caring for an aged person
there is every likelihood that the carer will outlive that aged person and therefore
has the ability to return to his or her former life. The reverse is most likely to be
the situation with a person with a disability.

- CRISIS MANAGEMENT

While the Victorian system does continue to successfully accommodate some
people with disability in supported environments, the resources available to it
for this task are extremely limited. This has meant that while it can seek to
upgrade its established facilities, it has simply not been able to meet the backlog
demand let alone the projected need arising from the ageing of carers.
Nevertheless, the current response from the bureaucracy appears to be that the demand is “being managed”.

This means that despite the existence of a list of people who have indicated a need or desire for supported accommodation, only a very few can be accommodated at any one time unless, of course, there is an “emergency”, i.e. when a crisis exists. Consequently, families have been led to believe (rightly or wrongly) that being on a list is no guarantee for access to supported accommodation as priority is given to urgent cases which usually takes up all available places. As a result it has been observed that one way to get on the priority list is to create a “crisis”. This “crisis” as stated earlier, can be in the form of refusing to collect a family member from respite or hospital or to simply “abandon” the person in some other way. These then become priority cases and while some accommodation is often found it may be neither permanent or be the most appropriate as it may be the only option available.

Of course, to abandon a child with a disability requires considerable desperation and is not something which many would choose. Consequently, most families simply try to struggle on, often at great personal and family cost.

Regardless of whether the “crisis” is being managed by government, the simple fact is that most families are just too exhausted and dispirited to keep fighting the system without achieving success. This is demonstrated time and time again when meetings to discuss supported accommodation issues are convened by disability organisations. These meetings are attended by scores and scores of older carers who come to seek some hope that before they die, they might learn of an accommodation option for their family member with disability. To date, most remain disappointed.

Even though bureaucrats and others may argue that demand is currently being “managed”, they ignore the potential impact of ageing carers on the need for supported accommodation. This, I believe, is becoming quite critical. As has been outlined earlier, families were “encouraged” for years to care for their child with disability at home, especially at the time when institutional care was abolished. While this encouragement was actively reinforced by government policy no adequate plans or programs were developed for the ongoing caring role when the family carer died or otherwise became unable to continue the care. The generation of family carers that were encouraged by this policy to provide that care at home is now reaching old age and logic would suggest that there would be a substantial increase in the number of families no longer able to care. Little data is available on this possibility and this gap in information must be assessed as a matter of urgency.
One of the additional great concerns about “crisis” management is that it does not allow for a person with disability to transition from one form of supported accommodation to another. As a result, placements under these circumstances are often extremely traumatic for the person with disability as well as the family.

As one family carer put it some time ago, people with disability “do not have to be subject to the double trauma of illness or death of their parent and move to social services department accommodation if parents are able to permit their offspring to leave home before this event”.

Funding that bears some relationship to the real need and with a component for transition should be a priority in disability services.

- MODELS FOR SUPPORTED ACCOMMODATION

The decision to close institutional residential facilities some years ago, with the objective of moving people with disabilities to alternative community based supported residential accommodation, was welcomed in the disability community. There was little support for the large congregate care options that were highly regulated, impersonal and frequently isolated from the community. Those with a disability and their carers, however, had an expectation that institutions would be replaced with accommodation options that were not only community based but that provided both flexibility and choice to meet the particular needs of an individual with disability. These, of course, were the very things that those institutions did not provide and as such, became the reason for their closure.

This process of transition from institutional care to community based residential care, however, has been slowed by lack of funds and by an inflexible policy framework. It has also not yet delivered a ‘whole of life’ care solution that provides appropriate supported accommodation to all people with disability including those who are ageing and unable to undertake employment or attend day placement activities.

It is true that, after decades of campaigning, most former residents of the institutions who had high support needs have been relocated in community residential units (the most recent being the final placement of people from Kew Cottages). Those with lesser support needs simply found their way into unsupervised boarding houses and were often abused with many subsequently becoming homeless and falling into the prison system – replacing one form of institutional living for another.
However, as a result of the lack of funds for the relocation of those with high support needs, few government-funded accommodation options were developed and even fewer were available to those people with disability who are being cared for within families. I believe that this position remains true today as limited funds are being absorbed in the refurbishing and redeveloping existing shared supported accommodation options rather than substantially expanding the total number available.

However, while the push by the disability community and others to abolish institutions had its origins partly in their size and the number of residents at any one location, it was more fundamental than that. It was about the lack of choice for the individual, the control and regimentation exercised over the residents and their total isolation from the community.

Consequently, great care must be exercised to ensure that the alternatives to a few large institutions do not themselves become a series of smaller institutions where choice and involvement are replaced by the need to conform to inflexible rules and supervision. The reality is that a house of three residents with a disability can be as much an institution as those it replaces unless it has at its centre the whole of life needs of the residents as determined by them rather than as decided by a central bureaucracy whose major interest is to comply with regulations and awards.

Size is, therefore, not the only factor to be taken into account and a range of supported accommodation options from small houses to larger residential facilities should continue to be supported and funded.

It is clear that the process of successful transition to appropriate alternative forms of accommodation is still to be achieved within Victoria.

The response from government has been to set out a few models that it is prepared to support. Some of these models are limited and inflexible as they require the potential resident with a disability to fit into a structure over which they have neither input nor control. The view that the person with disability might be a customer with the ability to purchase a service that he or she would wish to receive, has not been part of this process.

However, the DHS publication “Housing Options Unlocked” sets out a range of accommodation options that might be available provided there are vacancies and the person with disability fits the criteria. While this is an impressive list, all are limited in number and location or are being “piloted” without a clear indication that they will be approved or expanded. Entry for most accommodation options
are either through or controlled by the DHS which, in my submission, struggle to meet existing needs.

The main option noted in that publication is Shared Supported Accommodation (SSA). While this type of accommodation is highly desired and in very short supply they are relatively expensive to run and influenced greatly be the employment conditions of the staff who provide support to the residents.

The general consensus in the disability community is that most SSA operate under very tight constraints, financially and legally, frequently have very challenging residents but nevertheless in the main deliver a quality and caring service. Overwhelmingly, most staff providing support are highly qualified and committed to their profession and to their clients.

The concern is not about the existence of SSA but that there are insufficient to meet the demand. It is also seen as a “one size fits all” solution. It does not, for example, take into account the varying levels of support required by residents, possibly providing more support than is required for some residents, thus increasing the cost. In addition, SSA models may find it difficult to provide the level of independence residents might seek, thereby limiting their social or community participation. SSA are often not conveniently located close to day placement activity or to the resident’s family and seldom provide the opportunity for an individual to choose with whom they would wish to live, which is the expectation of most citizens. It is recognised that support workers and DHS staff try very hard to meet these individual needs but when they cannot do so the residents simply either loose their rights or their accommodation.

In the main, current SSA options in Victoria conform to a model that is a house with say 3 to 6 residents with disability supported by on-site professional staff. This staff is usually not rostered on duty during the time that the residents are expected to be at their day placements. This is creating real difficulties as people with disability age and are limited in their ability to attend work or day placements. As yet no supported accommodation option has been developed to meet this demand.

But even given these drawbacks, SSA is seen by many as an appropriate accommodation model for those with medium to high support needs.

This current supported accommodation model also restricts the development of options in partnership with families who might be willing to share the cost of either the construction of a residence or the provision of support. There are many families who have some capability to share the “burden” and would wish to do
so. This ability for families to contribute is now enhanced by the development of Special Disability Trusts by the Australian Government, which allow for the creation of trusts to pay for many accommodation costs. Special Disability Trusts are currently the subject of a review by the Australian Senate that could result in recommendations to facilitate their greater use.

The ability to develop supported accommodation arrangements with families is currently limited to the model offered through Housing Choices Australia Ltd. (HCA). This model is quite restricted and usually acceptable to those with disability who can live independently or with minimal support. It is acknowledged that HCA is currently reviewing the range of options and support to provide for more flexible models and should be encouraged. Also, consideration should be given to facilitating the entry of other housing providers into the partnership market.

Some models are being developed for accommodation options with alternative forms and levels of support. For example, some residential units have “lead tenants” who have limited responsibility for residents with disability and which are supplemented by Home and Community Care Support and similar programs. Other alternatives are a “key-ring” or “hub and spokes” model where a central unit with professional support oversees a number of residential units within a reasonable distance. Unfortunately, the “key-ring” model is restricted to one licensed operator in one region and is not supported to operate on a state-wide basis.

These models provide many benefits to the person with disability and government. They allow for residents to exercise some choice about whom they wish to live, enable a family or community to assist in the funding or management of the facility, fashion the level of support to the individual residents and achieve a cheaper outcome for government.

It should be noted that in 2005 the then Victorian Minister for Community Services established a one-off grant to several organisations to undertake thirteen accommodation innovation projects. These projects were evaluated in 2007 with the learnings published early in 2008.

From these thirteen initiatives, the Report drew a number of very important conclusions. One of those learnings proposed a framework of core functions for developing housing and support. The Report stated:

“Six functions, each with different timeframes were found to be associated with achieving long term housing and support. For each person with a disability, the nature and intensity of what is required will vary.”
The core functions are:
- Establishing a willingness for housing
- Understanding, building and coordinating support requirements
- Preparing to move
- Developing and locating housing
- Making the transition to a new home
- Follow up housing support.

The six functions identified to promote long term housing are not sequential and at times will be occurring concurrently.

Each of these issues is the subject of more detailed discussion in the report and should form the basis for future planning when developing new supported accommodation models.

It is also interesting to note that the Report proposed the development of an appropriate housing strategy and stated:

"The development of a housing strategy, reflecting the six functions described would provide a framework for regions to develop comprehensive locality-based responses. A localised housing strategy can integrate various ways housing can best be developed in their area and include housing initiatives beyond the Accommodation Innovation Grant Program and beyond Disability Services Division. Such a localised housing strategy would provide the opportunity to build and incorporate roles for regional DHS staff in representing, planning, data aggregation and analysis, and service development."

Each of these initiatives and learnings are greatly welcomed and need to be used as the basis for future planning.

As noted earlier, Housing Choices Australia Ltd. is one organisation that is doing some good work in this area and they need to be provided with both the funds and the encouragement to increase their research into alternative models of accommodation and support and pilot those seen as having application in Australia.

Other Australian states and territories are also engaged in exploring alternative accommodation options and some research into them may prove valuable.

It is also noted that the Australian Government currently has a committee of inquiry into alternative ways of encouraging additional finance into disability services including accommodation options. The Disability Investment Group
was established by the Hon. Bill Shorten MP in April 2008 and is yet to report. The findings of this inquiry should seek to be informed by the work of that Group.

What should be sought are a series of options that provide for choice and flexibility for people with disability and their carers rather than models which require those who wish to access them to conform to an inflexible set of terms and conditions.

In dealing with the need to expand the range of accommodation options comment should be made on the need for planning. At the moment, little coordinated and life-long planning exists for people with disability. Some planning may take place when a child attends school and the DHS seeks to assist with post-school activity planning which could include developing connections with groups to assist with employment and social activity. Accommodation is discussed at the time of developing these plans but the emphasis is directed to the development of general living skills and employment rather than accommodation placements which are simply not available.

This level of planning assistance is welcomed but it is not adequately funded or coordinated and can seldom result in a supported accommodation placement. It also occurs far too late in a person’s life and often when a crisis exists or is evident in the near future. What is required is a planning process initiated at the time a person acquires a disability and moves through the life stages of that individual. It must include planning to access appropriate supported accommodation and age care – in other words a whole of life plan that is constantly updated and revised.

Part of the planning process would be the existence of a “transition program” to assist people with disability to move from a home residency to an alternative form of supported accommodation. Often when a crisis develops in the caring family, the person with the disability can be plucked out of that family and placed in a residential unit. In those circumstances there is no preparation or training that would facilitate a successful transition. The consequence is that considerable trauma can result if a person with disability looses at the same time their parent carer, say to death, their family home and then, without the opportunity of choice, is placed in accommodation with others who they do not know. It is a situation that should not be tolerated but could be alleviated through a through process of planning.
• ACCESS TO INFORMATION ON SUPPORTED ACCOMMODATION OPTIONS

If there has been one common concern from carers of people with disability it has been the ability to find out what accommodation services are available both from the government or non-government sectors.

In addition, there is even a concern that one group of carers often find it difficult to find out what other family groups in other parts of the metropolitan region or the state are doing to meet their supported accommodation needs.

As mentioned earlier, DHS in 2007, developed a booklet on a range of supported accommodation options titled “Housing Options Unlocked”. This was an excellent starting point for information but listed services that were inadequately funded and therefore not readily available but with entry into most controlled by DHS. It did not cover the range of local or family funded accommodation options.

It was, however, a useful publication but of limited value to families unless they met the narrow conditions of eligibility or were prepared to wait for places to become available. It also disclosed approaches that appeared to be quite inflexible and did not encourage carers or people with disability to have any confidence that changes could be made to suit the needs of individuals.

As a result of the lack of flexible government funded supported accommodation, some family funded schemes have been developed. Some are totally independent of government while others have a component of government involvement either through grants or through the payment of limited support costs. These schemes are of great interest to carers however there is no structure through which information about them can be disseminated.

There is also a great deal of information on supported accommodation that some families and organisations have gathered from throughout the world but again that is neither collated nor easily accessible.

Often carers of people with disability are extremely isolated within the community and lack both the time energy and opportunity to go searching for information. That must be recognised and assistance provided to the disability organisations to pool and exchange information which, in turn, can be made available to carers in an appropriate way.

PART 3
RESPONSES TO ISSUES RAISED IN THE DISCUSSION PAPER
As proposed in the Discussion Paper the responses to the following issues are based on personal experience and informed by the experience of other carer families with whom we have had contact.

1. **Experiences of supported accommodation – availability, suitability and adequacy of care:**

As our adult daughter is currently accommodated, albeit with her parent carers, she is regarded as not being in a "crisis" situation and no accommodation option is available even though she has been on the so-called *DHS Needs Register* for some twenty years.

We have, on occasions, sought advice from DHS on whether she is ‘moving up’ the *Needs Register* but have been given the view that her assessment of need is still very low when compared to others. Our experience with other family carers has reinforced the view that she will not be assessed as needing supported accommodation until a crisis arrives!

As we have not yet had the opportunity to experience any supported accommodation it is difficult to make comment on issues of suitability and adequacy. However, our experience of those who are in shared supported accommodation is that the level of care is usually satisfactory - although the quality does vary significantly. Location, though, is frequently a matter of concern.

Of those with whom we have had experience who are in rental accommodation with limited support, real fears are held by families and people with disability about the security of that accommodation and the availability of suitable alternatives if their leases are brought to an end without sufficient notice. The rental market is experiencing unprecedented demand with rents high and owners and their agents often reluctant to rent to people with disability. The provision of information to real estate agents about people with disability could be of assistance.

2. **Information, planning and decision making in accessing supported accommodation:**

Information has been restricted to the DHS publication *Housing Options Unlocked* and to whatever is gained from attending seminars and reading publications of disability organisations and service providers. There is no information of what
other family carers are doing and no action by DHS to bring those carers together to review options or to plan together.

This has necessitated joining advocacy groups and other organisations in order to try and create personal networks to share experiences and plan for the future. However, even after thirty years, I am still finding new groups and experiences.

Modest but valued assistance with planning has been available through the post schools program and more recently with respect to the Individualised Support Program (Support and Choice package). While this program is only available to a very limited number of people it has been very useful in both identifying and enhancing those “living skills” that need to be developed in order to ensure a transition to all forms of accommodation. The concern, however, is that these limited packages are not regularly updated or revised in line with changing needs.

The reality is that no “Whole of life” planning is offered for all people with disability and certainly no planning provides any transition to supported or other accommodation. The consequence is that while some essential living skills are learned through individualised support funding packages, they cannot be put to great use without a move into supported accommodation, which is most likely not available. The skills are therefore, either lost or if they are retained it would only be through constant repeat training.

Nevertheless, the Support and Choice packages are an excellent initiative but should form part of a “whole of life” planning program for all people with disability part of which is designed to meet the need for supported or other accommodation.

3. Other models for supported accommodation funding planning and delivery:

As indicated, planning should be driven by the need to develop a “whole of life” plan as soon as the child is born with a disability or acquires a disability. That plan should then be revisited and revised at regular intervals.

That planning must eventually lead to appropriate accommodation with quality support to the extent required by the individual with disability.

The critical observation is that there is no one solution to this issue.

Consequently, it is suggested that when considering options for the provision of supported accommodation that the following criteria be taken into account:
• Flexibility in the type and location of accommodation be achieved with the support program designed for the individual through a case based approach;
• Arbitrary restrictions on the size of supported accommodation facilities, either formally or informally by DHS and others be removed and replaced by an approach that respects the accommodation wishes of potential residents – this could include living alone, in a small group of friends, in clusters throughout the community or in larger facilities;
• Supported accommodation arrangements should range from totally government funded facilities to the supervision of facilities that are either partially funded or totally funded by a community or family;
• New accommodation arrangements for people with disability to be developed along the type and style that are encouraged for older Victorians through “retirement villages” and other aged care services;
• Projects for supported accommodation be developed that could access funds that might be available through Special Disability Trusts;
• Provide “individualised accommodation funding” arrangements in such a way that it facilitates a private market for supported accommodation for people with disability;
• Create facilities for “transition” to allow people with disability to more successfully move into supported accommodation;
• Encourage disability organisations and support agencies to extend their involvement in developing new types of supported accommodation.

While I do not want to become too definitive about specific models, some ways in which these criteria might work out in practice could include:

• Providing an annual accommodation payment to people with disability with which they could purchase the supported accommodation they require. I understand that this has been used in other countries such as the Netherlands. This would have the advantage of developing a “private” market for this type of accommodation and would allow for the family to add resources to the total in order to purchase a different types and styles of accommodation, if desired. This would also enable three or four people with disability to decide to join together to live in one facility that would pool costs, guard against isolation and enhance social participation

• Utilising the Special Disability Trusts (or similar financial facility) to develop a joint equity and/or shared support costs model. This could
mean that government may provide a set contribution according to the level of disability (low, medium or high) on the basis that the trust or some other party picked up the remainder in a way that guaranteed the ongoing contribution. This is an extension to the Shared Supported Accommodation Model with mixed equity that could go to either the building or support or both and should be facilitated in such a way that small groups of friends could live together, if that was their wish.

- Provide a per capita grant to disability organisations or service providers, based on the level of assessed disability to assist them to plan the for the accommodation needs of their clients. Funding could also be provided to these organisations to “pilot” alternative accommodation models.

- Develop a shared accommodation option where government provide a $ for $ (or a $1 for $2 or more) with families or communities for the creation of small supported accommodation facilities especially targeting people with disability being cared for by ageing carers. This might be of assistance in rural or remote areas.

- Explore options with the “retirement village” industry to extend their role to meet the needs of people with disability with or without their aged parent(s).

- Investigate the extent that the “key-ring” concept of supported accommodation could be expanded, perhaps by utilising existing SSA facilities as the hub of the “key-ring”. This could be undertaken in partnership with families of people with disability of community organisations. The Government should also look at ways to extend the existing system beyond the Melbourne south east region.

- Expand the option for “cluster” housing where a group of people with disability could be accommodated in a series of housing units or flats either on one site or many and where lead tenant(s) could provide supervision and call on support when it is needed. This could also be undertaken in partnership with families or community organisation.

There are, no doubt, many other examples of how the criteria outlined above could be evolved into specific accommodation options.

4. Implications for individuals if accommodation is unavailable or inadequate:
If supported accommodation is unavailable the person with disability is:

- Denied the right to the choice of living arrangements to which other citizens are entitled;
- Required to continue to live with carers who are ageing and who may not share their expectations or interests resulting in limited opportunity for social or economic participation;
- Subject to possible reduced quality of care as family carers age and the person with disability may end up providing the care to the parent(s);
- Living with parent carers in a “protected” or even isolated environment and may not have the opportunity to develop their full capacity and ability to live a life of greater independence;
- Reinforcing a dependent attitude and expectation;
- Often unable to exercise choice over their expenditure;
- If allocated alternative accommodation arrangements in a crisis environment and without consultation or choice at the time when their family carer dies or can no longer care;
- Limited in opportunity to develop personal relationships with others.

While there is an impact on the individual with disability, it should not be forgotten that there is also an extensive impact on family carers and the wider family. While this will be discussed later in this submission, it should be recognised that the need for families to provide care can have a substantial economic impact on that family or other carer. For instance, they will have to meet additional costs and often forgo the ability to engage in employment. Social impacts also occur through isolating the carer from the community or experiencing family breakdown. It also may mean that older carers will not enjoy any “retirement” in the way others in the community expect.

If supported accommodation is found for the person with disability but is inadequate it could:

- Endanger the physical, emotional and mental health of the individual resident;
- Restrict the ability to undertake employment or social and sporting activity and isolate them from their family and friends, if inappropriately located;

Again, the implications are not just with the residents. For example, the trauma experienced by the family and friends of residents who are inappropriately accommodated is profound, especially if there is little opportunity to resolve the situation.

5. The level of care in the provision of supported accommodation:
As my adult daughter is still being cared for at home, I have limited personal experience on which to draw. She has, however, been able to access respite services, which have provided me with some exposure and from which I have formed most of my views. I have been able, however, to supplement this with information from other families who do access these facilities and through organisations in which I am involved that provide supported accommodation or advocacy services.

That experience and observation leads me to the view that the quality and standard of care in SSA facilities is fairly good but can vary greatly. Given the range and severity of disabilities that have to be accommodated it is quite remarkable that a reasonable level of care is attained. I am aware that here have been incidences where a resident may become violent or is otherwise disruptive to the unit and the quickness with which a resolution is found and implemented has been far from acceptable. I can only assume that this results from the lack of alternative accommodation options to which difficult people can be referred.

As referred to earlier in this submission, one issue that constantly arises is that SSA facilities are staffed on the basis that residents will be occupied elsewhere during the weekdays. This means that people who might be ill and unable to attend employment services or other day placements are not able to stay or recuperate in what are, in effect, their homes. This is becoming an increasingly serious problem as people with disability age given the added dimension that people with some disabilities (e.g. Down Syndrome) will age at a faster rate than others.

At the moment, SSA facilities are stretched to deal with these situations. As a resident will not be able to remain at the residence, they often attend their previous place of employment or other activity and pass the time with their friends and often become quite difficult to deal with. In some other circumstances, I have known them to simply “roam the streets” until it is time for them to return to their house.

Extended services, especially for those who are ageing is a real priority.

The other issue of concern is that the level of service provided in a funded service is greatly influenced by conditions of employment, including hours of work or job descriptions, and by the operation of quite inflexible occupational health and safety requirements (OHS). Issues of legal liability and the fear of litigation can impact on the level of service provided.

Employment awards and agreements can often determine what jobs can be done and under what conditions which, if applied inflexibly, will not always work in
the best interests of the resident(s) with disability. OHS requirements, especially around the issue of “lifting” may mean that residents are left without an appropriate service. Fear of litigation results in many facilities providing exceptionally conservative or minimal services which while protecting the provider and staff may leave a client with a very second class service.

Each of the above comments apply in varying degrees to the provision of respite services. To them, however, can be added the concern that people with profound disability can be housed in a respite service with others that have a mild or moderate level of disability. Given the range of disabilities at a respite house at any one time, a person might be scared or fear for their safety when they are required to share with others that have violent or disruptive behavior.

The response would normally be to offer another more suitable placement to the client who is compromised, however, the reality is that most likely there will not be any alternative facility available. Consequently, a carer family is confronted with the option of forcing the person with the disability to attend a respite (or accommodation) facility “in fear” or loose the access to it totally.

Another concern flows from the number of respite services is that even though there is an entitlement to a set number of days respite each year it is usual that there will not be enough days available to meet that entitlement.

6. The impact of current approach on carer families:

The overwhelming impact on carer families arises from the fact that little or inappropriate supported accommodation exists. It may be useful, therefore, to note some conclusions that have been drawn from research by other bodies.

Findings by the Australian Housing and Urban Research Institute (AHURI) set out in its Research Paper in 2007 titled Housing careers of persons with a disability and of family members with care responsibilities of people with disability are worthwhile noting. Amongst a range of findings I draw attention to the following:

- Disability reduces household income because of the limited employment opportunities available to many persons with a significant disability and in many case they have an impaired capacity to sustain paid employment. In addition, the care responsibilities of family members may reduce the amount of time they are able to work, and hence their earnings. Reduced earnings over the lifetime significantly restrict the housing opportunities available to these people. This results in ‘flatter’ housing careers when compared with the general population;
• Many households direct a considerable percentage of earnings into health and related products that are needed because of the disability. This in turn reduces household disposable income that could otherwise be directed into housing consumption;

• Many carers are concerned about how their family member will be looked after once they are unable to provide care because of age, death or ill health. Few were able to articulate concrete solutions to this challenge. Some of the persons with a disability also articulated views about this potential risk;

• The presence of professional carers in the home is welcome by many family members with care responsibilities because it offers respite, but it also adds another dimension to the relationship between the individual and their home. Their home becomes a place of work for others, and this changes the way in which that space may be used;

• Some participants in the study believed that governments had failed to meet their needs despite rhetoric to the contrary.

Caring for someone with a disability will usually mean that carers could become socially disadvantaged. As indicated, the caring role impacts on their social life, their financial situation, their ability to work, their health and their general wellbeing. Carers would agree that they need more respite and more emotional, financial and practical support and especially as many are single women often on low incomes.

Nevertheless the AHURI Discussion Paper did conclude with the comment that:

The report has shown that over the last 20 to 30 years there have been significant drivers of change, including increased demands by persons with a disability to be housed appropriately and independently; shifts in house prices that have limited the capacity of some groups with a disability to relocate or move to more appropriate housing; the emergence of new forms of care – including group homes; and price pressures in association with shifts in dwelling form and public housing provision that appear to be concentrating persons with a disability in outer suburbs.

Unless more resources can be made to deliver the variety of supported accommodation needed, families will continue to suffer financially and socially with an increasing incidence of mental illness and family breakdown.
7. **Issues in regional and rural Victoria, CALD backgrounds and Indigenous Victorians:**

I have very limited experience in each of these areas and cannot add greatly to the discussion.

In regional Victoria, the great challenge is to try and provide a range of supported accommodation services that are local and close to family and friends when the numbers at any one location might be quite small. One consideration might be to establish specialist but separate small facilities that connect with existing health, community or aged care services.

In addition, there are too few respite and other facilities throughout non-metropolitan Victoria even though the ability to partner with groups in smaller communities may be far greater.

Cultural and Indigenous relevant services provide very special challenges and to date they have not been dealt with very successfully and people with disability still appear to be mainly cared for through extended families. This often means that those people are isolated from the community and from others with disability.

Clearly, close consultation with both communities must be undertaken in order to determine the best way forward.

**RECOMMENDATIONS**

The following are some recommendations that are drawn from the above commentary:

1. The Victorian State Disability Plan should be revised with the objective of providing the highest priority to the provision of accommodation and especially supported accommodation options. The Plan should ensure the development and funding of regional and localised housing strategies.

2. The State Disability Plan and DHS policy should recognise the importance of coordinating housing with social programs and day activities through the implementation of an individualised “whole of life” plan that is revised regularly to reflect changing needs.
3. Revise DHS policy to recognise that a person with disability accommodated with family carers is not living in “their own” home and should not necessarily be classified as being satisfactorily housed.

4. Research should be undertaken by an independent agency to prepare a detailed state-wide assessment of the extent of the “need” for supported accommodation. The data should aim to reflect the need throughout the disability community and not just measure the “demand” for services which include only those who are existing users of CSTDA funded services and have registered an interest in accessing accommodation. Only through measuring need as against demand can a true picture of the supported accommodation deficit be determined.

5. Even in the absence of the information proposed in Recommendation 2 above, it is clear from existing published data on the demand for supported accommodation that both the current and planned availability goes no way in meeting the demand. As a result, it is recommended that the government determine a five to ten year plan to increase the number and range of supported accommodation options and particularly for those people with disability who are being cared for by ageing carers. That plan should include funding options in partnership with families, communities, charitable organisations and commercial enterprises.

6. The Government to establish an ongoing Innovation Fund that can fund trials for alternative supported accommodation options. The Fund should be adequately resourced so that it could respond to proposals for accommodation put to it by existing disability housing providers, community housing groups, disability organisations, commercial housing developers and family carers of people with disability. The learnings from the “Evaluation of the Disability Services Accommodation Innovation Grants scheme in 2007, should guide the development and operation of the Fund. In addition the findings of innovative projects should then be used as a basis for consultation with the disability community and built into the implantation of the State Disability Plan.

7. As interim measures:
• The proven projects from the Disability Services Accommodation Innovation Grants Project, 2007 such as Neighborhood Connections, Direct Life, Choice in Living, Access Accommodation the community Living project and others, should be identified and appropriately funded to operate throughout the state where demand is identified;

• In addition to the above, the “key-ring” style of supported accommodation service should be recognised as a proven option and should be expanded throughout the state to meet identified demand;

• Discussions be undertaken with the Australian Government and Local government to extend the operation of the Home and Community Care (HACC) packages and other “in-home” supports to assist those who do not need full-time support to live more independently;

• Establish or fund a central brokerage agency, similar to the Independent Accommodation Network (IAN) to assist carer families and those with disability find compatible “flat mates” (either with or without a disability) as well as having a role to find “lead tenants” to live with people with disability;

• Establish a “one stop shop” agency, perhaps at a local government level, where people with disability and their carers could go for information and assistance about programs delivered either by the Commonwealth, State and Local Governments. This facility should also be funded to put together workable packages of programs that could assist in placing a person with disability in supported accommodation and then refer them to the appropriate bodies;

• Fund and facilitate the creation of local networks of family carers and others who have an interest in supported accommodation options so that they can exchange ideas and plan for localised solutions and to connect these networks on a state-wide basis. Currently, many carer families are isolated within the community and groups in one area frequently are unaware of activity in other parts of their city or state;

8. Develop expanded “individualised funding” packages to all eligible people with disability and make the payments direct to them. This would put money into their hands that could be used to fund a “whole of life plan” and at the appropriate time, allow for the person to choose and fund the type of supported accommodation that they need. At this stage the “individualised funding” packages that do exist are too
restrictive and controlled and limited by resources and do not necessarily lead to accommodation.

9. Establish improved information on supported accommodation options through service providers, advocacy and other disability organisations and Centrelink. This information should be distributed to all people with disability in a "pro-active" way rather than only being available on request.

10. Commission experienced individuals and organisations to develop "whole of life" planning services that would guide the family and government in the provision of services at appropriate times throughout the life of the person with disability.

11. Explore connections between disability and aged care to determine if
   • Aged care type funding arrangements could be used to provide supported disability accommodation; and
   • Aged care facilities can be made available to people with disability who are ageing.

12. Transition training for people with disability who are seeking to move to supported accommodation be established so that the needs of all parties are successfully met.

13. Discussions should be undertaken with the real estate industry to explore ways of eliminating discrimination and delivering greater rental opportunities and security for people with disability.

14. Expand the number and location of respite services with some respite services specialising in related disabilities. Particular attention needs to be given to the availability of appropriate respite in regional and remote regions of the state. Experience discloses that many families caring for a person with disability are frequently unable to avail themselves of their "entitlement" to respite as it is either unavailable when required or simply not available at all.

---------oooOooo---------