29th September 2008

Family and Community Development Committee
Parliament House, Spring St
East Melbourne
Vic 3002

Dear Family and Community Development Committee members,

Karingal Inc and Gateways Support Services welcome the opportunity to make a submission regarding supported accommodation for Victorians with a Disability or Mental Illness. Please see our submission attached.

Both Karingal and Gateways are based in the Barwon South Western Region of Victoria and have a shared commitment to these high need Victorians. On a daily basis we see the serious consequences of the shortage of appropriate supported accommodation on individuals and their stressed families.

Community service organisations like Gateways and Karingal seek to work in active partnership with government to improve outcomes and quality of life for people with disabilities and mental illness and their families.

Thank you for considering our submission within your inquiry.

Yours sincerely

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Inquiry into Supported Accommodation for Victorians with a Disability or Mental Illness

Karingal Inc. and Gateways Support Services – Joint Submission

Karingal

Karingal is a not-for-profit community organisation that has been operating for 55 years and delivers a wide range of disability, aged and mental health services and mainstream employment programs. Karingal has extensive experience in the provision of accommodation and support services. Our services in the Barwon-South Western Region include shared supported accommodation, independent living units and a range of in-home, personal care and community access supports available to people with intellectual disability, physical disability, acquired brain injury, neurological conditions and people with a mental illness.

Karingal’s mission is to provide quality services that improve the lives of individuals.

Gateways

Gateways Support Services is a disability agency based in the Barwon South Western region of Victoria. Gateways has provided a range of disability services to children and adults with disabilities and complex needs, including respite and supported accommodation services for 20 years.

Gateways supports a significant number of people with autism and their families as well as people with multiple disabilities and/or complex health needs. Gateways also support a small number of people who have a dual disability eg intellectual and/or physical disability and psychiatric diagnosis.

Background

In the 1970s and 1980s, there was a move away from institutional care to community based care. Families who had a child with a disability were actively encouraged to care for their child with the advice that there would be a range of supports to assist them.

Approximately five years ago there was a shift in government policy away from expanding supported accommodation, to individualised support within family homes. Increasing the range of service models is a positive and caters well for particular groups. However, this change has severely disadvantaged and taken away hope for many families caring for adolescents and adults with moderate to profound disabilities, who are not able to live independently. For these families, they see no light at the end of the tunnel. They are faced with the prospect of caring until they die and not seeing their son/daughter settled into a safe and supported environment while they can have input into this process.

The Auditor General’s Report on supported accommodation 2007 notes that:

"DHS is unable to provide support for all those requesting it (unmet demand is around 1,370 people or 30 per cent), yet demand is increasing by around 4 to 5 per cent"
annually and DHS has not accurately quantified future support needs or the associated need for resources. The reactive nature of DHS’s response to accommodation needs, combined with the stringent prioritisation criteria, is likely to continue, and therefore perpetuate a crisis-driven system.

"DHS has estimated demand for Shared Supported Accommodation (SSA) will grow by around 4 to 5 per cent annually from the current level of 4,600 people. Some steps have been taken to address this growth but not in the structured and cohesive manner necessary to reliably address this growing demand."

"Over the past four years, DHS has created 77 new facilities to replace unsuitable facilities but has not increased SSA bed capacity."

Following is our response to the questions listed in the Inquiry document.

1. **What have been your experiences with supported accommodation in Victoria with regard to availability, suitability and adequacy of care for people with a mental illness or disability?**

Karingal on a day to day basis, is faced with the difficulties arising from the lack of availability of the range of supported accommodation options described in the Inquiry document. Based on a survey undertaken with key co-ordination staff and their knowledge of people with disabilities who access services through Karingal, the estimated demand for accommodation and support services over the next five years is:

- 101 people requiring shared supported accommodation (24hr support). 50 of the people have ageing parents/carers; and
- 36 people requiring housing and individual support packages to enable independent living.

Some of those waiting for services include:

- A 52 year old man with an acquired brain injury who is presently living in Residential Aged Care.
- A young lady with severe physical and intellectual disability who has been living in varying interim and respite support arrangements since February 2008.
- A young man who has been living in interim accommodation since November 2007.
- A 64 year old man whose mother has moved into a nursing home and who requires an individual support package to enable him to remain living in his family home.
- A middle aged lady who has been living on an interim basis in a respite services since January 2007.

Karingal operates a residential respite service in Ocean Grove. Since 2000 this service has, on an almost continuous basis, provided interim support to between 1 and 3 people who are waiting for a long term accommodation and support option. Invariably people live at Ocean Grove on an interim basis for a minimum of twelve months before they are able to move to a suitable long term option.
For people with a mental illness there appears to be a high reliance on the use of Supported Residential Services as they are the only option available. While these services may cover the very basic physical/ accommodation needs they are limited as there is

- A lack of outreach support to enhance and support mental health recovery goals.
- Inability to respond to the complex health care relating to the individual’s diagnosis with inadequate staffing (both in numbers and experience).
- A lack of long term planning to ensure a holistic integrated approach.
- Very minimal, if any activities or community based services for clients who need additional support.
- A lack of transition planning and support and no rental history results in people experiencing great difficulty entering general rental market and accessing rental or bond assistance.
- Compatibility issues including living with people who are frail aged or with people with varying disabilities.

Gateways currently manages seven community residential units for people with disabilities with complex needs – six in Geelong and one in Camperdown. The quality of care in disability supported accommodation is generally good with clear accountability under the Disability Act 2006. The Auditor General 2007 report (page 19) noted that “In the CSO’s we visited, we saw active support and person-centred approaches embedded in service delivery.”

Compatibility of residents is important but the big issue is extreme unmet demand.

Dual Disability - There is a lack of appropriate support and specialised placements for people with a dual disability, for example people with an intellectual disability, autism and a mental illness. Gaining access to recognised assessment services takes a long time and is Melbourne based. Access to the mental health system for people with a disability may take months or even years and access to behaviour services is also a lengthy process. It is very likely that in the meantime the person’s living situation will break down.

The coordinated care of these most complex people needs urgent attention at a strategic, service delivery and individual level to offer immediate and much needed support to families such as:

- A single parent struggling to care for her physically large autistic son who disrupts and physically threatens his young siblings with a knife. Two adolescent siblings are depressed and suicidal.

**Recommendation 1**
*That additional supported accommodation is made available for adolescents and adults with complex needs as well as for people with intellectual disabilities supported by ageing carers. (This is also supported by the autism state plan consultation process).*

**Recommendation 2.**
*That coordinated supports and specialist placements are available for people with dual disabilities.*
2. What is your experience in trying to access supported accommodation in terms of information, planning and decision making?

Access to supported accommodation for people with a disability is through the Department of Human Services (DHS) Disability Support Register (DSR). In our experience this process lacks transparency and independence of decision making.

DHS Disability Services is responsible for making a decision to register the applicant on the DSR. This includes the recommendation for Priority Status. There are no service users or community representatives included in decisions relating to registering a request on the Disability Support Register and determining 'priority status'.

People with disabilities, their families and service providers are advised that a person has been accepted onto the DSR but are not advised if they have been determined as having priority status. This leaves no mechanism to appeal this decision.

The Disability Services' Priority Status Criteria does not include homelessness or as is more often the case, 'hidden homelessness'. Priority is given to people wishing to move from funded Shared Supported Accommodation to independent living. It is not given to people wishing to move from inappropriate, more restrictive living situations such as Supported Residential Services, Residential Aged Care (over 50's) or 'makeshift' living situations such as motels, caravans etc or those living long term in respite.

It is extremely difficult for families to gain access to the supported accommodation system. People may be listed on the DSR for many months and even years waiting for an individual support package or a shared supported accommodation placement. The demand management strategy through the DSR puts up multiple barriers and many people simply give up. Gateways and Karingal attempt to support families by assisting them to complete the necessary documentation whilst also providing emotional support and interim support even though we are not funded to do this.

Other families see no choice but relinquishing care by leaving their son or daughter in respite, as they come to the conclusion that this is the only way they can gain a place in a crisis-driven system.

Because the DSR only measures immediate need, it does not promote or support long term planning.

In relation to mental health services there is no defined access to accommodation and support. For some people with a mental illness, despite modern treatment approaches and the ideology of community care, they remain as long-stay patients in hospital or community residential facilities unable to be discharged as there are no specialised accommodation and support options that can respond adequately to their psychopathology, disability or behavioural disturbance.

The health care system now includes a large group of patients who have responded to treatment, but have residual symptoms and require ongoing care and support, but do not have access to family or similar help. Historically, these patients' care pathways would have often involved lengthy periods in psychiatric hospitals. For these people the lack of access to safe, secure and supportive housing along with the right levels of outreach
support can lead to an exacerbation of their mental illness and severely impact their rehabilitation and recovery.

**Recommendation 3**
*That the DSR be reviewed and revised to ensure timely access for people requiring support, transparency of process, priority status and funding allocations.*

**Recommendation 4**
*That a long term approach to service system planning and design and individual planning is established immediately.*

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

**Transitional Accommodation Services**
- Safe, consistent and secure supported accommodation and support options for people while they are waiting for a long term accommodation and at the same time ceasing the use of respite for this purpose.
- Slow stream rehabilitation focus accommodation and support for people with very severe acquired brain injury to prevent admission into residential aged care and to enable individuals and families to plan for a return to the family home or to community living.
- Specialised recovery based rehabilitation options for people with chronic and severe mental illness.
- Accommodation and support options that can respond to the episodic and changing needs of people with progressive neurological conditions.

**Unit developments (1-6 units)**
- Communal living and opportunities for sharing support and mutual support.
- Accommodation for ageing carers and their family member.
- Transition to independent living.
- Alongside a 24 hr shared supported accommodation to enable back up support to people in independent living.
- Attached to family homes.

**Accommodation options connected to Retirement Village living**
- Located near retirement villages and offering long term accommodation for family members of people who are ageing.

**Shared Care Model**
- Offering part-time accommodation and support to either adults or children with complex needs and incorporating shared care with families/carers.

**Respite**
- Increased access to respite particularly facility based respite to assist families (that choose to do so) to continue to care for their family member within their family home.
Service Provision and Planning

Best Value
DHS needs to urgently move to greater use of Community Service Organisations (CSO's) to deliver accommodation and support services as CSO's deliver better value for money in terms of supported accommodation services.

Proactive Planning
Person and family centred planning at an early stage must guide the pathway that is developed to facilitate the provision of safe and realistic care for people who can not live without supervision. Ensuring that families who have born the responsibility of care for many years to have peace of mind is of paramount importance.

Matching Support with Accommodation
In all instances it is vital that the support component matches the accommodation component and priority is given to people to plan and achieve their personal goals in their living situation.

Housing
The housing component of the above listed options could be achieved through partnerships with Affordable Housing Associations or potentially with property developers. The present limitations associated with CSO equity into housing, and accessing Affordable Housing Association for accommodation options that include staff support, would need to be addressed.

Recommendation 5
That priority is given to establishing a continuum of a sustainable long term and transitional 24 hour support services.

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

People who are in critical need of accommodation and support services are compelled to access a range of interim accommodation and supports as there are no adequate or available alternate options.

‘Hidden Homelessness’ applies to many and varied living situations, or a series of these are ‘created’ for people who do not have an ongoing accommodation and support option.

These include but are not limited to:

- Supported Residential Services (SRS) – at least anecdotally there appears to be a greater reliance of the use of SRS' to meet the unmet need associated with accommodation and support. People are compelled to use these services as they are the only option available.

Supported Residential Services that primarily operate for people who are ageing are offered to people aged from early adulthood onwards. As a congregate care
facility that does not offer individualised support, it is not possible to align the use of SRS with the goals of the State Disability Plan 2002 – 2012.

- Respite Placements – living long term in a respite facility and the subsequent impact this has on people who wish to access respite.
- Motels, cabins, caravans and the like – people being placed in makeshift accommodation that does not provide a safe and secure option for the person with a disability and may not provide a safe working environment for their support staff.
- Residential Aged Care for those over 50 years of age.
- Continuing to live with family/carer past the time that this is a positive experience. This often occurs at great cost to the health and well being of all concerned.
- Rotating Couch – individuals with a mental illness seeking overnight or weekly ‘couch’ options with families and friends.

**Accommodation Innovation**

Accommodation Innovation Grants – DHS funding to enable selected organisations to develop innovative ways of supporting people with disabilities to locate sustainable housing.

The findings of this project demonstrated that there needs to be experts in housing to navigate through the complexities associated with different housing options and financing schemes.

The outcomes of this initiative for people associated with Karingal includes people purchasing their own homes, people accessing housing through private rental, government housing, affordable housing associations and the development of networks to support housing sustainability.

While the project was successful in securing housing for people it is limited by the lack of access to individual support packages for people seeking to move to a more independent lifestyle.

**Recommendation 6**

*That priority is given to aligning access to housing and individual support packages based on individual needs.*

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

The aged care sector demonstrates that private; the community sector and the health care sector are all capable service providers. There is though, a far more highly developed structure that underpins this service provision. This includes but is not limited to Approved Provider system, complaints mechanisms, accreditation processes and the Office of the Aged Care Commissioner. The Commonwealth Department of Health and Ageing is the funder and regulator of these services.

Apart from Supported Residential Services, the majority of accommodation and support service provision in Victoria is provided through state or local government and the
community sector. There is no consistency of accreditation, regulation and compliance monitoring across these services.

In relation to Shared supported accommodation, both DHS and NGO’s support people with varying needs yet in 2006, the non government sector was funded at an average rate of $68,545 per person and the government sector was funded at a rate of $92,460 per person in 2006, a differential of more than 25%. In addition DHS managed services have received a far greater allocation of capital funds over the past four years.

Supported Residential Services do not have the capacity to provide the level of care and specialised support required for people with complex care needs.

As noted previously "The Auditor General 2007 report (page 19) noted that “In the CSO’s we visited, we saw active support and person-centred approaches embedded in service delivery.”

Gateways consumer feedback from families includes the following comments:

“\textit{We have found all staff at (House Name) to be very caring and supportive of client D on her good and not so good days. She is always happy and supported in the things she wants or tries to do. She has learnt to be more accommodating to others needs and has learnt a lot of independence skills. We feel she is in a wonderful environment and we can't wait to see how far she can go towards self improvement and more skilled}”

"\textit{I could not be in a more supportive or caring environment}"

\textit{The people involved at (House Name) are some of the best and most appropriate for the job. The care that is given to the clients is of an exceptional standard}"

**Recommendation 7**
That at a minimum all new shared supported accommodation services are managed through Community Service Organisations.

\begin{itemize}
\item 6. \textit{What are the positives and/or negatives the current approach to provision of supported accommodation have on families and carers.}
\end{itemize}

For families it is a ‘no win’ situation. They are encouraged to plan for their son or daughter’s future but realistically unless their situation is critical, they will not be able to access accommodation and support services.

Additionally, the number of people using respite facilities for interim support limits access to respite.

We see enormous family stress as families struggle to balance the needs of the person with a disability with the needs of siblings, or are physically worn out by the demands of caring 24/7 for someone with complex behavioural needs or someone who is totally dependent for all their care, or a young person with an intellectual disability and mental illness.
The stress and demands on some families is exhausting and deeply demoralising. For example:

- A single parent struggles to care for her physically large autistic son who disrupts and physically threatens his young siblings with a knife. Two adolescent siblings are depressed and suicidal.
- Grandparents are physically exhausted and depressed after they attempt to support their single parent daughter to care for her severely autistic son with complex behavioural needs. The grandparents are distraught that they can no longer continue to sustain the family support.
- A single parent father cares for his son and other siblings until the young man with autism is 18. The father says clearly that he can not continue and will relinquish care leaving his son at respite unless a placement is made available for his son.
- A mother has cared for her daughter with a moderate intellectual disability hoping that when she becomes an adult she will move into supported accommodation, and the mother can then at last have some rest and time for herself. She is devastated and depressed to discover this will not happen until she dies. Her daughter then suffers a psychiatric episode and is diagnosed with depression increasing the burden of daily care.

This mother wrote:

"After being a carer for 21yrs now & with no light at the end of the tunnel, I would like to think that we have a right to live a NORMAL LIFE before we get too old.

Parents/Carer’s need to know, for their own peace of mind, that the person they care for is settled into accommodation before they die. The "Decision Makers" need to consider how traumatic it would be for our disabled child/adult to lose a parent or parents & then be ripped out of the family home & placed into care, because there is no-one else left to care for them.

These disabled children/adults need to be with people their own age, NOT ageing parents who’s priorities & interests are quite different to theirs.

There is probably so much more that I could say, not to mention the sacrifices we have made, because we wanted to care for our daughter in the very best way possible. Career moves have not been taken, working weekends for the last twenty years, so there was always some-one home to care for our daughter. The list could go on, but I won’t!!!"

Recommendation 8
The burden of care on families caring for people with complex needs is recognized and increased options for out of home care including residential respite are progressed urgently.

What issues need to be considered in the accessibility and provision of shared supported accommodation for people from:
• **Regional and rural Victoria** - The provision of supported accommodation should be available to people in their local communities to enable them to maintain their support networks. Access to public transport is a critical component of maintaining independence and enabling community participation.

• **Culturally and linguistically diverse backgrounds** – Services must have the capacity to respond to diversity of needs.

• **Indigenous Victorians** - This group tends to be under represented in disability services due to cultural reasons, so a targeted strategy based on consultation with indigenous Victorians seems appropriate.

7. **What other issues need to be considered which have not been addressed by the above questions?**

**Community Education**
Raising awareness and understanding of people who live in their community and who have diverse needs.

**Accessible Housing**
The lack of accessible housing and access to funding for major modifications is an ongoing issue in relation to assisting people to access housing and also in providing a safe working environment for support staff.

**Department of Human Services**
The roles that DHS plays in the service system includes individual and systemic planning, individual and systemic funding, multiple regulatory mechanisms, quality accreditation, and service provision. This creates tensions and conflicts for people with disability, families, service providers and the department.

**Service System**
We need to design a system which is:
- not crisis driven;
- able to provide a planned approach to a range of real and safe options for people with disabilities and complex needs, so that families can retain some dignity in planning for the needs of all their loved ones;
- able to lessen the enormous physical and emotional toll on families;
- designed to promote quality of life and continuing developmental options for people with disabilities;
- based on a sustainable workforce capacity and representing best value in the use of taxpayers funds; and
- innovative and provides a continuum of options.

**Recommendation 9**
*That DHS as a matter of urgency define its key functions and withdraw from incompatible elements.*