Submission prepared by the

Centre for Developmental Disability Health Victoria (CDDHV)

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

by the Family and Community Development Committee

October 2008

PART A: Introduction and overview by Professor Robert Davis, Director of the CDDHV

The goal of the CDDHV, as an academic unit associated with the Department of General Practice at Monash University, is to improve health outcomes for adults with developmental disabilities by enhancing the capacity of generic health services in Victoria. This is approached through education of health professional, research projects and clinical services. The CDDHV clinicians advise and support referring GP's through secondary or tertiary consultations and clinical assessment as appropriate, and provision of detailed educative reports.

As the CDDHV is a referral centre for assessment of medical and psychiatric problems of people with development disability from across the state, the clinicians at the Centre often face issues that are either caused by or contributed to by problems related to accommodation. Further to this, resolution of the problems for the person with intellectual disability or autism is dependent on finding suitable accommodation, a process that may take years.

The main problems will be discussed under four headings:
- Availability
- Suitability
- Support Infra-structure
- Accountability

Availability

With long waiting lists for access to accommodation across the state, placement is usually crisis driven. This means that the person and their carers remain in a continuing state of stress and at times physical threat while waiting for placement. We have many examples where elderly parents are placed in intolerable situations while waiting for the placement of their son or daughter. Given that these are life-long disabilities the need for accommodation can be anticipated and resources allocated well ahead of time. Instead, money is spent patching up situations that are unsustainable only to repeat the process when things inevitably fail.
Suitability

Related to the lack of available placement is the issue of suitability. People with intellectual disability rarely play any part in choosing who they live with. A person’s placement is often decided on by a place coming up at the time of crisis that has lead to the placement of the individual. Care should be taken to ensure that the placement both suits the new and the existing residents. It needs to be recognised that while house staff may have proved themselves capable of dealing with some of the more challenging behaviours loading the house with more individuals with challenges may result in a disintegration of what was a working environment. There needs to be greater communication between the accommodation staff and people making the decision on placement.

Support Infra structure

Staff will often have very basic skills as carers and often struggle with the extra demands that come with people with physical and mental health problems. This is compounded by high turnover in staff due to low pay scales and a lack of career path. The continuing reliance on casual staff results in inconsistencies and a lack of accountability. While Behaviour Support Teams provide support in the management of the clients with more challenging behaviours, the lines of responsibility mean that recommendations are at discretion of the accommodation management hierarchy. Houses dealing with complex social, medical and behavioural issues are unlikely to be well managed if the supervisor for the carers works off site. The position of house supervisor requires skill levels equivalent to that of a registered nurse with the ability to apply knowledge usually expected from bachelor level degree courses. There also needs to be a career path in place with support networks and opportunities to avoid burn out.

Accountability

There are limited processes in place to review just how well accommodation services are meeting the needs of individual residents. When parents are still involved then there is at least an opportunity to review a person’s progress and the suitability of the accommodation. When there are no parents then there is a risk of a person remaining in unsuitable accommodation for protracted periods. While GSPs and IPPs or their equivalent might be in place it is unusual that the accommodation gets changed unless there is some very strong advocacy from the parents or others or a break down occurs. There needs to be a prevailing attitude that reflects the needs and aspirations of people with intellectual disability.

The way forward

Currently there is simply not enough accommodation out there to support existing needs and urgent action needs to be taken to rectify this. There are a number of extremely well run services which rely on the professionalism of individuals and organisations often against the odds. There should be a
process that encourages promotion of best practice and for staff to work as extra support in these environments to build skills and attitudes. The skill set required and the level of responsibility demands that house supervisor level and above should have bachelor or bachelor equivalent qualifications. Having the Certificate 4 course relying on 'on the job training' where the standard of staff as role models may be questionable, limits the capacity for change.

**Part B: Response to questions suggested in the Discussion Paper**

*by CDDHV clinicians who have personal, professional and community experience of accommodation services for people with developmental and associated disabilities.*

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?

There has been an apparent decline in the availability of accommodation places relative to demand.

The vision when the Victorian government first started funding community-based residential units for people with an intellectual disability as part of Deinstitutionalisation and the recognition of the rights of people to live 'in a normal house in a normal street', was that small groups of people would live together in a long-term, stable setting with sufficient support to enable them to live lives as close to community norms as possible. For this vision to be achieved there needed to be enough places available for placement to take into account the needs of the group as and the impact of a new resident on the well-being of other residents as well as the needs of the new resident. With sufficient accommodation places available, in a variety of formats to meet the varying needs of this very diverse population, placements could be planned and executed in a way that ensured the best chance of long-term success for the person and the group. In the beginning, the commitment of the government and the department was high and the system seemed to be working well.

Since then there has been a broadening of the types of accommodation available for people with developmental and associated disabilities – in home support, outreach support, home board programs, co-residential programs etc as well as the more traditional staffed residential house (CRU/SSA) – but the overall supply has become increasingly inadequate to meet the needs.

This shortage of residential places has led to inordinately long 'urgent waiting lists' that do not really function as waiting lists as people's desire/need for accommodation is not actually addressed until there is an actual acute and serious crisis. Once a person is actually homeless or abandoned or their parents have died or become physically incapable of continuing their caring role, the person is placed in whatever temporary emergency or respite accommodation can be found and may live in very destabilizing circumstances until their case workers can convince the admissions
committee that theirs is the most urgent and compelling need for an available placement, whatever or wherever it is. Placement of very stressed people without an adequate settlement process in settings that may not suit their emotional and support needs can be very destabilizing and lead to adverse effects on the well-being of the individual, the other residents in the setting and the support staff caring for them and dealing with the results can be very costly for the service.

How much better, from all perspectives, is the scenario which is possible if there is an adequate supply of accommodation? The best scenario is when the young adult moves out of home to a supported accommodation setting with the support of their parents. The transition can be planned and parents involved in smoothing the process, informing staff about what their son/daughter does and doesn’t like; how they express pleasure, pain or illness; who their friends are and what daily routines they currently enjoy. The young person can be proud of their new home – after all they have moved out just as their siblings have! The parents can stay involved but have the ability to move into their retirement years having time for themselves, time for their partners and other family members, and time to contribute to their communities.

At the CDDHV clinicians very frequently see people with intellectual disabilities who have been referred because their behaviour is interfering with their capacity to function in society and putting them at imminent risk of placement breakdown in both their day program and accommodation. The behaviour may be a manifestation of psychiatric illness, autistic spectrum disorder, behavioural phenotype related to their disability, physical illness or pain, sensory dysfunction, frustration, relationship issues, abuse, isolation, anxiety or a combination of these and other factors. Our assessment can help elucidate causes and make management suggestions, but lasting improvement cannot be expected if the person lives in a setting that is unsettling, insecure and does not provide the physical and emotional environment and adequate familiar trained staff to meet their particular needs, or worse still is moved from setting to setting in a spiral of failed placements and escalating distress.

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

In the past, I have been aware of examples where the system has worked very well, with a person who was identified as being ready for supported accommodation but not in a crisis situation, has been on a local waiting list and been offered a place in a setting that was identified as meeting their needs when a vacancy has occurred. The person, their family, and the other residents in the house have all been involved in the decision making process and the carefully managed process of moving in and becoming part of the local community. This is normalisation, the way other people in the community approach moving into a shared accommodation setting, and some of these placements have worked effectively for over 20 years.
In the more recent past, I have advocated strongly to support the single mother of a young man with severe autism and intellectual disability who herself had mental health issues and could no longer safely care for her son. She needed a lot of support and practical assistance to deal with her ambivalence and self-blame and to become the very ‘squeaky wheel’ that it was necessary to be, to bring his case to the attention of those making the decisions and those with influence over them. In a situation of insufficient supply, it becomes a case of who can present the best case to win the available place and not everyone has the same skills and resources to make a convincing and compelling case. A place is filled but it may not be with the best person in the matter of long-term benefit and well-being of all involved, and it always leaves others - people with desperate needs and people who would blossom and be an asset in the setting – still unplaced.

At the CDDHV I am told by bewildered family members and defeated Case Managers that there is no prospect of placement within the coming years and that there is no point even presenting their case at this stage as they do not meet the priority criteria of homelessness to even be considered. If a placement is offered but family members have serious reservations about its suitability for their loved-one, they are under considerable pressure to accept it regardless of their misgivings. And once a person has a placement, the chances of then moving on to a more suitable setting are almost negligible unless the circumstances are exceptional. Similarly, where the environment in a house becomes markedly less congenial due a change in the resident mix, there is very little family members, advocates or concerned staff can do about it, and the quality of life and the safety and well-being of everyone can be severely compromised. Situations such as these can sometimes drive family members to take desperate and devastating actions to solve the problem.

Very little planning is possible because of the lack of accommodation. It situations of urgency (death or permanent disability of caregiver) the person with an intellectual disability is shunted into whatever accommodation is available on the day, often living in ‘respite’ for up to years at a time, in a household that changes every day of the week because of its need to provide respite accommodation to others. Families and people with an intellectual disability have no involvement in decision making apart from the right of veto, which, due to the usually dire circumstances, they are not in a position to exercise and even this can be removed from them at a Guardianship hearing if others argue that a Guardian should be appointed to make the decision.

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

As with the general Australian community, people with disabilities are a very diverse group with a wide variety of skills, personalities, interests, cognitive levels, communication styles, behaviour patterns, emotional strengths, sensory perceptiveness, mental and physical health, ages and cultural
backgrounds, and like others, they will change over the course of their lives. To meet the accommodation needs of all these different individuals there should be a wide variety of options to select from, and people should be able to move from one type of setting to another as their support needs, their desire and capacity for independence, their relationships and their physical and mental health changes, so that they are always in the setting that best meets their needs. To preserve stability and security, accommodation settings need to be flexible and adaptable in themselves, in the physical environment of the house and in the nature and quantity of support services provided to residents to meet their changing needs. It should not be necessary to move physically to have changing needs met, as for example with a group of long-term residents in a stable CRU who now are all facing the changes and challenges of aging. This again is normalisation, the way the rest of us do it if not constrained by adverse circumstances.

The scope of options should range from support to live independently, or with family/friends/partner, or with supervised support from a non-disabled co-tenant, through a variety of models of staffed settings in the community to, in my opinion, in order to meet the full range of support needs, a congregate care setting such as in currently provided by Colanda in Colac.

Whatever the model of the setting, each person’s placement should be supported in such a way that there are sufficient trained staff and others resources available to ensure the persons rights to physical care and safety, emotional well-being, meaningful relationships, life-skills training, meaningful occupation, leisure opportunities, community access and good health care, and the level of support/funding should be flexible enough to adapt to the person’s changing needs.

Planning: A commitment to work with families and the individual to plan the move into accommodation. The plan does not need to specify the date of the move, but does need to document family and individual preferences. The plan needs to be reviewed annually.

Delivery: Accommodation should be with due regard to individual needs and desires, not just according to departmental needs eg it is not necessarily beneficial for all individuals with challenging behaviour to be in one household where they learn from each other, or where staffing is adequate only to ‘manage’ the behaviour but not to so much else with the residents.

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?

If people do not have accommodation in which they are supported in a manner which meets their particular needs, then clearly, their accommodation is not adequate.

The implications of inadequate accommodation vary with the differing needs of different individuals and can include:
• Over-medication and sedation and the adverse effects on health and functioning that can result;
• Physical harm to the individual (and carers) due to an inadequate/unsafe physical environment or inadequate equipment;
• Physical or mental harm due to inadequate supervision or management practices;
• Inadequate management of medications and of health care;
• Poor follow-through on management advice from professionals;
• Self harm or harm to other resident/carers;
• Mental illness, particularly depression;
• Substantial and repeated property damage;
• An impoverished, restricted 'locked-down' home environment;
• Severe limitation of access to community activities, leisure activities, personal freedom and access to open spaces, the making of choices and financial resources;
• Intolerable stress on family or other carers, with family breakdown and in extreme cases murder/suicide;
• Repeated moves with a downwards cycle of unsuitable placements and deteriorating capacity to cope and a decreasing chance of being accepted into suitable placements;
• Physical/geographical isolation from family and a familiar community
• Culturally inappropriate settings;
• Impaired relationships with neighbours and the community;
• Involvement of the police and the criminal justice system.
• Increased consumption of workforce resources: medical, psychiatric, social work, psychology
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In the CDDHV clinics we see many people who are experiencing such adverse effects of living in inadequately supported accommodation and a feature of our management plan of includes letters of support to assist the case of those who are agitating/advocating for more suitable accommodation for the person referred to the Centre.

Providing sufficient well-supported accommodation for people with disabilities is expensive for the community, but dealing with the adverse outcomes of inadequate can be much more expensive for the community, and inadequately supported accommodation is false economy and a betrayal of the trust that the community has that people will be cared for humanely and according to Disability Acts and Human Rights conventions

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

The major issue here is not who runs the facility but whether they have adequate resources invested in care. Supported Residential Service’s (SRS)
in which individuals have their own bedroom with varying levels of shared facilities, Generally are unable to provide the necessary level of support. I have seen very well run and supportive examples of residential services in all three areas but that has resulted from dedicated staff, involved and expert house supervisor and a supportive higher management.

I don't have much personal knowledge of supported accommodation provided privately but have some difficulty with the concept of people taking on the care of vulnerable individuals with a view to making a profit.

I do not think SRS’s are set up to provide the level of support that is necessary for people who have significant intellectual disability or who have a mild intellectual disability and associated autism or mental illness.

In my experience, in both government and community-sector (not-for-profit) managed supported accommodation for people with developmental and associated disabilities, there is a genuine concern to provide good quality care and to promote the overall well-being of the individuals being cared for. However, the efforts of management and direct carers to achieve these aims are constrained by funding and policy issues.

The challenge of recruiting, up-skilling and retaining an adequate workforce of trained and experienced carers and supervisors in a field that is not well paid or highly valued as a career is compounded by the stresses on staff of working in settings where the support needs of the residents are not being adequately met, and stressed staff can exacerbate the increasing dysfunction which occurs in a setting where people are being adversely affected by lack of adequate support.

6. What are the positives and/or negatives of the current approach to provision of supported accommodation have on families and carers?

The positives are that supported accommodation is there as a possibility and aged parents are a priority so they can hope that their son or daughter will be placed in a suitable setting before a crisis arises due to illness, incapacity or death.

In-home supports and community access, respite and home-modification services are all invaluable to families who wish care for their family member with a disability as part of the family (either in the family home or in an independent setting under family supervision) but currently funding constraints and supply issues mean that the level of support that can be accessed falls well below what the family needs to function without excessive stress.

The negatives for carers and families have been referred to in previous answers.

A negative for organisations/management is the high cost of recruiting and training staff to replace those leave due to stress or disillusionment and the
high workcover costs for staff injured (physically or psychologically) by stressed and inadequately managed residents.

7. What issues need to be considered in the accessibility and provision of supported accommodation for people from:
   • Rural and regional Victoria
   • Culturally and linguistically diverse backgrounds
   • Indigenous Victorians

A more adequate supply of services overall, with funding tailored to meet the particular needs of the individual would mean the particular issues of these groups could be more readily addressed.

Ensuring that the training courses for people wanting to work in the disability field are made attractive for people from these backgrounds would be helpful.

Some regional towns, usually because there was previously an institution in the area, have quite a high density of supported accommodation places for people with developmental disabilities and a good variety of day programs and supported employment opportunities and leisure options open to people with disabilities. The ‘disability industry’ can be a important employer in the town and staffing in disability accommodation and programs tends to be more stable and experienced/mature than in founding the city. The town can have a generally disability-positive and accepting attitude and rural families tend to look to these towns for their support needs. This seems to be a situation that should be encourage and promoted.

8. What other issues do you think need to be considered which have not been addressed by the above questions?

More, please.