INQUIRY INTO THE PROVISION OF SUPPORT ACCOMMODATION FOR VICTORIANS WITH A DISABILITY OR MENTAL ILLNESS

Presentation to the

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Kew Cottages Parents' Association

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Background

Since 1957, **Kew Cottages Parents' Association** (KCPA) has promoted the welfare of residents at Kew Cottages (later, Kew Residential Services (KRS)), through support for families, representation, fundraising and associated activities, and has lobbied to secure better services and rights for intellectually disabled people.

KCPA was formed and grew during a period of severe unmet need in Victoria. Parents struggled to gain access to a place at Kew for their son or daughter, frequently struggling at home for many years in the face of an almost complete lack of community support and understanding.

Throughout the past fifty years, the continuing inadequacy of government funding has done nothing to alleviate long waiting lists for supported accommodation and has led to periods during which conditions at Kew Cottages were unsatisfactory (food quality was poor, as were clothing and services; there was overcrowding, and staffing problems). Furthermore, government has repeatedly failed to properly assess and quantify both current and future demand.

Too many of these factors have not improved in 2008, and in some instances – for example waiting lists for accommodation – have actually deteriorated.

KCPA is uniquely positioned to comment on the suitability and adequacy of care for people with intellectual disability in Victoria. Prior to the KRS Redevelopment, the majority of our members had relatives living at KRS. Therefore, we are familiar with the concerns of individuals living in both congregate supported accommodation and community-based supported accommodation.

In 2008, the Association supports more than 230 individuals or families who have a relative living in a DHS Community Residential Unit (shared supported accommodation). In addition, KCPA provides information and advice through a regular newsletter to more than 700 family members, direct care staff, friends and advocates who are supporting a Victorian with an intellectual disability living either in a Community Residential Unit (CRU) or at home.

From 2001 until May 2008, KCPA was involved in the redevelopment/closure of KRS and has maintained a strong role in supporting our members through the process, which involved residents of KRS moving into 93 new Community Residential Units located throughout the suburbs of Melbourne and elsewhere in Victoria. The houses have been purpose built to comply with DHS standards, and are supposedly designed to cater to the needs of current residents.

Introduction to Presentation:

KCPA's presentation focuses on the experiences of our members and their intellectually disabled relatives now living in Community-based supported accommodation, although we are highly concerned about many of the issues covered under the terms of reference of the committee, such as unmet need and, in particular, the needs of ageing carers.

Of particular concern to KCPA are individuals with intellectual disability, particularly severe or profound, with attendant high support needs, challenging behaviour, complex medical conditions, psychiatric diagnoses or communication and/or decision-making impairment.

KCPA considers that the following improvements are required to bring current supported accommodation up to an appropriate standard, and to ensure a more uniform standard is achieved across the service:

1. The establishment of a National 'Standards and Accreditation Framework for Disability Supported Accommodation'
2. Increased government funding to properly meet the needs of Victorians with intellectual disability.
3. A wider range of models of supported accommodation to respond to different individual needs.
4. An improved staffing system, including increased staff training and qualifications, decreased dependency on casual staff, and increased staff support.
5. Greater recognition in legislation, policy and practice of the role of families of intellectually disabled people.

1. Establishment of a National 'Standards and Accreditation Framework for Disability Supported Accommodation':

The inconsistency of quality of care and support being received by individuals living in KRS CRUs indicates the need for the establishment of a National 'Standards and Accreditation framework for Disability Supported Accommodation'. This framework should be established by the Federal Government through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), on a similar model to the 'Residential Care Standards and Accreditation' established by the Department of Health and Ageing.

A stronger more effective process is required than the current state-based model managed by the DHS. Under the current 'Quality Framework for Disability Services in Victoria' (which includes the industry standards for Disability Services) the DHS is responsible for measuring, monitoring and improving disability supported accommodation. KCPA is also concerned about the conflict of interest and lack of independence arising as a result of the DHS having responsibility for both measuring/ monitoring and improving disability services while also being one of the state's largest providers of disability supported accommodation.

The feedback and comments from KCPA members, and the experience of the Association in representing these concerns to DHS regional offices, have revealed a lack of consistency both between houses and across regions. This lack of consistency is demonstrated in a range of ways, including interpretation and implementation of policy, quality and skills of staff, and allocation of funding.

2. Increased Government Funding:

The families of residents of KRS were given a commitment by the State Government through the Department of Human Services, as part of the Redevelopment, that services and support provided in CRUs would be based on each person's individual needs and that as or when these needs changed, the service and support would respond accordingly. In practice, this has often proved not to be the case, as there is insufficient funding to meet this policy commitment. This affects all aspects of service and support, from provision of appropriate staffing levels, access to community inclusion and individual recreational activities, to the levels of staff support provided when an individual is admitted to hospital.

As an example, a former KRS resident was relocated into a CRU with sleepover staff. Despite his needs changing quickly in response to a pre-existing medical condition, the DHS was unable to provide active night staff, claiming that there was inadequate funding available in the region. The only option available would have been to move the individual into another house with active night staff had there been a vacancy. This belies the Government's commitment to a CRU model capable of responding to individual needs, including changing needs.

The same problem arises when the needs of individuals change upon release from hospital, necessitating periods of time in accommodation, such as nursing homes or rehabilitation centres, which often are unsuitable for the particular needs of the individual.

KCPA believes that the funding of places in supported accommodation must take account of the following:

- Contribution by an individual for accommodation charges must be such that there is sufficient money available from the pension to meet the other needs of the resident where these are not included as part of the accommodation charge. These include food, utilities, health, day training programs, clothing, transport, and support staff. (It must be noted that many people with an intellectual disability, particularly with high needs, or their elderly parents, are unlikely to have other sources of funding).
- Charges for rent must be arranged so that the resident will qualify for rent assistance.
- Recurrent funding per place for care costs must be based on the individual's needs, with different levels of funding depending on the level of care needed, determined in discussion with family/advocate.
- Funding, particularly for recurring costs, must be ongoing.

In KCPA's opinion, the issue of which sector (government, private or community) manages the provision of accommodation and care, is subordinate to the imperative of ensuring the provision of sufficient funding to build and maintain the accommodation and provide the level of care necessary to meet the needs of each individual resident. This particularly applies for people with severe or profound intellectual disability who often also have other significant or complex medical conditions.

Experience has shown that private and community sector services are often unable to meet the needs of people with higher and more complex needs due to their higher staffing and support costs. Until such time as private and community sector has sufficient willingness and capacity to cater for this demographic, KCPA considers that government must continue to provide supported accommodation.

3. Wider Range of Accommodation Options:

A major drawback with the KRS redevelopment was that the only type of supported housing offered was the stand alone Community Residential Unit. This was despite the repeated requests for alternatives - such as small-scale congregate care facilities or groupings of CRUs in close proximity with shared boundaries and some shared facilities and services - which many of our members believed better met the needs of their family member.

In general, it is considered that, depending on the individual and their particular needs, such alternative models of accommodation offer a range of potential benefits, particularly for people with complex medical care and support needs or challenging behaviour, or those with a disability that limits their capacity or desire to access and participate in the wider community. These benefits include:
- the freedom to move about in open space safely,
- the opportunity for residents to socialise with a diverse group of peers,
- a sense of community amidst staff, residents and wider community,
- the provision of support for families, and potential for effective monitoring of standards and lobbying for improvements,
- the potential for staff scrutiny and monitoring,
- the more efficient use of staff with specialised skills in caring for residents with complex medical needs within a region,
- a reduced delay in these staff responding to a medical emergency when one occurs,
- an increase in staff support and professional development opportunities,
- an increase in sharing or provision of resources and services, and
- the capacity to provide staff with the skill and expertise to manage complex medical needs or challenging behaviours.

Based on feedback and comment from members, the 4-6 bedroom CRU has the potential to provide responsive, individualized and well-staffed supported accommodation. However, there are many factors that undermine the quality of care and support offered, and therefore impact on the quality of life of each individual resident.

Of particular concern are the needs of people with very complex medical needs which can only be properly managed by trained nursing staff, and people with very challenging behaviours which require skilled and trained staff familiar with their needs. In some instances, the CRU model struggles to appropriately cater to needs. For example, families have reported that staff sometimes have insufficient capacity or skill to recognize the deteriorating health of individuals they support which can result in placing the individual at risk or, at the very least, compromising their wellbeing and quality of life. Additionally, the staff working with these individuals also have increased support needs, and risk suffering from the stress and isolation of working in a small CRU remote from others.

Unfortunately many residents in CRUs are living in the community but are not part of the community. In many instances, the individuals are more isolated in their CRU than they were living at KRS. The lack of alternative models of accommodation is a major contributing factor to this state of affairs.

The following principles must guide the types of accommodation provided:

- The widest variety of accommodation types possible must be available so that the option most suitable to the needs of each individual seeking accommodation can be offered. A similar range of accommodation options that exist in the wider community should be available to people with intellectual disability. KCPA considers that forcing individuals into one model of accommodation because of their disability is discriminatory.
- Well-established standards for buildings must be used where relevant. Eg. Standards used by DHS for CRU's built as part of the KRS redevelopment to meet the requirements for people with an intellectual disability requiring shared 24 hour supported accommodation except that more outside space should be provided.

KCPA considers that the location of accommodation should:

- Be in areas where there is a demonstrated need.
- Be in reasonable proximity to family members when requested.
- Be in reasonable proximity to day support activities and other services (medical, dental, recreational).
- Be in reasonable proximity to other CRUs to maintain and foster existing relationships, and also to create a sense of support, friendship and community.
- Ensure that the individual remains within their local community.
- Ensure availability of appropriate transport including a vehicle dedicated to the house where an individual is unable to use other transport independently.
- Ensure prospective neighbours are fully informed regarding any proposed housing.
- Ensure there will be ongoing access to sufficient qualified and trained staff as required and as individual needs change.

4. Improved Staffing System:

The quality of the current physical accommodation for former KRS residents is consistently high (bearing in mind that the KRS redevelopment houses are all new). However the quality of care and support being received by individuals within the houses is variable. The improved physical environment in which all former KRS residents are living does not necessarily compensate for the variability and, in some cases, reduction in the standard of care and support being received there.

Based on communication with our members, individual residents may suffer from one or more of the following issues:

- Extremely high dependency on the ability, skills and personal attributes of individual house supervisors as a determinant of the success of each individual house.
- High levels of casual staff and/or staff turnover with the resultant lack of consistency of care & support.
- Insufficient familiarity with the needs of the individual clients, particularly medical and behavioural needs.
- Lack of quality, skilled staff. Examples include insufficient staff trained to identify emerging health conditions or concerns, administer insulin injections, manage bedsores or properly fit incontinence aids.
- Lack of sufficient support for staff.
- Inconsistencies in managing medical needs (medical & dental appointments, frequency of scheduled appointments/treatment with specialists)

The following principles must guide the types of support and care provided:

- The great shortage of skilled and trained support staff must be addressed as a matter of urgency.
- Service management must provide more active support to house staff.
- Funding needs to be allocated to provide high quality courses to offer the necessary qualifications and training.
- More effort must be made to decrease the dependency on casual staff.
- More effort must be made to increase the qualification and training of casual, part-time and permanent staff.
- More effort must be made to resolve the existing problems with the staffing roster model which effects the ability of CRUs to attract staff, particularly to part-time positions.

5. Improved legislation, policy and practice regarding the role of families and/or advocates:

The Disability Act fails to make provision for or define the role of families in the lives of their disabled relative, in particular in decisions affecting them. This is of particular concern for people with a cognitive and/or decision-making impairment.

As a result, families are often isolated and/or unsupported, and too often find themselves in an adversarial role with house staff.

In the DHS CRU system, provision of information to families is inadequate which means that many families do not feel sufficiently informed and, therefore, empowered to advocate effectively for their disabled relative.

It is acknowledged that the effectiveness and quality of the service provided to individuals in supported accommodation is frequently dependent upon the presence of an active advocate (family member or other) who is involved in the day to day life of the individual. There are currently far too many obstacles impeding and/or discouraging families from being actively involved in their relative's life.