FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into the provision of supported accommodation for Victorians with a disability or mental illness

Melbourne — 22 October 2008

Members
Mr B. Finn  Mr J. Scheffer
Mr J. Perera  Mr A. Somyurek
Mr W. Noonan  Ms M. Wooldridge
Mrs E. J. Powell

Chair: Mr J. Perera
Deputy Chair: Mrs E. J. Powell

Staff
Acting Executive Officer: Mr M. Bromley

Witnesses
Ms L. Godwin, executive officer, and
Mr J. Scully, vice president, Kew Cottages Parents Association.
The CHAIR — Thank you very much for coming along. I will not go through the formalities again because you have been here all morning and you will have followed what has happened. I will ask you to make a verbal submission.

Ms GODWIN — I am Louise Godwin. I am the executive officer of the Kew Cottages Parents Association. I have with me Jim Scully, who is our vice president. I would like to thank you all for inviting us to present today. To start with I will provide some background about the association, just to create a context.

Since 1957 the Kew Cottages Parents Association has promoted the welfare of residents at Kew Cottages — later Kew Residential Services — through support for families, representation, and associated activities. It 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 50 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 staff 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 or unmet need 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 redevelopment of Kew residential services, the majority of our members had relatives living at Kew. Therefore we are familiar with the concerns of individuals living in both congregate supported accommodation and community-based supported accommodation.

Today, in 2008, the association supports more than 230 individuals or families who have a relative living in a DHS community residential unit. In addition, we provide 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.

From 2001 until May 2008 KCPA was involved in the redevelopment or closure of Kew and has maintained a strong role in supporting our members through the process, which involved residents of Kew 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.

Our presentation today will focus the experiences of our members and their intellectually disabled residents now living in CRUs, although we are highly concerned about many of the issues covered under the terms of reference of the committee, such as unmet need, in particular, and the needs of ageing carers. Our particular concern is individuals with an intellectual disability, particularly those with severe or profound intellectual disability with attendant high support needs, challenging behaviour, complex medical conditions, psychiatric diagnoses or communication and/or decision-making impairments.

KCPA considers that the following improvements are required to bring current supported accommodation up to an appropriate standard and to ensure that a more uniform standard is achieved across the service. We believe there may be good reason to see the establishment of a national standards and accreditation framework for disability supported accommodation. Secondly, we believe that there must be increased government funding to properly meet the needs of Victorians with intellectual disabilities — that is, to properly meet individual and specific
needs. We believe there has to be a wider range of models of supported accommodation, again to respond to different individual needs. We believe there has to be an improved staffing system, including increased staff training and qualifications, decreased dependency on casual staff and increased staff support. We finally believe there needs to be greater recognition in legislation, policy and practice of the role of families and, we should also add, advocates of intellectually disabled people, particularly, just to reiterate, people who fit that category I spoke to before — those with particularly severe and profound or complex disabilities.

I will talk first of all to the establishment of a national standards and accreditation framework for disability supported accommodation. We have found that there has been an inconsistency in quality of care and support being received by individuals in Kew CRUs and believe that this indicates the need for the establishment of a national standards and accreditation framework for disability supported accommodation. We believe that the framework should be established by the federal government through the Department of Families, Housing, Community Services and Indigenous Affairs on a similar model to the residential care standards and accreditation framework established by the Department of Health and Ageing. The reason for this is that we believe that a stronger and 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, the DHS is responsible for measuring, monitoring and improving disability supported accommodation. This concerns us greatly because we are 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 whilst also being one of the state’s largest providers of disability supported accommodation. The feedback and comments from our members and the experience of the association in representing their concerns to DHS regional officers have revealed a lack of consistency both between houses and across regions, so this is operational within the houses and also the operational mechanisms within the regions or practices. 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.

The second point I will speak to is increased government funding. The families of residents of Kew were given a commitment by the state government through the Department of Human Services as part of the redevelopment of Kew residential services 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. This encompassed not just illness or changing needs but in particular ageing needs, bearing in mind that many of the residents of Kew or former residents of Kew have an average age of probably 50 up to, I think, about 74. In practice this is often proved not to be the case; this is in terms of the ability to respond.

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 Kew resident was relocated into a CRU with sleepover staff rather than active night 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. In fact this particular individual, shortly after the attempts to get active night staff, passed away, and his death is the subject of an inquiry by the coroner and an internal investigation by the DHS.

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. We believe the funding of places in supported accommodation must take into account the following. We are concerned about and believe that the contributions 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. Something we have found from communication with our members is that the move into a CRU has, for a very significant number of individuals, increased their costs and limited their abilities to take part in additional recreational activities, for example. 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 and/or advocates. 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 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 the private and community sector has sufficient willingness and capacity to cater for this demographic, KCPA considers that government must continue to provide supported accommodation.

I note at this point the points that were made by Marsha in Scope’s presentation about the non-government demographics’ shortages of funding in being able to respond to this particular demographic, and I would like to just make a point of noting that it need not necessarily be an unwillingness of the community sector to respond to the needs; it is just the issue of whether or not it has the capacity.

On the issue of a wider range of accommodation options a major drawback for the Kew redevelopment was that the only type of supported accommodation 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 behaviours, 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 the wider community; the provision of support for families; the 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 those 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 our members, the four-to-six bedroom CRU has the potential to provide responsive, individualised 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 the other category of people with very challenging behaviours who 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 recognise 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.

Another concern is that many residents in CRUs may be living in the community but they are not part of the community. In many instances the individuals are more isolated in their CRU than they were when living at Kew. The lack of alternative models of accommodation is a major contributing factor to this state of affairs. We believe the following principles must guide the type of accommodation provided. We must see the widest variety of accommodation types available so that the option most suitable to the needs and wishes of each individual seeking accommodation can be offered. A similar range of accommodation options that exists in the wider community should be available to people with intellectual disability. We believe forcing individuals into one model of accommodation because of their disability is discriminatory. We support well-established standards for buildings being used where relevant — for example, the standards used by DHS for the CRUs built as part of the KRS redevelopment to meet the requirements of people with intellectual disability requiring shared 24-hour supported accommodation. We feel that there should be more outside space available as a general rule, though.

We believe the location of accommodation is also very important. We believe accommodation should be located where there is a demonstrated need. It should be in reasonable proximity to family members when requested. The experience of our members of having their children relocated in early childhood to an institution that was a long way away from families certainly was detrimental, and we do not support that. It should be in reasonable proximity to day support activities and other services that the individual will need: medical, dental and recreational services.

It should be or could be in reasonable proximity to other CRUs to maintain and foster existing relationships, and also to create a sense of support, friendship and community. This is a notion of creating — or acknowledging, I suppose — communities within communities that we all belong to. We all belong to the wider community and certainly benefit from living within the wider community, but we all also participate and belong to smaller and more personal communities, whether through churches, schools or neighbourhoods, and that is something that is often not addressed or acknowledged for people with intellectual disability — that they have both needs.

We would like the location of the accommodation to ensure that the individual remains within their local community; that there is availability of appropriate transport; that prospective neighbours are fully informed regarding any proposed housing; and that there must be ongoing access to sufficient qualified and trained staff as required and as the individual needs change.

The next issue is improved staffing systems. The quality of the current physical accommodation for former KRS residents is consistently high, bearing in mind that the Kew redevelopment houses are all new. However, the quality of care and support being received by individuals within the houses is variable, as we have acknowledged earlier. The improved physical environment in which all former KRS residents are living does not necessarily compensate for this variability and in some cases the reduction in the standard of care and support that is being received there.

Based on communication with our members, individual residents may suffer from one or more of the following issues within their houses: an extremely high dependency on the ability, skills and personal attributes of individual house supervisors as a key 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 and support; insufficient familiarity with the needs of the individual clients, particularly medical and behavioural needs; and a lack of quality skilled staff. Examples of this include insufficient staff trained to identify emerging health conditions or concerns and trained to
administer insulin injections, manage bedsores or properly fit incontinence aids; a lack of sufficient support for staff; and inconsistencies in managing medical needs, such as medical and dental appointments.

We believe the following principles must guide the type 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; and more effort must be made to resolve the existing problems with the staffing roster model which affect the ability of CRUs to attract staff, particularly to part-time positions.

Finally, one of our principal concerns is the role of families and/or advocates; again, for this key category our target demographic is people with severe and profound intellectual disabilities. The Disability Act, we believe, fails to make provision for or adequately define the role of families or advocates in the lives of their disabled relatives, particular in decisions affecting them. This is of particular concern for people with a cognitive and/or decision-making impairment. We believe that frequently families end up feeling isolated and unsupported, and too often find themselves in an adversarial role with house staff or regional management. In the DHS CRU system, provision of information to families is highly inadequate, which means that many families do not feel sufficiently informed and therefore empowered to advocate effectively for their disabled relative. Once again the demographic of our association is very elderly. In the DHS in particular the prime mechanism for accessing information is the internet, and in the main it is just not a medium for securing information. It creates huge barriers, I believe, for elderly parents and advocates.

It is very widely acknowledged through research that the effectiveness and quality of the service provided to individuals in supported accommodation is frequently dependent upon the presence of active advocates — family members or others — who are involved in the day-to-day life of the individual. We believe there are currently far too many obstacles impeding and discouraging families and advocates from being actively involved in their relative’s life.

The CHAIR — Thank you very much for that long submission; it was very interesting.

Mrs Powell — Thank you, Louise. There were some concerns about the former Kew cottages because of understaffing and lack of training, and so then the residents were put into the community, and your suggestion is that there was not enough funding so they were not really in the community. There are now some concerns about the CRUs that the residents have gone into, and again it is about attracting appropriate staffing and a lack of choices. This would probably occur just as much in rural areas. Can you give me the answer? Is it just funding, or is it a matter of making sure that we have got forward planning, given that a number of ageing parents, as we said before, do not see themselves as carers but see themselves as parents, and it is only when there is a crisis situation that they are looking for somewhere to put their child — who might be 50 or 60 — when they are older? How can we best get the register to plan and say, ‘This is what the need is’, and how do we make sure there are those alternative choices of accommodation that are appropriate?

Ms Godwin — This is a difficult question for us to answer because I do not feel like the association really has enough knowledge about unmet need and what is occurring for families caring for their children at home to represent them, so it is difficult for me to answer that question. I will take the first part of the question, which is about staffing and how to resolve these issues with staffing. Again, I am sure there are people or organisations far better placed to answer this question. Perhaps if HACSU presents later in the day this might be, and I am sure it is, something worth talking to them about. All I can say is there needs to be some holistic management planning or decisions made about how to overcome this problem. For us the prime issues are casual staff,
problems in attracting staff and the quality of the staff. It is a very complex issue, and I just do not know that we are in a sufficient position to be able to answer the question. I am sorry.

I do not know whether Jim might have something to add, but in terms of the issue of demand predicting need, I suppose our insight would be primarily historical, from the point of view of what the association experienced back in the 1950s and 1960s when the issue was the same. I think at that time the issue was — as I think Scope addressed — the need to have a properly administered mechanism for assessing current and future need. It would seem fairly apparent that that is not in existence at the moment.

Mrs Powell — Thanks.

Mr Noonan — Louise and Jim, thanks for your submission. You have put some substance in here which will be of great value to our committee’s deliberations, which is always very beneficial. Given your history, you are uniquely placed to make some assessments about where we have come from as opposed to where we are now and where we might be going. I gather from your submission that clearly there is an issue of funding, but in terms of your background in your submission, I did not pick up on your first page whether or not you believe the direction was right for — as you have documented here — the residents to move into 93 new community residential units. Could you expand on whether or not that was the right decision in hindsight? A comment I picked up — and this is the second part of the question — was that those 93 new residential units were supposedly designed to meet their needs. I wonder whether or not you could expand on where the deficiencies might be in the current system in your experience.

Ms Godwin — That is a very complex question, because I guess people would generally know that the redevelopment itself was a very complex process. The association, based on what our members have told us and continue to tell us, still believes, as I have outlined in the submission, that there should have been, in terms of the Kew redevelopment, a wider range of accommodation options provided. I think it is fair to say we are optimistic about the 20 CRUs that are located on the Kew site. Here we have 20 CRUs that are located currently within about a third of the site, so they actually are in quite reasonable proximity to each other, and we can see the benefits of that form of co-location or clustering of houses. We are beginning to see potential for staff support and crossover of skills, a continuance of the community, and a continuance of support for individuals and their families and for staff. The general feeling of the association, however, was through the process of the redevelopment there should have been a wider range of options.

Jim might be better placed to speak to this. On the whole we have to say that individuals have managed the transition across into CRUs from an institution. On the whole they are doing well and we are hearing very positive things from family members, but the consistent issues that come up for those individuals are primarily the issues to do with staffing. We have some issues with finding appropriate day programs. Given the ageing demographic of the cohort from Kew, we have a similar issue to one that Scope mentioned — that is, as they are ageing the CRU staffing structure cannot respond to their changing needs as they no longer wish to attend full-time day programs. For example, if individuals fall out of day programs, they fall into a bit of a gap in that the houses cannot necessarily respond to having people at home.

Mr Scully — There is another issue about the people who have moved into the CRUs. Maybe a demographic that has had difficulty is people with complex medical needs. For example, if a resident goes to a hospital for a procedure, when they come back to their home they might find that the care provided is not as skilled and not as attentive to detail as what they would have once received. For example, at the former Kew site there was a medical centre, and once they were taken out of the hospital they were provided with a period of time to recover from their procedure and to have specially trained staff available to make sure that there were no infections and that everything had gone well. That is not so readily available in the CRUs. There are instances of family members having to take up that slack a little bit, and even waiting in
emergency departments and things like that. We are acutely aware of the fact that our membership is ageing and they are less capable of providing that kind of care effectively.

Ms WOOLDRIDGE — I suppose it is really following on from that line of thinking, which is whether the CRU model has not worked for some and where they have ended up. What have been the consequences? You have touched on it a little bit, Jim — talking about ending up in emergency departments. What are the consequences of the CRU model not meeting the needs, either as they age — some go in and it meets them and then they does not over time — or are there some examples of where it just has not met their needs and they have ended up in a different situation altogether?

Ms GODWIN — Not through the course of the Kew redevelopment. Nobody has been moved out of a CRU. There are features of houses that have not worked. Some houses have issues in the not ideal matching of individual clients. Ultimately this is one of the issues for the CRU model, and I think Scope touched on this. Because of the funding model, even though in theory individuals should be grouped according to compatibility, and that is certainly what we were told and families were told as part of the redevelopment, the reality is often quite different. For example, in relation to the issue of active or sleepover staff, the funding model demands that if you have active night staff everyone in the house must need active night care. Active night staff will not be provided — or there will be a reluctance to provide these staff — if just one individual in a house requires them. I should not speak in such absolutes because I do not have sufficient knowledge about what happens in every CRU to do so, but certainly from our experience that is an issue. Grouping of individuals is not just about compatibility; it is about compatibility of needs and care requirements, even down to things such as day programs. It would appear to be preferred that they all attend the same day program because strategically it is easier for staff. That is a particular issue.

As families have consistently said throughout the last 50 years, it just keeps on coming back to the quality of the staff. It is all about the quality of the staff and the care they are getting from those staff. That is such an important factor. The success of the Kew houses has depended very heavily on the staff who are actually in the house. Unfortunately this is a movable feast because it is constantly changing. I think I mentioned in the submission that research through La Trobe has recently found that the quality and the abilities of the house supervisor can make or break a house. If you put a house supervisor who is not working in a house, you have a house that is not functioning and where potentially things will go wrong for the individuals. So much is required. As I said earlier, I certainly would not hasten a guess at how to resolve this issue. No doubt it is something that many heads will have to get together to look at. Something I hear often from staff is how isolated they feel in the house; how they often do not feel supported by management if somebody has complex medical needs or if something changes. I think this is a big issue — that the Department of Human Services management structure does not allow for enough staff support. Sorry, that was a very long-winded answer.

Ms WOOLDRIDGE — What happens over time? There are these dedicated, purpose-built CRUs for Kew but I suspect people will move, families will move. Over time do the former Kew residents then become integrated within the whole CRU system and then other non-Kew residents end up in what were designated Kew houses? What is the evolution of the client group?

Ms GODWIN — That is what is occurring. Given the age of the former Kew residents certainly they are passing away, and as they pass away individuals from the service needs register in their region will be placed in the vacant rooms, so yes, that is right. They will continue to transition and eventually in the fullness of time there may not be any Kew residents living in them.

Mrs POWELL — You mention the word ‘transition’. In aged care there is a transition from independent living to hostel-style living where there is dormitory-type accommodation and then obviously the nursing home. Can you see a style of that type of accommodation working
where residents are in CRUs and as they age and have more complex needs and require more skilled medical procedures and so forth, they go into another, bigger facility where their needs are met?

Ms GODWIN — Certainly a number of our members would believe that that would be a better model for their family member taking into consideration their needs and also their care demands. For example, a recent concern that has arisen for one of our members — and it sounds very minor — is to do with the fitting of continence aids for an individual who is also diabetic. The mother feels the complete care needs of this individual are not being provided through the CRU and the skills of the staff. I believe she would consider that her son would probably be better off in some form of aged-care facility.

Mrs POWELL — I did not actually mean to go into an aged-care facility. What I meant was that type of model but for people with a disability or a mental illness.

Ms GODWIN — Yes. Jim?

Mr SCULLY — I am not sure but I think it goes back to what the previous speaker said about having a range of options available. Each individual should be assessed on their own needs and not the general needs of the other residents in the place where they are living. For example, if it did arise that an individual in a particular house had extra needs we should not be looking at just whether they need to move into a different type of facility. We should be looking at how we can provide the option of them staying with the people they have lived with for 15 or 20 years in their own home but still provide the level of care they need. I know it does not quite answer your question. I do not know whether a facility exists that is appropriate for the level of care required by an elderly intellectually-disabled resident but I just think there does need to be a range of options. Each individual has to be assessed on their needs and there have to be options available for them to receive the care they need in their home. At the moment, there is not much flexibility once the situation of an individual changes.

Mrs POWELL — I guess that is where we are coming from. Those options need to be available. If you are going to have to pre-plan, they have to start to be built now.

Ms GODWIN — Absolutely.

Mrs POWELL — If the opportunity for somebody going from the cottage back into home is not available because the parent is ageing, there has to be some other accommodation option for that person — an individual support package but perhaps in a larger facility.

Mr SCULLY — Or not just another accommodation package available but another caring package available. That could be caring within that same accommodation — a model flexible enough to allow them to have their package changed within where they are living at the moment because that might be the most suitable option.

Ms GODWIN — These were the sorts of commitments that the department gave the parents’ association through the process. A lot of our members lobbied very hard to see an aged-care facility built on the Kew site because they believed there was a sufficient, I suppose, proportion of former Kew residents who either would be better accommodated in some form similar to an aged-care facility because of their needs and their age or who may require that in the fullness of time. The DHS response to that, the government response to that, was that the CRU model — again echoing back to a point we made earlier — should be sufficiently flexible to be able to respond to the changing needs of individuals as they age. As Jim is highlighting now, it seems that perhaps in instances this has not been the case as their medical needs change. It would seem that there needs to be increased flexibility in terms of what supports can be provided to the individual in the house.
Mr SCULLY — Other models of housing could perhaps potentially be more flexible, too, such as having several CRUs in close proximity, because that might be a more flexible model. But as Louise said, there is the potential within the current CRU model to be flexible also. But I guess all options have to be looked at.

The CHAIR — In the CRU setting have you had any experience with people from indigenous and culturally diverse backgrounds and what their special needs are?

Ms GODWIN — I suppose the demographic of residents or clients who lived at Kew was very, very wide. There was a very, very wide cultural demographic. But as an institution, I suppose its ability to respond to those varying cultural needs was probably limited. My feeling would be, or I guess to answer that question, again it so often comes back to the same factor — that the existing CRU system’s ability to respond to those different cultural needs really falls very heavily on a positive relationship between families, advocates and the house, and in particular the house staff, so they can work together to create a sort of environment that reflects lifestyle and things that reflect the individual’s cultural background, and also the ability and capacity of the staff to factor those individual needs into the way they support and care for the individual. That would vary from one house to the next. I do not think it is anything we can speak about in any general manner.

Mr NOONAN — I go to the part of your submission that talks about staffing and makes reference to families reporting that staff sometimes have insufficient capacity or skill to recognise the deteriorating health of individuals they support. Could you provide the committee with some detail on what checking goes on for those that Kew represents and advocates for across those 93 CRU units? Arising from that could you comment on whether or not there is a capacity for existing staff to upskill, or alternatively whether or not there is a need for a different type of staff — to move about a region, for example, and look at this issue you have included in your submission?

Ms GODWIN — Yes. I guess the best way to answer that might be to take an example of something that occurred in a house with an individual who had pre-existing but worsening bed sores and who moved into a CRU. The existing skill of the house staff was insufficient to be able to manage those bed sores properly and led — this has happened in two instances, actually — to the individuals passing away through infection. Now we do not see this as a criticism, as a flaw — well, as a flaw; we are not criticising the staff. The issue, I think, in using this as an example is the existing system. If that individual had been in a house where there were medically trained nursing staff, there would have been less of a likelihood that those bed sores would have worsened to the extent that they did. Unfortunately there were not medically trained staff in that particular house. We can see great benefits in having, as we have spoken to, an increase in the level of qualification of house staff, particularly for the demographic of individuals we represent.

Mr NOONAN — Can I be really clear? It would be useful for us to understand what happens now, and if you are suggesting existing staff could be upskilled, that is also useful for the record.

Ms GODWIN — We definitely feel that the level of skill and qualification of house staff has to increase significantly. Back in the 1950s and 1960s, under the institutional model, they were entirely medically trained and it was only nursing staff who cared for the individuals. Quite correctly, things have changed since that time to where — again depending on the individual needs — it is not necessary for somebody to be medically trained to look after, care and support individuals with intellectual disability. However, it all falls back to the needs of the individuals. We do believe that there needs to be an increase in qualification. Jim, you might be better placed to — —
Mr SCULLY — I think providing training courses to existing staff is part of the answer. It is not through wanting dedication that these situations arise. A lot of it would be helped through the training of existing staff.

Mr NOONAN — What happens at the moment? Is there any regular health checking? That is what I suppose we are trying to come to terms with.

Ms GODWIN — The difficulty at the moment, I suppose, for us is that we feel — the association feels — that there is not sufficient monitoring of what occurs in CRUs.

Mr NOONAN — Is there any?

Ms GODWIN — The main or official form of monitoring is by community visitors. That, you would be aware I am sure, is done through the Office of the Public Advocate. Community visitors perform an increasingly important role. The strengthening of their rights, I suppose, through the recent Disability Act is a very positive thing because at the moment they are the monitoring body. For the association, one of our concerns through the process of the redevelopment of Kew is that we have lost the capacity — parents are losing the capacity — to perform that role, through the relocation of people into CRUs.

The informal monitoring that goes on is very, very dependent — and this is what I alluded to at the end of the presentation — on having an active advocate, a friend or family member, somebody who visits regularly and actually is in a sense the outside eyes, like community visitors are, but just is in regular contact with the individual, to be able to monitor things. Community visitors I think visit the houses maybe twice a year. The ability of an outside individual to pick up if there is some form of deterioration in an individual’s health is precarious. It is dependent on it coinciding with a visit by community visitors or an outside family member or advocate coming in.

I should qualify this and say that of course the first point of monitoring all of this is the staff. We have not by any means come here to try to criticise the existing staff; that is not our objective at all. I guess the point we would most like to make is that we think that in general they are underskilled and underqualified. Because of the availability of staff and the difficulties in securing staff it is not always possible to match a house that might have people with very high needs with appropriately skilled staff to care for them. This applies also particularly with houses where there are people with challenging behaviours. It is incredibly difficult to get staff to care for those individuals anyway. There is a very high dependency on casual staff and a very high turnover of casual staff and therefore typically those houses function much more poorly than the other houses — because all the things that the individuals actually need in terms of consistency and experience of the staff just are not present.

The CHAIR — Thank you very much for that detailed presentation. We will send you the transcripts for you to make any alterations that you wish.

Witnesses withdrew.