

**FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE**

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

Melbourne — 5 November 2008

Members

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Witnesses

Ms C. Pearce, public advocate, and

Ms J. Bush, manager, policy and education manager, policy and research, Office of the Public Advocate.

**The CHAIR** — All evidence taken at these hearings is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to provisions of the Parliamentary Committees Act 2003, the Defamation Act 2005, and where applicable with the provisions of reciprocal legislation in other Australian states and territories. Any comments a witness makes outside this hearing may not be afforded such privilege. We are recording the evidence and will provide a proof version of the transcript to each witness at the earliest opportunity. Please introduce yourself and give a brief description of your organisation if you are representing any — I believe you represent the public advocate — and make a verbal submission.

**Ms PEARCE** — I am Colleen Pearce and I am the Public Advocate.

**Ms BUSH** — I am Janine Bush. I am the manager of policy and education in the Office of the Public Advocate.

**Ms PEARCE** — The Office of the Public Advocate provides services to people with a disability across Victoria and has two operational areas relevant to this inquiry; the Community Visitors Program and the Advocacy/Guardianship program. In the last financial year 590 volunteer community visitors made 5,654 visits to people in mental health units, disability accommodation and supported residential services across the state. The Office is also guardian for around 1,200 of the most vulnerable Victorians, a large number of whom reside in mental health facilities, disability accommodation and supported residential services. The key theme arising out of the Community Visitors Board annual report tabled in Parliament last week and was the impact of the lack of accommodation options on vulnerable people in our community.

The frame of reference for the work of the Office is human rights and the two most important human rights frameworks are: the recently ratified UN Convention on the Rights of People with a Disability and the Victorian Human Rights and Responsibilities Charter. The relevant charter rights are freedom of movement, freedom of liberty, freedom to be treated with humanity and respect for inherent dignity when deprived of liberty. I mention these rights because there are people in the system who cannot fully exercise these rights because there is a lack of suitable accommodation for them. This lack of accommodation options means their movement is restricted and in some cases, their liberty is denied.

Another key issue is the economic and social costs of failing to provide suitable accommodation for vulnerable people. Research tells us that a person's mental health and wellbeing can improve or deteriorate as a direct consequence of their housing circumstance. Our community visitors see this first hand in the work that they do. In particular, the failure to provide appropriate accommodation contributes to increased ill-health, increased usage of health services, and consequently, higher health costs. There is a huge economic cost in the failure to provide adequate housing supports.

But it is not just the economic cost; it is also the social cost. Disempowerment, social isolation, lack of autonomy and restriction in movement are all indicators of the social costs. A further impact is on people in care who are unable to move to a less restrictive environment. These people are known as the 'bed blockers' and are found in numbers the mental health and disability services systems. They are stuck in the system because there is a lack of alternative care or accommodation for them. This is particularly true in the mental health system where there is a dearth of discharge options and, as a consequence, patients are staying longer in a locked mental health services when they may have in fact been eligible to move to a less restrictive environment. The lack of respite services puts additional stress on systems and increased distress for individuals and their families.

OPA has quantified the cost of one person housed in inappropriate accommodation. 'Bill', a single man in his 50s with a moderate intellectual disability, was admitted to emergency respite when his mother was unable to continue to care for him. The average length of stay in emergency respite is 26 days. 'Bill' remained at the respite service for 345 days because there was no other accommodation available. Respite care costs approximately \$500 per person per day. 'Bill's' stay

cost \$170,000. Had he resided in a CRU for the same length of time, at a cost \$300 per person per day, the savings would have been \$103,000. The Office is not just concerned about cost savings, we are also concerned about the effect the protracted stay in respite had on 'Bill's' emotional wellbeing. He was unable to form longer term relationships with his peers because the very nature of the respite service means that people move on. After the security of living with his family, the transient nature of the respite population began to erode his sense of belonging and his behaviour became more problematic. In turn, the use of restrictive practices was considered to modify what was considered to be increasingly problematic behaviour.

Over the past 12 months, community visitors gathered data for their 'Long-Stay Project' and in the process identified 99 patients across the state held in mental health services for unacceptable lengths of time. Forty had been held in mental health units for more than five years and 16 for more than 10 years. Many were unable to be discharged because of the lack of services providing ongoing 24-hour clinical and non-clinical support. The lack of appropriate accommodation options for people currently in the mental health system leads to blockages and hinders the capacity of people to move from one level of care to another. The social and economic cost of holding these 99 patients is very high.

Our mental health services were never intended or designed to provide long term accommodation to the mentally ill. In effect, they have become holding facilities because there are no other accommodation options available. While some people cannot move on, other people cannot get in. This is a real problem for many users of our mental health system. When the Office opened in 1986, it worked mainly with people with intellectual disabilities in state-run institutions, and the cry was, 'Help! Get us out'. These days, the cry from many people is, 'Help! Get us in!' The exceptions are the long-stay patients who generally have dual diagnoses, a mental health problem combined with either an acquired brain injury or an intellectual disability. For people with complex needs, there are not enough options in the system.

There is also the cost of providing hospital-based care when less expensive accommodation may have been more appropriate. As I said earlier, some patients continue to be accommodated in mental health facilities for up to ten years. Why have they remained in the system for so long? One also has to question the efficacy of their treatment. Of course, some people need continuing care, but most do not need it in the most restrictive and expensive environment. Surely there must be better options.

Our second case study is of two women in their 50s, both of whom have intellectual disabilities as well as mental health issues. They were considered ready for discharge from a secure extended care unit in 2000. Eight years later, they are still in the system. They leave each day and go to a day placement and then they come back and are locked up at night. It is our view, and certainly the view of many staff in the health system, that with 24-hour support and appropriate accommodation, people like these women could have an improved quality of life-and the beds would be freed up for other people.

The Office would like to see an immediate injection of funding to provide additional community-based accommodation and support services. This would free up the more intensive bed based services for people who are currently unable to access them. Additionally, there needs to be better forward planning. Do we know what the real demand for services is? More effective data analysis would enable better forward planning for the increasing number of people in our community who experience mental health problems.

Many people discharged from mental health services move into the supported residential services because there is no other alternative. Increasingly, people with complex and ongoing support needs are being discharged to these services. However, these services are generally unable to provide the level of support to people who have only recently released for a mental health facility and may continue to be very vulnerable. The impact on individuals with high support needs and low income can be a reduced quality of life and unmet health and social support needs.

Consequently, their behaviour can become increasingly challenging and restrictive interventions may be required. In such circumstance, a person's emotional and mental outlook can deteriorate rapidly and they may end up back in a more restrictive environment. Often they have few family supports and limited social networks. After 10 years in a mental health service, a person may well lack social skills and is unlikely to have maintained a support network. It may be incredibly difficult for them to participate in community life.

Recently community visitors came across a woman who had presented to hospital emergency units 50 times in a 12-month period. The cost to the community of someone presenting at a hospital emergency 50 times is just enormous. The community visitors recognised the woman was lonely and depressed following a recent separation. Arrangements were made for a community mental health worker to drop in once a day, and not surprisingly, result was an immediate and significant reduction in this woman's admissions to the emergency department. From this case study we see that a small amount of support can have an enormous impact on our already pressurised hospital system.

People living in supported accommodation are frequently engaged with one or more service systems such as mental health, aged care, disability, alcohol and drugs services. Staff of my Office and volunteers frequently report the failure of communication across service systems. For people with both an intellectual disability and a mental health issue this is particularly problematic and there is a tendency for each service system to say: 'No, you are not our problem. You belong in another service system. You have to go somewhere else to get the help you need'. Human needs rarely fit into neat little service silos. But it is not just people with dual disabilities that experience this problem. People with lifelong disability who are ageing, people moving between regions, people living on the boundaries of regions, people wanting to move from one region to another, all experience difficulties accessing the services they need. The service system needs to be more responsive to the needs of individuals and more attention needs to be paid to addressing the lack of service integration and support.

The Office believes that DHS should more actively promote cross sector collaboration. This could be achieved through incentives that encourage collaboration and partnership approaches. For example, a hospital has recently approached my Office wanting to find a way to reduce the time it takes to appoint a guardian for elderly patients ready for discharge to other care services. As you know bed based care is more expensive than other forms of accommodation. The hospital and the Office plan to develop a pilot program targeting elderly people leaving hospital care. The benefits of such a project are two fold. Firstly, there would be a reduction in hospital costs and waiting lists. Secondly, it has the potential to make a big difference to the lives of many elderly people who may have their time languishing in hospital reduced.

Residents in supported accommodation services may pay between 85-95 per cent of their income in accommodation fees, leaving them very little to live on. Most cannot afford public transport; they cannot go out; they cannot buy cigarettes; they cannot have a drink. For many Victorians with a disability, just having an occasional night out or a holiday, having friends or family over for a meal, having a hobby, being able to pay bills on time, not going hungry and heating a home is not possible. These are fundamental to a normal life and yet are denied to this vulnerable group.

Women living in supported residential services are particularly vulnerable. For example, the Office is aware of many very vulnerable women living in supported residential services where the majority of other residents are vulnerable men. After paying for their accommodation fees they have little disposable income left. How do they pay for what most of us would consider basic necessities? I will leave that to our imagination. Not surprisingly, risky and antisocial behaviour increases when people are unable to participate in normal community life. People should be able to live rich and fulfilling lives and to be treated with dignity and respect. This cannot happen when they are unable to participate in activities that all of us here would take for granted. To give these residents the opportunity to participate in community life the Office believes the amount of

income that SRSs are able to take from residents' income should be capped. This may mean greater government support for the SRS sector.

Another of the issues the Office sees across all sectors is a lack of sufficiently qualified and inexperienced staff. Inadequately trained or inexperienced staff can have a profound impact on the resident's quality of life. It is particularly difficult to support residents with complex needs such as autism spectrum disorders, Huntington's disease, acquired brain injuries and people with dual diagnoses when the workforce is inexperienced, underpaid and increasingly, casual.

Community visitors have reported errors in the dispensing of medication in disability services. They attribute this to an inexperienced, increasingly casualised, or part-time workforce that is sometimes unable to identify the individuals they are giving medication to. Community visitors worry about the potential serious consequences of a medication error on the wellbeing of residents. Our Office would like to see mandatory minimum qualifications, workforce planning and improved pay and conditions for staff. Staff employed in the disability sector are typically some of the lowest paid in the community.

In conclusion, the closure of the three remaining institutions in Victoria, Colanda, Sandhurst, and the Oakleigh Centre must be a priority for government. This year Kew Residential Services closed. The Office strongly supported this closure and supports the closure of all remaining institutions. The fact that there are about 200 Victorians still living in disability institutions state is a shocking indictment on us all. In order to close all remaining institutions and move the residents into more appropriate community settings we need to ensure that there is funding for a wide range of accommodation options. Thank you.

**Ms WOOLDRIDGE** — Thanks very much, Colleen. Congratulations on your combined annual report as well, which I think was a good opportunity to bring some of these themes together. You have done incredibly well. I am interested in touching on an area that does come up in the report but is not covered in your presentation, which is the difference between government-provided and non-government-provided accommodation. What have you found in relation to perhaps quality of care and also the facilities and environment of the two different types of supported accommodation?

**Ms PEARCE** — Community visitors believe that community services organisations, which provide excellent service, are not getting their fair share of capital funding. This means their facilities are often more run down and fall short of being maintained at an acceptable standard. Community visitors have recommended a more just and equitable allocation of funding to improve the conditions of facilities provided by community service organisations.

Many community service organisations use their own accommodation and, all too often, rely on fundraising or charity to maintain these facilities. The Office believes that much of the accommodation they provide is not of an acceptable standard. It is the inadequate level of capital funding that is the issue not the recalcitrance of individual providers. Community service organisations should not have to be responsible for raising capital to ensure accommodation is provided at acceptable levels.

**Ms WOOLDRIDGE** — Do you see a difference in the quality of care or staff and workforce in the two different sector providers?

**Ms PEARCE** — Once again, this is not meant to be a criticism of the community service organisations as the Office believes they do the best they can with the funds they are given. However it is very difficult for smaller providers to attract appropriately qualified staff. They are unable to remunerate their staff at the same level as government and larger community service organisations. There are also issues for the providers around the quality and qualifications of staff. Again, this is not meant to be a criticism of these organisations, but rather it is a comment on the difficulties smaller organisations sometimes face in recruiting and retaining staff.

**Mr NOONAN** — Thanks, Colleen and Janine. I am interested in the solutions that you have offered and specifically that the government inject more funding for both accommodation and support options. During the course of our hearings we have heard of a number of residents, short and long term, who have taken up support packages in order to move to more independent living arrangements. Can you provide us with some views on those individual support packages and their impact on assisting in alleviating some of the bed blockages that you have referred to?

**Ms PEARCE** — The Office strongly supports the move towards individualised funding. This is an important initiative, because it empowers people, enables them to have a greater say in the way they want to live their life, and in gives them greater autonomy. Individualised funding is however, only part of the story. There are still people who require housing and other supports who cannot get what they need to live full and independent lives. The two go hand-in-hand; you cannot have one without the other. Policy and guidelines must be developed to ensure that people with an intellectual disability can fully participate in the planning and decision-making about individualised funding. It is important that they are able to fully participate in this process, that they have a greater measure of control over their own lives. In order to achieve this there needs to be significant changes in the way people with an intellectual disability are seen and treated and this will no doubt be particularly challenging for some service providers. Again, while the Office strongly supports individualised funding there also needs to be an injection of additional funds into supported housing options in the community.

**Mr NOONAN** — Just by way of follow-up, then, do you have any sense from your visits of how many individuals might be seeking in the future to perhaps take advantage of an individual package to live more independently?

**Ms PEARCE** — I am not aware of the number of people may want individual package to live more independently. In order to ascertain how this in the future there needs to be an investment in more forward planning. Supports are needed to help people with an intellectual disability understand what an individual package could mean for them. The emphasis should be on support to help people plan for their future. Recently, La Trobe University held a conference on individualised funding for people with an intellectual disability. Speakers from Reinforce, a consumer advocacy organisation, spoke about individualised funding from their perspective. While they liked the idea, they said no one had spoken about it to them and they expressed some confusion about what it was and what it could mean for them. They had only recently heard of individualised funding and did not think many of their members knew much about it or how to access it. They argued that there should be greater funding for consumer bodies like themselves to enable them to talk to people in Community Residential Units and to assist them to understand what it was all about.

**Mr SCHEFFER** — Colleen, thanks for your presentation. In passing through, you took us back to 1986 and the beginning of the deinstitutionalisation process. I was thinking as you were saying that that since that time, some 22 years ago, a lot of things have changed. You have chronicled some of the very important weaknesses where we are now. If I could ask you to reflect for just a moment on the new Disability Act 2006, so it is still relatively new, and the state disability plan, the individualised plans and individual packages that you just endorsed in your previous remarks, the mental health green paper that is currently being circulated, the additional funding for disability services under A Fairer Victoria, the \$120-something million for mental health in the last budget, a range of initiatives that have been put in place over the last few years. Do you think they are facing in the right direction or are there major flaws in that overall strategy and program that have been pursued in the last years?

**Ms PEARCE** — The initiatives you mention are all important steps in the right direction — there is absolutely no doubt about that. The Disability Act is a new act, and like many new acts there are still some issues to be worked through. In particular, I am very pleased to note that the introduction of supervised treatment orders has meant that guardianship is no longer used to civilly detain individuals who may pose a risk to themselves. One aspect of the act that

continues to be of concern is the low usage of independent persons who have a legislated role in explaining to an individual why they are to be subjected to restrictive interventions, or perhaps held in seclusion. DHS's statistics show that in only 18 per cent of cases are independent persons being used in this role.

The Disability Act represents a significant improvement on previous legislation and goes a long way to ensure that the rights of people with a disability are recognised and advanced. It is challenging for service providers, who have to step up to the plate. The world has changed greatly since the process of deinstitutionalisation commenced, but along the way there are increases in: the complexity of people who are access community and health services; the number of people with dual diagnoses and; the number of people with complex problems that do not fit neatly into service system silos. While there have been significant steps forward, the complexity of people and the lack of appropriate accommodation remain issues of concern.

**Mr SCHEFFER** — Do you think that complexity and those multiple needs that you have talked about are being picked up in documents like the mental health green paper?

**Ms PEARCE** — The reforms outlined in the green paper offer an opportunity for Victoria to continue to be steps ahead in relation to models of health care for people with a mental illness. An enhanced focus on early intervention and prevention needs to be supplemented with a strong commitment to meeting the needs of people who have fallen between the cracks of the current system - people with complex needs, people in the criminal justice system, people who are homeless or at risk of being homeless.

While I applaud the paper, I eagerly await the government's response to both the green paper and the review of the Mental Health Act. The Office believes a new Mental Health Act should not just focus on involuntary detention but instead should see compulsory treatment and involuntary detention as part of a continuum of service that begins with early intervention and prevention. It is important that the new mental health act describes this continuum of care.

**The CHAIR** — You recommended that a cap should be introduced on the percentage of income that is taken from residents. What sort of a funding model should there be? How do you fill the gap?

**Ms PEARCE** — The Office has not developed a particular funding formula or a method of calculating what the cap should be. However what we know is that the thousands of people residing in pension-only supported residential services are some of the most vulnerable people in Victoria. As I said earlier, many residents spend between 85-95% of their pension on accommodation. This leaves very little disposable income to spend on things that you and I might consider basic necessities such as going out for a meal, having a drink or having a hobby. Many cannot afford the cost of public transport and become increasingly socially isolated. When people are left with only 5-15% of their pension to live on for a fortnight, there are significant social consequences — not just for the health and community services sectors but also for the criminal justice system. You don't have to be a rocket scientist to see what is happening to these vulnerable individuals: It is reflected in the higher number of people with a disability that are moving through the criminal justice system.

**Ms BUSH** — Our community visitors have made a recommendation that there be a cap of 75 per cent, but it is not based on a particular formula at this point.

**Ms WOOLDRIDGE** — Just following on from Johan's question, which was very broad, about disability and mental health and action over the last eight years, when we focus back down on supported accommodation and look at your old annual reports, every year for the last nine annual reports you have called for more supported accommodation. I think you are incredibly strong this year in terms of that message. The Auditor-General published a report last year saying

there had been no new beds in the previous four years. In the context of all the other changes, could you reflect on what is the reality, and has supported accommodation shifted in this period?

**Ms PEARCE** — For at least 9 years community visitors, through their annual reports, have stressed the need for more supported accommodation. The social and economic consequences of not addressing the accommodation issue can be found in the increasing numbers of complex clients in the mental health sector, in the criminal justice system, or amongst the homeless population. Deinstitutionalisation was an important milestone but unfortunately, the need for a broader range of supported accommodation was not recognised at that time. It is important that we recognise very real human cost; the ‘bed blockers’ struck in the system, desperate to get out, or those, equally desperate to get in.

**Ms WOOLDRIDGE** — Has the additional funding, or the new act, changed that?

**Ms PEARCE** — In our view, no. While there have been significant improvements in the lives of many people with a disability, and the move to individualised packages is very welcome, the system as a whole is still in need of a further injection of funds. We applaud these new initiatives, they are very welcome, but these initiatives do not meet all the support and accommodation needs of many vulnerable Victorians.

**The CHAIR** — Thank you very much for your presentation.

**Witnesses withdrew.**