

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Melbourne — 22 October 2008

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Mrs S. Mortimer, treasurer, Concerned Individuals and Parents Advocacy on Intellectual Disability.

The CHAIR — Thank you very much, Stephanie, for coming along. You are from CIPAID?

Mrs MORTIMER — That is right, yes.

The CHAIR — Would you explain what it means?

Mrs MORTIMER — CIPAID is an organisation that started some 30 years ago out of a concern for what was happening to residents in institutions. CIPAID's priorities have been housing options for people with disabilities and generally the welfare of people in institutions — what has happened to them since they have been in institutions. CIPAID is the Concerned Individuals and Parents Advocacy on Intellectual Disability.

The CHAIR — You have 3 to 5 minutes maximum.

Mrs MORTIMER — I thank this committee for the opportunity. I am the treasurer for an organisation called CIPAID. I provide full-time care to my sister, who has a dual disability. She used to reside in a department community residential unit, which I found to be very much an institution with institutional practices. I have outlined some of these in my submission to the committee.

My sister came home subsequent to opposition from the department. Their attitude was a disgrace. They gave information to the Office of the Public Advocate which was not correct regarding policy in shared-care arrangements for families and the department. As a result it sent the police to my home to seize my sister. My sister became unwell when she was forced back into the CRU, and the Office of the Public Advocate had to ring me and ask me to bring her back home. I now have an individual support package, and I employ my own staff and use a service provider as an intermediary for a fee. My staff provide invoices for the work they have done. This model is called family governance and has been available through the department for over 10 years but is not promoted. This model allows flexibility, and the money in the package goes about three times the distance.

I will start with a story which is old and harks back to the Kennett era, but things are the same today. A group of families, 12 in all, got together and bought some land on the peninsula. The one family was going to live in a house in the middle of the property, and they wanted to build an E.W. Tipping house at the front and one at the back to house 12 people with disabilities, including their son. There would have been no need for sleepover staff. The department refused to staff this facility because the people with the intellectual disabilities were not at the top of the waiting list, now called the disability support register. The project could not go ahead without staffing.

It is DHS policy that there should be only five people in a house, but from my sister's experience an institution is not defined by the size of the roof but by the relationships within the house. Why are we not allowed to have village-style accommodation for people with intellectual disabilities? Why can we not have clusters? Why does the department thwart innovative models? Villages would be ideal for some people with high-support needs, and Gordon Ashley, a former member for Bayswater, has been overseas and documented for Parliament the advantages of this sort of accommodation, how it works et cetera. Many parents would contribute to housing but are thwarted by the department. Many parents would leave a trust to a service provider of their choice on the guarantee that they would provide care for their loved one until they die, and then the trust could go to the service provider. But inquiries by our group have established that this cannot be done because the service provider is obliged to take someone at the top of the disability support register. There are CRUs which are privately owned and run, and funded by the department and residents' pensions, but as an organisation we have been unable to establish how this is done so that we can maybe fund something ourselves. There is one that was started by parents in Boronia, but we cannot find out anything about it.

Woody Marriott from Ambleside Tours has made inquiries, and he has hit a brick wall no matter who he speaks to at the department. We have approached people who own these CRUs, and they have refused to meet with us to tell us how this funding works. So we have willing organisations and willing parents who are keen to contribute but are stifled by the disability support register at the department. The one-size-fits-all model is a disgrace. There are no innovative options like the ones the Transport Accident Commission is using. Waldreas Lodge Hostel in Wantirna Road, Ringwood, is an example of how things can work — this is a TAC-funded model. It is village with independent living units, hostels for young people with disabilities, hostels for older people with disabilities, and a nursing home on the same site. The TAC also has independent living units with five units on a site and a sleepover facility in the same grounds. The sleepover person can be contacted during the night by any of the residents in the five houses.

I personally believe that many of the problems with housing stem from the attitude of government departments and bureaucrats. In my case my sister could have funded half a unit herself. With her individual support package she could have had her staff coming in. She wanted to share it with a friend who was highly skilled and could drive a car. The department refused to move with the ISP package application, and in fact it took four years to get this individuals support package, with the employment of a full-time advocate on my sister's behalf. Families should not be put to such disadvantage. All we need is a willingness to support families in options.

Respite care is similarly affected. The Gippsland Carers Association had a 12-bedroom house it could use for respite, but funding was not approved because it was congregate care. It did not matter to government that carers in Gippsland had an average of two days respite every 17.2 years. As long as the department sticks with idealistic and bureaucratic ideas, family members will continue to suffer and die not knowing what will happen to their loved one. It does not finish here, as many estates are contested in the Supreme Court for extra provision for the person with the disability. Informal negotiation which bears no cost is never tried. With huge legal costs, this leaves the person with the intellectual disability with less provision for their life, and their need is greater.

I think the whole attitude towards families and people with disabilities is one of authoritarian mismanagement, a complete lack of understanding and an attitude that says 'We know it all and families do not'. The families have been fighting for 50 years, and nothing has happened. Will it be another 50 years before something is done? Dr David Sykes from the Office of the Public Advocate wrote a paper called 'Choice is not an option'. I recommend it as reading for the panel.

Witness withdrew.