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7th October 2008
Mr Jude Perera, MLA
Chairman
Family and Community Development Committee
Parliament House
Spring Street,
East Melbourne Vic 3002

Dear Mr Perera,

Re: Inquiry – Submission – Supported Accommodation

Please accept my submission to your inquiry into "Supported Accommodation for those with Disability and Mental Illness."

I address these issues under the headings that you have provided.

Accommodation Currently Available

Extremely Physically Disabled

For the extremely physically disabled there is no accommodation available. Emergency waiting lists are in excess of 6000 while just 20 to 30 are placed each year. The list is known as the "Death List" as accommodation will tend to only come about when the parents die. These parents must carry out hospital intensive care tasks within their own homes for the remainder of their lives. In some cases 30 to 50 years. This means they must bath, lift, change, feed often via a stomach tube, medicate. It also means that they must remain a prisoner of their own homes and live apart from the normality of the rest of the community. It is not uncommon for parents to abandon their siblings at a respite centre in order to get the care they so desperately need.

When parents die it is a practice to place young people with sound minds but extremely disabled bodies into Older Persons Nursing Homes. There they are left to live the remainder of their lives with the horror of death around them on a daily basis.

Intellectually Disabled

Intellectually disabled people are often placed in very poor standard "Special Accommodation Houses" where mistreatment is common. There is no government funding and no standards are set or regulated to protect these people. There are many examples of the despair experienced on a day to day basis as the private operator attempts to care for the younger mentally disabled on just their surrendered pension. The fear of drawing attention to these "third world" facilities is that they might be closed down and the residents will have no where to live at all.

Some time ago State Government closed down the State accommodation facilities for these people because of the extremely bad conditions. They were

replaced with nothing and most found themselves on the streets or in sub standard boarding houses. It has been shown that many of them became violent without care and found themselves confronted by the law and punished without due consideration to their plight.

Current Government Accommodation.

The minute accommodation provided by Government funding is a mere token in addressing the need. It enables politicians and bureaucrats to state that there is accommodation available, when in fact there is none.

The only Accommodation is the family home where parents try to care for their siblings in isolation from the community until they die and leave their child to an unknown future. Politicians that I speak to well recognise this, and are applauded and ashamed that their parties do not address this "black hole" in the welfare system. A group of people who do not have the capacity to march and protest who are housebound with their charges.

In my work with people in these situations the most common 2 statements which come from parents are:-

"I gave up any hope of getting help years ago, but if only there was somewhere that I could have my child cared for while I have a rest" and
"What will happen to my child when I die?"

The Government's Response to Supported Accommodation

Federal and State Governments are well aware of the extreme lack of supported accommodation, but governments of all political persuasions fail to act on it.

Government must stop the talk fests that have now been conducted over the past 30 years and act to rectify this horrific state of affairs.

Alternate Approaches to Addressing Unmet Needs

Redirect Funding

If the government cannot address the needs directly then they should cease to fund the huge departmental bureaucracy which digests the greater part of Government funding

They should instead forward financial credits directly to parents and/or community based groups to provide co-operative housing facilities.

Currently the machinery of Government has an insatiable appetite for the very limited funds available and just a trickle reaches the targeted families and their siblings.

Fund Local Government

Local government is the government closest to the people. I suggest that Federal and State Government fund and empower Councils to take up this care and need as seen in the United Kingdom.

Estimation of Need for Supported Accommodation

The need is immense and varied. Classes of accommodation need to be established to match facilities to the specific needs of the various groups and state of disability. If the emergency waiting list is in excess of 6000 and growing, then there must be many tens of thousands out there in need of accommodation.

The Adequacy of Alternate Accommodation

For those who can walk and who can rely only on a pension, there are few facilities which can provide a decent standard of accommodation.

For those who cannot walk who are paraplegic and quadriplegic, there is no accommodation available save a token placement as previously mentioned.

Appropriateness of Service Providers.

The adhoc Service providers that attempt to sustain families in their homes because of the lack of suitable accommodation are distressing. Government currently hand over this care to "Agencies" who are usually unable to provide the care or continuity of service.

Agencies claim they cannot recruit staff. Carers are very over worked and are among the lowest paid in the community. Huge expense is incurred in the bureaucracy handling, discussing, meeting, educating and administrating a process which often has little outcome for the recipients.

The Agency system is currently in a break down situation and carers are often left to their own devices without support in their homes while they wait in vain for accommodation,

The Impact on Families

Over the past 30 years I have observed the disastrous impact on families because of the lack of accommodation facilities. I have observed the following.

Suicide of Carers

Suicide of Carers after taking their siblings life

The most common is a breakdown of marriage and just one left to cope

Neglect of other siblings

Nervous Breakdowns of Carers and a decline in their mental health.

Extreme financial hardship

Inability to deliver complicated and demanding care (as in quadriplegia)

At meetings of "The Respite Network" I have listened to the despair and lack of hope that parents have.

Example.

A young single mother in her mid twenties who has a mentally disabled child.

She shared how her child screams for 22 hours a day. Few carers could come and if they did they would not return. There was no facility available to care for her child.

She stated that the only way out that she could see, was for her to take her child's life and then commit suicide.

Example 2

An elderly couple with a disabled daughter who is a quadriplegic, with many other complications but inwardly intelligent. They share how after 30 plus years that they are unable to lift, change, administer feeding by tube through the stomach wall any more. They have been on the waiting list, or the "death list" as they call it for emergency accommodation for the past 6 years and there is no hope in site that accommodation will ever become available. They say the only outside advice they are receiving to obtain relief is that they must abandon their daughter at a government respite facility... They struggle to do that as they know she may be put into an old person's nursing home which would mentally destroy her.

Accessibility for Specific Groups including Rural/Cultural/Indigenous

Such luxury of considerations can hardly be considered when the basic need for anyone in need is not in place. The need is to put the care in place and then consider how it might be refined when the emergency waiting list has been addressed.

Conclusion

I congratulate Parliament in undertaking this Inquiry. There have been many forays into this need to no effect. Please act and overcome this appalling state of care for our most vulnerable within the community

Yours faithfully



Alan G Field OAM

Citizen of the Year

Volunteer of the Year

Paul Harris Fellow

Member & Past Chair of Nillumbik Disability Advisory Committee

Secretary Australian Disability Support Alliance

Advocate Judge Book Residents Association

Carer

Cc: Jenny Macklin MP

Steve Herbert MP

Nillumbik Shire Council