



Paul
Bourke/ParlOfficer/PARL
10/09/2008 03:10 PM

To lara.howe@parliament.vic.gov.au
cc
bcc
Subject Fw: Submission for Inquiry into Supported Accommodation
for those with disability and mental illness

----- Original Message -----

From: lesevans [lesevans@girton.vic.edu.au]

Sent: 09/10/2008 03:06 PM ZE10

To: Paul Bourke

Subject: Submission for Inquiry into Supported Accommodation for those with disability and mental illness

Dear Paul,

Please find attached a submission for your committee. Please let us know when you receive it, so I can pass this knowledge onto the other members of our group.

Regards

Les Evans

24 Murphy Street

Bendigo VIC 3550

The Executive Officer,
Family and Community Development Committee,
Parliament House,
Spring Street,
East Melbourne
Victoria 3002

Accommodation letter to State Government Enquiry.

Re: Inquiry into Supported Accommodation for those with disability and mental illness.

To Family and Community Health Committee.

To the Honourable Mr. Jude Perera,

We are a group of parents whom have disabled children who have formed a group, we are all faced with the untenable position of attempting to find supported accommodation for our children. Over the last twelve months we have written to our local members for support and guidance as to how to address this unmet and critical need.

We appreciate that this committee has been formed to identify and investigate the concerns families face. We need to share a worry with you and that is the number of committees like yours that have been formed over recent years to investigate a similar set of circumstances. For example: In 2007 the Senate Standing Committee of Community Affairs produced a report which suggested in part that there is a large unmet need for supported accommodation in Australia for people with a disability. It is also worth noting that Deakin University in October 2007 released a report on the well being of Australian carers, which suggest they have the least sense on well being of any group of the general population. As you can imagine we are afraid that we may receive yet another report that merely identifies rather than addresses the unmet needs of Victorian carers.

Please find below our responses to Terms of reference: items 4 and 7 which are those most relevant to us.

Once again we thank you for your support and endeavour to address the crisis we face because of the unmet need for Supported Accommodation.

Item 4. The impact of Victorian families of insufficient supported accommodation.

- **Inability of families to take holidays.** Forced to match holidays to match service providers. (While they take leave, families are forced to have leave to care for their children with a disability.) Consequently no holiday.

- **The requirement to reconsider work.**

Full time is not an option for some, workloads and work commitments are compromised due to lack of availability of care, some parents unable to even access employment. No flexibility in work commitments. When respite is given it is under the terms of the respite giver, not necessarily the needs the family requires.

- The social constraints on families are severely compromised. E.g. a simple dinner invitation will be dependent of the availability of care and access to that care.
- Trying to maintain the family unit is constantly compromised. Any event which two parents would like to attend is normally negotiated to see which parent can go, due to one parent required to be the care giver. If you are a single parent this is nearly impossible to achieve. Many families struggle to maintain the family unit and the breakdown of most is the norm. This is particularly evident to our families.
- The impact of siblings is paramount, some sibling have the left the family home not to return or have made choices to study in alternate locations in attempt to have some normality in their lives.
- The social development, emotional and mental health of siblings is all distorted because of the shame and difficulties of inviting friends to the family home. When the sibling with a disability displays constant challenging behaviour, the ability to socialise in the family home is compromised.
- Physical health of the parents.
- The immense financial pressures, families go to extremes to include and support the person with a disability, e.g., extra person on holidays, outings, purchase of equipment, e.g. tandem bike.

All families are aware that there are emotional and financial commitments in the raising of any child, however, parents strive to allow "normal children" to become independent, in the belief that one day they will leave the family home. This is not the case with a child with a disability, what parents find highly offensive is the expectation that we will maintain the standard of care for our child with a disability until we die. It should not be in any circumstances a legacy for the siblings of a child with a disability.

It is a constant concern that preoccupies our whole lives what will happen to our children when we are not there, how will we continual to maintain the standard of care that our children are entitled too. As we become older, the care of our disable children becomes more challenging. The constant drain on our emotional and physical strength becomes more and more obvious.

Our children deserve a quality adult life, where they can share their life with their peers and are not isolated from the general community as the care givers get older. Parents become so isolated due to the constraints of having a child with a disability, their social network narrows and thus the support they desperately need narrows too.

What is confusing to us as a parent group it that are children have been assessed and meet the criteria for access to supported *accommodation* , in fact members of this group have been recommended to have supported accommodation, but then we are informed that you cannot have it because there is no

availability. The situation that currently exists causes a moral hazard for parents, their options being is to relinquish care of the child by declaring them a ward of the state or alternatively the child or the carer being placed at risk. This is not a position that any parent should be placed in.

Item 7. The ability of country Victorians to access supported accommodation and the appropriateness and quality of care they receive:

It is extremely difficult for families to access this information, when we are informed of supported accommodation options ,if and only if our child is at risk, then they will be offered a place in the first available position, this could be anywhere in Victoria. This will need to be accepted in order to receive supported accommodation. This further isolates the person with a disability from their ability to connect to their family, and places more emotional and financial hardships for the parents. It has become clear to us that there are many families in Bendigo seeking supported accommodation, this huge need is unmet. Placement of young people with a disability in nursing home facility is totally inappropriate and should not be an option.

The Department of Human Services appear to have a certain model that will service unhoused people with a disability, but this is not meeting the needs of the families. Our group requires a home that will potentially house 5-8 young adults with varying needs, all of which require continuous supervision. Some members have offered to build a home and give it to the government to service this need, however this offer was declined on the grounds that "I didn't understand the situation" . We do understand the situation, as the recurrent costs far outweigh the initial capital costs of supplying the premises. There appears to be a lack of creative thought in the provision of recurrent funds. The department of Human Services should be meeting the needs of the collective families and not isolating by individualised funding which in itself is not economical. Parents need to be treated with greater respect; they can define the needs for their children and can conduct themselves in a way that can provide the best outcomes.

There is a significant need for the provision of support accommodation. At the moment, the current trend of individualised funding merely bandaids the underlying problem of lack of supported accommodation. While respite is an important interim measure is it only an interim measure, and does not meet the long term requirements of fully supported accommodation.

We thank you for addressing this crisis.

Our group would be happy to provide more information on their needs or to address the committee.

Yours sincerely,

Les and Leonie Evans, Christine and Trevor Phillips, Peter and Florence Cantwell, Kerry and David Johnston, Judy Sheaf, Liz and Tony Knox.

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