

AOC 15/7/08

From: Tony & Heather Tregale [vk3qq@optusnet.com.au]
Sent: Tuesday, 1 July 2008 8:16 AM
To: Committee, FCHY (REPS)
Subject: Carers Submission, "Better Support for Carers" - Committee, FCHY (REPS)

From: Tony & Heather Tregale
Sent: 1 July 2008
To: Committee, FCHY (REPS)
Subject: Carers Submission

Dear Secretary,

We wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into **Better Support for Carers.**

Although we are no longer first-line carers for our youngest son, Paul, now 32, we were so until he was 21. We would like to be now, but it would be hell for us, as there is virtually no respite, and the Victorian Government is hell bent on in-home support, with no extra respite facilities, in contrast to supported accommodation group homes.

In the earlier years, we used local authority HACC Services, friends and neighbours to give us a break from 24/7 care. In later years, there were specific respite facilities, which were under used at the time. But not now! So we got good breaks, at that time, from 24/7 care.

Nevertheless, as we were getting no younger, and could depart this world at any time. So, if we did not pursue permanent supported accommodation for Paul, he would have nothing when we were no longer, or not able.

We had been Community Visitors for many years, so we knew how questionable supported accommodation group homes could be, especially those where the Victorian Department of Human Services (DHS) was the service provider.

We agonized over seeking Paul a group home, but considered we could fight to improve the level and quality of service. And, we are **still** fighting the bloody minded public service bureaucrats, here in Victoria! Paul's quality of life care has been shocking for most of the time he has been living in a DHS group home. And, we have the wall to wall evidence to prove this!

Therefore, the best place for family members with an intellectual or multiple disability is to be living with caring parents in their home. Unfortunately, try as we may, we parents do not live forever, or are able to provide care forever, and do need some life without the 24/7 commitment of care.

Caring parents naturally provide, over the years, extensive behaviour

management and skill training, etc, etc for their family member with a disability. Although they know much of this will be lost if their family member ever goes into a group home, as many group homes are just minder services, they are so desperate, they will eventually accept any "roof and four walls". However, we know parents who say they would rather commit dual suicide, than have their family member behind the unaccountable closed doors of group homes.

Because of the inconsistent and crises driven DHS services here in Victoria, as reported by the Victorian Auditor General in his recent report, we have our son, Paul, with us, and visit him as often as possible. And a large percentage of the time we now have, not now being first-line carers, we spend actively encouraging the captive market, crises driven, DHS to fully implement the direction, intention and spirit of the department care policies, standards and values at their service points. The intention being, that parents will not, otherwise, have a choice of care.... Being, "minder" or "nothing", if ever they get a break from providing 24/7 care in the family home! Those who have lived in a quality home with caring parents, deserve similar when those parents have done their time.

In conclusion, we support those ageing parents doing it real tough, with no future for their family member or themselves. In-home support is not the answer, especially with little or no respite. Where carers cannot be totally relieved of their caring role, they must be supported with adequate and effective respite. And, we draw your attention to two videos produced in Western Australia. We consider these as essential viewing for the "Committee, FCHY (REPS)". These videos are entitled, "It's a Long Road" and "Going the Distance". Contacts: Carers Association WA, Tel: 1800-242-636, and i.d.entity.wa Tel: 08-9474-3303.

Yours, sincerely,

Tony & Heather Tregale
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