Supplementary Submission No. 830.1
(Better Support for Carers)

Aoc 17/10/08

ATTENTION: THE SECRETARY OF THE COMMITTEE
THE HOUSE STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH
INQUIRY INTO BETTER SUPPORT FOR CARERS

SUPPLEMENTARY TO SUBMISSION #830

As a carer for the past twenty years, with no foreseeable end to this role, I would like to emphasise to the Committee that possibly my major coping strategy is to have a positive attitude. I try not to dwell on the negatives of my situation, and believe that support and services will improve. For those of you who have read 'Pollyanna' you will understand what I mean when I say I play the "Glad Game'. Having said that, I realise that the only way your Committee will be able to advise the present government of the changes required, is to inform you of the negatives.

In my original submission there was a glaring omission on my part. RESPITE. I would like to inform the Committee of a specific circumstance here in Wagga Wagga.

In late April/early May 2006, a group of families with children requiring very high support were informed that their access to the respite cottage here would be stopped at the end of June 2006. This specifically affected twelve families. Our children did not fit into their funding criteria. There was no other suitable respite service available to us.

We, along with numerous other families who also believed their access to respite could be terminated due to 'funding criteria', contacted DADHC, our local member, Daryl Maguire, and John Della Bosca, the then Minister. The local media became involved.

After weeks of stress for the carers, we were informed that DADHC had reached an agreement with that service would continue to be provided until June 2007, with negotiations during that period for a long term solution. were adamant that they were not prepared to provide ongoing services to anyone other than their target group...those young people between six and twenty-four years of age, with a primarily physical disability, and only a mild to moderate intellectual disability. We had a stay of execution, but no reprieve.

In mid July, 2006 we were told that DADHC would probably fund a full time respite house for this region, so as a group of carers we mobilised. We approached a local philanthropist regarding setting up a not for profit organisation, put together a proposal outlining our needs, which we distributed to anyone we felt may be able to help and we had an amazing response.

In early November 2006 we were advised by DADHC that tenders would be called in the not too distant future. Things were looking promising and we felt we had a chance. We had done everything asked of us. We had legal and accountancy representation, we had a person with all the right qualifications and experience to manage the service, we had been offered land to build on, we had the offer of $2,000,000.00 to build with, the services of an architect to plan the specific purpose home and we were in the process of putting together policy and procedure manuals. And then it happened. decided to come back into the picture.

After all these months of effort, and belief that our family members had the chance to receive the best service possible, we were advised that there would be no tender. .

It was nearly State election time and much was made of the announcement of funding for a 24/7 respite house for Wagga Wagga. In January, 2007 we were told that would be receiving the ongoing funding, to 'expand' their service...a service which didn't want us, and which seems to believe that administration takes priority over care.

It is now October, 2008 and there are seventy families still waiting. The State government, in their wisdom, purchased a totally unsuitable property in September, 2007. That house has been sitting vacant for twelve months waiting for major renovations to be approved by the local council and tenders to be offered and accepted for the alterations to be done. (see attached letters) Even if this ever happens, there are other problems.

There are restrictions on who can access the service and when. There are issues with age, type of disability and safety for service users and staff. And families have no input into any of these decisions

It is a nightmare.

In comparison, two new respite houses have established and are up and running in Albury in the same time period.

While a promise of improved services should be a positive for carers, this situation has created more stress, and disillusionment with the system.

It seems that the State Government in NSW gives priority to larger, established organisations when allocating funding. I can understand why they may believe that to be the best course of action, but many of the larger organisations whose administration and management structures continue to grow, have lost touch with the true reason for their existence....the care and support of people with disabilities and their carers.

Yours faithfully

NARELLE