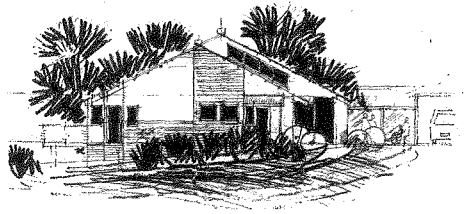


Submission No. 17
(Inq into better support for carers)

A.O.C. 3/6/08

nardy
house
quarara



Nardy House Inc.

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**ATTENTION : THE SECRETARY OF THE COMMITTEE . THE HOUSE STANDING COMMITTEE ON
FAMILY, COMMUNITY, HOUSING AND YOUTH.**

INQUIRY INTO BETTER SUPPORT FOR CARERS

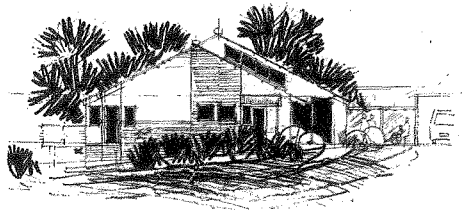
8 PAGES TO FOLLOW

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2/06/08

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guarantees



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**PARLIAMENT OF AUSTRALIA
HOUSE OF REPRESENTATIVES**

**HOUSE STANDING COMMITTEE INQUIRY INTO BETTER
SUPPORT FOR CARERS**

Members of the Nardy House Inc. Committee place this submission before the Inquiry. A brief background related to the group appears below and a full history of related activities of this group is attached as an appendix. We believe that for the time we have been in existence the role of carers of people with profound disabilities has not been acknowledged nor adequately supported and that the reasons related to this lack of support are monetary. We have addressed the terms of reference from our perspective only and have offered solutions that we see as benefiting people with profound disabilities and their carers. These solutions are, at times, applicable to the wider community of carers.

BACKGROUND: THE NARDY HOUSE PROJECT

The Nardy House Committee was formed fourteen years ago initially as a Committee of Bega Valley Shire Council. A donation of five and a half acres of land was made to the group and its main aim was, and still remains, to provide permanent accommodation to people with profound disabilities. We gained charity status, from the Taxation Department, while still working under the Council.

The planning of the Nardy House project resulted in a three-stage facility. These stages reflected the very high support needs of the people who would be using the facility and the requirements of their carers. The first stage was a respite facility for six people with profound disabilities; the second stage a permanent accommodation house for six people with profound disabilities; and the third stage a therapy room and pool for use by clients and local residents with therapy needs.

RESPITE

The Nardy Respite facility is now operating on a twenty-four hour/ seven day a week basis and is providing for the needs of very high-level support clients. Clients require assistance with every facet of everyday living and are, in most instances, wheelchair confined. Planned and crisis respite is available. The centre is being run by DADHC in conjunction with the Nardy House Committee for its first two years of operation. At the end of this period it is envisaged that Nardy House will be operating the service as a DADHC funded Non Government Organisation

THE NEXT STAGE

The Nardy House Committee has commenced Stage 2 of the Project. Bega Valley Shire Council has passed working drawings, the survey pegs are in place and the slab work has commenced

TERMS OF REFERENCE

One of the most noticeable tasks associated with people with profound disabilities is the amount of paperwork that surrounds any application for any service or support. We have found that over the period of our existence there is no end to the number of inquiries related to carers, caring and people needing caring support yet the real challenges requiring real monetary support are infrequently met. There is a constant assessment of need. The data and discussion related to carers needs already exists. If it does not then past work has been pulped and we can again remake the wheel. Further to this a person with a profound disability progresses and changes only minimally over long periods of time. While updating information regarding their situation might be necessary on occasions reworking tedious application forms for respite or service provision is time wasting, inefficient and soul destroying for the carer.

SUGGESTED SOLUTION: All people with high-level support needs be appointed a Case Manager. There is one file format; a copy of the file is with the Case Manager and the Carer and/or person in care. It is filled in once, updated when necessary and is used for all applications for service. The format should be as simple as possible and should not be varied at whim by incoming bureaucrats. Nor should the format be varied when a new Minister (one requiring a clean slate) takes the reins. It should not be repetitive and ask for the same information six different ways and for the form to be in triplicate. The format should be applicable Australia wide or at very least Statewide. There should be a statistical information section related to this format that feeds into a central data base (automatically) that contains no personal information but keeps the Government aware of the level of disability and the level of care required to cater for this disability. This should stop the continual assessment process that gathers statistics and does nothing with the figures except judge them out of date in order to begin again. We do not, as a country, have a huge population and we should be able to assess the needs of this relatively limited number of people effectively.

The activities of carers are limited by the support they are given. The emphasis on in-home support, because it is believed to be economically effective, has turned carers'

homes into service provision points and has effectively entrapped carers within their own homes. Many highly skilled people have been de-skilled by the necessity of the caring role. The reward for care is de-skilling, entrapment and poverty. While great joy is derived from the caring role by many carers they feel that they are treated with enormous disdain by those in power (both economically and monetarily).

SUGGESTED SOLUTIONS: Centre- based respite for people with very high support needs that do not mix behaviourally disturbed people with people who are vulnerable to physical, verbal and psychological abuse from those more capable than themselves. Payment of a wage for the caring role that allows highly skilled people the choice of re-joining the workforce and/or employing someone in their place. Assistance to set up small business enterprises within the home if desired and in-home support to run the business while undertaking caring. The introduction of a Nationwide Compulsory Insurance against Disability & Accident scheme that funds all levels of disabilities in an appropriate fashion. This scheme should include disability of all kinds: genetic and acquired and should take the form of whole of life support and needs a levy that is generous enough to cover carer wages.

Most carers have one constant fear. What will happen to the person in my care if something happens to me? They cannot effectively plan for the future because there are not the choices available to them to do so. Carers of people with profound disabilities only choice is an aged care facility. While people with profound levels of disability need nursing care most do not require medical care (if they do they go to hospital). Aged care facilities do not represent reasonable future options for carers and are resorted to as a last unpalatable option.

SUGGESTED SOLUTIONS: Offer a choice of group home models appropriately staffed to cater for the long-term supported accommodation needs of people with very high support needs. Ensure carers have knowledge of placement options available to them and assure them that when they can no longer undertake the caring role there is a place for the person in their care. Also ensure that if circumstances change they can freely take up the role of again caring for the person with the disability if they choose to do so.

Denise Redmond
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Nardy House
2/6/08