SUBMISSION TO THE INQUIRY INTO BETTER SUPPORT FOR CARERS

Firstly, I would like to inform the Committee of the care needs required by my daughter, Sally, who is twenty years old. Sally is a delightful young woman who wins the hearts of most people who take the time to meet her. She has a smile which lights up any room and a laugh which makes others feel happy to be alive. We love our daughter dearly and spend our lives trying to make her life the best it can be. To do this we need help.

Sally's disabilities were present from birth but have not been able to be formally diagnosed. The following is an excerpt from an appeal made to DADHC when Sally was assessed as being able to 'Transition to Work' at the end of her schooling in 2007, but the information is still relevant. Thankfully, common sense prevailed and Sally was reassessed as requiring very high support in a Community Participation program.

> Sally has profound intellectual and physical disabilities. She cannot walk, talk or feed herself. She is incontinent.
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> Sally uses a manual wheelchair which must be pushed by her carer as she does not have the physical or mental ability to manoeuvre it herself.
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> Sally's communication is non verbal – grunts, squeals, cries, clicks and screams – similar to an infant. She is reliant upon her carers to interpret these sounds and to meet her every need. When Sally's needs are not met she bangs her head against her wheelchair and makes loud noises of distress. Sally does not appear to understand any instructions.
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> Sally needs to be spoon fed mashed foods, as she cannot chew. Feeding takes up a lot of her carer's time. Sally drinks from a baby bottle, using a teat. One of the few thing's Sally can do for herself is to hold her bottle, but the carer must first place the bottle in her mouth and position her hands on the handles. She cannot pick the bottle up or get it into her mouth unassisted. It is best to position Sally in a prone position to drink, otherwise most of the liquid is dribbled down her front. This requires the carer to lift Sally from and to her wheelchair at least three to four times during the day. [and that is only during the day – mornings, afternoons and evening add to the number of lifts for feeding, bathing, toileting and just position changes to stop pressure sores]
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> Sally has epilepsy which is generally controlled with medication. Seizures occur occasionally, caused by sodium level fluctuations. It is critical that her carers monitor Sally's fluid intake to avoid this happening.
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> Sally is almost 20 years old and in nappies. She has total urinary incontinence. Over the years some patterning to bowel function has occurred, so luckily for her carers there is only an occasional bowel accident during the day. Again lifting is required to attend to Sally's toileting needs.
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> Sally's sleep patterns are erratic and as her primary carers, we must attend to her during the night whenever she is hot, cold, wet or thirsty or even just when she has decided she has had enough sleep so everyone else in the house should be awake as well. It is rare to have a solid night's sleep, and common for Sally to wake numerous times during the night.

> Basically caring for Sally is similar to caring for a six month old infant, albeit a 40 kilogram infant.
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> We both suffer chronic back problems and the worry of what may happen to Sally in the future is constantly on our minds.
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> As Sally's primary carers, we need as much assistance as is available. While we are not 'aging carers' as per [NSW] DADHC criteria, we are in our fifties and live in a constant state of sleep deprivation and physical and mental stress.

Over the years I have found that some of the major stresses in my caring role are caused by unavailability of services or difficulty to access services if they are available, due to waiting lists and now that I am moving into the older age bracket, I have a constant concern for my daughter's future care.

We now live in a Wagga Wagga, a major regional centre, but have spent time on the far south coast of NSW, in the Snowy Mountains and in Sydney. It does not seem to matter where you are, there are never enough allied health workers. Access to occupational therapy, speech therapy and physiotherapy is limited, if available at all. (see 1. practical measures, etc below)

Equipment such as wheelchairs, hoists, orthotics, special seating and continence supplies add a huge amount to our family's ongoing costs. Yes, there are some programs in place which provide assistance, but it is never enough. In September last year, Sally's orthopaedic surgeon suggested that she needed a new wheelchair. To apply for it through PADP in NSW we were required to have an occupational therapy assessment. As DADHC has only one occupational therapist for this region, it took months before the necessary reports, recommendations and quotations could be compiled. Finally, the application was lodged in late April and I had notice from the local PADP in mid May that their budget did not allow them to approve purchase at this time and that they will reassess our request on a needs basis each month. Sally's current chair is still deteriorating, but we have to wait. We cannot afford the $7000 it will cost. We definitely cannot afford a wheelchair accessible vehicle or a purpose built home or any home for that matter. We are in the private rental market and cannot even modify the premises. . (see 2. practical measures, etc below)

These are the day to day needs we encounter but my major concern is for Sally's future. At present it seems that the only way to become eligible for permanent supported care for a family member is to reach crisis within the family or to abandon them. State government funding for permanent care supported accommodation will never be enough. While we are able to provide at least basic care for our daughter, we have no hope of a permanent care placement for her.

I would hate Sally to lose her parents and then be placed in care where she knew no-one and no-one knew her special needs. Not only would she lose her parents, but also her home and her life as she knows it. She needs to be settled somewhere while we're still around to make sure she is happy. (see 3. practical measures, etc below)

I hope this sets the scene for the committee and you are able to truly consider and hopefully recommend some if not all of the following suggestions.

- **The role and contribution of carers in society and how this should be recognised**

We have all heard the wonderful words spoken by many and varied people about the great contribution carers make in society and I am pleased that there is some recognition of my seemingly never-ending role. However, words do not put food on the table, or compensate carers for the loss of earnings they may have made, or help to accumulate savings for the future, or fund a retirement which is unlikely to come anyway. We are feted during Carers Week and given a 'bonus' in the Budget if we fight for it. Carers of working age need to be paid a wage commensurate with the work they do. **Carers need to be recognised as workers who are providing a vital service which would otherwise need to be provided by the Government**. (see 4. practical measures, etc below)

- **The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment**

Carers are employed. We work 365 days per year, 24 hours per day.

Having said that...until my daughter turned thirteen she was eligib**le to** access after school care and school holiday care and I tried to maintain paid employment. Once after school care was not available I had to find a position on a part-time basis, and that was not necessarily easy. If you consider the details of my caring role as outlined earlier, you may be able to understand that, try as I might, and even with the most understanding employers, I would not be considered the most reliable employee. My daughter's needs had to be my priority. During my years as an employee it was necessary for me to drop everything and go to my daughter on a regular basis. Seizures at school meant hours for me in hospital emergency departments, sicknesses meant that I used all sick leave, parental leave and compassionate leave and school holidays meant annual leave plus more were taken. Even if bulk respite care had been available (which of course it wasn't), with a limit of 63 days per year of respite, including time spent in hospital, before my Carers Allowance of a meagre $100 per fortnight was affected, school holidays could not be accommodated. (see 5. practical measures, etc below)

Even when I was at work I was not always able to work to full capacity due to physical and mental exhaustion caused by my caring role.

Social isolation is a part of most carer's lives. No matter how caring and understanding friends may be, the restrictions on carers of people with high support needs make it difficult to maintain close ties. Most of our friends are now in a position of relative freedom. Their children are grown, they are able to socialise without having to find a 'babysitter'. At fifty I still cannot go out for dinner without major planning for the care of my daughter, let alone holiday for a week or two. Even if I could organise care, how would I afford it? And I am one of the lucky one's who has a partner who works.

Because my partner works and earns a reasonable wage, I am not entitled to a Carers Payment. I am responsible for the care of my daughter for 168 hours per week, but receive nothing. Had I not been in this position, I would have been able to work and our family income would have been much greater. **There should be no income test for eligibility to the Carers Payment for one income families.** (see 6. practical measures, etc below)

- **the practical measures required to better support carers, including key priorities for action**

These measures are not necessarily in order of needs priority, but in order as they appear in this submission.

1. A program which encourages more therapists to train is needed. Perhaps a reduction in HECS fees or scholarships to assist those who would like to become allied health professionals and inducements for those professionals to work in rural and regional areas should be introduced.
2. An increase in funding for equipment and continence supplies is needed. While the previous Government extended funding for continence supplies to a broader demographic, the actual amount has only been increased from $470 to $479. This increase covers approximately six nappies or one days needs.
3. Permanent care needs are as varied as the people who need those placements and their types of disability. I believe we need different accommodation models with different levels of care. At present this state government seems to believe that the only type of permanent care provision should be group homes with a maximum of five residents and minimal staff. Group homes are ideal for some and integration into the local community is essential. While I would never want to go back to the bad old days of institutions, I believe there is an argument for cluster accommodation models of care. For some reason, it has become accepted that only older people are happy to live in larger complexes such as retirement villages and nursing homes. More and more people with severe and multiple disabilities are surviving childhood and living into middle age or longer, and therefore the number of younger people needing high levels of permanent care support is increasing. We have all despaired at the thought of young people living in old age facilities, but at present there are few other options for those who require high or very high support when their families are unable to care. Small complexes, accommodating say ten to fifteen residents with varying levels of care needs, in four or five interconnected homes with communal kitchen/living areas would be ideal. A respite home incorporated into the complex would be a bonus. This would enable a transition for those who are not necessarily ready for full time care, and provide some peace of mind for families. The federal government should take responsibility for this type of accommodation, similar to their role in nursing home provision.
4. Carers provide care for 168 hours per week. They do not enjoy the luxury of paid holidays or superannuation. Even when the person they care for is in respite or lucky enough to attend a day program for a few hours each week, they are still ‘on call’. That works out as 4.4 full time jobs (8.8 if under OH&S two carers are required for lifting and personal care needs). The average weekly wage as reported by the ABS in February, 2008 is $885.40. So the worth of a carer should be $885.40 X 4.4 or $3895.76. Even if you do these calculations using the minimum wage, carers save the government billions of dollars each year. The carer payment, if you are entitled to it, is $273.80 per week. Carers should be taken out of the Social Security system and employed by the Federal Government at a rate commensurate with the care they provide. I am not suggesting $3900 per week which is what they are worth, but at least a living wage with benefits. Respite time should be classed as annual leave and sick leave. Redundancies related to the length of time spent caring should be paid

when the person they care for has entered a permanent care facility. Superannuation would contribute to financial security for the future of the carer. The government would have some return from this by way of taxation and a lesser likelihood of carers needing to depend on the pension in their old age.

5. When the person you care for is in hospital, care does not stop. When a person with high support needs is in hospital, the carer is more often than not by their bedside. The high level of care required cannot be provided by our already overstretched nurses. Even if the nursing staff had the time to provide extra care, they do not know the person or their means of communication or their needs. Carers allowance should not be reduced for time spent in hospital.
6. Most families today depend on two incomes to meet basic needs. Is it fair to make carers of working age live on one income? $273.80 per week is half the minimum wage for a carer in paid employment for a 38 hour week. Because a family is able to organise their lives and one member of a couple manages to continue to work in a reasonably paid position they are disadvantaged. The income test for eligibility to the Carers Payment should be abolished for one income families.

- **strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.**

The practical measures outlined above would go a long way in assisting carers in all these areas.

Thank you for providing this opportunity to put forward my views.

Narelle Hughes