

Submission  
No 88

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

Name: Name suppressed  
Date received: 12/08/2010

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*Partially Confidential*

**Submission to the Inquiry into services provided or funded by the  
NSW Department of Ageing, Disability and Home Care (ADHC)**

Date: 12<sup>th</sup> August, 2010

The Director  
Standing Committee on Social Issues  
Parliament House  
Macquarie St  
Sydney NSW 2000  
Fax: (02) 9230 2981

Dear Director and Standing Committee on Social Issues,

Thank you for providing the opportunity to make this submission into the inquiry of services provided or funded by the NSW Ageing, Disability and Home Care.

(a) the historical and current level of funding and extent of unmet need

*My husband is a complete quadriplegic at C4/C5 level after a rugby tackle resulted in a spinal cord injury in April 2007.*

*In consideration of the Terms of Reference below, my submission outlines my issues, their impact on my family and proposed solutions to address these issues in point format relating directly to the Terms of Reference.*

*At present in NSW my husband qualifies for 35 hours of care per week, yet I find I am constantly struggling with all that is required of looking after him, our seven year old daughter, running a household, looking after the house, working part time, and in a constant state of panic of "we don't have enough money to survive!!!"*

*Prior to returning to northern NSW, which was our home for 10 years prior to his accident, we lived in a Govt. provided disability house in QLD following the 10 months he spent in Princess Alexandra Hospital in Brisbane. In QLD the carer hours we were provided with was 43 hours per week, and I was entitled to one week per year of respite where he was given an overnight carer who – also looked after our daughter. This was not only invaluable to my sanity, but also the 43 hours per week gave me a lot of help. The 35 hours per week is only just enough to do the duties required for personal care (bowel therapy, showering, dressing, hoisting etc), and there is no extra time to help me with anything else – which I desperately need!*

*The things I struggle with are the things that he previously did, and although it sounds like I am from the 1950's – the "man jobs"! Cleaning out gutters, lawns, fixing things in the house, chopping firewood, garden maintenance, house maintenance issues, problems with the van, all that kind of stuff, and even if we did have extra carer hours – legally they are not allowed to do these kinds of jobs. In an ideal world*

*our friends would be offering to help with all of this – but they had helped so much since his accident in the first couple of years, and now all have returned to their lives and their own problems in raising their families etc.*

*On top of this – what happens when I'm sick, burnt out, need a break? Nothing, I can't get sick! The reality is he can't take care of me when I have problems, and neither can our seven year old daughter. An example of this is last year I hurt my neck and after going to the Commonwealth Respite Service and them offering me 1.5 hours per day to have my own carer, this was great – they came in the afternoons and made dinner and bathed our daughter. But what about the rest of the time, I still needed to feed my husband, myself, grocery shop, get to physio appointments etc, get her off to school and picked up, do washing, cleaning, and everything else. I was supposed to be "resting" but I don't know of anyone who's husband is a quadriplegic ever getting the opportunity to rest.*

*What I would propose is funding for extra care hours per week, OR hours per year which we could choose to use in whichever way we see fit.*

*On moving to NSW the agency told us it was a good idea to bank at least one hour per week for times such as those listed above. We have recently started doing this (one hour per week), but at a great cost to us – less carer hours for my husband, which then of course I need to fill myself. I honestly fear for how our future looks – I'm 37 now, but how am I going to manage when I'm in my 50s, 60s, 70s? Looking after a quadriplegic husband is physically demanding.*

(b) variations in service delivery, waiting lists and program quality between:  
(i) services provided, or funded, by ADHC,  
(ii) ADHC Regional Areas,

*Service delivery – so far, we have been with two different agencies in NSW in only 18 months. We first signed up with paraquad, which offered appalling service and less-than-appealing pay rates to their employees, and therefore we found it very difficult to get carers on weekends, and due to them not ever being able to recruit enough permanent staff for us, we often had carers turning up from other agencies to fill shifts – which is very unsettling for us as a family. Next we moved onto Australian Home Care, primarily because they offer a better pay rate to carers, and because they have an office locally, and we felt we would receive better service – and at least be dealing with "faces" and not just over the phone whenever we had problems. This has turned out to be no better, and still there are rostering issues, and on top of this, our main gripe which we were assured would not be a problem with AHC is that we would like carers to be able to be in the house when we are not here with our permission. For example if I need to race off for work, and is taking our daughter to school (he's in a power chair), we might both need to leave the house by 9am. This means the carer also has to leave the house then, although there is still 30 mins left of their shift which is mopping up in the bathroom after him, dealing with overnight drainage bottles etc, and finishing all that is required on a morning shift. The agency will not budge on this issue, however it was part of the reason we went to the new agency – as they said that wouldn't be a problem. Now they have found out that it's not allowed. Very annoying!*

*I have nothing to say regarding waiting lists as I haven't experienced that. With regards to regional areas, it's preferable to have an agency office nearby when you live in a "rural" area such as we're classed.*

(c) flexibility in client funding arrangements and client focused service delivery,

*I believe that the funding arrangements aren't flexible at all. Yes, to some degree they are client focussed (the service delivery) but as I pointed out above, if they were client focussed they would take into account that all clients have different needs and require different services. For example, if my husband didn't*

*have me (his wife) he would need help with shopping, paying bills, making appointments, doctors and specialist appointments, being driven places, cooking for him and meal preparation etc, washing, hanging, folding, ironing etc. Single clients need help with all of this, yet are not given any more hours and somehow – I don't know how they do it! In fact, I don't know how we do it, and I believe it's not until someone in parliament or a high-profile Australian celebrity gets a spinal cord injury that systems will change, and that our needs will be revised, taken into consideration, and then possibly met.*

(d) compliance with Disability Service Standards,

*I can't answer this question.*

(e) adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services,

*Our complaints AHC are currently under review.*

(f) internal and external program evaluation including program auditing and achievement of program performance indicators review, and

*It is appalling that carers are paid a minimum amount for training for a half or full day, and not their regular hourly rate. It's their time which is being taken up – and most of them have other jobs which they're having to take time off for. Yes, it's good to offer further training or refresher courses, but surely they should get paid adequately for it?! I believe that when the agency is back on track (they're having staff issues) then their performance indicator reviews will be fine – AHC (Coffs Harbour office) are pretty good at listening to our concerns, even though the office is our closest office – they have had many management problems.*

(g) any other matters.

*1. We have recently been granted \$2000 to spend on a family holiday – we leave for a week away on the 4<sup>th</sup> September. This is amazing – it's our first family holiday since his injury, and is very much needed. We thank the Govt organization for this opportunity, and while we know it's a pilot programme, we are very hopeful it will be ongoing as it would ensure our family could have time away each year – which is very important!*

*2. I can't believe that once a patient is discharged from the spinal unit in hospital, that there is no further support offered. Since leaving hospital my husband has not had any physiotherapy, which I find astounding – and we can't afford to pay for it, and there are very few services offered to us up here in northern NSW. If there are services – how are we supposed to access them, find out about them etc? there is no public transport if you're in a wheelchair, the trains have stopped running and the buses don't cater for wheelchair users. Taxi's are too expensive, and quite frankly – when our van eventually dies, we'll not be able to replace it. It's hard enough finding the money for new tyres, registrations, insurances etc.*

*3. living on a disability pension & a carers payment is literally a joke. \$400 odd per year provided for medical supplies – also a joke. We're very fortunate that due to a lot of fundraising by our local community in the first year after his accident that we've now got a relatively small mortgage, yet paying for the day to day items, medical supplies, insurances, registrations, rates, bills etc is nigh on impossible. This means we do not have the money to pay for the things we need help with as I'd outlined in (a.) above. IF*

*you could provide extra carer hours, or "maintenance" hours to help with things around the house, life would be a little less stressful.*

*4. counselling – since his accident I have felt that I needed counselling at various times. Even though I have received a mental health care plan from the Doctor that ensures I don't pay the full price, it's still out of my reach financially. Surely Social workers could be provided on an ongoing basis, to help with families deal with the trauma of a spinal cord injury?*

*5. I would like to make it known that i'm not just complaining for the sake of it and not getting up and doing something about it myself. My husband had always worked full time, and in the years leading up to his accident was self-employed. I am no longer able to work full time job due to the care which he needs, and caring for our seven year old daughter. My husband is obviously unable to work full time either, and even when he has finished his TAFE study (landscape design on the computer as he was previously a landscaper & horticulturalist) he will never be able to work full time due to his health issues. It angers and frustrates me that we are good hard working people who are now struggling to stay afloat and pay our bills.*

*I have so much more I could say and issues to raise, yet I have found in the past I am banging my head against a brick wall – and quite frankly, I'm exhausted. Bottom line is, we're grateful for the help we receive, but it's not enough. If I could find a miracle for my husband and give him back the use of his body, internal organs, and dignity – I would in a flash. In the meantime, all I can do is learn how to live with this horrific injury, learn how to support him and our daughter, and hope that we will receive more support both financially and with carer hours in the not too distant future.*

*I understand that all the submissions made to public Parliamentary inquiries are made available to the public on the NSW Parliamentary website, and while I don't want for my submission to be confidential as I believe that people need to read of problems to gain more understanding and insight, I also don't want to have my name on it. Is this possible?*

*Again, thank you for providing the opportunity to make a submission to this very important and timely inquiry and I trust that the committee will make appropriate recommendations to address any issues.*

*I would also be happy to appear as a witness in person to answer questions and/or provide further details to clarify the content of my submission).*

*Yours sincerely,*