Dear Commissioners

I have attached a photocopy of a letter sent to me from DADHC re services allocated to my son Adam that he has supposedly not used and therefore will be taken away from him shortly.

I have also attached my reply with the reasons for the non uptake of said services.

The story is long and involved but you will ascertain from my tone my complete and utter frustration with the whole system.

The fact that these public service bullies think they can dictate to the “poor disabled” by threatening to withdraw services that had already been withdrawn(note in my reply) shows some of the problems the clients have to deal with.

Most of them do not have the strength to fight nor do they have the option. They need the services doled out to them by these people. Rarely do they come up against a mother angry enough to take them on.

As I age, I will probably require services myself (God forbid) and Adam will most definitely, I would hope by then a more sympathetic system may be in place and people are treated with a little more dignity than occurs now.

I have submitted this document to you as part of your enquiry. If possible I would like you to add it to an earlier submission I sent to you

Yours

Mrs Sally Johnston.

Retype for the Web

Human Services
Ageing, Disability & Home Care
Level 5, 83 Clarence Street
Sydney NSW 2000

Dear …….

I am writing concerning your allocated hours under the Attendant Care Program, administered by Ageing, Disability & Home Care (ADHC), Department of Human Services NSW. You are currently approved for 15 hours per week.

The objective of the Attendant Care Program (ACP) is to assist individuals who need high level personal care support to continue to live independently in their own home. ACP provides assistance in situations where a person requires over 15 hours of personal care support per week.

Your service provider, Community Care Northern Beaches (CCNB), has contacted the Attendant Care & Physical Disability Unit (ACPDU) regarding your current services. CCNB has advised that since the time of your approval in April 2009, you have elected to receive only 7 hours of personal care support per week. As noted above, the minimum allocation for ACP is 15 hours per week.

ACPDU understands that CCNB is subcontracting your services to Home Care Harbour North. ACPDU has contacted [Person C], Service Centre Manager to discuss your services. She has advised that the branch is able to fund your current services through the Home and Community Care (HACC) program.

ACP will continue to fund your hours of care until 31 July 2010. Should you wish to increase your personal care assistance to the minimum 15 hours per week prior to this date, you can discuss this with your CCNB case manager, [Person D]. If your do not wish to increase your current level of support, the offer of ACP will be withdrawn and your services will be funded under the HACC program. This will be an administrative change only and will involve no change to the services you are currently receiving.

If you have any questions or wish to discuss this matter further, please contact me on [suppressed].

Yours sincerely

[Person A]

[Name suppressed]
Attendant Care and Physical Disability Unit.

Dear [Person A]

I would like to discuss with you the letter dated 5th July 2010 addressed to Adam Johnston re the number of hours taken up with the CCNB since April 2009.

It appears you either have no recollection of why we only “elected” to receive 7 hours of care after our approval in April 2009 or you have forgotten.

However, I could go back further than that, right back to the unfortunate time that I answered the advertisement for the pilot program for aging parents of children with disabilities.

From that moment on we were both overwhelmed with interviews and paperwork.

Not only from [Person B] but several other hangers on with some sort of interest in duplicating information we had already given.

Then somewhere in the process the idea of a pilot program got lost and we were on a hiding to nowhere.

Suggestions that had been made in the initial interview and were a long term vision of what we would like in the future, all of a sudden became a priority and were thrust upon us.

The idea of the extra hours mentioned in your letter were going to be given to us and had been approved, but we were told that they must be put together with what we had already with Homecare but now under a different provider as your department did not deal with Homecare and we could not have both!!!

There began a very sorry saga that still rings in my memory. I will never forget the phone calls from [Person B] who could not believe that we wanted to stay with Homecare and told us in no uncertain terms that we could not. Her tactics seemed a little desperate and had I not experienced it myself I would not have believed it. She tried to set son against mother to get her way and I remember one particular phone call at work when I was involved in a very serious situation and she was abusing me down the line. That particular phone call ended when you arrived in the background and said that the powers that be had approved that we could stay with Homecare after all. Well bully for them.

By this stage we had had enough but [Person B] had not. She then involved a service provider who had a man who would attend Adam every second Thursday evening, bring him home from a regular function and put him to bed. She was still disappointed at our stubbornness but insisted we try this service. There was a program put together that covered at least the next six months

The man dutifully turned up, picked Adam up from his function (about five minutes drive from home), brought him into the house and put him to bed.

I think we saw him three times before he decided it was all too hard and never returned.

Then the fun started again. It was insisted that whatever he was made to do was an OH&S risk so we had to have a full OT assessment. (a little late wouldn’t you think).

Eventually along came the OT who decided there was too much lifting involved so we would have to provide a mobile frame that could lift Adam from his chair and into bed. The next visit she brought along a couple of rather large cumbersome objects but insisted that this was what was required. We selected (rather dubiously) a particular one and off she went. Many weeks went by but eventually we got a call saying the frame had been approved by PADP.

Many weeks later (again) we were notified that although the frame had been approved there was no money available and the wait would be about 12 months.

So where do we go from there?

I am just so grateful that Adam and I were able to stand up to the bullying of said [Person B] re giving up Homecare. Had we not done that we would have lost that as well with the new provider insisting on extra facilities that as yet I still do not have.

As I have been doing said “difficult “ work for many years and I am now 66, it makes you wonder doesn’t it.

So please tell me how we could have used the hours given to us. No one would be allowed to come because of the possibility of injury as stated above.

I could continue this sorry saga and fill you in on the car disaster also instigated by [Person B], but I feel it all a waste of time.

To return to the original idea of the pilot program, the idea was a good one, the fact that all of us aging mothers(mostly) are going to need increasing assistance as we find ourselves not able to do what is required, is approaching rapidly. The problem is all of this is governed by insufficiently trained public servants who tend to think they know better than the parents on what and when they require assistance

How it all got lost in the detail is beyond me. Maybe it was mentioned along the way, maybe not, but the haste in which future suggestions became tomorrows’ needs was astounding.

I should have known better than get involved. It will be a long time before I do again.

Adam and I will survive somehow, probably a little better and longer had we not been subjected to the above fiasco.

For you to now send an ultimatum on hours we have not used, because we can’t use them, because we need equipment we can’t have, is just typical of the whole sorry situation.

I have copied this letter to the Productivity commission into Disability Care and Support, primarily as an example of what shouldn’t be a recommended model to the Federal Government.

Adam is in discussions with [Person C] at the moment about other service possibilities, because, while very dissatisfied with this program, we recognise that it is the only functioning proposal in the state.

Yours

Sally Johnston