

On Friday, 13 October 2006 I was one of three people who appeared before the Senate Community Affairs Committee on behalf of the Client Guardian Forum. Following our interview with the Committee, Senator Clare Moore asked me to provide more information on a couple of issues raised at the hearing. I would be grateful if you could forward this email to the relevant Senators.

ASSESSMENTS

Senator Moore asked for details of my experience of assessments.

From comments made by Senators it would appear that many people with disabilities (PWD) are subject to regular assessments. In the case of my 31 year old daughter I haven't found this to be the case (even though she now needs 24/7 supervision) until my husband and I applied for funding in 2004, when there was money available for ISPs. In the hope that we may be fortunate enough to be able to start transitioning our daughter from home into her own accommodation we submitted an application which got to the short list (although we were told later that this had been a mistake!) It was at this point that an assessor came to our home to interview my husband and I (the presence of our daughter was never suggested, and the fact that she still had not woken at 11am that morning, which is quite common, raised no questions whatsoever). At the end of a 2 hour interview it was suggested that we probably wouldn't be successful in obtaining the large sum required to implement our plans and suggested that we apply for enough money to enable us to have one week's respite a month, which we agreed to.

There was apparently a mix up with our application and it got on to two lists – short list and unsuccessful. The upshot of all this was that we did not receive notification either way. On contacting the department I was told of the mix-up and I asked for a copy of the assessment which was sent (probably in error) and on the bottom the assessor had written "Funding for alternative respite options not recommended."

The suggestion of a National Assessment Plan, as is done for aged people, concerns me in some respects. My understanding (which could well be wrong) is that aged people all have the same assessment at the time they are seeking accommodation in a nursing home, i.e. to the same end. The needs of PWDs are so varied and can be for one particular type of service, i.e. speech therapy or respite, so a general assessment could become very invasive on privacy for little or even no advantage to the individual. I have to wonder whether the people complaining about constant assessments are referring to younger children, i.e. early intervention and school age, where many types of therapy may be of benefit.

A number of doubts/questions arise, such as –

1. Is the cost of a NAP (which will be substantial) justified against the benefits?
2. How will such assessments be applied? At individual or macro level?
3. Will a NAP become a wedge between State and Federal responsibilities similar to supported employment?
4. Are there privacy issues such as the individual's safeguards against use by other departments or even the public?
5. How often will individual's need to be assessed because of changing capacity

While not wishing to sound too negative and not doubting that some advantages can be identified, it is absolutely essential to have a clear idea of just what a NAP involves before commencing to pursue this idea further.

The software package developed in South Australia, in my opinion, would be a wonderful tool for families to have at their disposal.

PORTABILITY OF FUNDING

At the time of our arrival at the hearing, the ACT Minister for Disability and Executive Director of the Department were being interviewed and were questioned on this issue. When Senator Moore asked me after our interview about Assessments I said I had actually had experience of the problem of portability and she asked me to include my story in this email.

We were living in Wagga Wagga and our daughter was in receipt of a PSO package. As with many families we thought long and hard about the move my husband had been offered because of all the concerns for our daughter, but felt that it was wrong to deny the family the benefits this move would make for us all. To start with we rented a house in Queanbeyan as it was situated in NSW and brokered into Canberra services. (There were none in Queanbeyan.) At this stage I began talking to the ACT Department of Disability and was told that they would identify someone the ACT was still funding who had moved to NSW on about the same amount of funding so that an exchange could be made. This person was identified over the next few weeks and the ACT Department began talking with the NSW Dept. Every time I rang I was told that it would work out but they were waiting for this or that from NSW. This went on for many months and in the end I got a letter from NSW saying that they would only fund our daughter for another 12 months. At this point of time I was told that although it was taking a long time it would work out and the ACT Dept. wouldn't see us without funding. On the strength of this we bought a house in Canberra close to our daughter's services. Soon after I received a phone call from the ACT Department telling me that they had discovered there was NO policy to cover portability of funding so this exchange could not go ahead but because of the promise they had made, did provide funding for some of the services our daughter was receiving.

On taking this issue up I was told that transferring money in this way between States or Territories was a bureaucratic nightmare and that there was no system for accounting for such a transaction!! It seemed very wrong to me that families were being denied portability of funding because of a bureaucratic problem – not making the system work for the benefit of families. Another reason given was that States like Queensland would be disadvantaged because there were more proposed transfers to that State.

ACCOMMODATION SUPPORT

Should some funding become available for accommodation after the next CSTDA conference I would just like to emphasise why it is so important to have at least some of funding specifically targeting the sons and daughters of mature carers – say over 65. Whenever any funding becomes available it is only those people deemed to be 'in crisis' that get anything. If something isn't done to allow mature carers to transition their PWD into independent accommodation everyone is going to end up in

a crisis situation. While we as families of PWD are constantly told that we have 'no rights' as far as funding is concerned the worry just increases as to what is going to happen. I know it's not an ideal world but your help to start providing funds for aged carers to be able to move their offspring into independent living would at least provide some comfort. I think the story I related about the 85 year old widow with her son still at home is an absolute disgrace and cannot understand why her case was not seen as a priority. It's not just the PWD who is vulnerable but older carers are too as they just don't have the fight left in them to get what they need.

Thank you for the opportunity of being able to talk to the Client Guardian Forum submission and for adding the above comments.

Yours sincerely

Christine Smith