

RASAIID



LETTER TO JENNY MACKLIN – Federal Disability Minister

3/11/08

Letter to Jenny Macklin Federal Disability Minister

Dear Ms Macklin

I am sure you don't remember me. We spoke briefly after the signing of the CSTDA in Sydney. I told you how desperate we are for supported accommodation for our intellectually disabled sons and daughters and that we need it now, so that we may have a retirement after decades of caring. I said although our sons and daughters will need it after we are dead, it is NOW that we must have it, because we have earned a break. You then went into the press conference and quoted my words. When you came out, you found me and told me that you had been able to use them.

I want you to know that nothing has changed for us out here in the world of disability since we had that conversation and I can see nothing on the horizon that will bring about change. In the last year, one family that I know in my extensive network of carers has received a supported accommodation placement for their daughter. However, three ageing carers have died while still caring, without ever having had any experience of retirement or the peace of mind of seeing their person settled out of home. This is the future for all of us unless your government can do something.

Here in NSW we are told the state government is broke. DADHC is incapable of delivering the services we must have. This is mostly because it is grossly under-resourced and but also because it is inefficient. Is it too much for us to ask that the Australian government, the collector of the bulk of our taxes, takes over responsibility for disability service provision, or at least injects substantial more funds into the sector. May I remind you of your election promises:

- (a) that you will move towards population based benchmarked funding for people with a dependent disability
- b) that ageing carers would be a priority under the CSTDA.

I see no evidence that these things are starting to happen. In fact, in NSW, under DADHC guidelines, the sons and daughters of ageing carers are not a priority for supported accommodation. The priorities are:

- (a) the children coming out of DOCS - if we had relinquished our children at birth they would now have a place of their own. By caring for three or four decades, we have jeopardized their chance of independence.

- (b) the people coming out of corrective services - should we teach our sons and daughters how to steal so they will eventually be a priority for supported accommodation?
- (c) the people who are homeless, whose support arrangements have broken down, who are in emergency accommodation - this means that we must abandon our vulnerable adult children to the care of a government department that has no place for them in order to force their hand to eventually make a place.

These are all the choices that a caring family has in Australia in 2008. It is clearly just unacceptable. We have been raising this issue for so long that it is not possible that our governments do not know about it. The only explanation I can find is that our sons and daughters are not sufficiently important, that they have the potential to cost too much and that their parents are the cheap and easy answer to the problem (plus they never go on strike). Yet most other developed countries have come to grips with this issue and pride themselves on their humanity and egalitarianism. This, the supposed land of the "fair go", is content to abandon and exploit its ageing carers and their intellectually disabled offspring.

I think that part of the reason we find ourselves in this plight is that we, who do 97% of all the caring of the disabled in NSW, have no voice and no representation. All the policies about us are made without us. For some time now, we have been calling for funded grass-roots family advocacy that is democratically elected and drawn from our own ranks of parent/carers of people with an intellectual disability. No one can speak for us who has not lived our life or walked in our shoes. Our issues are discrete and different from those of the carers of the elderly or the infirm. They are around the manifold problems that come with lifetime caring and predeceasing the person cared for. We cannot be lumped together with carers who look after a family member or friend for a short time and then resume their normal lives.

This is why I am aghast at the suggestion that Carers Australia should be chosen to represent us. It is only recently that they realized that we existed, let alone that our needs and concerns are unlike those of other carers. I am particularly concerned about a statement I read in the summary of the Carers 2020 Forum around the issue "Representation". There were thirty-one posts in this section of the Forum and carers were arguing that they could not be represented by paid professionals or by anyone who had no personal experience of their issues. The summary acknowledged this but went on to say:

'On the other hand, some carers did not agree with this position. They argued that there is a need for both funded advocates and funded care representatives and called upon Carers Australia to provide carer input at federal, state and local levels.'

It is imperative that you understand that just one post expressed these views. By magnifying this statement and changing it to the plural, the summary has made it seem as if there is a whole school of thought supporting this viewpoint. This is extremely dishonest of Carers Australia and it grossly misrepresents what was stated on the website. This action causes Carers Australia to betray the trust of we carers and to lose credibility with us. It disqualifies them from ever being our representative or speaking on our behalf.

We have a number of highly qualified, articulate and committed carers who would make excellent advocates for our issues and who would have our undivided support. Please find a way to fund carer family advocacy so that we who do all the caring may at least have a say in our own destinies.

While we are discussing representation, may I add my voice to what I am sure is a swag of protestations over the lack of people with a severe or profound intellectual disability or multiple disabilities on the National People with Disabilities & Carer Council (NPWDACC). If such people are too disabled to speak for themselves, then their carer, parent, next-of-kin or appointed person should be chosen to represent

them. If people with a severe and dependent intellectual disability are going to be always left out of such forums, how is anything ever going to change for them or for us?

Yours Sincerely

Estelle Shields

Lifetime Carer of Daniel Shields