

8 September 2006

Mr Elton Humphery
Committee Secretary
Community Affairs Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Humphery

We wish to make a submission to the Senate Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement. We write in our capacity as parents of a profoundly disabled fifteen year old young man.

Our son has Angelman Syndrome, a neuro-genetic disorder. Some of the features of the syndrome are profound intellectual disability, epilepsy, no speech, sleeping disorder, challenging behaviours, short attention span and hypermotoric activity. Further information can be found at www.anglemansyndrome.org Our son, Callum, is physically very strong and this makes dressing, shaving and changing his nappy very difficult.

We are members of the Angelman Syndrome Association, a national support group for parents and carers of persons with Angelman Syndrome. Kerry is the ACT Vice-President. We are aware from our contacts through the Association that parents in many States are quite desperate about the lack of out of home permanent residential options for their children. We share this concern as we are in discussions with the ACT Government about long term care for Callum. We have been told that funding may not be available for several years.

We are also aware that some parents of persons with Angelman Syndrome are very anxious about the uncertainty about the post-school day programs available nationally. Some of the agencies providing these programs have to retender annually. Whilst agency accountability is important, in practice, parents of profoundly disabled persons have fewer services to choose from.

Our experience with Angelman families shows us that nationally, with regard to both residential placements and post-school recreational placements, there seems to be ad hoc arrangements where each family has to go into bat on their own, against other families, to obtain scarce services for their child and family. This is undignified, unedifying and by far the worst aspect of caring for a disabled person.

Yours faithfully

Keith Bradley AM and Kerry O'Kane