

21 June 2010

Disability Care and Support Inquiry
Productivity Commission
GPO BOX 1428
CANBERRA ACT 2601

Dear Sir/Madam,

DISABILITY CARE AND SUPPORT INQUIRY

We received the attached document and are interested as we had a daughter who had Rett Syndrome (severe disability) and unfortunately, passed away at age 13 years.

We are interested to know what the insurance scheme entails and from limited information we have been able to get, there seems to be little reference to the insurance scheme in the terms of reference... Long term Disability Care and Support Scheme.

We lived in Melbourne when we had our daughter and it was a constant battle to get assistance. Briefly this included:

1. Early intervention services
2. Appropriate kinder and school facilities
3. Physio aids.
4. Home improvements and aids to help look after child in the home.
5. Support from local councils such as home help and baby sitting/short term respite
6. Longer term respite so families could go on holiday. Very Special Kids Organisation in Malvern Victoria is superb but there needs to be about 10 of them and fully funded.
7. Easier access to wheelchairs, vehicle hoists etc. Government grants and subsidised purchase should be considered.

8. Subsidies for special food and formulas for procedures such as peg feeding.

Other matters that need to be addressed include:

- An increase in the Carer's pension and a review of the means test that is applied. A parent with a severely disabled child cannot work.
- There needs to be vastly improved and additional long care facilities.
- Improvements to Residential care facilities and additional facilities.
- Reduction/Consolidation in the number of Government Departments and Agencies that provide services.

Our experience was that we had to fight for every aid and facility and having been involved in the area for 20 years, we saw so many people just give up in despair as they did not have the stamina or time to take on the myriad of Government Departments and agencies that purported to provide services.

Typical of the Government whereby the weak and needy are just left behind.

This sort of attitude left families in financial difficulties, totally stressed environments and often led to marriage breakdowns.

We would certainly like copies of any documents that may be relevant to the above and are happy to make further submissions if required.

We have been in Moyarra the last three years which is near Korumburra in Gippsland and we would be particularly interested in what is proposed for country people. It was a nightmare in the City so we cannot guess what it is currently like in relatively isolated country areas.

We have no objections to our comments being made public.

We would appreciate your comments, please.

Thanking you in anticipation,

Yours faithfully,

Trevor Browning

Trish Browning