SUBMISSION TO –

SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

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This brief submission to the Committee addresses the following issue raised in the Terms of Reference -

"(b) The appropriateness or otherwise of current Commonwealth/Territory joint funding arrangement, **including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;"**
(Our emphasis).

Our comments to this point are based on the experience of the past 20 years raising our intellectually disabled daughter.

A brief background -

Our daughter became ill at 13 years of age when she developed a form of epilepsy which is intractable and intellectual regression occurs.
After 10 years of testing, analysis and experimentation we have no causal reason for the epilepsy and limited control whereby seizures have never stopped but severity is manageable. She has multiple types of seizure activity.

We have seen our daughter slowly decline in mental capability from someone who could attend normal school; converse and look after her own health, ride horses, take part in representative athletics to someone who must be monitored 24*7, bathed, dressed and sometimes fed. We have not seen stability in her condition yet at 32 years of age. There are days when she can partake in her community activities with a carer like Meals on Wheels, shopping for people in a local nursing home, delivering magazines and newspapers to patients in the hospital. Other days she is unable to function because of non convulsive seizure activity and is unable to speak, feed herself or take part in any activity. Every day is different and is impossible to plan for.

Neither of us can work full-time as it requires both of us to attend to our daughter, partly to provide a break for the other but also because at times it requires 2 people to attend to our daughter's personal needs.

While my wife and I can still provide the 24*7 care needed this must come to an end sometime. Although we are both only 62 it becomes increasingly possible either or both of us will not be able to continue our role if health issues were to arise.

However we do not believe any existing service can presently manage our daughter's health sufficient to allow some quality of life **unless** we are able to train carers based on our experience.

Government assistance

Our daughter has one weekend a month in residential respite but what we need is a structured plan for her to transition from our family home to accommodation of her own which will be a very lengthy process which we need to start now.

Submissions to increase the level of funding to allow greater care at home and/or services, particularly to increase the level of overnight respite, have not been successful.

The fact is (based on our submissions for funding) we are not regarded as a "priority" within present funding levels and therefore unlikely to achieve further funding under present guidelines.

(It is worth noting also that there is common feeling amongst carers that the level of existing funding is decreasing in real terms such that the service hours will decrease).

Because we are not presently classified as a priority we are greatly concerned there will not be an opportunity for our daughter to live away from the family home in order to prepare her for life without us.

Should our daughter have to wait for our demise to become a priority?

It appears that the next guaranteed level of funding we can expect is when we are 70, consisting of 4 weeks a year respite care through the Mature Age Carers Program. **We therefore consider our situation to be part of the "unmet need for accommodation and support".**

Unmet Need

There are various forms of "unmet need" associated with intellectual disability with the situation of the aging of parents and their children being just one. But from our experience the "unmet need" of aging parents is significant and growing.

The problem needs to have a guideline established as to what parents can expect in the way of an ideal living arrangement for the future and to have a pathway by which governments expect to achieve the "ideal".

Parents need an expectation that their children will be properly cared for at the appropriate time.

We urge the Committee to identify the unmet need of aging parents and recommend on the appropriateness of funding to meet this need.

Our aims for our daughter

The following illustrates the type of program we see as meeting our daughter's longer term needs but which can only be achieved through higher levels of funding and support.

There are 2 principles we focus upon –
1. That if we die suddenly there is a plan in place to look after our daughter which maintains some quality of life, and
2. Preferably, we could move our daughter into acceptable accommodation before we are not able to look after her ourselves

To meet our preferred approach we see there are 3 stages in our daughter's life
A. Access to accommodation and care for greater time away from home – say 2-3 days per week
B. Extend time away from home to 5 days a week
C. Move full time into accommodation when we are too old or death intervenes.,

To achieve this plan what is required is funding to form a joint home with another 1 or 2 persons so that the 24*7 level of care can be achieved at sensible cost and that a "family" atmosphere is developed in the home. We need this funding in sufficient time to put in place the structure and training of carers before we are unable to do so.

Because our daughter's various epileptic conditions require practical experience to manage, it is essential that there is adequate time for us to train a core of carers in her needs. There is likely to be a higher community cost overall to **not** put in place our transition plan.

Conclusion

From our perspective there is a flaw in all Governments handling of disability issues whereby funding is not available to allow persons of +60 years of age to start to be able to prepare their intellectually disabled children for life without parents. The issue we outline is not peculiar to us alone.

I do not believe anyone without personal experience knows what it means to live with an intellectually disabled child. While the impact on family living from an intellectually disabled child is significant, it is surpassed by the worry and concern of not having a solution to the future.

In finding a solution an issue of course is the source and quantum of funding.

From our perspective the source of funding, that is, Commonwealth or Territory, is irrelevant. However the sharing of responsibilities between Commonwealth and Territory seems to make it more difficult for carers to achieve their objectives.

The issue apparent to carers of intellectually disabled is simply that total funding needs to be increased to better match the unmet need. The quantum of social funding is a concern for any society, however, in our opinion, current funding choices by Commonwealth and Territory governments leave room for readjustment if fairer comparisons are made of priorities.

Whether the available funding is being applied efficiently or not may be part of the Committee's determination but it is not central to meeting the "unmet need".

The present approach of apparently ad-hoc programs provides no certainty for aging parents as to whether a satisfactory quality of life will be achievable for their intellectually disabled children.

What needs to be done is for governments to identify the "unmet need" and put in place plans to address each type even if completion takes a few years.

Governments must commit to longer term plans for the whole of life issues met by the intellectually disabled and their families. Aims and aspirations should be established so that parents can see what the future should hold for their children.