Unmet Needs at Senate Inquiry into CSTDA (Commonwealth State/Territory Disability Agreement

- We need to have one funding agency only from the Federal level of Government.

- We need to have an Office for Disability alone – one stop.

- Families need to have adequate funding given to them/or their agent to provide adequate funding for services that the FAMILY needs. We are all different and should not be put in a one-size fits all funding cycle.

- Unmet needs can be varied.

- A vehicle to provide transport for high-support needs persons – should be partly funded by the government. We had to go to a great extra expense to finance a “disability van” eg hoist – dual air-conditioning etc so that our daughters can access the community.

- We need service providers to provide a reliable service to us (eg so we know the worker is going to show up if someone is sick, on holidays etc: not turn around and say “sorry we have no staff” and thus we miss out on our respite/activity for our daughters.

- The service provider needs to be affordable. At the moment Central Wellington Health Services in Sale charges my family $66 per hour (because I have a small funding package) for services ie worker/carer after 6.00pm on weekdays or on weekends – services which fall on a public holiday are not available due to the outrageous charges.

- I am on work-mode 7 days a week, 24 hours each day, 365.25 days each year, with no pay, not even on public holidays, our caring responsibilities don’t go away on public holidays or weekends.

- Respite should be more flexible and available when the family needs it, or when they wish to have it, and where and what type of respite suits the family situation, for example, the Government facility Community Residential Units (in Sale for adults) has people attending from all over Victoria, (even from Melbourne).

- Our local area needs more use of our facility for local clients. The government needs to provide services for disabled people under 65 years of age into every town, just like the aged care sector receives.

- There are not enough respite facilities available throughout Victoria; therefore our local respite unit is flooded with out of town persons, restricting the availability to our own local people. This is an unmet need, which needs to be addressed in the metropolitan area.

- Appropriate transport for varying support needs for people with disabilities are needed also, there are not enough vehicles to carry wheelchair, walking frames, hoist access etc. restricting access into the community.

- Flexible respite services should be provided to families free or at a low cost from the Department of Human Services. The bucket of funding available for low cost respite services is not adequate to fairly distribute to the community and is therefore not widely known in the community. More communication to families is needed to that families can make an informed choice as to what services are really available.

- We the primary carers do not get holiday pay or a 30 hour workload with weekends and public holidays off.

- We need planned programmes in the community that are ongoing and funded by the government (just like the services for "normal" folk have within their community, they can attend dances, outings, movies, shopping, sporting activities, social activities, school holiday programs etc but the catch is we all need a carer (paid) for our sons and daughters to attend – and most of us can't afford this luxury.

- Shared supported facility based accommodation (CRU) should be available in every town (aged care have this luxury and choice) but our sons and daughters under 65 years can what??? --- yes !! stay at home with us -- where is the choice.

- We are prisoners until the day we die – old age and retirement will not be a joy for us!! As we have our adult disabled still at home – why can't we have part-time shared and supported accommodation provided by the government, at an affordable cost and locally?

- But guess what – once a "carer" reaches the age of 65, and you are on an Aged Pension, you are not eligible for a carer's annual bonus, even though you are still caring for your disabled person – how fair is that?

- Staff that help us to look after our adult children with high support needs NEED to have sufficient training before service providers send the worker out to work with the family – some staff are dangerous – in their training I am sure some "nursing care" training would be of great assistance for the worker to carry out their work with respect to their duty of care. Some agencies are sending their staff to care for disabled people who are not trained, unsupervised and are deemed to be "training on-the job", where is the duty of care here?

- Individual $$$ funding packages should be ongoing and increased yearly in line with the increase in the cost of living: or increased as the needs change by each respective family.

- Families should not have to beg or prove why they need financial assistance. They should be able to buy the service or article, or program, equipment, etc as required. The Department of Human Services needs to work more with families or their case worker so life rolls on without all this riddle of when/where and why and if and how much we are given dollar-wise and not told what our needs are, the family is the best to know where the funding is most needed. Choice for families needs to be maintained and supported, not red-taped.

- Disability Services and programs need to continue, but government must provide adequate funding to service same, to provide adequate and safe care and environments for our sons and daughters to maintain a happy, safe, comfortable, affordable, useful and work opportunities within their own communities and abilities, just like you do in yours!

- Adequate funding should be included so families can choose therapies and other methods of supporting their adult children e.g., chiropractor, homoeopathic, massage, dentist, etc. Carers and their families deserve to be treated as equals and all parent-carers (aged, young or whatever) should receive the $1000 bonus paid to recipients who care for adult children.

- Lifelong, unpaid carers need support and to be listened to. This discrimination must cease and united we stand as we are entitled to services for ourselves and those we care for.

- As a mother of two high-support needs adult children who have come along way with the help of their parents…. (dare I even think of how many $$$$ I have saved the government over these last 28 years) I will not give up and continue to be a voice for and on behalf of my girls rights and needs, and others.

I fully support the National Carer’s Campaign for a better deal for parents and carers of people with disabilities and their families.

Anita Geach-Bennell (mother & wife)
President
Wellington Special Needs Network Inc