



A national voice for families of children with a disability

20 July 2007

The Hon John Howard MP
Prime Minister
Parliament House
Canberra ACT 2600

The Hon Peter Costello MP
Treasurer
Parliament House
Canberra ACT 2600

And all Premiers, Chief Ministers and State and Territory Treasurers, including:

Mr Jon Stanhope MLA, Chief Minister of the ACT
The Hon Morris Iemma MP, Premier of New South Wales
The Hon Clare Martin MLA, Chief Minister of the Northern Territory
The Hon Peter Beattie MP, Premier of Queensland
The Hon David Rann, Premier of South Australia
The Hon Paul Lennon, Premier of Tasmania
The Hon Steve Bracks MP, Premier of Victoria
The Hon Alan Carpenter MLA, Premier of Western Australia

Dear Prime Minister, Treasurers and Premiers and Chief Ministers,

We write to:

- 1) Thank those of you who have provided a considered response to our letters of 23 May 2007 and 30 May 2007 regarding the Commonwealth State and Territory Disability Agreement (the CSTDA);
- 2) Suggest a constructive way forward to achieve a good CSTDA outcome for children and adults with a disability and their families across all areas of Australia and;
- 3) Request that all correspondence between your governments related to the CSTDA, from 3 April 2007 onwards, be made publicly available.

The current CSTDA negotiations are critical to building a sustainable disability support system for today's children and adults with a disability and their families, and the next generation. With this CSTDA, you and your governments have a crucial opportunity to develop a long term vision for a high quality disability support system.

As indicated by the recent Senate Inquiry into the CSTDA, there is an urgent need for better planning throughout the life cycle, from the time of initial identification of disability and through all the critical times of transition into the adult years.

We believe that the current CSTDA negotiations should be undertaken with a view towards 2022. We suggest that this long term thinking for today's children and young adults with a disability in 15 years time may assist in promoting a more productive approach to the conclusion of 2007 CSTDA negotiations.

Our 10 point plan for the 2007 CSTDA is summarised in an attachment (page 6 of this letter). Our plan includes some modelling of the required level of additional investment we believe your governments should make in the lives of children and adults with a disability and their families through the CSTDA. We also believe there is a need for strengthened accountability measures to ensure that every dollar of government money invested in disability related support achieves value for money outcomes. Our interest in the CSTDA is about much more than the quantum of money invested in it. What matters is outcomes 'on the ground' for children and adults with a disability and their families in every area of Australia.

(2)

Disability Assistance Package and 'Withdrawal of the 50/50 offer'

The context for this letter, and the next round of CSTDA negotiations, includes the Disability Assistance Package announced by the Australian Government on 28 June 2007 and a subsequent announcement by the Minister for Families, Community Services and Indigenous Affairs that the Australian Government was now withdrawing the previous '50/50' CSTDA matching offer to the states of New South Wales, Queensland, South Australia, Tasmania and Victoria.

Needless to say, we were extremely disappointed to see the 50/50 matching offer being taken 'off the table' for those five states. As indicated in our previous letters, providing that both levels of government begin with an appropriate approach to indexation and (population) growth, we believe that the 50/50 offer provides an excellent opportunity for states and territories and the Australian Government to implement significant improvements to support and services for children and adults with a disability and their families throughout all areas of Australia.

We hereby request that your governments resume CSTDA negotiations starting with agreement about the long term outcomes required and work up to a sustainable funding agreement for the next 15 years. We expect much more from the current CSTDA negotiations than a short term 'fix'. While the original 50/50 offer from the Australian Government had significant merit, subsequent negotiations need to consider component parts such as:

- Addressing currently identified unmet need as an urgent priority
- Ensuring that an equitable and sustainable funding formula is agreed (eg. 50/50 with adequate indexation and growth)
- A quantifiable funding commitment to lifetime support for today's children and young adults with a disability, and planning for the next generation

In regard to the commitments of your individual governments, we also request that you provide us with answers to the following questions:

- 1) What level of indexation is your government prepared to fund in relation to your contribution to the CSTDA in 2007/08 and subsequent years?
- 2) What level of (population) growth related funding is your government prepared to fund in relation to your contribution to the CSTDA in 2007/08 and subsequent years?
- 3) What level of 'new money' has your government already committed to invest in CSTDA related services and support in 2007/08 and subsequent years? (And note, in the process of answering this question it would be appreciated if you could provide official figures for total CSTDA related expenditure of your government for 2005/06 and 2006/07, in addition to estimated total expenditure for 2007/08 based on existing commitments).
- 4) What level of 'new money' over and above indexation, growth and already committed 'new money' is your government prepared to invest in the CSTDA in 2007/08 and subsequent years?

We also request that all of your governments release all intergovernmental correspondence relating to the CSTDA from the period 3 April 2007, including provision of copies to us. Verbal reports have provided a wide variation in accounts of the 'facts' about what has occurred since 3 April 2007. It would be helpful for all concerned to see the correspondence and thereby increase the extent to which 'facts' are known. We would also like to request copies of all future intergovernmental correspondence relating to the CSTDA.

(3)

Government co-ordination and looking to the future

Through the Disability Assistance Package, the Australian Government has signalled an intention to become directly involved in building, owning and operating certain types of services (including accommodation) for certain types of families (those with adult children with a disability aged 40 years or older where the parents are aged 65 or older). This and other aspects of the Disability Assistance Package have provoked a range of responses from our members.

While it is easy to criticise aspects of the Disability Assistance Package from a narrow state/territory government perspective, it seems to us that there are plenty of positives in the Disability Assistance Package that can be built upon, as long as they can be successfully merged with existing arrangements.

If there is still time to negotiate aspects of the implementation of the CSTDA related components of the Disability Assistance Package, it would seem sensible to discuss options to ensure that implementation occurs with the best possible co-ordination between the two levels of government.

In our experience, families of children and young adults don't much care which level of government funds what - "It's all the same (taxpayer's) money isn't it?"

What matters is:

- 1) The quality and actual availability of services 'on the ground' in our towns and suburbs and remote rural areas across all areas of Australia
- 2) That access to these services is no more difficult than it needs to be, and
- 3) That money isn't wasted on bureaucratic inefficiencies eg. unnecessary duplication of government administration.

Point 1 of our CSTDA plan suggests that current negotiations be undertaken with a view to 2022. We want everybody involved in the negotiations to consider the future of today's children with a disability aged 0-4 years who will be aged 15-19 years in 2022, today's 5-9 year olds with a disability who will be 20-24 years of age in 2022, today's 10-14 years olds who will be 25-29 years of age, and so on.

Disability should be one of the easiest social service systems to plan ahead for. Given what is known about today's children with a disability and their families (and we know who they are and where they live and where they go to school), it should be easy to predict and plan appropriately for a system that will cater for their needs during the immediate post-school years and later in adult life.

At all levels of government administration, and across all ages and stages of transition, there needs to be much better and more sophisticated approaches to long term planning to assist children and adults with a disability and their families. This includes the crucial post-school years (ages 15-24) in relation to post-school options, accommodation and related community living support. There needs to be considerable effort put into better co-operation between the Australian Government's employment related support systems and state and territory government systems for post-school support for young adults with a disability and their families. Likewise, it is now well accepted that better co-operation between governments is required in relation to the interface between the disability and aged care systems.

(4)

Normal life transitions to 'away from home' accommodation for young adults

A key point of our letters of 23 May 2007 and 30 May 2007 related to the need for the accommodation support systems in all states and territories to be totally revamped to allow for adequate forward planning for the needs of today's school age children with a disability during their post-school adult years. We suggest that assisting young adults with a disability to access appropriate accommodation during the age 18-25 years should be considered by government along the same lines as policy in relation to young children with a disability attending preschool and school, ie. it is a normal life transition that should be actively planned for and supported at an age-appropriate time.

We would like to request that you answer the following questions:

'Does your government agree with the principle that all young people with a disability aged 18-25 years and their families should have genuine choices and options for the young person to take the normal life transition to suitable accommodation outside the family home? If so, what steps are you taking with your approach to the CSTDA (or other policy initiatives) to initiate action on this matter of principle?'

If you don't agree with this principle, please specify the nature of your disagreements and any alternative principles that you believe should govern public policies relating to accommodation for young adults with a disability aged 18+ years and their families.

For example, the focus of the Australian Government's Disability Assistance Package on accommodation for those with a disability aged 40+ years has raised the obvious question amongst our family members with younger children, ie. is the government assuming that our children should stay living at home with us until the age of 40?

If a young adult with a disability and their family genuinely agree and are happy with the idea of living together until the young adult is aged 40 or older, then of course that is a choice that we can all support, but if this situation occurs only because there is no other choice (ie. there are no viable out-of-home accommodation support options for the young adult with a disability) then this is an entirely different matter.

The choices and options relating to accommodation for young adults with a disability need to consider all family members, including young adults with a disability themselves. Policy in relation to disability accommodation should not be driven solely by parent/carer concerns, it must also focus on the needs and aspirations of young adults with a disability. For example, it should not be assumed that a young adult with a disability would prefer to stay living with his or her parents until the age of 40. In most instances, if genuine choices and options exist, the most healthy and productive arrangement for all concerned is for young adults with a disability to move to suitable 'out-of-home' accommodation within the same time frame that is considered normal and healthy for young adults who do not have a disability.

In our view government policy should not, either directly or indirectly, promote the idea that adults with a disability should stay at home living with their parents until they turn 40 years of age. Young adults with a disability and their families have a right to expect an approach to public policy that promotes access to appropriate accommodation for adults with a disability at an age-appropriate time. Via your answers to the questions above, we look forward to your views about the principles that should govern public policy in relation to accommodation and related community living support for post-school age young adults with a disability.

(5)

Level of investment required in the CSTDA

Our letters of 23 May 2007 and 30 May 2007 suggested that the level of investment required in the CSTDA is \$1.1 billion per year in genuine 'new money' from the Australian Government, to be matched by states and territories, along with adequate funding for indexation and growth.

While some of you might consider this request to be unreasonable or unaffordable, when you consider the level of unmet need amongst today's population of adults with a disability and their families (and meet the people directly affected) and the future needs of today's children with a disability and their families, the level of investment we're suggesting becomes not only 'affordable', but an urgent priority.

On a positive note, with \$212.88 million per year in new money* recently allocated by the Australian Government through the Disability Assistance Package (and reports of significant pledges of new money from WA, ACT and NT), we are now that much closer to an acceptable level of funding for the current CSTDA.

What is now required is a frank reassessment by all governments of an appropriate level of additional investment in this CSTDA, along with a commitment to an appropriate growth-based funding formula for subsequent agreements.

In addition to further 'new money' from the Australian Government, we assume there will be significant 'new money' committed by all states and territories to the current CSTDA, along with appropriate approaches to indexation and growth. Our 10 point plan for the CSTDA (see attached) suggests one possible methodology for an appropriate new funding formula. We would welcome your feedback on our Plan and any alternative suggestions you have that would provide better outcomes for children and adults with a disability and their families.

Finally, it should be noted that while we have once again focussed on the issue of accommodation and related community living support, we also recognise that there is a range of other important areas where improvements to government policies are required. These include public transport, child care, workforce assistance for parents of children with a disability, recreation, accessibility, Home and Community Care (HACC), schools and early years support. In focussing on accommodation and related community living support, we do not mean to downplay the importance of the need for action in other areas. There should be room in the CSTDA and other government policy initiatives to provide for improvements across a wide range of services and support.

We look forward to hearing from you and to the successful conclusion of CSTDA negotiations.

Yours sincerely,

Anne-Maree Newbold, President and Michael Gourlay, CEO

*Note: Of the elements of the \$1.8092 billion Disability Assistance Package, \$1.0644 billion has been included in our CSTDA calculations, with the \$744.8 million of initiatives relating to Carer Allowance (Child) and Early Years (Children's Services), worthy and appreciated though they are, considered as outside the CSTDA. On this basis, the \$212.88 million per year figure is derived by dividing \$1.0644 billion by 5 years.

AAFCO's 10 Point Plan for the CSTDA

1. That both levels of government agree that by 2022, total funding for the CSTDA should involve an equitable split of funding between levels of government (with disability employment services to be included but income support payments (eg. Carer Allowance) to remain 100% an Australian Government responsibility and kept outside the CSTDA). Aids and equipment should also be included within the CSTDA.
2. That benchmarks for the 2006/07 'beginning point' regarding total CSTDA funding and government funding splits be documented and made publicly available for each state and territory based on 2005/06 and 2006/07 expenditure.
3. That CSTDA negotiations regarding funding levels to apply in 2007/08 and beyond begin from modelling and implementing a new 2007/08 'beginning point' that involves:
 - 2007/08 CSTDA expenditure to include a minimum for indexation of 3.0% and a further 3.0% for population growth (6% in total for indexation and growth combined) to apply to the contributions from both levels of government in 2006/07;
 - The quantum of the CSTDA related Disability Assistance Package announcements of the Australian Government (ie. including everything except the Carers Allowance and Children's Services) to be added into the calculations with the assumption that these funds will be deployed evenly across all states and territories on a per capita basis;
 - The quantum of any specific CSTDA related expenditure commitments that state and territory governments have already publicly announced (and will be implementing) in 2007/08 to be added into the calculations;
 - To the extent that new state and territory commitments for 2007/08 add up to less in quantum than the state and territory share of the new funding from the Disability Assistance Package, states and territories to provide new 'matching' funding immediately for implementation in 2007/08; and vice-versa, ie. to the extent that new state and territory government commitments for 2007/08 are more than the state and territory share of new funding from the Disability Assistance Package, the Australian Government to provide new 'matching' funding for immediate deployment.
4. That both levels of government agree to 6% increases of this base level of CSTDA funding (as per Point 3 above) for each subsequent year of the CSTDA agreement.
5. That in relation to 'new money' for unmet need to apply from 2008/09 onwards, that the Australian Government commits to an additional \$887.12 million per year for the CSTDA to be matched 50/50 on a per capita basis by all states and territories.
6. That the states and territories who fall below the average national figure for the state and territory share of CSTDA funding (as per Point 3) be encouraged to provide additional funding over and above the level suggested in Points 4 and 5 above.
7. That feedback from parents/carers and people with a disability about service quality be systematically built into the processes for implementation and review of the CSTDA.
8. That the scope of the proposed 'high level' Inquiry into Delivery Options for Disability Accommodation be expanded to include (1) forward planning for the accommodation and related community living support needs of young adults with a disability aged 18+ up to and including the year 2022 and (2) options for the introduction of a 'no-fault' style insurance scheme to assist in providing a more secure funding base and promoting an entitlement-based approach to services and support in the future.
9. That all governments co-operate to implement a new approach to forward planning for assistance to children and young adults with a disability and their families, based on substantially improved data systems and knowledge of people's experiences of key transition periods: initial diagnosis/identification of disability; the early years and transition to school; transition from primary school to secondary school; Centrelink changes at age 16 and the transition from school and other changes at age 18+.
10. That all Ministers involved in CSTDA negotiations give specific consideration to every recommendation of the Senate Inquiry into the CSTDA, and provide a written account, with explanations of rationale, regarding the extent to which each recommendation has been accepted and implemented as part of the CSTDA.