

23 May 2007

The Hon John Howard MP Prime Minister Parliament House Canberra ACT 2600	and	The Hon Peter Costello MP Treasurer Parliament House Canberra ACT 2600
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Dear Prime Minister and Treasurer,

In our roles as President and CEO of the Australian Association for Families of Children with a Disability (AAFCD) we write on behalf of families with sons and daughters with a disability to urge your government to take a more co-operative, decent and fair approach to the current renegotiation of the Commonwealth State and Territories Disability Agreement (the CSTDA).

In a society as prosperous as ours, it is a sad indictment of our priorities that so many Australian children and adults with a disability and their families are continuing to go without access to the support they need to enjoy a decent quality of life. Of particular concern is the lack of a co-ordinated, planned approach to the provision of accommodation and related community-living support (sometimes referred to as accommodation support or supported accommodation) for young adults with a disability. In addition to the immediate needs of a range of families with ageing parents caring for adult children with a disability aged in their 30s, 40s and 50s, when the parents of today's 16 year olds with a disability look forward five years (to the end point of the next CSTDA) to when their child with a disability will 'come of age' at 21, what do they have to look forward to in relation to the support available to their child and family?

The CSTDA is a key driver of the amount and quality of support available to our children and young adults with a disability and their families. The decisions you and your government make in relation to the CSTDA will have a direct impact on the lives of many hundreds of thousands of Australians with a disability, along with their siblings, parents, grandparents, uncles, aunts, friends and others who support them.

When disability affects your family, especially when it involves a child or young adult with a disability, it tends to become your No. 1 priority in life (and No. 2, 3, 4 and 5!). People with a disability, families with a child or young adult with a disability, and all their extended family and friends have an intense interest in the outcomes of the CSTDA negotiations and will be closely observing the behaviour, attitude and commitments of all parties involved in the negotiations.

So far, it is something of an understatement to say that we have not been impressed with the approach taken by representatives of your government, nor have we been impressed with the approach taken by state and territory governments. Some of the politicians involved seem more interested in attempts at election year political point scoring than actually getting on with the job of looking at the issues, examining the evidence, and reaching agreement about a decent and fair CSTDA for the future.

In the pages that follow, we propose a way forward that involves some give and take by both your government and state/territory governments. It is a genuine attempt to assist the CSTDA negotiations to get back on track to where they should have started, above 'politics' and focussed on the very real and immediate needs of children and young adults with a disability and their families.

(2)

Agreement Structure – Multi-lateral and/or Bi-lateral

There seems to have been considerable debate about whether the new CSTDA should be built on the back of one major multi-lateral agreement covering the whole nation or a combination of a more basic multi-lateral agreement together with newly negotiated bi-lateral agreements separately covering each state and territory.

You can imagine that families with a son or daughter with a disability on a waiting list for services haven't been particularly enamoured to learn that the bulk of the recent meeting of Ministers to negotiate the CSTDA seemed to be spent debating (and not agreeing) on the merits of a multi-lateral versus bi-lateral approach. In the words of one family member, "What matters is the services on the ground in the real world, it's all the same taxpayer's money isn't it, why can't they just get on with it?"

We do not have a strong view on whether one major multi-lateral agreement is a better approach than a more basic multi-lateral with substantial new bi-lateral agreements. Our interest is purely and simply the real world outcomes for children and young adults with a disability and their families in every town and suburb across Australia.

Subject to addressing major concerns about indexation and 'growth' (see below), as well as incorporating an appropriate agreement about proportional contributions from each level of government (see also below), it seems to us that the approach of a combined multi-lateral and bi-lateral approach could work just as well as one major multi-lateral. The important outcome is that services and support for families and their children with a disability are substantially improved in each state and territory. This can be achieved irrespective of the multi-lateral/bi-lateral structure of the agreement.

Indexation, 'Growth' and 'Real' New Funding

Leaving aside for the moment the discussion of the extent of 'unmet need' amongst our population of children and adults with a disability and their families, before any sensible discussion can take place regarding genuine 'new money' to address unmet need in the CSTDA, it is fundamentally important that the Agreement includes decent and fair levels of indexation and 'growth' funding for all states and territories. This is a basic beginning point that should have been easy to establish and agree upon from day one.

Your government's current offer of only 1.9% indexation and no 'growth' is grossly inadequate and completely unsatisfactory.

Indexation and 'growth' are components of the CSTDA that simply allow the level of funding and service per head of population to remain unchanged. Adequate base levels of funding for indexation and 'growth' in the next CSTDA are absolutely crucial to ensure that any subsequent discussion of 'new money' is indeed new money and not simply money that helps to play catch-up for the loss of service due to inadequate indexation and 'growth' funding.

Governments and bureaucracies of all persuasions are very adept at presenting budget and funding numbers in a way that reflects them in the best possible light. Regarding the CSTDA, we would urge your government not to underestimate the intelligence, sense of fairness and fighting spirit of families of children with a disability and our capacity to identify attempts at bluff and spin with CSTDA numbers.

(3)

Indexation, 'Growth' and 'Real' New Funding (continued)

Your current offer of indexation is 1.9%. Anybody who lives and works in the real world where CSTDA funded services and support are delivered knows that the costs of providing these services and support are increasing at more than 1.9% per year.

Your own Treasury predicts that inflation will be 2.75% next year. We understand that, historically, CSTDA related indexation has been tied to a particular wages outcome formula (Wage Case Index-2) rather than the Consumer Price Index (CPI) measure of inflation. We also understand that your government may have taken a 'whole of government' approach to funding indexation and that the CSTDA offer may simply reflect the settings of this whole of government approach.

Nevertheless, the facts are, in reality, the inflation related cost increases of providing CSTDA services and support are running at more than 1.9% per year. In most instances, the providers of CSTDA related services and support do not have genuine opportunities to implement the sort of efficiencies that might be available to a large government department to offset costs and manage a shortfall between rising costs and income.

Make no mistake, to the extent that CSTDA indexation is below 'real world' cost increases of providing services and support, it will contribute to a decline in the support available to children and adults with a disability and their families.

We strongly urge your government to offer a more decent and fair indexation figure for the CSTDA. The current 1.9% indexation offer must be revised upwards to reflect the real world cost increases of providing CSTDA related services and support.

Indexation is one key component of ensuring that the level of support for children and adults with a disability through the CSTDA doesn't decline. Another key component is provision for 'growth'.

The meaning of the term 'growth' as referred to in the CSTDA is not well understood by people in the general community. Indeed the bureaucratic use of 'growth' is a misnomer in that it doesn't relate to growth in service levels per head of population. 'Growth' relates to growth in the population (and/or needs of the population) requiring service. It is for this reason that we have persisted up to this point with the awkward use of quotation marks in referring to 'growth' throughout this letter. 'Growth' isn't really growth at all, it's just what is needed (together with indexation) to stand-still and maintain the status-quo in terms of the existing level and quality of service. Inadequate provision for growth in the CSTDA (and/or indexation) equates to a cut in the level or quality of service to children and adults with a disability and their families.

We must confess to being incredulous when Minister Brough's initial CSTDA offer to the states and territories offered no growth funding, nil, zero! Was he kidding? Did somebody at FaCSIA forget to put it in? Did Treasury think it would be fun to see if states and territories and/or family and disability advocacy groups were asleep and wouldn't notice? Is your government banking on the whole growth concept being a bit complicated for the media and families to understand? What possible justification could there be for not putting a reasonable growth proposal on the table with your initial CSTDA offer?

(4)

Indexation, 'Growth' and 'Real' New Funding (continued)

Imagine if there were 100 extra children needing to start at a public/government school in the electorates of Bennelong or Higgins next year and the State Government Education Minister said, "Sorry John, sorry Peter, we only have X number of places in school for children based on last year's figures, we can't be expected to account for population growth so these kids won't be able to go to school, I'm sure you'll understand they'll have to stay at home". It wouldn't happen. If there are 100 extra children in any area of school age, your government and the states and territories work and plan together so that the number (and location) of school places is expanded in line with population growth.

Australia's population is growing and Australia's population of children and adults with a disability is growing at a higher rate than that of the general population. Amongst the range of factors contributing to this growth is the longer life expectancy of people with a disability compared to previous generations. People with a disability of all ages are now living significantly longer. One consequence of this is significantly increased demand for the range of accommodation and community-living support services for children and adults with a disability funded through the CSTDA.

Your government has access to various reports that attempt to quantify 'growth' in demand/population for CSTDA related services and support. We are also aware that some states and territories have commissioned actuarial reports on CSTDA related 'growth'. From a budgetary point of view, these growth estimates are substantial, as high as 5% per year, although other estimates are in the range of 2-3%. There is also some variation in projected growth rates between states and territories which largely mirror general population changes, so it may be necessary to consider different growth rates for each state/territory rather than one national figure.

In any event, we can't stress strongly enough that the CSTDA must include a decent and fair growth figure, certainly one above zero! We further suggest that your government should take leadership on this issue immediately and make a decent and fair offer in respect of growth in addition to a suitably revised indexation figure.

We do not profess to be experts in the technicalities of calculating growth and indexation, but through your Treasury, the Reserve Bank, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and various other commissioned studies by actuarial experts, it is likely that decent and fair numbers for indexation and growth are readily available to you and state and territory governments.

Our experience tells us that a decent and fair indexation figure might be in the range of 2.5%-4.0% and a further 4.0%-5.0% for 'growth'.

Our request to you is that you immediately make a CSTDA indexation and growth offer to the states and territories within this range, whilst also maintaining your existing offer of a 50/50 contribution in relation to new money over and above indexation and growth. It is only after you have adequately provided for indexation and growth that the 50/50 offer can be considered as 'real' new money.

(5)

Unmet Need

The term 'unmet need' sometimes does not adequately describe the sorts of real life family circumstances we are referring to.

Unmet need isa family with a child aged 3 who has only recently been diagnosed with a disability. Amidst the emotional stress of trying to come to terms with the diagnosis, the child's parents have been urged by medical practitioners to maximise their child's life chances by immediately seeking early intervention support services. The parents soon discover that there is a twelve month wait for access to early intervention in their area. As every minute ticks by, the parents worry about the life-long impact of their child not getting access to the early intervention recommended by the medical experts.

Unmet need isa family of two adults and three children that includes a 14 year old child with a disability who used to get access once every three months to a weekend of high quality support through a community based respite house, but who now face the prospect of substantially reduced access to this type of support due to the respite house being converted to a long-term accommodation house as a crisis response to an acute accommodation shortage for older adults. The parents are particularly worried about the impact the reduction of service will have on the siblings, aged 16 and 12.

Unmet need is the three different families with children with a disability aged 17, 24 and 32 who all separately over a three week period took the enormously difficult decision to 'give-up' trying to care full-time for their children at home and, in the absence of any hope of getting access to long term accommodation support through the normal channels, decided not to pick up their children from respite, thereby forcing the state government authority to provide accommodation (which they did by closing a respite house and converting it to a long-term accommodation house thereby reducing access to respite for other families).

Unmet need isa mother and grandmother of a 22 year old with a profound disability who both have serious back related health problems due to the young man's care needs but who haven't even bothered applying for supported accommodation for him because they know, quite rightly, that under current arrangements in their state they would have no hope of being considered a priority for allocation of scarce accommodation resources until such a time as their physical and/or mental health deteriorates much further.

Unmet need is two parents, now late 70's, who have been caring with pride and passion for their daughter with a disability for all of her 46 years. They are concerned about the difficulties they face in organising appropriate accommodation and support arrangements for when they will no longer be able to care for their daughter full-time.

Unmet need is a whole lot more than just these five examples. The point is, CSTDA related unmet need is about real people and real families who need and deserve better support than they are currently receiving from current CSTDA arrangements. The situation has been well documented in the recent report of the Senate Standing Committee on Community Affairs, '*Funding and operation of the Commonwealth State/Territory Disability Agreement*' (February 2007). The Report recommends a substantial funding increase to meet unmet demand. While the quantification of this is a work in progress, there are many thousands of families on waiting lists around the country with their unmet need exactly quantified.

(6)

Unmet Need (continued)

Without doubt, the biggest area of unmet need (and the most costly to address in budgetary terms) is long-term accommodation and related community-living support (accommodation support). This includes not only the capital costs of building appropriate housing but also the ongoing recurrent expenditure required to provide appropriate levels of community-living support for people with a disability and their families.

Why did the situation facing the parents of the 17, 24 and 32 year olds in the examples above become so desperate that they felt they had no alternative but to take the heartbreaking decision to not collect their children from respite?

In relation to the 22 year old, what are our plans and expectations in relation to where that young man should be living and with what support? Is it reasonable to expect that the young man will be cared for full-time at home by his mother and grandmother until he is aged 23, 25, 30, 40, 50? At what point, and based on what criteria, should the young man and his family become eligible for government funded assistance in relation to long term accommodation and support?

The same question can be asked in relation to the parents of the 14 year old. The parents are coping OK now with his care and support. If the respite and general support needs of the whole family are adequately addressed (which is no certainty mind you), it is more likely than not that this young man will be able to live with his family for the next 5-10 years, but then what? Sometime from the age of 21-25 years, the chances are that one or both of his siblings will have taken the normal life step of moving out of home to live independently. Will the young man with the disability also have that opportunity? Will he and his parents have any genuine choices and options when he is aged 21-25 in relation to decent quality accommodation and support outside the family home? Or is it your government's expectation that in return for a bit of respite support every now and again that the parents should continue to provide his primary care for life despite the great personal, physical and financial costs to themselves? Or perhaps it's your government's expectation that one of the siblings (and/or his partner) should assume primary care responsibilities throughout their adult life?

In our view, policy makers at the national and state/territory level need to initiate a major overhaul of the approach to long term accommodation and community-living support for young adults with a disability and their families. In addition to a substantial injection of new money into this CSTDA by both levels of government to expand accommodation support options for people and families in urgent need today, the accommodation support systems in all states and territories need 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.

Public policy in the area of 'post-school' support for young adults with a disability and their families should be guided by a set of principles based on providing all 'post-school' young adults with a disability (aged 18-25), and their families, with the same sort of rights, choices and opportunities that are taken for granted by families of young people of the same age who do not have a disability. In relation to accommodation and community-living support, by the age of 21 years, every young adult with a disability and his or her parents should have a genuine choice and opportunity for the young adult to take the positive step of a 'normal life' transition to a suitable form of independent accommodation, with appropriate levels of on-going community-living support.

(7)

Unmet Need (continued)

When young adults without disabilities complete their schooling at around age 18 years of age, we expect them to make the transition to some form of further education, training or employment. We also expect that at some stage between the age of 18-25 years, it will be a healthy and normal life transition (for the young person, their parents and the family as a whole) for the young person to move to some form of independent accommodation, whilst also maintaining regular contact with their parents and any brothers or sisters in the family.

While government decision-makers at both federal and state/territory level do seem to have accepted the idea that public policy settings should actively assist children with a disability and their families to enjoy the normal life transition to preschool and school (although there is still some significant work to do in this area to achieve high quality educational outcomes for children with a disability), there are no clearly articulated principles governing our public policy settings in relation to assisting young adults with a disability and their families with the normal 'post-school' life transition to independent accommodation outside of the family home.

We suggest that assisting young adults with a disability to access appropriate supported accommodation during the age 18-25 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.

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, we would assume that with your government's contribution to the next CSTDA, in addition to providing significant new funding to address the urgent accommodation support needs of families with sons and daughters with a disability who are already aged 25 years or older, you will also commit to a strategy to address the future accommodation support needs of today's population of families with school age children with a disability.

We suspect that while government decision makers at both Commonwealth and state/territory levels might agree with our proposed principles in relation to normal family transitions for young adults with a disability aged 18-25, there is a general concern that implementing such a principle might be cost prohibitive for government.

There is no getting around the fact that decent quality supported accommodation for people with a disability does cost a significant amount (although we prefer to think of it as an investment rather than a cost), both in capital and recurrent expenditure.

Over the years there have been various attempts to quantify the level of unmet need for accommodation support. We are not convinced that any of these have produced a figure that accurately reflects the real level of unmet need, but it is worth noting that in the recent report of the Senate Standing Committee on Community Affairs, *'Funding and operation of the Commonwealth State/Territory Disability Agreement'* (February 2007) politicians across all party lines found themselves agreeing with the recommendation that, "The Commonwealth, State and Territory governments should jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support" (page 101).

(8)

Unmet Need (continued)

The key to modelling the overall level of investment required to address today's immediate accommodation support needs of adults with a disability, and planning for future generations, is a detailed analysis of the demographics of disability, incorporating both type of disability and different levels of need.

We represent families of children with all types of disabilities across the full range of severity. Every child and young adult with a disability is unique and every family circumstance is different. The level of government funding support needed by different children and adults with a disability varies according to family circumstances and type/severity of disability. The number of young people with the most profound disabilities, for whom the most intensive support is required, is actually quite a small subset of the overall population of children and young adults.

Further, we do not expect that government will provide for 100% of the costs of providing accommodation support for all families through the CSTDA and/or normal budgetary means. Indeed there are other significant means of assistance available from philanthropic, community and family sources that should be better harnessed and encouraged to complement the funding available from government.

However, there is no doubt that the development of a decent system of supported accommodation for young adults with a disability and their families is reliant on a commitment to substantial new investment in this CSTDA by your government and state and territory governments.

Without access to key demographic data, we are not in a position to model with any precision the shortfall between the costs of a decent and fair system of accommodation support for people with a disability and the funding which is available around Australia today from government and the community. On the best information available to us, in addition to adequate funding for indexation and growth, we believe that the next CSTDA should include additional unmet needs funding of \$2.2 billion per year (shared at \$1.1 billion each between your government and state and territory governments), with the bulk of this dedicated to accommodation support. To some people, this might sound like a lot of money, but in the overall budget context, it is modest and affordable.

Adjustments to reflect proportional government shares of total funding

The commitments and performance of state and territory governments in the provision of CSTDA related funding and support for children and adults with a disability varies considerably. Over the life of the past CSTDA, most reports suggest that Victoria, Western Australia and the ACT have been amongst the better performers, with recent initiatives in New South Wales having brought that state to a comparable level of investment, albeit from a low base in previous years. All states and territories, including NSW, Victoria, WA and the ACT can do much better with the level of investment they make to support children and adults with a disability and their families. We have no doubts that in overall terms, states and territories can afford to provide a 50/50 share of the \$2.2 billion per year investment in new unmet needs funding that we propose be included in the next CSTDA. We therefore have no argument with your government's approach to offer matching contributions on a 50/50 basis for new unmet needs investment. Indeed, to the extent that the offer does indeed reflect 'real new money', we commend you for your 50/50 approach. It is indeed an opportunity that the states and territories should welcome and embrace.

(9)

Adjustments to reflect proportional government shares of total funding (continued)

However, we do have some sympathy for those 'better performing' states and territories who might consider that a simple 50/50 approach to new money in some way disadvantages them by not taking into account their comparatively better overall level of investment in CSTDA related services and support. Excluding disability employment services (which are 100% Commonwealth funded), currently, some states and territories (the better performing ones) are contributing to the CSTDA at above 80% of total funding (with your government's contribution being below 20%), while others are contributing below 80% (with your government above 20%).

Some people would consider that the CSTDA is due for fundamental reform and re-negotiation of Commonwealth and State/Territory responsibilities. It does seem odd, for example, that the important area of aids and equipment for children and adults with a disability is outside of the CSTDA and remains 100% a state and territory responsibility with no dedicated Commonwealth input or funding.

In the spirit of your 50/50 offer for new money, one approach would be to progress over time to an arrangement where total CSTDA funding is based on a 50/50 split. However, based on existing arrangements, we acknowledge that it might be unrealistic to expect your government to commit at this time to a 50/50 split of total CSTDA funding. Nevertheless, we believe the new CSTDA should include a mechanism to ensure that the 'better performing' states and territories are not disadvantaged. One possible mechanism to achieve this would be to start this new CSTDA with a minimum benchmark of 20% for the contribution of the Commonwealth. This proposal would involve additional funding from your government to those states and territories who are already contributing at above 80% of total CSTDA funds (NSW, Victoria, WA and the ACT), whilst not penalising children and adults with a disability who live in other states and territories. Needless to say we are not advocating for a reduction to 20% in the Commonwealth contribution in those states and territories where it is currently above 20%. Nor are we suggesting that 20% should be enshrined as the target level of Commonwealth contribution in the future. Rather, over time, the Commonwealth share of the CSTDA should increase well above 20% in all states and territories.

Family and Voter Responses to Federal/State CSTDA Political Games

Families of children with a disability are a proud and passionate group. We are fiercely protective of our children's rights and we don't take kindly to decision-makers who do not take the time to listen, truly listen, to the issues that affect us and our families. Any politician involved in CSTDA negotiations who is more interested in political game playing than the real issues for our children and our families will be judged accordingly. The needs of our children and families should be above 'politics'. At this point in the CSTDA negotiations, we are extremely unhappy with aspects of the approach taken by your government and the approach of all state and territory governments.

Your government's recent budgets have included many welcome initiatives for families of children and young adults with a disability, but the lack of any new allocation to the CSTDA in your most recent budget (aside from provision for 1.9% indexation) was a major disappointment. The budget was a missed opportunity where you could have demonstrated the leadership our families need through a clearly articulated long-term national vision, backed by concrete financial commitments, to address the critical needs in relation to accommodation and related community-living support for children and young adults with a disability.

(10)

Summary of CSTDA Action Requested

CSTDA negotiations need to get back on track and operating at a level that is above 'politics' and focussed on the needs of children and young adults with a disability and their families. In our view, the key next step required is for your government to initiate a revised offer to the states and territories that includes a commitment to:

1. CSTDA indexation in the range of 2.5%-4.0% per year.
2. Additional CSTDA 'growth' funding in the range 4.0%-5.0% per year.
3. An additional \$1.1 billion per year in unmet needs funding (to be matched by \$1.1 billion per year from state and territory governments)
4. Additional funding to ensure the CSTDA begins with a Commonwealth contribution (exc. employment) at 20% or more in all states and territories.

Will you commit to do these four things? If not, please explain why and outline your alternative plan for the CSTDA.

Finally, we note that your existing offer includes references to strong measures of accountability and quality assurance. We agree wholeheartedly that there should be strong and robust methods to ensure that government and the taxpayer gets 'value for money' quality outcomes from all new and existing CSTDA expenditure.

We would welcome an opportunity to meet with you and/or representatives of your government to discuss our CSTDA proposals. We would also like to discuss a range of other important issues for families of children with a disability that fall outside the boundaries of the CSTDA, including: early childhood intervention and emotional support for parents in the early years; pre-school and school education; aids and equipment; disability advocacy for children and families; poverty and financial hardship facing many families of children with a disability; Centrelink payments; health and Medicare; Home and Community Care (HACC); childcare and employment assistance for parents of children with a disability, including a particularly disadvantaged group of families with teenagers with a disability who have difficulty accessing out-of-school hours care; improvements to taxation, superannuation and other policies (eg. Special Disability Trusts) to encourage family and community contributions to disability support, and; whole of government approaches to ensure an appropriate sensitivity of disability issues is built into all government policy areas such as transport and communications. We would also like to discuss long-term opportunities to introduce a form of government sponsored 'no-fault' insurance to assist in covering the costs of providing disability services and support. There is much that can be learnt from the successful operation of transport accident schemes in Australia and overseas. We suggest that the whole Australian community could benefit from taking the best of the lessons from these schemes and applying it to our thinking about all Australian children and adults who are born with, or acquire, a serious life-long disability.

We look forward to a positive response from you and trust that you have found this correspondence helpful in working towards a CSTDA outcome for children and adults with a disability and their families of which we can all be proud.

Yours sincerely,

Anne-Maree Newbold, President and Michael Gourlay, CEO