

**SUBMISSION TO THE SENATE COMMUNITY  
AFFAIRS REFERENCES COMMITTEE**

**Inquiry into the funding and operation of the  
Commonwealth State Territory Disability Agreement**

**Submission of Michael Carroll and Alli Paterson on behalf of Alec Carroll**

We would like to make a submission to the Community Affairs References Committee Inquiry into the funding and operation of the Commonwealth State Territory Disability Agreement. The submission refers largely to our personal experiences as parents of, and carers for a person with a disability.

Prior to addressing our main points, we believe it is appropriate to share some information to place our submission in context.

We are the parents of a gorgeous four-and-a-half year old child named Alec. Delayed speech and behavioural problems were our first clue that Alec was having more difficulty than his peers in communicating. We commenced speech therapy on a private basis which led to us seeking further advice from a paediatrician, psychologist and diagnostic speech therapist.

The professional assessment is that Alec has classic autism but is high-functioning with no intellectual disability. Any diagnosis of a disability is difficult for parents to accept, and just as difficult is coming to terms with how to meet his needs now and in the future.

Alec is considered eligible for some services in Western Australia and receives three hours a week in therapy from the Autism Association of Western Australia. We also purchase additional hours of speech and occupational therapy through a private provider at \$75 a session.

We consider ourselves fortunate to receive any assistance at all as our contact with families in similar situations indicates that across Australia there is little consistency in the cost and accessibility of early intervention services. We are also fortunate in being able to afford additional therapy sessions – although still not as much as our son needs. We are examining the option of drawing further on the equity in our family home to pay for additional services.

We are a single income family, and receive a small carer's allowance of around \$90 a fortnight in addition to our family payments. This amount does not quite cover the fuel costs (our sole vehicle is a 2L 4 cylinder family sedan) incurred in driving our son to various locations for therapy and the gap is growing each week as fuel prices increase.

We come up short – there's no real tax offset of any value for being a carer, the carer's allowance bonus of \$600 that arrives each year with the budget looks nice but in our view really is just a way of applying a form of indexation to some of the additional expenses we have incurred throughout the year.

We are willing to do whatever it is we need to do in order to ensure that our son receives the therapies he requires to allow him to reach his potential and participate in and contribute to Australian society. We are currently bearing the larger proportion of the costs for this. The state government is sharing this through its funding of the Autism Association and the federal government contributes a little more through its contributions to the state through the CSTDA. In pragmatic terms, the outcome from our efforts and the efforts of those who share responsibility for

funding will be a person who contributes to the economic and social life of the nation and this contribution will outweigh the cost of early intervention many times over. It will ultimately be the federal government that reaps any financial rewards through our efforts, and we believe it is not unreasonable for families and carers to expect that the federal government provides better support to families and carers.

Recognition could come through tax benefits beyond those applied currently, for example, making the whole amount of money spent on therapy a tax deduction. The federal government should also invest heavily (through the states) in early intervention. Whatever action is taken will come too late to help our family in terms of early intervention, but we cannot stress enough the critical role that early intervention plays in delivering personal and family outcomes.

There is no way we would advocate shifting dollars from other areas of disability funding – this would be a gross injustice to other people with a disability who in many cases have high care needs. This is unmet need, we know it needs greater funding, and while the state budget did include additional funding there was not nearly enough. Even this though was significantly greater than that provided by the federal government – who will be the main beneficiaries of the efforts of families and carers.

As a family we don't really want to hear governments debate funding accountability, we want to see our governments take responsibility and we'd certainly rather see them compete for who can deliver the best support rather than who should get the credit for the support provided

In the meantime though, our family faces the financial and emotional stresses of raising an autistic child, and our activities are restricted by the difficulties we face each day. Yet we consider ourselves fortunate, our son is participating in mainstream schooling at kindergarten, he is intelligent and affectionate and we have access to resources that allow us to supplement the services he receives with additional services.

## **1. An examination of the intent and effect of the three CSTDAs to date.**

In a general sense the agreements seem to have consolidated the approach to providing disability services and provided a point of coordination for these services in each state. In Western Australia this point of coordination is the Disability Services Commission and in our experiences the Commission provides a good level of information to carers about the services available. This is notwithstanding the inevitable communication failures that occur from time to time from any large organisation.

Our experience of the CSTDA has only been with the conditions established under the third (or current) agreement. Up until the diagnosis of our son with Autism in 2005 our links with people with a disability, their carers or disability services had been incidental at best.

We now find ourselves interested in, and engaged with 'disability' as a concept and as an impact on people who have a disability and people who care for a person with a disability.

Our observations are that there are a lot more people who have a disability, who are carers for or who are related to a person with a disability than might be imagined.

If you described this group as a constituency then it would be palpably large, and if it were to unify as a political force it would rival or surpass most other interest groups in Australia. There are indications that this is occurring and we know that autism support organisations that we have joined are actively building links with other disability advocacy groups. We think the third CSTDA has encouraged this somewhat through support of advocacy for people with disabilities but we think there are more significant environmental drivers to this coalescence that are related to the needs of people with a disability not being met.

The current agreement includes a very positive preamble but taken as a whole it is difficult to see how this preamble and the national strategies are supported by the conditions of the agreement and the bilateral agreement that is related to it.

We think the intent of the agreement/s is therefore positive, and our experience of services delivered at the state level has been good. As mentioned earlier, the little good service we do receive is not enough, and we understand that needs must be prioritised among the many people with a disability. However, the intellectual knowledge that our son is receiving the services he is eligible for (given current resources) does not in any way assuage the anguish in the knowledge that his needs are not fully met, and that even with our additional commitment through drawing on savings and personal resources, there will still be gaps that could be addressed.

Imagine then the anguish of families who are unable to do the little extra we have, who must rely only on the meagre services available from governments. The long term outcomes for their sons and daughters are bleak, and there will be significant future personal, social and economic costs.

To us, one of the great failings of the CSTDAs is the lack of cohesive strategic vision linking all of the agreements. In our case I refer specifically to the fact that there is no demonstrated understanding that application of funding at one point can reduce need later and can assist in avoiding situations where need is only addressed when the situation for families and people with disabilities becomes critical. Addressing need when it has reached a critical point is almost always a more expensive exercise than intervening at an earlier point and developing the capacity of families and carers to manage by providing appropriate resources.

We hear the words spoken from the Prime Minister that families are the cornerstone of the nation, and from others in government that carers are valued and that people with a disability are encouraged to participate. What we don't see is a demonstration that these words are more than rhetoric. Over 100,000 children are directly affected by Autism and this represents tens of thousands of families who care for these children. There are thousands more adults with autism, many of whom are also still cared for by their families.

The cost of providing this care is enormous, financial, social, emotional and lost opportunities to participate in life are all hallmarks of the experience of many Australian families. These costs have been recognised in words by the federal government, but not in action through appropriate levels of early intervention funding that would help reduce costs later.

The CSTDA needs to be able to include some consideration on the continuum of life with a disability. Proper planning needs to occur so that as well as meeting the needs that exist now, future need is considered and all possible action is taken now to reduce need later.

It is difficult to make a submission regarding an agreement that as parents we don't fully understand. But if the CSTDA is supposed to make life better for people with a disability and help them participate, well we do understand that. If the CSTDA is supposed to support families and carers in providing adequate care, then we understand that intent also. If the agreement is supposed to be a partnership between the federal government, the states and the territories, we can see how some of that intent is written in words, but we do not see it demonstrated on the part of the federal government who are at best minor contributors in funding and service delivery, even given their role in employment services.

We think that there needs to be an agreement such as the CSTDA – it helps focus some funding at a point where it is needed, it is in effect a good start, but the 'start' has been going since 1991.

We would ask for more collegiate work rather than combative work in developing future agreements.

We would ask that adequate planning, including long term planning becomes hallmark of an agreement that should be a shining gem in Australian Government policy.

Disability is not political – there is broad consensus and bipartisan support at all levels of government – why then has it been so hard to acknowledge the depths of the problems and provide adequate funding? Why has the amount provided by the federal government grown so slowly? Why is indexation on federal contributions provided at an amount less than the increasing costs?

We believe that there are ways to make it easier for families and carers – tax relief is one avenue, appropriate resources through the CSTDA are essential (and the current resources are NOT enough).

We have tried to provide information to the Senate Committee, rather than recommendations alone and we sincerely hope that our submission does inform the Committee Members about some of the issues for people who are supposed to be the focus of the CSTDA. Thus our one recommendation about the CSTDA is that it must have an articulated and practical centre around people and their needs.