Submission to Productivity Commission Inquiry into Disability Support

15 August 2010

Background:

This is a personal submission. I am a mother of a 13 year-old girl who has severe spastic quadriplegic cerebral palsy. I have 3 other children; boys aged 15, 11 and 6.

Disability is expensive:

On the next page there is a summary of our daughter's equipment expenses to date. The table also shows to what extent the equipment was funded through the Aides and Equipment program, and how much additional funding had to be found ($119,899 extra in total).

Finding extra funding is stressful, time consuming and inefficient:

- We have spent countless hours writing applications for top up funding for basic equipment such as a wheelchair or a standing frame.

- It can take months or even years to find the extra funding (by which time the price has gone up). Our daughter's scoliosis went from mild to extreme in the 18 or so months it took to get funding for a new wheelchair. Her old one had served her well for many years, but was no longer suitable as she developed rapidly worsening scoliosis. Earlier provision or an appropriate wheelchair may have prevented the scoliosis getting so bad so quickly, and would have saved her a lot of discomfort.

- There are many generous people and organisations out there, and we have benefited greatly from their kindness.
  - Even so, applying for charity is invasive and humiliating. We have had people turn up on our doorstep out of the blue to "check us out" before approving a grant.
  - We have felt an obligation to go and speak at lunches and dinners to say thank you for the money. People are kind but curious, and often we have felt that we, or our daughter is "on show".
  - We are articulate and educated; this has helped us obtain grants. Provision of essential equipment for a child should not depend on how well their parents can express that need.
- Now we have a case manager who does a lot of this for us. Sometimes it seems that she is paid by the state government to write submissions to the state government to try and get some extra money for equipment. Finding funding takes up all her case management hours.

- We pay a premium to Australian suppliers. The Aides and Equipment program won't allow us to purchase equipment directly from overseas, even if it is much cheaper. Buying direct would mean we'd lose the A&EP contribution, which means it would not usually be worth our while. But it also means that we're having to find extra funding just to pay Australian suppliers' monopoly profits.

Equipment costs, AEP funding and Top up funding to date:

EQUIPMENT HISTORY

Date	Equipment	Cost	AEP contribution	Top up or not funded
1998	Infant standing frame	$513.00	$ 513.00	$ 0.00
1999	Giraffe Chair	$1,500.00	$ 500.00	$ 1,000.00
1999	Bath Support	$1,322.00	$ 500.00	$ 822.00
2000	Seating for stroller	$1,352.00	$ 1,180.00	$ 0.00
2000	Car Seat	$2,700.00	$ 850.00	$ 1,850.00
2002	Mulholland Growth System	$12,500.00	$ 3,500.00	$ 9,000.00
2002	Dynamyte 3100 ECD	$14,815.00	$ 4,500.00	$ 10,815.00
2003	Daessy mount	$1,409.00	$ 0.00	$ 0.00
2004	Mobile shower chair	$2,000.00	$ 997.00	$ 1,000.00
2004	Mods to wheelchair	$2,022.00	$ 2,022.00	$ 0.00
2005	Car hoist	$18,000.00	$ 0.00	$ 18,000.00
2007	Prone standing frame	$3,182.00	$ 542.00	$ 2,640.00
2008	Ceiling hoist	$3,300.00	$ 3,300.00	$ 0.00
2008	Power chair base	$6,000.00	$ 6,000.00	$ 0.00
2008	Pressure cushions	$842.00	$ 842.00	$ 0.00
2008	Customisation of wheelchair	$2,750.00	$ 2,750.00	$ 0.00
2008	Dynavox V max ECD	$14,472.00	$ 6,000.00	$ 8,472.00
2008	Bigger leckie prone standing frame	$3,500.00	$ 0.00	$ 3,500.00
2009	Motorised wheelchair	$20,000.00	$6,000.00	$ 14,000.00
2010	Leckie Supine stander	$10,000.00	$ 550.00	$ 9,500.00
2001/2002	2nd Manual chair/Growth system	$5,500.00	$ 0.00	$ 5,500.00
2001	Hart Walker	$10,000.00	$ 0.00	$ 10,000.00
over the years	Beach Buggy	$400.00	$ 0.00	$ 400.00
over the years	Manual back up w/c for community access (steps)	$6,000.00	$ 0.00	$ 6,000.00
over the years	Sleep system	$5,500.00	$ 0.00	$ 5,500.00
over the years	Hospital Bed	$2,500.00	$ 0.00	$ 2,500.00
over the years	Rifton toilet seat	$1,000.00	$ 0.00	$ 1,000.00
over the years	Swing	$1,000.00	$ 0.00	$ 1,000.00
over the years	Second skin, AFO's Hand splints	$2,000.00	$ 0.00	$ 2,000.00
over the years	Switches, keyguards	$1,500.00	$ 0.00	$ 1,500.00
over the years	4x Trikes	$3,900.00	$ 0.00	$ 3,900.00
	TOTALS	$161,479.00	40,546.00	119,899.00
over the years	Home mods	LOTS !!		

The battles are exhausting:

We have to advocate for everything for our daughter. Kindergarten aide time, a school program, all those equipment needs, medical and therapy services .. . . . it is not her disability that is exhausting and stressful, it is the battle for basic rights. This battle takes us away from the simple enjoyment of and time with all of our 4 children. It affects our health and well-being. Many families break up under the stresses we go through.

The future is frightening:

It's not rocket science; our daughter's current and future needs could be mapped out now and planned for, including a natural, supported move away from the family home into appropriate supported accommodation with some friends she'd like to share with, when the time is right. This is a natural, human progression.

There is no way this could happen without a massive injection of funding into accommodation. The long-term accommodation system is beyond crisis, it is simply not functioning at all. This is an inditement on a modern progressive society. We can't think about our daughter's future, or ours, because there is no framework to think about it in. There are just scary and heartbreaking stories.

The system is in crisis:

It seems that family crisis is a key allocation criteria, in particular for accommodation. Even so, there are no spots. I have seen grandparents weeping in despair at a public meeting about disability support, as they describe how badly they need help, and appropriate supported accommodation for their violently autistic grandson. They sat there crying while they said they couldn't go on like this. They were surrounded by (kindly, sympathetic) strangers who sat in total, shocked, silence. It is not a scene I will easily forget. To my knowledge they still don't have a spot, or certainly didn't for some time after this meeting.

The system is massively inefficient:

We have just spent hours going through our daughter's package with her case manager and a reviewer. Her package will need to increase because of her changing needs. We've been told that a package may not be available for a while, so our case manager has to apply every couple of months for "top up" funding while we wait. Net result – we're still getting the respite and personal care services our daughter needs, but our case manager is spending a lot of time doing repeated applications.

Our daughter's schooling is inadequate:

Although this submission is about disability support, I feel compelled to mention that, with the break up of special schools and the move to "inclusion" – which I fully support; our daughter spent the first 9 years of her education fully integrated – there has been a loss of expertise on how to educate children with cerebral palsy. Often their learning needs and methods are different, and there simply is not the support for this either in mainstream or special schools. Our daughter's educational opportunities have in no way been maximised.

The current system is hugely inequitable:

Our daughter is a surviving twin – she became brain damaged before birth due to complications of a twin pregnancy. Had she received her brain damage in a car accident on the way home from the hospital, her needs would be covered by the TAC. Provision of disability services should never be based on how the disability was acquired.

A new expenditure model:

As I understand it the last time some sort of national insurance scheme was proposed, in the latter part of the Whitlam years, it faltered due to concerns about expense, and also what support would be provided. These days we have the advantage of a TAC expenditure model which could be adapted/applied to all disabilities however acquired.

Would this be expensive?

I think it is not possible to talk about the expense of a comprehensive system without properly taking into account the implicit costs of the current system; huge financial and emotional burdens on families, family break down, unfulfilled potential, huge inequities. A colleague once suggested to me that this random huge burden on some families could be compared to funding the national budget by randomly plucking individuals off the street and selling them into slavery. Huge acute costs on some so the majority pay a little less. This is not the way a modern, civilised society should operate.

Further queries?

Life is busy and this submission has been put together somewhat rapidly, but I am happy to elaborate on any of the points or answer questions if required.