"WELL SAID RASAID!"

Submission to the Productivity Commission by
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For far too many years, Disability Dollars have not been used to actually help people with disabilities or their families. The majority of the Disability Dollars never reach the coal front. They are syphoned off by the '**Disability Industry'**. This industry re-invents the wheel on a daily basis all over Australia. There are conferences, investigations and jaunts where the same thing is discussed over and over again. Many of us are hoping that this Productivity Commission Inquiry will redirect these monies directly to people with disabilities, where it is surely destined.

Disability Dollars are being spent pushing philosophies instead of delivering services.
The Disability Industry provides research, conferences, round-tables, discussion papers, philosophies, jaunts & junkets. What do they achieve? They do not achieve anything new; they simply discuss the issues and put out new papers around these same issues. philosophies and thoughts.

What right to they have to spend millions of dollars every year on conference after
conference where they convince each other that 'they are doing a great job'?

Here is a letter written by a fellow carer and friend, Estelle Shields to NDS (National
Disability Services) in December 2008. I think it says it all:

Dear Gabrielle,
I seem to write to National Disability Services each year to point out to you that there seems to be no shortage of funds for junkets and jaunts like the conference at the Menzies in February and another at the Grand Chancellor in Hobart. If you were to drop in on one of your conferences without knowing something of disability in Australia, you would be convinced that we have a thriving disability industry and that all is well. You would see the gathering of "senior government representatives, politicians, academics and advocates" and you would listen to the rhetoric around "Quality service environments that grow from strength to strength" and "responsive and innovative disability services" and "the singular goal of enhancing the lives of people with a disability and their carers and families". You would no doubt find that many of the chardonnay/coffee-sipping
delegates actually believe the hype. You will find no-one to challenge or contradict any statements made because the "carers and families" will not have been invited and they will have no representatives to speak for them. Although these are the people who do more than 97% of all the care and accommodation for people with a disability in this state, they will not have a voice at your conference because they will not be invited. If they are alluded to at all, it will be in some passing reference to "unmet

need" or "ageing carers", but this will not dampen the theme of the conference, which will be how well we are doing, how far we have come, going from "strength to strength" and more self-congratulations.

Make no mistake about it, none of it reflects how things really are. We have carers in their seventies, eighties and yes, nineties, who have been begging for supported accommodation for decades. We have a whole generation of people with a disability who may never know the independence that leaving home brings.

We have families with dual citizenship who leave to access services in other countries that we have never heard of here. We have workers in the field who come from overseas and exclaim with horror that we are decades behind in service provision in this country. We have successive governments who turn their backs on us and say it's all too hard. We have carers who are afraid to die because there is nowhere in this whole rich and lucky country for their family member to go. We have families who live in chronic poverty because they have never been able to work. We have other families who have never had a holiday, because getting respite is like winning the lottery. Other countries have legislated rights for their disabled citizens that we don't even know exist.
The reason for this dire state of affairs is that the people who live this life twenty four hours a day, that is, the families with disabled members, have no voice, no say in any forum or policy decision and no representation.

We have to look to organisations such as NDS and what do we get? We get "industry conferences" which are so expensive that the cost is not publicised. We get delegates to those conferences who use disability dollars to attend. We get a gathering of people convincing each other that the sector is flourishing, things are improving, they are all doing an essential job and everything is rosy.

Well, don't kid yourselves. The disability service sector in this country is a national disgrace, an outrage and the cause of the greatest shame. It sits together with our other great shames, the treatment of our indigenous and our refugees. The only difference is that in these cases, there are groups of outspoken people working to raise awareness of the plight of these peoples. In our case, we have NDS and they and their members have a "head-in-the-sand" approach, so the community at large never even hears of our distress, our despair and our overwhelming need. How many people with a disability in Australia could achieve supported accommodation for the cost of your conferences, I wonder?
Yours sincerely
Estelle Shields
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When we hear of another Disability Conference funded through the ‘Disability Industry’ which claims to look at the needs of carers and people with disabilities, we shudder.

We have a saying amongst the many Carers I know. Put simply it is: “About us - Without us!” Again… There is a lot riding on this Productivity Commission Inquiry. The future lives of so many people depend on the outcome. We need an NDIS. We need to know that there is some provision for people with disabilities, their families & carers. It won't happen soon enough to help us but it must happen. Disability Services in Australia are third world standard and all the politicians know this. The problem is that it is so big an issue, so devastating an issue that they simply do not know where to start, so they don't, they run for cover.

The second issue I must speak of is Accountability. It seems to me (and many, many other carers) that our governments are afraid of knowing just how many people with disabilities are in desperate need. For if they knew, they may have to address this need. There are no lists of people in need of supported accommodation. If there are no lists, there can be no accountability. There must be accountability.

Families of people with disabilities in desperate need of support are ignored or tossed from pillar to post. If only we knew that there was some provision for our precious children, if we knew that there was suitable supported accommodation for them when we can no longer care, then we would be able to continue to care for as long as possible.

As things stand, there is almost no provision of care for our sons and daughters; provision is minimal, the places that the governments talk of are given to others.

Children coming from DoCs and those leaving the juvenile justice system. They too need this assistance, but it seems that their needs are addressed and there is nothing left for the families who have reached crisis point. The so called *places* are allocated elsewhere.

We are left with one option; we must relinquish our children to the state. This is the only way we will find supported accommodation for them. This is not always suitable accommodation either. The Advocacy groups tell us to do this and if we don't follow their directive, they say sorry we can no longer help you and they walk away. This is the way it is for us.

I have relinquished care of my son. I did this to save his life. I had no other choice. If only someone in both the State and Federal government could take a deep breath and actually listen to the families, find out just what is happening in the real world, our world. Both of these governments must become accountable for people with disabilities and their families. People are in fact dying for lack of care. Families are desperate; their lives are horrendous as they battle just to get through another day. Please do not continue to close your eyes, let us speak, let us tell you how many of us there are. We need help not blinkers!

What the UK government said in their early edition of " Valuing People": *"People with learning disabilities [intellectual or multiple disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. Valuing People sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities."*

LISA Comment: We are yet to see a similar commitment from Australian governments, although Bill Shorten is doing well to educate and motivate the bureaucrats.

Nevertheless, we see mostly strategies on how government departments can avoid doing anything but build bigger bureaucracies. And buy, not manage their way.

We see departments buying external agency services because department management are unable set, monitor and maintain direct care staff work values to provide quality of life care within staff job descriptions and departmental care policies, standards and values.

So it's not funding, it's attitude! Without work and outcome expectations being set, monitored and maintained, more funding means more lore, bureaucrats and bureaucratic attitudes.

Yet most parents seek only to depart this world in peace and reassurance their family member, with so little in their life, will receive consistent and meaningful quality of life care.

For most with an intellectual or multiple disability, this is quite simple care - Certainly not rocket science! Just commonsense interaction, developmental and social activities by direct care staff who treat the residents like their second family.

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