

Submission
No 29

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

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Partially Confidential

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Submission by Lyn

Carer / mother of aged 32 with multiple disabilities including ID, epilepsy, autism
& mental health issues

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 Inquiry will assist to redirect these monies directly to people with disabilities, where it is surely destined.

Firstly; Let us look at the Disability Industry. Here are my thoughts on this:

Disability Dollars are being spent pushing philosophies instead of delivering services. The Disability Industry provides research, conferences, roundtables, 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 do 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, to NDS (National Disability Services) in . I think it says it all:

Dear

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 organizations such as NDS and what do we get? We get "industry conferences" which are so expensive that the cost is not publicized. 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?

One more time I will ask you. Read my email out at both of your conferences.

Yours Sincerely

Estelle

(Reproduced with permission)

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 Inquiry. The future lives of so many people depend on the outcome. Disability Services in this state are third world standard and all the politicians and bureaucrats 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 Adhc is afraid of actually admitting to the massive level of unmet need. They do not keep a 'register of need'. They do not want to know nor do they want it known. For if they admitted to this knowledge, they may have to actually address the 'unmet 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 and almost nonexistent, the '*places*' that they 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.

Note: A '*place*' can be an hour of '*drop in*' support each day, or it may be in supported accommodation with anything up to 24 hour supervision. The latter is extremely hard to get and the former is more the norm. We know of several men with severe cognitive disabilities who function at or around the mental age of 5 years. Alarming, these men only receive an hour or to of drop in support. They are very much at risk and we fear for their health and safety.

Also bear in mind that some of the providers of this '*drop in*' support have problems and often don't turn up at all. I have heard of this happening regularly in many situations.

So what can we do? We are left with one option; we are told that we must relinquish our children to the care of 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.

The system is crisis driven. Not planned in an orderly fashion giving consideration to the families or their sons and daughters with disabilities. The results are heartbreaking and devastating to say the least. This usually happens when a parent, often the mother dies. The person with disabilities will then lose everything: Their family, their home, their friends, their workplace and their community. This will happen in one foul swoop as they will be whisked away to a respite unit and possibly moved around for a period of time and then, when a group home is eventually found, it will surely be a long way from everything and everybody that they have known and trusted throughout their lives. The sad thing is that Adhc will have known of these situations for years. If only we could plan and ensure our children our housed and safe – close to home and their existing networks. If we could do this before we die? This is what we want. This is what our children deserve.

I have relinquished care of my son. I did this to save his life. I had no other choice.

If only the Adhc bureaucrats could take a deep breath and actually listen to the families, find out just what is happening in the real world, our world. They 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 and ears, let us speak, let us tell you how many of us there are.

We need help not blinkers.

Regards Lyn