SUBMISSION TO THE PRODUCTIVITY COMMISSION
Disability Care and Support Enquiry
Colin and Rosemary Iversen

We are parents of a 19 year old young man with cerebral palsy.
Andrew has severe disabilities

COMMENT
Andrew is now 19 years old and has cerebral palsy. Andrew is confined to a wheelchair, and

- cannot communicate using normal language
- cannot walk unaided
- cannot get up or go to bed without assistance
- cannot dress himself
- cannot shower himself without assistance
- requires assistance with all toileting functions
- often requires assistance with feeding and drinking
- has only gross motor movements with his left hand

In other words Andrew needs 24 hour care. He currently attends an adult day centre, five days a week, with some weeks at home for “holidays”. Andrew also receives a once a month 3 night period in respite care.

OBSERVATION
Parents with children with such severe difficulties have faced and continue to face an unequal burden in terms of the provision of a suitable quality of life for both themselves and their families as well as the disabled person him or her self. Whilst this primarily focuses on the disabled child there have been on our case, and we understand in many other cases, profound impacts upon other siblings.

COMMENT
My wife and I are both in our 50’s, and the burden Andrew will increasingly present is of considerable concern to us. Andrew needs to be placed in a fulltime home care situation, with other similarly or less disabled persons, with carer staff. He is increasingly difficult to maneuver in all situations when movement in and out of the wheelchair is required, and this is becoming a physical and psychological burden on us both. We are also aware that Andrew needs to have a secure and appropriate place of residence in the event of one or both of us passing away or no longer being able to care for him during to illness. We are aware that often in these circumstances young disabled adults are placed in old peoples homes or hospital beds, which is no place to situate a young person, which for all his disabilities, maintains a lively interest in what goes on around him.

OBSERVATION
As we, his parents, reach the end of our working lives, decisions about where Andrew can be satisfactorily placed and his needs met are an increasing concern to us, and to others like us. We are only too aware of the appalling situation so many parents find themselves in, caring for middle aged sons and daughters whilst in their sixties, seventies and eighties, restricted in what they can, lacking flexibility in the twilight years

of their lives, and often financially drained. The pensions provided in no way compensate for the difficulties experienced and the ongoing associated costs, and are certainly insufficient to provide much care. Note that we are paying $37 per hour to have someone look after Andrew after he returns from the Day Centre whilst we are both at work. Unfortunately Andrew cannot let himself in and cannot be left alone.

Of equal concern are the myriad stories we hear of young people being placed in hospitals and aged care facilities when parents are unable to care for them. We are also aware of demands made on parents to relinquish all rights with respect to their child when placed in such facilities, with restrictions placed on decisions about care decisions, medications, visiting hours and entertainment / education options. In such cases parents are treated by members of the relevant bureaucracy, as little more than a nuisance to be avoided and excluded at all costs. Although we need, albeit desperately, to have our children looked after, this is not a sign that we wish or want to exclude ourselves from involvement in their lives. Sadly others often think otherwise,

COMMENT
We are also aware that State and Federal systems have been aware of Andrew’s predicament since not long after his birth, and that for all this time we have heard about the concept of “unmet need”, to the point where it almost seems to be a piece of jargon, to which no-one pays much attention. Unfortunately we do not have the funds or ability to arrange permanent away from home care for Andrew.

OBSERVATION
It is extraordinary that State and Federal governments have known about our children and their disabilities since shortly after their birth, but have taken no steps to consider that in 20 years or so these children will need support and that it is unfair to expect their parents to provide this once they have reached adulthood. The question is when are State and Federal governments going to start forward planning to ensure that for instance, children born in 2010 with severe disabilities, will have supported accommodation places with all the necessary support in 2030. Centrelink and government in the 2 states in which we have lived have both known about Andrew in one way or another all his life. Yet we are faced with indefinite waits for accommodation (admission/acknowledgement to us by the Victorian DHS). In reality there is little chance of Andrew ever getting the required accommodation, and most parents do not have the resources to provide this, as resourcing goes well beyond simply providing the actual physical place. All this is not rocket science: really just plain common sense, of which git seems governments have remarkable little.

COMMENT
People like Andrew cannot speak for themselves, and therefore require others to speak on his behalf. We therefore that the Productivity Commission makes recommendations on what can be done by the State / Federal governments to meet their responsibility in caring for those at most need in our community, people with disabilities. We note with interest how in the current debate there has been a huge emphasis on providing for the health system and for the elderly, and whilst we applaud such measures, we ponder on why nothing is ever said about the fate and future of young people like Andrew, and the

parents, who are currently their primary carers, and many of whom are much older than we are, and who are still caring for their profoundly disabled children***. Perhaps it is because those in politics know that the majority of these people cannot vote, and therefore it is convenient to ignore their plight.***

OBSERVATION

It is our experience that government is driven primarily by financial/ bottom line concerns and its concern for people with profound disabilities is but superficial. We see this in the kinds of questions asked by Centrelink in one size fits all assessment documents that are an insult to parents of young people with profound disabilities: such as when will the person affected start work: after 6, 12, 18 or 24 months. Young people like Andrew will never work, and for government bodies to design assessment questionnaires like this is appalling. It is also our experience that most of what we have found out about the rights of people with profound disabilities has been through the experience of others. It seems on the face of it that State and Federal departments deliberately hide or protect information so that the financial costs can be deferred for as long as possible. There is little or no providing an open and easily accessible interface of information for families burdened by children with profound disabilities. It is our direct experience that there is little or no transfer of information between sections of Centrelink when children move from under 16 to over 16, yet in most cases nothing changes, and certainly in the case of severely disabled children with cerebral palsy nothing will ever change, yet Centrelink thinks it appropriate to re-assess the child in every aspect, including the potential ability to work!!

I also attach the following comments drawn from others involved in this debate, and heartily endorse them. They make the essential points as or more elegantly than I can. Additionally, and most importantly, they reflect our own experience.

FROM JEAN TOPS, Gippsland Carers Association

In Gippsland there are more than 176 adult people on the endless wait list for cared accommodation services. Across Victoria the figure is almost 3,000. Over 13,600 Victorian people with care needs and aged over 37 years still live with aged parents; parents who are too afraid to die because sons and daughters will have nowhere else to live. Across Australia the story is the same, Mrs Tops said.

The extraordinary burden this places on ageing parent carers and struggling families is well documented. Everyone knows there is a crisis, but our political leaders ignore the facts and do nothing.

FROM Lyn Allen, Parent, and Vice President of RASAID Inc., NSW

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
(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 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.

COLIN and ROSEMARY IVERSEN