

**SUBMISSION TO THE HOUSE OF
REPRESENTATIVES INQUIRY INTO BETTER
SUPPORT FOR CARERS.**

July 3rd 2008.

Summary and priority strategies.

(to the tune of 'A Policeman's Life' from the Pirates of Penzance by Gilbert & Sullivan and
with apologies to both.)

When a carer's not engaged in her careemployment,
her careemployment.

When she's not a-hanging washing on the line,
She loves to earn a little bit of money,
bit of money
and have a social life a little of the time.

When a respite funding comes in for the quarter
She loves to lie a basking in the sun,
in the sun.

Ahh take one consideration with another,
with another
A carer's life is not an appy one.

Priority Strategies.

PRIORITY STRATEGY 1

Create a system where the carers of people with severe and profound disability who wish to work in paid employment can have a carer come to their home and look after their 'caree' at the times when they are working and the 'caree' has nowhere else to go.

PRIORITY STRATEGY 2.

That the Community Participation Programmes be required to provide a socially useful life skills programme on a 5 day per week 6-7 hour per day basis, especially in regional areas.

PRIORITY STRATEGY 3.

That funding be specially assigned for the employment of people with severe and profound disability.

Further that this funding not based upon their deemed economic productiveness but their right to contribute and participate in their community in a socially useful way. That this funding be focused in regional areas to small not for profit community organisations who buy virtue of their size and familiarity in their community can provide individually tailored programmes.

PRIORITY STRATEGY 4

Humanise Centrelink. Allow them to take a holistic and gentler approach to the lives of families who care for people with moderate, severe or profound disability. Treat such families with the respect and dignity they deserve. Empathy training for Centrelink staff. Identified workers in each office who can be approached by and work with Carers. And

Put all the chairs back so that my son can sit down while I wait in the queue this will benefit everyone as I wont have to chase him through the open plan office and Centrelink workers wont be startled.

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TO SET THE SCENE.

Its 9.30pm on July 3rd and I'm having an early night. I've thought a number of times over the last two weeks that I should write something for the Inquiry but I'm so tired, tired, tired that the thought of putting anything on paper is overwhelming. But I'll do it anyway!!!!

I'm 53 years old and have been a single Mum for nearly 12 years to my two children. They rarely see their father who has provided little or no financial or other support over the time since he left. I live in regional Australia and from a carer's perspective it's very different to living in a city.

My son Edward has severe autism, is non verbal, 17 years old and 6' 2".

Last Tuesday while putting on Edward's socks I thought I would suggest that the Committee begin by dressing each other's feet - putting on each other's socks and shoes- This is such a small thing but it is physically hard, has to be done every day and in my case if the socks don't match can be extremely emotionally draining. All facets of a carer's life.

(People with autism rely on constancy and routine to make sense of the world and socks which don't match can be the beginning of a disorienting and distressing day. Luckily I found another pair! Kept for just such a situation.)

POVERTY or DOLLARS AND SENSE.

No one can live on the carer's pension. So let's stop kidding ourselves about that.

Stop making it so hard for the carers who want to work to do so.

Change the mindset at Centrelink that makes them presuppose that carers have the primary aim of ripping off the system.

Increase the carers pension to a living wage level so that the financial strain, which is the most debilitating of all the burdens a carer carries is removed.

On a brighter note I received my \$1,000 bonus payment (earmarked to pay some outstanding bills) this week and for the first time in a very long time I did our grocery shopping without having to add the total up in my head before I reached the checkout – it was like an overseas holiday!

I didn't spend any of it but just knowing it was there and I wouldn't be caught short was luxury.

Life is financially precarious for many people at the moment but this combined with the constancy of caring for my son and the bleakness of our future when he leaves school makes life very much harder for us. This is one, but only one, of the reasons why I make the effort of being in paid employment.

When Edward leaves school it looks like I will have to give up paid employment because of the reduction in hours available to him in the local Community Participation Programme. (see Sailing to the edge of the world and into oblivion).

As a working carer the ultimate irony is that I earn less than the paid carer's who look after my son

because my hours are limited to school hours,
because there is no form of care for him when he is not at school and I am working,
because my income is limited by Centrelink's punitive and self perpetuating approach to working carers.

**OILS AINT JUST OILS! Sol. or
Working is not just about the money.**

PRIORITY STRATEGY 1

Create a system where the carers of people with severe and profound disability who wish to work in paid employment can have a carer come to their home and look after their 'caree' at the times when they are working and the 'caree' has nowhere else to go.

I have been in paid employment of one sort work or another since I was sixteen. Paid employment was and is a key element of my identity as a person.

*Paid work is essential for me as a carer in maintaining my own 'mental elf'.

*I am a better carer for my son if I have the opportunity to use my mind, energy and skills in the wider community.

*I have a right to society's acknowledgement of me as a valued and productive individual who is so much MORE than the primary carer for my son.

*When I am at work I am not just Edward's mother and carer.

When my son was diagnosed at age 3 I was working part time and had just submitted my PhD application. I gave up paid work and was granted leave to withdraw my PhD candidature.

I devoted myself to providing the extra support and care that both my children needed to survive in the world faced with this enormous challenge.

As well as the usual early intervention (not the great 'cure all' it's currently made out to be) and medical interventions and hospital visits etc I held voluntary positions on a number of community organisations involved with disability.

Without the voluntary work of parents and carers many of these small but extremely effective organisations would fold and their services would be lost. This is especially the case in regional centres.

When my son was 10 years old I began to think about some form of paid work and found that most of the work skills I had developed over my working life were no longer in demand and no one was interested in employing, on a paid basis, a forty something single woman with two kids one of whom had a disability and acted strange.

I worked voluntarily for a few community organisations and eventually gained a part time paid job with one of them.

This money meant that while we still lived below the poverty line (Henderson') we could afford a few things and I could pay the outstanding bills such as Council rates which had been slowly accumulating.

This job was mostly during school hours and when it was not my son was cared for by my teenage daughter (during school holidays and between 3.00pm and 5.00pm two afternoons per week.). This situation broke my heart but it was the only way I could keep my job and the money (then \$19.70 per hour) it brought in.

The respite care available to me – approximately 6 – 8 hours per month depending on what time of day I use it is not supposed to be used to allow me to go to work. My son's age, now, and disability exclude him from holiday care programmes and

As a result my daughter still carries the burden of school holiday care and out of school hours care. And it still breaks my heart. This sorrow on top of all the others is the hardest to bear.

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The skill one develops by being a carer would be of exceptional advantage to most employers. The ability to think creatively and outside the square, extremely good problem solving skills, dogged determination, and patience in the face of rigid stupidity would be useful in most areas of employment – not to mention finely tuned ability in form completion and submission writing.!

What employer wouldn't want a member of staff who was indefatigable in getting their work done, who could multi task as naturally as breathing and with experience of successfully operating within the smallest budget known to man.

FAR FROM THE MADDING CROWD.

Living in regional Australia has many advantages but is extremely difficult for carers of people with disabilities.

There is a cruel lack of competition in the provision of things like Community Participation programmes and we are placed in the position of taking what is offered or nothing. People in Sydney can access more than one programme if they feel inclined or finding an alternative is easier if it only a train ride away.

Supported accommodation is at crisis point. In our town someone has to die at present before a place becomes available.

Inquiries don't visit regional areas so you miss out on the personal touch of seeing us and hearing our voices and those of our children. I note that this inquiry has listed only capital cities on its website.

Come to visit me and I'll make you all lunch.

CRIME, PUNISHMENT AND THE PENSION.

Can anything be done to change the mindset of Centrelink and the amount of paper and proving that one has to go through. The hoops through which I had

to jump to apply for Edward's 16 year old disability pension and the doctor's reports and proofs of identity bordered on the farcical. Especially, since he has been on Centrelink's books as a child with severe disability since he was 2 years old and had lived in the same town at the same address for all his life.

The mere fact that I had to be put onto NEWSTART and forced to search for full time employment (had I found any I would have had to resign my part – time job), despite my caring responsibilities not having changed for the three months it took to process Edward's pension (you're not allowed to apply before your child turns 16) was beyond my belief and understanding and made me very angry and fearful.

PRIORITY STRATEGY 4.

Humanise Centrelink. Allow them to take a holistic and gentler approach to the lives of families who care for people with moderate, severe or profound disability. Treat such families with the respect and dignity they deserve. Empathy training for Centrelink staff. Identified workers in each office who can be approached by and work with Carers. And

Put all the chairs back so that my son can sit down while I wait in the queue this will benefit everyone as I wont have to chase him through the open plan office and Centrelink workers wont be startled.

SAILING TOWARDS THE EDGE OF THE EARTH AND INTO OBLIVION.

Or "What I'm going to do when I leave school"

PRIORITY 3.

That funding be specially assigned for the employment of people with severe and profound disability. Further that this funding not based upon their deemed economic productiveness but their right to contribute and participate in their community in a socially useful way. That this funding be focused in regional areas to small not for profit community organisations who buy virtue of their size and familiarity in their community can provide individually tailored programmes.

PRIORITY STRATEGY 2.

That the Community Participation Programmes be required to provide a socially useful life skills programme on a 5 day per week 6-7 hour per day basis, especially in regional areas.

In a little over a year my son will leave school.

I have been advised that he will be only eligible for the 'Community Participation' programme and although his disability is categorised as severe will probably be funded for a maximum of two and a half days a week the rest of the week he will be at home with me FOR THE REST OF HIS LIFE.

As this programme currently operates he can expect with other clients to visit the local library once a fortnight and possibly borrow a book, to buy groceries for a meal once a week, to have morning or afternoon tea with his paid carers once or twice a fortnight in summer there may be swimming but this is often cancelled if there are no male staff to assist with dressing etc.

This is not "Participating"! This is patronising and boring.

The rest of the time he can expect to spend in a rented house watching television or playing computer games.

Could the parent who wants this for their child as a life plan please stand up? A disturbing and destructive distinction has recently developed between those who have mild or moderate disability and those in the severe and profound ranges.

At least in my town the only option now for people with severe or profound disability is the in aptly named 'Community Participation Programme'. This is run by only one organisation with no competition and a focus on expanding its size rather than tailoring its services to the individual needs of their 'clients'. This has now reduced the programme to one of largely 'babysitting' people with severe or profound disability between the hours of 9.00am and 3.00pm. (shorter than school hours).

People with mild to moderate disability at least get the offer of some form of supported employment.

To the best of my reckoning the problem set in when the former Howard Government insisted that a supported employment enterprise had to demonstrate its profitability before attracting Federal funding. I am not sure of the details of this measure but do know that many of the old so called 'sheltered workshops /employment situations have closed down and their workers are now in Community Participation Programmes because they are not productive enough.

A measure of a society's level of civilisation is the way in which it treats its most vulnerable members.

To our everlasting shame we now have people who are denied work because they are deemed in dollar terms to be 'not productive enough'.

What would George Orwell make of this level of economic rationalism?

The long and short of it for me is that my son wont even get the chance to have any sort of work paid or voluntary and the sense of social identity and belonging to his community which work brings. – Not happy Jan!!!

His only option at the moment is a Community Participation Programme run by one very large and impersonal organisation which determines its own fees and if we don't like what they offer we can lump it.

THE END

Thank you for this opportunity to tell some of my story and I beg you on bended knee if your inquiry does nothing else pleas let it adequately and appropriately fund Community Participation Programmes so that I don't have to give up the work I love so much, and have fought so hard to keep, when my son leaves school.
