

Submission to Parliamentary Inquiry – Better Care for our Carers.

Thank you for the opportunity to contribute to this much needed and overdue Parliamentary Inquiry.

I am a full time Carer for our severely disabled adult son, and have been in this role for over 20 years. I identify with all points this Inquiry will investigate, and hope that my experience in the caring role for such a long time can add to your knowledge of the issues we face on a daily basis. I shall address the terms of reference one at a time.

RECOGNITION OF THE ROLE AND CONTRIBUTION OF CARERS IN OUR SOCIETY.

We are a unique group of people, who do what we do either because of necessity, or because we choose to, or a mixture of both. For me, it is a bit of both.

Fear of possible negative outcomes if our son lives in a situation outside of our family home are based on incidences that have occurred in the past while our son has been in State run respite care. He has been given another person's medication, been injured by other stronger and more boisterous support receivers, and attended one respite center where a person receiving support drowned in the bath because not enough staff were engaged to ensure the safety of all young people. This does not fill a parent with enough confidence to make the choice to place their child into a situation that may not provide the safety, love and joy that the family home provides.

The lack of funding for alternative residential accommodation makes the choices few and far between anyway, so there is the necessity part of the equation. There are never enough to go around. We therefore choose to have our son remain in our home, where we know he is safe and warm and not being abused. There is no risk that we will have to live with the guilt of making a choice that does not have a good outcome for our son – something I could never forgive myself for.

We work day in and day out, but we're not seen as workers. We save society a 'bucket load' of money, but are never thanked for that. We are the hidden army, as we have neither the time and energy nor the money to participate in society to any great extent, so we are unnoticed and easily ignored.

I feel that the Government's attitude towards Carers has a huge impact on how Carers are perceived by society at large. We're treated by Government as Welfare recipients -as Pensioners – even though a large percentage of us are nowhere near Pension age. The Carer Payment (which used to be called the Carer Pension – the words might have changed, but the concept hasn't) is incomprehensibly linked to the Aged Pension, as if somehow we are the same group of people. And yet we are mostly families with children to educate, jobs to attend and a lives still to unfold. We're not Pensioners – that is a huge misunderstanding, and a huge obstacle to how support is delivered to us. Whilst we are evaluated under the same rules and conditions as Pensioners, we will never be seen as a sector of society with an entirely unique set of needs, requiring a unique plan of support. We're not at the end of our lives – even if some days it feels like we are - we're families

in the process of trying to build our lives, raise children and acquire assets we will need later on in life.

The other financial assistance available to us is the Carer Allowance – again a name that demonstrates the sad and ill conceived perception of the support we require.

Government needs to more clearly recognize Carers as important and distinctly unique members of our society by treating them as such – we are the only ‘welfare recipients’ that work 7 days a week for our small token and in the process save society a huge amount of money. We’re not unemployed, we’re not aged, and we’re not disabled ourselves. There will always be people in our society that through no fault of their own, or even their parents, will need extra help to survive and thrive in the modern world. Government needs to recognize that, and to acknowledge that Carers are their partners in providing assistance to those who need it.

Supporting that recognition with the full physical and financial support needed to ensure that Carers do not themselves become disadvantaged whilst helping Government to care for others is a necessary commitment that Government needs to make. When you make other people aware of the real cost of care and the comparison to the paltry assistance you receive for your caring work, they are shocked, and the words ‘slave labour’ are nearly always expressed.

If you treat Carers as welfare recipients and give us peanuts, society only sees us as worthless monkeys. An important element of Carer Recognition is to publicly acknowledge the huge contribution to Society Carers make – a saving of some \$30 billion per annum, and to see that a far larger part of that saving is returned to us in the form of support.

In summary, a change in attitude towards Carers at a Government level is needed. Total reform of the way financial and physical support is delivered to us so that we are no longer ‘welfare recipients’ with all the stigma that is attached to that, but partners who carry out critical work for Government in a cost – effective way. Until then I don’t believe we will truly feel that we are valued members of society at large.

THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS, WITH PARTICULAR FOCUS ON HELPING CARERS TO FIND AND/OR RETAIN EMPLOYMENT.

These are two separate issues which interact with each other but which need to be dealt with individually.

BARRIERS TO SOCIAL PARTICIPATION

There are nothing but barriers.

Financially – few of us can even think of having a social life. There is no money left in the kitty for such fantasies. Even a drive in the country is more than many can cope with as petrol prices continue to rise to unthinkable levels. It is enough to struggle to serve up three good meals a day cooked at home without considering the price of a luxurious take –away or a meal in a restaurant. Children’s sporting interests have to be carefully considered – and often denied, as the budget just doesn’t support entry fees, uniforms, lessons or whatever else is needed.

Then there's the car – many of us have aging vehicles that we cannot afford to run around unnecessarily, because they have to last for many, many years. We can't entertain the idea of a new one. Much of the running around we do is for the person we care for, but there is no assistance for that – we have to bear those costs and the wear and tear ourselves, worrying where we will find the funds for repairs or a new (secondhand) car if the one we have fails.

If you have a wheelchair or another mobility device to consider, then there is the issue of loading and unloading that which is physically taxing, and just extra work. You don't even consider going out without the person you care for – there is no support available to allow you to do that – so wherever you go, so does the wheelchair. When I go shopping I have to push the wheelchair and pull my shopping trolley. There's no one to help me, and it is just a way of life. My son enjoys his outings to the shops, so it is a nice day out for him, but a burdensome one for me.

Sadly, the total isolation we tend to live in prevents us from making and keeping acquaintances. We just don't get the chance to socialize and make friends, and our lives are so misunderstood and feared by people outside the disability sector that they tend to keep a distance, and not visit.

Holidays, I have just found may also remain just a dream. My husband and I have never had a holiday, and had the chance to take one in September this year. I have spent the past two weeks looking for respite for our son so that we can take our first holiday in 31 years. The Commonwealth Carelink Centre did some shopping around on our account, and found a centre run by a large organization. It sounded like it would offer the right sort of care for someone as disabled as our son, - until today when we got their quote. For 9 nights, the quote was \$7,222.33. Because he is wheelchair bound they have to employ an extra staff member, and the price doubles. How ironic – I have to lift my son several times a day every day, and I just cry when I think how much I receive in contrast to the outrageous cost of formal care. Of course the holiday is off – we cannot afford it.

FINDING AND/OR RETAINING EMPLOYMENT.

Too many barriers here to comprehend as well

. I have been working for the past 10 months, just 2 days a week. I have grown in self confidence and enjoy my life as someone other than a Carer. The difficulties I am faced with however mean that my working life will probably be unfairly short.

When I first applied for the position I now have, it was a full time position. I desperately wanted to work full time, as I had been forced into my Caring role over 20 years ago, and had missed the financial benefits and mental stimulation that working had provided. I also wanted to be free of the continual and insulting personal probing that Carers are subjected to if they receive a payment from Centrelink. The major issue which concerned me however, was the lack of superannuation I had after 20 odd years of full time caring. My husband's contributions leave us far behind the average.

I tried desperately for 6 months to obtain some support for my son in the family home so that I could work and he could remain living with us. Letters to the Minister for Disabilities in Queensland were eventually met with a resounding NO – there was not

even one hour of support that I could access, so I was a prisoner in the system. Why would Government pay someone a real wage to look after my son so that I could gain some dignity from paid employment, when if they kept me where I was, they could continue to get the same/better level of care for a few cents per hour?

This is the dilemma we face. Government likes to pretend that we CHOOSE to be Carers, but the reality is that we are caught up in a terrible situation which requires us to take drastic and sometimes devastating action to free ourselves from.

I was eventually offered a part time position by the employer, on two days when my son attends a local respite centre. If my son is ill I cannot attend work as I have not been able to find anyone who will look after him in the home, and he is not allowed to attend respite if he is ill. On those days, I just lose my income.

Recently the Federal Government stated that people on \$150,000- per annum were 'hardly rich'. Why then does the Carer Payment run out when the family income level reaches \$63,000-? When other 'welfare' payments are available to people earning such high levels of income, it hardly seems just to prohibit a couple from earning more than \$63,000- when one member of that couple is in forced unemployment. This is a grossly unfair situation.

As previously stated, we are often young families, who have the same level of financial commitment as others. We do not get much financial support, and that stops at an unreasonably low level of income. And yet, to think about getting a job to help the family cope financially is fraught with constant stress and worry. You are at the mercy of available funding and access to facilities, which can be taken away from you at any time. There is no back up available, no emergency support, nothing.

Two weeks ago the only Service Provider in my area advised me that they will not be able to support my son on the two days I work as at 1st July 2009. I was left with the worry and stress of having to find another service provider – an impossible task- or give up my job. With just two weeks before the change is to take effect, my situation is still not resolved, and in honesty, after waiting 20 years to find a job, I will choose to keep my job rather than have to stay home in isolation to provide unpaid care for my son.

I have also become aware that the original Post School Services package of \$16,000- per annum that my son receives is now almost worthless. As the cost of formal care has increased over the years, the value of his package has failed to keep pace. Whereas that sum originally provided for 2.5 days a week of individual support, it now barely provides for 2 days of support in a cheaper group setting, and only one day of individual support. Even if I did find another Service Provider, the funding my son receives will not cover the cost if I cannot find a group setting, so that I can continue to work. The amount I earn for my two days would be eaten up if I had to pay for the extra day, making it a worthless exercise.

How is this situation allowed to happen? Why must Carers live with such worry and uncertainty about their own future? It is surely a violation of our Human Rights to expect us to just put aside our own lives because Government has not invested sufficiently in the needs of the less able in society. One has to be wealthy and have an army of readily available support personnel to afford the luxury of a disabled sibling or child in the current situation.

Another stress factor in working is trying to keep within Centrelink's rigid and aggressively controlled regulations. If you have been able to find work within the strict

25 hour per week limitations set by Legislation, you have extra reporting to contend with on top of with the already demeaning and intrusive reporting you are put through on a constant basis receiving a Carer Payment involves.

Even if all Carers received the full Carer payment and Carer Allowance they would hardly be overpaid for the contribution their work provides for the community. Neither of these payments should be means tested – and a great deal of stress would be lifted from Carers shoulders. If Carers do choose to work, every effort should be made to ensure that their needs are met, and that their decision to work does not entail more stress than their caring role already brings with it.

PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS INCLUDING KEY PRIORITIES FOR ACTION.

Physical support

In home support for Carers who wish to work, which fits with their needs. Not just those over 65 – a ridiculous minimum age cutoff to qualify for the ‘working Carers support funding’ -can’t imagine there are too many in that category – but ALL Carers.

Realistic and affordable respite that Carers can afford to pay. They get paid a pittance for doing the same job, so can hardly be expected to afford the ridiculous rates charged.

A commitment from Government Departments to uphold their own Charter of service standards, by not cutting services to people who rely on them, but guaranteeing the ongoing support so that Carers have some certainty in their lives

Real people in Government departments who understand and care about the hurdles we face. We are too often left to face them alone, because the work load is too great for your contact in Government, or they just don’t care enough to help you. We cannot do it alone – the job is just too hard. Often there is no one to turn to, and the impact on your mental state is unbearably large.

Respite that you don’t have to book many months in advance so you can have some spontaneity in your life.

Equitable amount of support to be provided to people in regional and rural areas as those who reside in urban areas.

Financial support

I do not believe the current method of providing financial support to Carers is fair. It certainly fails to reflect the true value of the work Carers do. I feel the current method of providing support reflects Government’s failure to recognize the unique needs of Carers and their families, and their value. The system treats Carers as ‘welfare recipients’, and fails to acknowledge that they actually work for the financial support they receive. The system strips Carers of their dignity and privacy. If a Carer’s partner works, the caring

role does not decrease, but the level of financial support for that Carer does, so Carers and their families are disadvantaged.

It needs to be a priority that the financial support for Carers be equitable, and not subject to the stringent rules that currently exist. Non means tested Carer payments would relieve some of the stresses of trying to comply with the complex rules and regulations that dealing with Centrelink entails, and would also lead to all Carers being supported in a more equitable manner.

The financial support given to Carers needs to realistically represent the true cost of caring. Anything less will always leave families struggling to deal with the financial pressures of life for the whole of their lives. This is discriminatory and an unfair price for a family to have to pay for something they did not bring on themselves.

STRATEGIES TO ASSIST CARERS TO ACCESS THE SAME RANGE OF OPPORTUNITIES AND CHOICES AS THE WIDER COMMUNITY, INCLUDING STRATEGIES TO INCREASE THE CAPACITY FOR CARERS TO MAKE CHOICES WITHIN THEIR CARING ROLES, TRANSITION INTO AND OUT OF CARING, AND EFFECTIVELY PLAN FOR THE FUTURE.

When salary sacrificed income is factored in to assessment of income for Carer Payment in July 2009, Carers will once again be left without the opportunity to put some funds away for their future. After years of being told we had to start to be responsible for supporting ourselves in retirement, and encouraged and rewarded for doing so, we're now being punished. I will have to make a choice between giving up the care of my son and leaving my employment, as the main incentive for me putting extra pressure on myself and the family unit will have been taken from me. This is counter productive, and a disincentive to Carers to remain in paid employment, and to continue their Caring role. What Carers need is for Government to acknowledge once again that the unique set of circumstances that surround Carers, require a different approach to the other groups they are thrown in with when policy changes such as this are made. Employment is not always an option for Carers, and even when it is it may be too difficult for them to continue. Are they to go into their later years as poor as they have been forced to live their earlier years?

I have not had the chance to put funds away for retirement for two decades, so am way behind the rest of the country in terms of my ability to survive old age. My husband, who has always been employed, receives a modest income of \$32,000, and his contributions are nowhere near the recommended amounts for people of our age. The Carer Payment I receive is already means tested against my husband's income and now my own income, reducing my Carer Payment to \$80- a week for the 5 days I look after my son, and the morning and evening care on the days I work. He is wheelchair bound, has no speech,

needs to be bathed, dressed and have all his needs catered for. A bargain for the Government, but hardly morally just.

During the past 10 months, we have taken the opportunity to contribute extra funds to Superannuation in the form of Salary Sacrificing. This was the main financial issue I wished to address with my employment. From 1 July 2009, we will no longer be able to take advantage of this opportunity to fill the gap left in our Superannuation by 20 years of unpaid caring without having the small amount of Carer Payment I receive either reduced to virtually nothing or cut completely. For the small amount of Payment I will receive it will not be worth the added stress of having to deal with Centrelink and I will give up caring for my son so that I can keep working and actually reap some benefits from my efforts – such as communicating with other human beings, and feeling valued.

A Carer is often out of the workforce for decades, and may find it impossible to return to work if their caring role comes to an end. A person with no skills, and who also has not had the chance to accumulate savings because they have been forced to live in poverty on 'welfare' will certainly not be in a position to transition gently out of their caring role. I cannot respond beyond this to this particular term of reference, as it implies that we have choices in our caring role, and about when and how we transition out of it. That just isn't true. We are captive in our role, unless we have the courage to do what many are forced to do – abandon their child because they can no longer go on without support and without choices.

As a final expression of my experience of life as a Carer, I would like to summarize the past three weeks of my life.

The three week period started with a phone call to say that in 5 weeks the Support Association which has managed my son's small Post School Support package for the past 9 years would no longer be supporting him on the two days I work, as at the 1st July 2008. I was already very upset that I was going to be deprived of the opportunity to contribute to a superannuation fund for my own retirement, and that once again my chance to improve my future was taken from me. I had heard this good news only a week or so prior.

Since then I have spent days on end on the phone to the Office of the Minister for Disabilities, without anyone wanting to hear my concerns, or do anything about them, Disability Services Queensland – who appointed a Support Facilitator – we didn't have one before that, the Association that is withdrawing support, and other Associations. No one was at all concerned that both Disability Services Queensland and the support association had known of this development since at the latest October 2007, but had chosen to wait until the 11th hour to advise those who would be affected. On Tuesday and Thursday I went to work.

I was sent a form to update my son's very, very, very old but current application for an Adult Lifestyle Support Package, which I filled out and returned to Disability Services Queensland. No one can tell me when the next review of this funding is – it seems to be a secret that no one knows the answer to, and no one wants to find out. It may be tomorrow – it may be next year. I don't know and no one can tell me.

The next week I had to send away mine and my husband's pay slips for the past 3 months to Centrelink – in case I had lied to them and had stolen from the Government when I

received my \$80- a week Carer Payment. This is the second time in 5 months I have had to go through this demeaning and insulting process.

I still spent every day on the phone, talking to anyone who could point me in the direction of help. I made an appointment to meet with a representative from a service based 100klm away to see if they could assist me. No one in Disability Services Queensland had any other ideas.

I received a review form from Centrelink for my son's Mobility Allowance – they come every year. I filled it out, and had a representative from the support association do up a letter to accompany the form, and it was posted off. I received the offer of a lifetime for a holiday, but did not get excited as it probably wouldn't happen. I started to look for respite for my son – 3 months in advance of the holiday time in the hopes that we might be able to organize something. I rang Centrelink to inquire if they had finished sifting through my pay slips as they don't have the courtesy to advise you – you have to ring them.

My husband and I attended a meeting with the hierarchy of the Support Association to see what could be done to resolve the 'situation' as they called it which now existed with me wanting to work, and them no longer wanting to support my son (and 6 other families). We found out that the package that had once purchased 2.5 days a week of support now would only fund 1 day of individualized support. Another blow to the prospects of finding another solution to my dilemma.

I went to work on Tuesday and Thursday.

This week I continued the phone calls. I met with a representative from another support association. They could only offer 1 day a week from my son's current package, and that did not include mileage.

I received the quote of \$7,222.33 for 9 nights respite for my son so that my husband and I can take a holiday, so that is the end of that wonderful dream.

I received another Mobility Allowance review from Centrelink. They did not receive the other one – or so they say, and I have 2 weeks to get the whole thing done again or the Allowance will be cut.

I went to work on Tuesday and Thursday. I don't know if I will be able to go to work in 2 weeks time, nothing is resolved, and everyone in Disability Services Queensland and the Minister's Office have put the matter completely out of their mind.

I am tired, sad, fed up and ready to do something drastic. I am not a person who matters in this society, and I cannot take it any longer. All those who know my family have supported my desire to find my own life now, saying that this life is too hard for anyone to bear. Do you realize this is the sort of horrible life we lead? Things have got to change. We have no life, and at age 50 I have completely run out of the push needed to keep on going. If there are no vacancies available for our son in a facility of our choice, I intend to do what so many others are forced to do and abandon the son I love so much. I want my life back, and if it means having to do something drastic to achieve that, then so be it.

Deborah