

Doc 28/7/08
Submission No. 1080
(Inq into better support for carers)



Inquiry into Better Support for Carers

Prepared for: House Standing Committee on Family, Community, Housing & Youth

Prepared by: Gina - parent & carer

Contents: Two (2) Section Report
CarerInquiry PartA.pdf
CarerInquiry PartB.pdf

4 July 2008

INQUIRY INTO BETTER SUPPORT FOR CARERS

what I should have been told five years ago...

We regret to inform you your child has had a disastrous outcome from this illness. He has suffered a severe global hypoxic brain injury. It is a significant brain injury and he will be severely disabled. More importantly I should inform you that henceforth you, as his parents, will also be treated by the bureaucracy, therapists, NGOs etc as though you too have suffered a brain injury.

We will remove your choice in determining the best option of care for your child and ensure you have no choice in how your child's needs can best be met. Your intelligence, concerns, demands, rationale and requests will be constantly questioned as being unrealistic and/or selfish.

In Australia we will ensure the easiest path is that of a 'non inclusive' lifestyle on the fringe of mainstream society for carers and people with a disability - as you would imagine, anything else is too costly and too difficult for the multi-level, multi faceted, non synchronised, fragmented services for the State/Territory and Federal governments to manage.

Furthermore you should no longer refer to yourselves as parents. We will remove that joyous notion and 'rite of passage' as we would prefer to have you labelled 'carers'. While we acknowledge you are simply 'parents' of a child with additional needs this may infer some responsibility on us the Government, and also the broader community, to adequately address those needs to ensure your child has an 'inclusive life' for the duration of his life.

With you in the 'formal caring role' we are able to push the responsibilities of care and inclusivity back to you - we will call it "Community Based Person Centred Care" (CBPCC). Please be assured though, we will limit your choices in how to best provide CBPCC for your child and you will be required to provide information to us on a regular basis, on a multitude of forms which we will not put on a centralised database, so you will need to provide this same information to every government department repeatedly and often.

Mr and Mrs some history for you... CBPCC came about as a result of significant financial hardship at both State and Federal levels of Govt - we needed to make budget cuts so an opportunity was seized to de-institutionalise the most marginalised members of society - the disabled and frail and, let's face it, their accommodation model (institutions) was costing us a fortune and there were 'rumblings' there had been a great disservice done to some of these people. It was the perfect opportunity... "what a success" we proclaimed - a society without devalued constituents.

Unfortunately as it came from a 'financial based' decision rather than truly being a social choice we overlooked some of the ramifications of such a decision. Most importantly we removed CHOICE and failed to recognise the needs of those we had now charged with the CARE of the now (supposedly) VALUED people with a disability or illness.

While all the above may seem "over the top" it is the reality of what we have experienced in the last five years. That being said I thank you for the opportunity to provide you with my views on how we as a nation can DO BETTER in looking after and recognising carers and the enormous role they are tasked with.

My feedback comes from the viewpoint of the parent of a five year old boy with severe multiple disabilities. While I have tried to think more broadly than just our situation, I do not have a real understanding of what is important for the young carers in our society, the adult child caring for their aged parents or the spouse caring for a partner and therefore ask you take that into consideration when reading my submission.

Caring for my son in the current climate of red-tape, crazy rules, government inefficiencies, ill informed therapists is difficult, but the true role of caring for him and being his Mum is not hard.

I have to soon start the "begging process" for a wheelchair which should be an automatic right, then I have to try and fathom how to get a wheelchair into the vehicles we own. I find those decisions stressful and hard, I don't find him needing a wheelchair hard.

I find balancing his need for therapy and my need to work to pay for his therapy hard, I don't find his therapy hard.

I find the additional (and sometimes exorbitant) cost of the 'extra' things just to bring him to an equal level with his 'able bodied peers' hard.

I find it hard to accept that the Governments think this is OK.

I find it hard to accept that people want to put limitations on my child.

I find it hard when they tell me not to strive for him having an independent life. I want both him and us to have the opportunity for some form of independence when and if the time is right.

I find it hard to accept that access to most things is a drama.

But, I don't think Governments should pay for everything. There should be normal child rearing costs we are all responsible for. For example...

I don't agree that an 18yo boy on tube fed formula at \$150 odd dollars a month is a problem, I am sure this is a 'huge' saving to what an able bodied/non disabled 18yo boy would 'devour' from the grocery shopping. But it is the other costs that should be covered so that this item isn't "the straw that breaks the camel's back".

The new Rudd Government in their first budget deemed there needed to be a 100% increase in the threshold for the Private Health incentive scheme. It is only appropriate that the same percentage increase be applied to the threshold for the Carer Payment which would take the income test to approximately \$130K. This along with tax deductibility of items and the implementation of some of my other suggestions would just about bring us back to a level playing field.

All I ask for is choice and realistic, sensible policy.

As a parent of a child with significant, multiple disabilities I don't want to be pitied – that would be disrespectful to my wonderful son who has fought so hard to survive against the odds.

My life isn't hard the red-tape is.

Yours sincerely

Gina

cc: Mrs Joanna Gash, Federal Member for Gilmore

1. The role and contribution of carers in society and how this should be recognised.

Recognising Carers

1.1 ACTION

Firstly acknowledgement should be given to carers that their role is real and not taken for granted – the best way to do this is to actually ACT on this inquiry. Carers are tired of being asked for input, into Government inquiry after inquiry – we are the people with the least amount of time yet arguably, the greatest need. The new Rudd Government needs to acknowledge the role and contribution of carers by taking the findings seriously and putting sensible plans into actions without delay. An example of the Rudd Governments reluctance to actually do the right thing by Carers can be evidenced by the outcomes of the previous Government's review into the Carer Payment not being implemented by Mr Rudd until July 2009 and there being a subsequent 12 month gap between the Carer Adjustment Payment ending and the new Carer Payment Rules commencing.

1.2 REGISTRATION

If you are a carer you should be "registered" with an appropriate government body as such. You should be issued with an official Carer Card which will provide access relevant services (eg if you are providing care for a child who satisfies Carer Payment Rulings due to the severity of their condition you should be eligible to the maximum Carer services regardless of whether you satisfy the means testing requirement to actually receive the payment. The information regarding our 'caring role' should be centralised on a database and accessed by all relevant departments without the need for repetition of information. For those moving in and out of Temporary Caring Roles this should be recognised and recorded appropriately eg in the instance of siblings sharing the care for ageing parents, all may be recognised as 'registered carers' with only one at any given time being recognised as the CURRENT carer. This can change from time to time based on circumstance. In this instance the list of carers should be on the card similar to the Medicare numbering system. Any updating of information should be able to be undertaken electronically once the initial registration of carers has been made.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

1.3 AN APOLOGY

The Government should apologise and acknowledge the current system came about by 'budgetary stealth' not as a result of greater social recognition and change. They have let down the most valuable members of society – carers - who don't stand up to fight, because they are simply too busy and too tired to protest. Carers save the Government millions if not billions every year – but at what cost to them personally. It is not appropriate to 'sentence families to lives of second-class citizens' simply as a result of the "lottery of life" dealing them a 'bad hand'.

The upside is that the Government "got lucky" and there is social benefit to the de-institutionalisation as the 'norm' for people with disabilities or ill health. But, there should still be the choice for this type of option for those who seek it. Aged Care Facilities, the "Young Care" model of nursing homes, campus style accessible housing options for young (or old) people, group homes, independent living models, accommodation within the family home etc are all valid and viable forms of accommodation. Most importantly all these options offer CHOICE – all must be available. Carers need to know there are appropriate options available for the person they care for when they can no longer do so, or that person chooses a greater level of independence from the carer.

1.4 REMOVE MOBILITY & ACCESS COSTS FROM THE CARING ROLE – ACCESS IS A RIGHT

Appropriate compensation and financial assistance should be provided to carers based on the level of care they provide. For example children under 16 with a profound physical disability should receive a Mobility/Access allowance separate to the carer allowance and/or payment. This should NOT be means tested and should be, at a minimum, at the level of the Carer Payment. Accessible toys, equipment, technology etc is exorbitantly expensive – there needs to be compensation to cover this to allow this child an "ordinary" childhood experience.

The Government should also look at ways to reduce the costs to families for these items. Currently it would be cheaper to have a parent and child pay to fly to the USA, purchase a power wheelchair and fly home than to purchase the same chair here in Australia – this is a crazy system where businesses have been allowed to profiteer off those requiring these needs. The advocacy groups, organisations (eg Spastic Centre, NSW) and other representative groups have allowed this to perpetuate rather than truly looking after their clients and forcing prices down. Why have these organisations not campaigned for every power toy to come already 'switch adapted' in the manufacturing phase rather than expect parents to pay a premium of approximately \$100 per toy to have it adapted for special needs switching. The components at manufacturing stage likely cost less than \$1.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

1.5 **CENTRALISATION**

It is frustrating when you know that your State Government doesn't value Carers as much as another State. The management of Carers, Disability Services etc must be centralised under the Federal Government to ensure equality to all Carers. The States play political games with Disability & Carer Services, we are pawns in their folly – they use us as leverage for money from the Federal Government, then they mismanage the funds by providing poor service, wastage and doubling up of services. Enough is enough. We need to be taken seriously, cut out the inefficient middle level of Government and prove the Rudd Government is serious about providing better support for carers.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

2. **The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment**

Social Participation

2.1 THE GREAT DISABILITY EPIDEMIC

The greatest disability in Australia today isn't physical or medical – it is social - the greatest barrier to people with a disability and their carers is ACCESS. Put simply, if you are caring for someone with a physical disability then both of you are restricted in where you can go and what you can do. There is both a physical access barrier and a significant cost barrier in being able to have true accessibility and an inclusive life in Australia today.

2.2 BANNING STEPS? ARE YOU CRAZY...

Until such time as Australia (the so called Clever Country) can design and/or at least source a fully accessible stair climbing, kerb jumping, all terrain mobility option then building codes need to be changed to discourage the use of steps/stairs in any building. It sounds outrageous, but this is the major hurdle to access everywhere. Every council should be made to ensure EVERY new building (even domestic homes) has a pre-approved ramping option for single story homes that can be installed without additional DA applications at any time. Every two storey home must contain an area with a removable floor on the second (and above) storey to allow for the installation of a domestic lift in the most cost efficient manner. The Government could then source and install these options to allow people to stay in their homes regardless of any physical disability as with this method the home was designed to allow for complete accessibility at the planning stage when/if needed with minimal cost and disruption.

2.3 AFFORDABLE VEHICLES FOR CARERS

Vehicles providing for Wheelchair Access are extremely expensive. There are some innovative products hitting the market and the Government needs to embrace these eg Carony Car Seat/Wheelchair combinations. Families need to be provided assistance in the purchase of these vehicles (\$50K+) and modifications (at approx \$35K) need to be provided to those who require them. Options for families caring for people with physical disabilities could include:

- Interest Free Loans for the purchase of vehicles requiring modifications.
- State Government Exemption from Stamp Duty for Carers not just a disabled driver
- State Government Exemption from Registration costs for accessible vehicles
- Fuel rebates for families requiring to drive accessible vehicles and/or supply of gas or green conversions to assist with fuel costs.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

- Federal Government to introduce Innovation Incentives for the development of accessibility options
- Allow importing of pre-modified vehicles from overseas.
- Provision of an accessible vehicle to the physically disabled person. Eg once our son reaches driving age he would then be eligible to receive an accessible vehicle registered to him that is used for his transportation by his parents, family, friends, peers, driver, aide, carer, respite worker etc. The type of vehicle could be in the form of a small car eg Honda Jazz with the Carony seat/chair adaptation or a VW Caddy style van with ramping and wheelchair tie-downs. An electronic log book would be ideal to ensure any driving infringements are sent to the appropriate driver at the time. This is freedom and empowerment of the individual and relief for carers from the constancy of care as their young child reaches adulthood – regardless of the severity of the disability.

Economic Participation

2.4 FIND AND/OR RETAIN EMPLOYMENT

Employers need to be encouraged to engage carers. The truth is we are not the most desirable employees as we have this constant underlying risk that the person we care for will require intensive caring at some point. We might need to be away from work for extended periods of time if they are unwell or we are unable to get back up care.

Some schemes that may assist in increasing the 'attractiveness' for employers to put on a 'registered carer' are:

2.4.1 Carer Fixed Term Leave

A scheme similar to legislated Maternity Leave whereby 'registered carers' can apply for leave from their employer for a fixed term with the confidence their job will be kept open for them on their return.

2.4.2 Temp Staff Backup

A scheme whereby the Government subsidises the employer for costs incurred in securing temporary staffing for up to four weeks per annum to cover off additional time a carer may require in order to fulfil their caring duties. This would mean a standard industry could offer a carer four weeks annual leave & six weeks personal leave as part of their employment conditions without the employer being "worse off" for employing a registered carer.

2.4.3 Exemption From Payroll Tax

Exemption from State Government Payroll Tax (NSW is an example) in the calculation of wages for the employment of 'registered carers' means those business close reaching the threshold requiring them to pay Payroll Tax may consider employing a 'registered carer' rather than not employing anyone.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

2.5 ACCESS TO OOSH, LONG DAY CARE, AFTER SCHOOL CARE OPTIONS FOR WORKING CARERS

2.5.1 OOSH Care & After School Care

Greater opportunities for the provision of 'out of school hours' (OOSH) care for school age children with disabilities. Funding for Aides for safe inclusion and transport arrangements to get the child from school to the OOSH care centre is essential or to provide School Holiday Care inclusion. Parents of a disabled school age child should not pay anymore than other families for their child to attend OOSH programs. Any school age child currently requiring aide time must be guaranteed appropriate aide funding at the same rate (eg 100% for child with profound disabilities) for OOSH care if requested. Another option is the choice of a parent to have the OOSH care undertaken in the home by an aide. Financial Assistance should be provided to the family to ensure appropriately trained people can undertake this role which is much more demanding (eg incontinence, mobility, tube feeding, lifting requirements) than the normal 'baby sitting' duties for children without high support needs. Many employment roles cannot be curbed to meet school hours and therefore Carers of children with significant support needs are restricted in their options for Full Time hours as a result of the lack of after school care.

2.5.2 Long Day Care

There should be no limitation placed on the number of hours a child over two can attend Long Day Care if the parent is in paid employment on the days the child attends. Currently if you wish to secure more than five hours at an approved Long Day Care centre you have to seek Federal Minister Approval. This is hardly providing 'equitable' options for the carer or the child with disabilities and places significant restrictions on the carer/parent in their attempts to secure work.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

3. The practical measures required to better support carers, including key priorities for action; and

A Fresh Start

3.1 DEVELOPMENT OF A DISABILITY FRAMEWORK

The Federal Government needs to establish a Disability Framework for the social and economic inclusion and FULL PARTICIPATION of people with disabilities. Until such time as this is achieved then Carers, by the nature of caring for 'excluded citizens', will also remain 'excluded'.

We need to cease 'tinkering' with outdated, poor performing policies and programs we need to have a complete overhaul in the thinking used in developing a framework for Australia.

Marcia H. Rioux PhD in a speech to the World Bank in April 2008 said

"A *disability* framework" provides a lense through which it is possible to evaluate policies, programs and funding initiatives to ensure that they are a coherent whole reflecting the same goals and based on the same assumptions about disability."

Disabilities are the natural diversity of a population – they don't need to be 'normalised' they need to be respected and accepted. The investment into every member of our society to ensure full participation might seem costly – however, the REAL COST of not investing in this group is far greater socially, economically and emotionally.

It costs a lot to "warehouse" disabled people for the entirety of their lives. Imagine if an upfront investment in that person meant they became a social and economic participant, a tax payer, a contributor, a teacher, a student.

What cost to human dignity to only have people engaged in your life because they are paid to be there - your carers, your aides, your therapists, your respite workers. Through investment in the person they stand to develop real friendships, real skills and real value in the community.

3.2 BI-PARTISAN SUPPORT FOR A WAR CABINET ON DISABILITY SERVICES AT THE FEDERAL LEVEL

Jo Gash, Member for Gilmore passed a motion in the lower house earlier this year calling for the bipartisan support for a Federal Disability Service Strategy. Mrs Gash was representing this electorate and I fully support her in this endeavour as it has come about from her listening to us.

3.3 INCLUSION PORTFOLIO – GREATER IMPORTANCE

I acknowledge the Rudd Government has claimed "inclusion" is important to it by having dedicated a ministerial portfolio to the task. The problem is, while Deputy PM Julia Gillard is arguably the most capable member of the Rudd Government, she is also the busiest having two other major portfolios to manage in Education and Workplace Relations. If the Rudd Government is serious about "An Inclusive Society" it must make this a stand alone portfolio with an appropriate Minister who can focus wholly on the task.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

4. 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.

Same opportunities & choices as wider community

4.1 GET SERIOUS ABOUT BEING AN ACCESSIBLE SOCIETY

Remove the concepts of mobility and accessibility from the definition of disability. Provide the person being cared for a mobility allowance and equipment to ensure all their access costs/needs are met. When you restrict the person with the disability – I am sure there are other countries that do this better than us with NZ and the UK just two examples. A young child with no mobility should be provided both a powered source and a manual source with appropriate seating and technology supports to allow empowerment, independence and mobility at a similar age to their non-disabled peers (eg a baby crawls at 6-9 months – a physically disabled child should also be given independent mobility options at the same age). We are teaching them “learned immobility” and restricting their independence by having bureaucrats decided that as carers “we should be grateful” for getting assistance with a manual mobility option by the time they four or five – depending on the waitlists. SMART® Wheelchairs with line following technology or collision sensor technology should be invested in and pursued to allow everyone independence regardless of physical and/or cognitive limitations. Just the notion of not having to be literally “attached” to the wheelchair of the person you are caring for is a liberating ideal for both the carer and the person being ‘cared for’. The technology is there, we just have to embrace it.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

4.2 REMOVE THE FINANCIAL GAP

Disability equipment is expensive as are the pursuit of non-mainstream therapies. When your ability to earn normal income is reduced and you are then trying to find tens of thousands of dollars extra each year to provide for your child with a disability then you really struggle. There has to be a broadening of the items you can claim as tax deductible in relation the provision of care for your child. Currently a therapy has to be 'referred' by a doctor to make it eligible to be claimed for a rebate. There needs to be a Board established to address the ability to claim therapy costs for overseas or non-mainstream therapies. Doctors can't in many cases refer these as they do not know enough about them, nor do they have the inclination to learn about them. A board of experts (broad minded) should be made available to assess a families application for tax deductibility for a therapy not 'referred' by a doctor but being undertaken.

All equipment, educational material, technology options should be 100% tax deductible less any mobility allowance and/or education allowance being fully expended.

If we truly want to allow carers to have the same choices and opportunities as the wider community we need to level the playing field by removing the financial discrepancies in providing care and equipment to a child with a disability or additional support needs.

Carers should be grouped with the "low income earners" when it comes to strategies to provide compensation for pending programs such as the Carbon Emissions Trading Scheme.

4.3 THE SIMPLE ART OF JUST "GETTING AROUND"

Imagine the option of providing anyone caring for a person with physical disabilities the luxury of having the information on where there are ramps, lifts, accessible toilets etc at their fingertips. How to get around the city or town with ease without going from inaccessible dead end to inaccessible dead end - technology is the key. The GPS navigation systems should contain all this information for every town in the country. Until such time as all our streets, shops, buildings are accessible carers (not to mention independent people confined to wheelchairs). A program could be established for the collection and ongoing management of this information for the many school leavers with significant physical impairment for which there are very limited care/work/life options.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

4.4 LIFE AFTER SCHOOL FOR THE CHILD AND THE CARER

Once some of these teenagers/young adults with significant support needs leave school they no longer have options to access a meaningful lifestyle. There are not always work options, appropriate day care options or modified work programs, tertiary education or participation options. So while a carer may have had the opportunity to secure work through their high school years, there is a very real risk this may not be able to continue when they leave school as there may not be any support options available for them. Options need to be made available to everyone. Children are supposed to grow up, leave home, get a job, it is the natural sequence... but when the child has a disability restricting this we need to ensure there are still opportunities for them to achieve this natural sequence if that is their choice.

Carers Choices

4.5 CHOICE OF CARE APPROACH

For too long Disability services have been chopped and changed depending on the minister in control and the advocacy groups manoeuvring for control all the time ignoring those that really need to be consulted – the individuals, the carers and the families haven't had a real say, why, they are too busy just trying to survive the kind of life imposed on them and keep up with all the 'red tape' and form filling required of them by those who think "they know better".

As the parent or carer of our child, we shouldn't lose our rights to choose how to raise our child. Nor should we lose the right to choose the type of medical care, therapy or intellectual programs we might determine are best for our child.

For example, as the parent of a young child with multiple disabilities I don't need respite yet. I need money to try and purchase appropriate equipment, make house modifications to accommodate wheelchairs, hoists, seating systems etc. So for me, an allowance or payment (more than the \$50 per week Carer Allowance) would go a small way in allowing me to meet our present needs. But when my child is older then we may well need a break from one another and then respite would be a need. Our care approaches need to be flexible, dynamic and not bogged down in waiting lists and red tape. We need to be proactive not reactive to a situation. The Government needs to accept we mostly do a good job and make good decisions and they need to support us in our pursuit to provide the best choice of care for our child.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

An example of organisations/therapists wasting our time is the fact my child is incontinent – primarily because he is severely physically compromised and can't even sit unaided. In our region our State PADP won't provide nappies until the child turns five and then I have been told they will supply the equivalent of one per day. There is some other funding available but to be eligible you have to have received a rejection letter from the PADP office, once a formal application is prepared by an appropriate medical professional, then you have to make an appointment with an incontinence nurse to determine that the child really is incontinent and have this confirmed by a Paediatrician by paying for an appointment to have it confirmed, probably you will work with the incont. nurse to determine the best nappy out of the limited supply as clearly you have not been using what works for your child to date, and if you are lucky and there is some charity funding available you might be lucky to get 12 weeks of nappies supplied. Imagine if our son simply received a Nappy Allowance as part of his support package and we used the money towards augmenting our own nappy supply.

This type of 'over complicating' simple needs happens in every aspect of the provision of care.

4.6 FLEXIBLE RESPITE PROGRAMS

There are some good programs around where people are provided flexible respite models. These include the provision of Respite money to be used for the carer for respite, education or self-care needs appropriate to them. They are able to manage how they can use the funds to their and their families benefit. It is simple, straightforward and should be considered on a broader platform. Funds could be used towards gym membership to enable the carer to stay fit, build muscles for the lifetime of lifting ahead of them and generally stay in shape – that is the beauty of flexibility.

4.7 SLUMBER PARTIES

The only type of respite I would have sought in the last five years if there was such a thing is a 'sleep over' respite where I could drop my 'notoriously nocturnal child' off after dinner to an appropriate respite centre knowing he would have a 'night shift carer' one on one (or a greater ratio if manageable) and I would collect him before breakfast the next morning. I would have been able to have a 'luxurious' uninterrupted nights sleep, and he would get to do whatever he wanted sleep or not, for the night. This model could also be used for 'night shift workers' of children without a disability at a higher premium to help subsidise costs and even as a 'baby sitting' option for parents wanting a night out – again at a premium price. Essentially it is an accessible 'long day care centre' for night time.

FEEDBACK ON TERMS OF REFERENCE prepared by Gina

4.8 LUMP SUM PAYMENTS

Mr Rudd spoke of his idea of spreading payments like the \$600 lump sum payment (one off) over the course of a year. This is a bad idea. We struggle to make ends meet as carers and so the act of saving up for the purchase of 'bigger ticket' items is difficult. A lump sum payment helps in this regard and should this type of payment continue, it should remain in its current lump sum format. The other consideration is that when you spread a payment such as this it has ramifications on those people who receive utility/rental/pension assistance based on their 'normal income'. Any small weekly increase to their income, such as Mr Rudd suggested, would not be beneficial to those carers most needing assistance.

4.9 UNDERSTANDING THE COST OF CARE

If I simply relied on the Carer Allowance to try and meet just my wheelchair accessible vehicle and house modification requirements it would take me 46 years to accrue the \$120K I need to save. The Carer Allowance is totally inadequate when put into the realms of equipment/mods for physical impairments. The Government needs to really understand just how much everything costs when providing for physical impairment and look at ways to reduce this burden.

4.10 CENTRELINK – MATCH MAKING FOR MUTUAL BENEFIT

A system to allow greater community engagement for the Carer, the person being cared for and a whole different group is to open up a scheme whereby Registered Carers can access volunteers from the pool of citizens on specific programs through Centrelink who have to undertake a certain number of hours paid employment or volunteer work. For this type of program to work, the carer has to be able to 'vet' the potential volunteers with Centrelink providing an accessible tool to manage details of those who wish to be considered for that role. I should only be on a volunteer basis by both parties. Volunteers would need to be covered by workers comp/public liability provided by Centrelink insurance so the Carer can have them covered appropriately to undertake duties.

Planning for the Future

4.11 **INSURANCE: WHAT HAPPENS IF SOMETHING HAPPENS TO THE CARER?**

The government should assist carers with the purchase of appropriate life and permanent disability insurance in today's financial environment \$1 million could provide an income of close to \$50K per annum which should help in providing the replacement cost of part time care in the home. This could be done in a number of ways.

- OPTION ONE:

Once you are a registered carer you could become eligible for full tax deductibility of Life/ Permanent Disability Insurance in your Annual Tax Return – just as Income Protection Insurance is tax deductible, this type of insurance should be deductible for registered carers (it could be pro-rated based on the percentage of care you provide).

- OPTION TWO:

The Government pay for Carer Life/Perm Disability for coverage up to \$1 million per carer (in the case of parents of children – both parents) for registered carers. The Govt should be able to bulk buy and save money.

- OPTION THREE:

The Government bulk buy and make available to carers the option to purchase reduced cost Life/ Permanent Disability Insurance.

4.12 **SUPERANNUATION: RECOGNISE THE IMPORTANT ROLE CARERS PROVIDE VIA SUPERANNUATION**

The Government needs to assist carers with the accrual of Superannuation. A carer out of the workforce has no hope of accruing super and therefore the Government needs to recognise their role and assist in the provision of superannuation.

- OPTION ONE:

Provide Superannuation Guarantee payment equivalent to that of someone earning average weekly wage to those 'Registered Carers' which can be pro-rated depending on the percentage rate of care you are providing.

- OPTION TWO:

Registered Carers receive a minimum "\$2 for \$1" top up by the Government on any voluntary contributions made to their super fund. Eg if a voluntary payment of \$1000 is made the Government will match it with \$2000. It is very scary to consider how an ageing couple would live while still caring for a profoundly disabled adult child when they are unable to contribute to Superannuation.