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(Inq into better support for carers)
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AUSTRALIAN GOVERNMENT STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH

SUBMISSION TO INQUIRY INTO BETTER SUPPORT FOR CARERS

3 JULY 2008

SUBMISSION BY

National Carers Coalition

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Executive Summary -

Inquiry into Better Support for Carers

The term "carer" has become so generic that it is pertinent to define what this submission to the Inquiry into Better Support for Carers refers to when the term "carer" is used.

In general use the word "carer" has evolved to mean virtually anyone who provides care and support to another person, no matter if this support is minor or if this support is so great that it overrides the caregiver's entire existence and leaves little time for any kind of quality for an independent life. Parents and foster parents of able children are all now called carers.

Paid disability, aged care workers and pre-school workers are called carers. We now have animal carers and environmental carers and this generic use of the word 'carer' forces the original carers to call themselves "unpaid family carers" to differentiate themselves.

This submission is about unpaid family carers of people with dependent disabilities.

The term "working families" is another term that is used extensively but it seems to lack quantification. What is a "working family"? The inference is that a working family is a paid working family. Not all working families earn the same pay. Indeed, some do not get paid. Considering the hours of work and the type of work performed Caring families are the hardest "working families" in the community.

The National Carers Coalition has a long record and proud history of highly valuable and credible contributions to government. The principals of the NCC have been involved since as early as 1999 in a number of groundbreaking working groups such as The National Disability Advocacy Review and the National Family Carers Voice Committee.

The National Carers Coalition makes this submission subsequent to submissions previously made to past Senate and Parliamentary inquiries. These submissions include:

- Commonwealth Heads of Government (COAG) submission in November 2005;
- Senate Community Affairs Committee Inquiry into the Funding and Operation of the CSTDA in July 2006;
- The Australian Government Budget Process in January 2008

The National Carers Coalition strongly advocated the increase of carer funding to the Senate Inquiry into the funding and operations of the CSTDA 2006. The Primary Recommendation of that inquiry was for: **'substantially increased funding to be made available by both Australian and state/territory governments'.**

This was entirely consistent with the National Carers Coalition submission and was almost exactly what the NCC submission recommended.

The National Carers Coalition is in constant contact with carers who relate their concerns about their responsibilities and their absence of rights. In contrast to their aged peers, older parent-carers remain responsible for their adult disabled children and the ordinary expected changes of late middle age – retirement and children becoming independent – is not ever going to happen unless supports are put into place that will allow parent carers to retire from the care role.

Most carers live in isolation, poverty and despair. A vast majority of their marriages fail; they have been unable to accumulate assets and the cost of working means they cannot afford to work.

The National Carers Coalition contend that what is abundantly evident from all the research available to government is that unpaid family Carers have - No Legal Rights, No Government Legislated Entitlements, No Family Carer Advocacy and No Voice in Policy and Planning.

The over-arching theme of carers' letters to the NCC is about the failure of Governments and the broader community to appreciate their contributions to the wellbeing of Australian children, adults and elderly citizens who require support and care. The failure of governments and society to recognise and reward families for this work is seen to be both exploitative and abusive.

"One of the key issues to emerge from research is that carers and their families experience high rates of mental health problems. Carers had significantly worse mental health and vitality and higher rates of depression than the general population".

It is clearly evident from the statistics on carers who receive financial remuneration from government via carer payment or carer allowance, that direct financial payment discrimination is a significant contributor to the failing health and wellbeing of family carers.

Australia lags far behind other progressive societies in providing family carers with rights and entitlements. Whilst some state governments have introduced "Carer Recognition Policies" and some state governments have even legislated for Carer Advisory Committees to be formed i.e. Western Australia these are far from uniform across the nation and are completely resisted in states like Victoria.

In contrast, services to support carers throughout the UK are provided by local government. The Carers (Recognition and Services) Act 1995 illustrates the progressive attitudes of UK society and builds on previous legislation that gives carers the right to ask for their own assessment. Legislation in the United Kingdom to Support Carers is articulated on council websites across the UK, Wales and Ireland.

In order to appreciate the growing need to recognise the role of life-long family carers of persons with a dependent disability, we need to take a look at Aged care services and growth patterns as reflected in the size of the demographic and the funding provided for services both out of home and supporting carers of the aged.

The 'rights' and 'entitlements' that family carers of people with dependent disabilities do not equate to those in the Aged care sector.

Ironically Foster families as volunteer carers, have 'rights' and 'entitlements' that family carers can only dream about. Research has shown us that foster carers receive direct payments that are **Means Test Free** and **Tax Exempt**. This indicates a gross form of discrimination against family carers for whom **Carer Payment is Means Tested and Taxable.**

Foster Carers also have access to up to 50 hours of family day care a week and can still do paid work without penalty. Foster carers as volunteers may relinquish care at any time without stigma or penalty. "Foster Care Allowances paid by State and Territory governments do not fall within the test for FBT and CCB purposes, as the ATO does not consider remuneration received by people who are volunteer foster carers to be assessable income" - (The Australian Foster Care Association)

Whilst the payments to foster carers are made by the states it must be clearly understood that Means Testing and Tax Exemption are the province of the Australian government. Family carers have no entitlements to 'Means Test Free' and 'Tax Free' remuneration for doing exactly the same work as foster carers!

The fact is carers of adults with dependent disability are forced through penalties imposed by governments to live in extreme poverty even while earning a reasonable income. How can a wealthy nation justify this? No other familial group is expected to meet the costs of care of an adult for an entire adult lifetime, which is decade after decade of forced care with no provision made for free choice.

If money is earned and care is needed to earn that income this cost of care must be paid for out of the earned taxed income of the carer of the adult requiring care which usually makes working financially unfeasible. There is no ‘pot’ of funding that automatically comes into play to assist working carers. Nor are there tax offsets.

The Means Testing of Carer Payment prevents thousands of full time carers from accessing this benefit because they are recipients of other welfare payments such as age/disability pension or who have a partner who is employed. This makes a mockery of the claim that Carer Payment is a benefit for caring!

A fulltime caregiver of a person with a disability is not eligible to access holiday respite until they are 70 or the person they care for is 65 or more under the Aging Carers Respite Initiative (ACRI). It is irrelevant whether the carers have been caring for 30 years or for 6 months.

How do we understand the paradox of where a 30 year-old carer of an aging parent qualifies, yet a 55 year-old carer of a disabled child does not. If carers are not given timely breaks they risk burn-out. This is partly why carers have such high incidences of depression, physical conditions and illnesses.

It needs to be stated here that in Australia there is **no legislated entitlement** to lifelong and age appropriate supports for people with a disability.

How can we recognise the role carers play in our society if we don’t give carers a funded family advocacy network so that their voices can be heard across all barriers?

We contend that the government has a moral responsibility to ACT NOW to fund a disability family advocacy network to ensure that our most vulnerable citizens and their carers have links to the world outside of the family home where many are imprisoned by a failure to give carers a better and fairer deal.

The NCC is at the forefront of promoting the urgent need for a disability family advocacy network. Our submission to the 2008 Federal budget detailed how it could be implemented and why it was necessary.

There is much rhetoric about the place and role of the carer in our society. There is universal agreement that carers are a most valuable asset to our society but are amongst the most disadvantaged and that they should be accorded the recognition and importance to which they are entitled.

This submission espouses the need for introducing population based benchmark funding. The NCC is at the forefront of the push for population based benchmark funding to be introduced to disability services. Our submission to the Senate CSTDA Inquiry discussed this proposal in detail, including a formula for implementation that mirrors the benchmark funding that has existed in aged care for decades.

Recommendations

That the Committee for Family, Community, Housing and Youth recommends:

1. The Federal Government immediately make funding provision for the implementation of a Disability Family Advocacy Network, commencing with grass roots regional bodies who will nominate their state and federal peak bodies as articulated in our submission addendum.

2. The Federal Government immediately legislate for Carer Rights, including the right to care or not care , the right to Carer Assessments and Entitlement to Support Services.

3. The Federal Government legislate for the introduction and funding of Population Based Benchmark Funding of Disability and Carer Support Services as a matter of **First Order Priority.**

4. The Federal Government immediately legislate to ensure that all full time family carers have access to **means test free** and **income tax exempt** carer payments that will include a cost of care component with no 25 hour work/study/ volunteering rule.

5. The Inquiry by the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs into financial security for carers and seniors make a stand-alone report on financial security for Australia's 2.6 million carers to the Henry Commission Review of Australia's Future Tax System.

6. The Federal Government ensure that service agreement negotiation with the states and territories foster the provision of long day care for older children and adults with dependent disability aged less than 65 years to facilitate paid work opportunity for carers and to relieve the burden of caring on stressed families.

7. That the Federal Government ensure people with dependent disabilities have Legislated entitlements to assessments of need and access to accommodation and support services to meet those needs.

Foreword:

Created, and driven wholly by unpaid family Carers of people with dependent disabilities the unfunded National Carers Coalition (NCC) joins thousands of caring families in the common belief that:

> 'There must be radical reform of caring family support services throughout the nation in order that long suffering families may find relief from unrelenting burdens of care created by an absence of rights, and entitlements and crushing levels of unmet support needs.'

The NCC began with a very public '*Walk a Mile in My Shoes Campaign'* commenced in the second half of 2005. On September 13 of that year hundreds of people participated in the *Walk A Mile in My Shoes* day across the nation. More than 1,400 pairs of worn out shoes were placed on the lawns of parliament house in Canberra and similar demonstrations occurred in Victoria, South Australia, NSW, Queensland and WA where state and regional rallies were held concurrently.

In November 2005 the NCC made an initial submission to the *Commonwealth Heads of Government* (COAG) for an urgent review of the Commonwealth, State and Territory Disability Agreement (CSTDA). This then formed the catalyst for our subsequent Submission to the *Senate Community Affairs Committee Inquiry into the Funding and Operation of the CSTDA* in 2006.

In making this submission, we inform the Australian Government that our struggle to be heard is perpetuated by the absence of any funded disability family advocacy and support service. We most strongly resent this discrimination against caring families of persons with dependent disabilities for whom we provide over 92% of the cared accommodation throughout the nation.

The overwhelming view of families supporting the *Walk a Mile in My Shoes campaign* was a call for a National Carers Network funded by Government at the Regional, State and National Level to give caring families a 'Voice" to government and a place at the policy and planning table on services and support that directly affects their every day lives, thus creating a level playing field with Disability Person Advocacy and Service Provider Peak Advocacy.

In January 2008 the NCC made a further detailed submission for the funding of a disability family advocacy network to the Australian Government Budget Process. Copies of the submission were made available to the Minister for Community Services, Jenny Macklin asking for support. We are yet to receive any response from the Australian Government.

The National Disability Advocacy Review of 1999, the later National Family Carers Voice Committee (set up by the then Minister for Family and Community Services) and the Senate Inquiry into the funding and operations of the Commonwealth, state and territories disability agreement 2006, strongly recommending the funding of Disability Family Advocacy. In 2008, nothing has changed.

Caring families remain isolated without a funded voice or advocacy network. It is against this background and with these limitations that we make this submission.

We seek to 'break the silence' on the exploitation of 2.6 million of Australian families who do not have any rights and who do not receive a fair deal from the Australian Government that owes them a debt it cannot repay.

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CONSTRAINTS ON CARING FAMILY INPUT TO THIS INQUIRY

We welcome the Australian government's initiative in calling this INQUIRY into BETTER SUPPORT FOR CARERS. However we express our deepest concern that the absence of any carer family advocacy or support network for the 1.6million families caring for a person with a dependent disability means that very few caring families will have the opportunity to respond to the inquiry.

This undeniable fact makes the INQUIRY into BETTER SUPPORT FOR CARERS problematic for government in achieving a widely representative carer family response. The very short timelines for submissions to be delivered is problematic for the same reasons. The National Carers Coalition together with its local voluntary networks is making every effort to inform caring families, but we fear that the vast majority of families will not know that they can have a say.

The very short timeline severely impacts the submission capacity of NCC as a voluntary carer network and we therefore beseech your attention to the submissions we have already made on the subject of achieving 'Better Support for Carers' in the form of our:

1. Submission to COAG November 2005 calling for an urgent review of the CSTDA in delivery of effective services to people with disabilities and their unpaid family carers.
2. Submission to the Senate Inquiry into the Funding and Operations of the Commonwealth, State, Territory Disability Agreement (CSTDA) July 2006 from the caring families perspective, with an urgent call for the introduction of population based benchmark funding to relieve burgeoning unmet and under-met need; and
3. Submission to the Australian Budget Process 2008 for funding of a regionally based grass roots Disability Family Advocacy Network.

We attach a copy of our Submission to the Senate Inquiry and our submission for funding of a Disability Family Advocacy Network as addendum to this submission in order that we are not forced to rewrite all the major issues already raised with government in regard to better support for carers and those we care for.

It is critical that the Family and Community Committee understand that "better support for Carers" is also directly linked to better support for the people with dependent disability for whom we care on a daily basis.

We emphasise our concern that although the 29 Recommendations of the Senate CSTDA Final Report articulate a way forward for "Better Support" for the majority of all family Carers, the implementation of those recommendations has not yet occurred. A principal finding of that report was that 'the burden of care on families was crushing and unreasonable.' Moreover, there are clearly matters affecting family care that are not included in the CSTDA Inquiry report and we will seek to articulate those issues here.

In addressing the Terms of Reference (TOR) for this Inquiry then, we ask that you revisit the issues raised in our major submissions 2 and 3 listed above as being absolutely germane to this Inquiry.

Terms of Reference overlap

We make the observation that the terms of reference as set out by the Committee are overlapping in subject matter. The role and contribution of carers, how they should be recognised, barriers to social and economic participation and access to the same range of opportunities as the rest of society are interdependent. The views of carer authors who undertook to address one or more of the TOR to this submission will therefore overlap.

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

The Australian Bureau of Statistics (ABS) Survey of Disability Ageing and Carers (SDAC) defines a 'carer' as *" a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long term conditions, or older persons. This assistance has to be ongoing, or likely to be ongoing, for at least 6 months……. The assistance is for one or more of the following activities: cognition or emotion; communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self care and transport. (p71)*

The role of family carers in society can best be described as an irreplaceable accommodation, care and support system for people with dependent disabilities, handicap or frailty. Irreplaceable not only because of the cost savings to society on out-of-home care, but because families provide the care out of love and commitment, but often out of extreme sacrifice of health, wellbeing and welfare for themselves.

The term 'carer' has become generic to virtually mean anyone who provides care and support to another person, no matter if this support is minor or if this support is so great that it overrides the caregiver's entire existence and leaves little time for any kind of quality for an independent life. Parents and foster parents of able children are all now called carers. Paid disability and aged care workers and pre-school workers are called carers. We now have animal carers and environmental carers and this generic use of the word 'carer' forces the original carers call themselves **unpaid family carers** to differentiate themselves. This submission clearly is about unpaid family carers.

The role of family carers crosses all social and financial classes. The family care role is rarely one taken on by choice; it comes about through circumstance. Parents do not usually want to recognise themselves as carers, nor to be recognised by others as carers, they would prefer to remain either mothers or fathers but because of the low level of care and services that Australian governments commit themselves to funding, the mantle of 'carer' usually settles as their children grow into adults.

Carers of an age-dependent spouse are very different carers, they have had decades of their lives together where they have had opportunity to finance a nest, to have had an adult relationship with the person requiring care and over decades have developed community and family relationships with an extended network of family and friends that belong to this relationship.

In Australia you are more likely to receive supports for yourself because of your age related disability than you are to receive supports, services or an accommodation placement after providing unpaid care for decades for a son or daughter with a lifelong disability.

There is an increasing cohort of aged parent-carers as their adult children with a disability also get older which places a significant strain on the parent-caring relationship. Due to advances in technology people with disabilities now have a similar life expectation as the general populace.

Services to support these adults with dependent disabilities are at best limited and at worst discriminatory when compared to living options available to aged care and the general population.

Research and the carers contributions

Much research is undertaken to describe the depth and breadth of this contribution carers make to the welfare of loved ones who rely upon them for shelter, food, warmth, love, care, protection, inclusion and advocacy. Much is also written about the value of that care and contribution to society and the national budget bottom line.

It is however, worth repeating here the fundamental and basic statistics to bring into focus just how much reliance government and society really places upon family carers to care, and will form the basis for discussion for how carer's contributions should be recognised. The Australian Institute of Health and Welfare (AIHW) utilises the ABS census and SDAC data to produce a number of disability related statistical documents including Australia's Welfare, the latest edition of which was published in 2007. Key relevant statistics from this publication are:

Persons with a disability, handicap or frailty

- 3.9 million Australians experience a disability, handicap or frailty (20% of population)
- 2.6 million were aged under 65 years (15% of population aged under 65)
- 1.3 million people had a severe or profound disability meaning they sometimes or always required help or supervision with self care, mobility or communication
- 590,000 older people have severe or profound disabilities
- 706,600 persons under 65 years old have a severe or profound disability and are calculated as the 'potential population' for funded disability support services.

(Potential population = The number of persons with severe or profound disability that will potentially require CSTDA funded services under the Commonwealth State and Territory Disability Agreement – Minimum Data Set 05-06)

Family Carers

- 2.6 million family members are informal carers representing 13% of all persons living in households and 12.5% when children under 15 years are excluded
- Primary carers (main providers of care) make up 20% or 520,000 of the total number of carers
- The estimated FTE* of informal family carers in 2006 was 1,039,000, or more than double the people employed to provide and support welfare - 481,000 FTE.

(*Full Time Equivalent = paid weekly 40 hrs of work by non managerial employees in caring professions x 48 weeks/year – Australia's Welfare p310)

The Imputed value of unpaid care in 2006 was $41.4 BILLION

Should the reader be ready to dispute the unpaid carer dollar value figures above, here is another simple exercise. Take the 706,000 people with a severe or profound disability aged less than 65 years; as identified by AIHW as 'potential population' for disability accommodation only, and multiply by the average cost of a government funded accommodation support service of a conservative $45,000 per year and the cost saving to taxpayers is $31.7BILLION in disability services alone. It should also be noted that at least 20% of disability services are delivered to persons with a moderate disability who also receive informal care from families.

(The CSTDA Minimum Dataset 2004-05 p9-122:- identifies the number of services users of supported accommodation as living in large residential, small residential, hostel and group home facilities-the total number of users Australia-wide was 15,793. Other accommodation support units were attendant care, in-home support, alternate family placement, and other accommodation support- total users 19,242. The combined total was 35,030 users. Total Australian expenditure for all these accommodation support services was $1,798.8million)

Therefore the average national cost per person for accommodation support was $51,135.

There can be little doubt that the role and contribution of family carers is undervalued, taken for granted, exploited and clearly sidelined by our governments and our society; by all those who should care. The volumes of research speak it loudly and clearly. The AIHW in their Australia's Welfare report 2007 says of carers and their role:

AUSTRALIA'S WELFARE 2007 SAYS:
'The supply of informal carers, and changes in factors affecting this, is a matter of concern to policy makers'

Australia's Welfare 2007 also says:

Informal care for frail older people enables many older people to avoid or delay admission to residential care and supports consumer preferences to remain living in the community. The number of older people with high care needs living in households is growing because of population ageing. Between 1998 and 2003 the older household population with profound or severe limitation who received some form of assistance increased from an estimated 320,300 to 395,300 people (AIHW 2003:Table 3.4; AIHW 2005:Table 4.8). Over the same period, the number of people who received assistance from both formal and informal sources of care or from informal sources only increased from 308,800 to 382,500. At the same time, mature-aged people are being encouraged to increase their labour force participation to counter the anticipated labour shortage resulting from population ageing; and again:

The impact of long-term caring has generally been framed either as a stressor that worsens over time or as a process of adaptation whereby carers accumulate coping skills (Cuskelly 2006). The experience of care giving is multifaceted, with positive and negative aspects, and changes over time as the carer and circumstances change (Rowbotham 2005). In addition, carers bring different personal, financial and social resources to the role. Their experiences, and their desire for formal support services, differ (Cuskelly 2006).

The issues for carers of people with different types of disability have been highlighted by recent work. A review of mental health care in Australia found that the carers of people with psychiatric disability may find their role more demanding due to an ongoing lack of treatment and accommodation services for the person they care for (MHCA 2005).

Carers have articulated the pain and discrimination often:

A Victorian Carer wrote in 2002

"I am the 58 year old single mother of an intellectually and physically disabled 24 year old son who lives at home with me. Today, I stand before you aging rapidly: the memory is over loaded, either that, or early senility has commenced; the body is crumbling; the belief system that told me hope springs eternal is beginning to turn nasty! Before my sons birth, I saw my future being one where one would remain married despite the ups and downs of married life; where one would stop work for a certain time to look after the baby, but at some point resume a stimulating career. I would be in a position to take an annual holiday, to save for the future: for the child's education; weddings; grandchildren etc. Most importantly I could look forward to retirement and the opportunity to engage in the many leisure activities that are offering for our Senior Citizens. Not too unrealistic I would have thought.

Twenty-five years on, I find I have been single for 23 years, living on the poverty line, and the word 'holiday' is something that exists, for me, in the dictionary and travel brochures. I have relatively few friends, as I will not put my son aside for others convenience- and see very little of my family who keep as far away as possible and who give him as wide a berth as allowable at family celebrations such as Christmas"

The giving (contribution) is immense and taken for granted: Parent Carer NSW

"Confused and heartbroken here I sit. Two weeks ago I made a decision that for the sake of my personal health and my family's wellbeing I could no longer care for my almost 11 (big boy) year old son due to his ongoing unpredictable aggression, epilepsy and autism due to Tuberous Sclerosis Complex. Naively I thought there would be a group home somewhere for him to have a controlled and structured environment with all of the emotional attachment. Now he is in a respite centre blocking a bed (the second one blocked)WHAT IS GOING ON???? I love him soooo much and miss him, I see him every Sunday for lunch. I want the very best for him, I am left with no other choice but to have him foster cared for (Life without Barriers), this was the only option DADHC gave me that was even remotely close to what I want for him. I asked for a Group Home and they said that there aren't any available, that they are only being maintained. The ENORMOUS GUILT OF EVERYTHING is almost consuming me. But I know I can't go back now to the way it was for my family."

Until governments implement population based benchmark funding and provide the resources to match, the marginalization of caring families will continue.

The Responsibilities are not matched with Rights or Entitlements

Carers constantly tell us about their responsibilities and their absence or rights. In contrast to their aged peers, older parent-carers remain responsible for their adult disabled children and the typically expected changes of late middle age – retirement and children becoming independent – is not ever going to happen unless supports are put into place that will allow parent carers to retire from the care role. Most live in isolation, poverty and despair. Marriages have often failed, they have been unable to accumulate assets and the cost of working means they cannot afford to work.

The over-arching theme of carers' letters is about a failure to appreciate their contributions to the welfare of Australian children, adults and elderly citizens. The failure of governments and society to recognise and reward families for this work is both exploitative and abusive."

How can we recognise the role carers play in our society if we don't give carers a funded family advocacy network so that their voices can be heard across all barriers?

Elderly Parent Carer NSW

"For one person to have total care and responsibility for the life of another, day in, day out, is just too enormous a task. *Workers usually are only allowed to do an eight-hour shift with a seriously disabled person. Because a mother (usually a mother) is tied by, love and devotion to that person, those who are responsible for these Disability policies, turn a blind eye.* They must be brought to the realization that MOTHERS ARE PEOPLE TOO AND HAVE HUMAN RIGHTS AS WELL. They also turn a blind eye as far as discrimination is concerned. This discrimination covers a very wide field, due to the fact that we unpaid Carers take on total care and responsibility for the health and wellbeing of the disabled person. Government imposed "Rights For The Disabled" are gravely impinging on almost every right of the primary Carer....rights which most people take for granted. It has been shown that the caring role adversely affects the health *of* the primary Carer. This alone should be a concern of the Government who force people into this role.... There is a great deal of anger out here and many of us are simply slaving away day after day wondering when some-one is going to take up the cause of the plight of the Carer. We do not have the time, money or energy to do anything about it. Thank you and God bless your efforts on our behalf'.

There is an increasing cohort of aged parent-carers as their adult children with a disability also get older, which places a significant strain on the parent-caring relationship.

Aged carer Country Victoria

"Mary(name changed to protect privacy) has a habit of picking at her clothes especially when *she is upset or* worried about something. She doesn't like storms, or heavy rain or wind, In fact I guess you could say she really *worries about the weather, reading* the weather reports first in the paper and watching the sky for signs of rain. On a bad night it is nothing to find 'in the morning that the nightie and Knickers that she wore to bed are totally annihilated. I used to cry as I hung her expensive clothes on the line and realising that they were really only fit for the garage man's ragbag. We've stopped it to a certain extent, but on a night when fierce storms are predicted the family saying has become "Looks like a two-knicker night coming up tonight!"

"We DO worry whether she will ever be lucky enough to get placement in a residential house, Although it isn't a really pressing issue at present as our health is good, but her Dad is 70 and I'm not too many years away from it myself. We would like to see her happily settled somewhere before we pop our clogs, but there are many in much more dire circumstances than us. As well as caring for Mary we have another daughter who is of low intelligence who is in a sometimes violent relationship which has produced several children, Whenever the wheels fall off in that household we are the ones who pick up the pieces, look after the kids and set things as right as they will ever be, so that the kids can have as normal a life as they deserve. We try to provide some sort of stability in their lives- it's the least they deserve.

Also, my mother is 90 years of age. She lives alone in her own home which has become too much for her to cope with, but she stubbornly resists every effort to move her into something more suited to her ability to cope. Therefore we also do for her - shopping, gardening, driving her to doctors etc and checking each day that she is alright. Her sight is going and she is getting quite frail, I feel it won't be too long before she will need to move in with us also. So as you can see -WE ARE still CARING!"

Caring Families are losing hope in a just and fair future

A Western Australian Mum writes:
"How can I give my young family hope for the future of this nation when the Federal Govt. just doesn't care about hundreds of thousands of its people? My heart is breaking when I think of this, not just for our family, and all the other families, but for Australia as a nation. Where did our egalitarian values disappear to?

Celebrating Australia Day becomes a pretty empty celebration... We are not making so much progress as a nation as small children embrace children with disabilities in their school playgrounds and elsewhere? As these children teach their parents and grandparents that people with disabilities are just like them: you know ...they have feelings, dreams, highs and lows, they love and mourn, they enjoy belonging...

Our seven year old daughter says, "Why does that man (or woman, with Down syndrome or some other disability that is readily apparent to her) live with his Mum and Dad? Doesn't he want to be a grown-up?"

Yes, the Government and its deliberate acts of withholding dollars that would enable hundreds of thousands of Australians to live dignified lives is, sadly, a Government that is "unAustralian." Shame, shame on them.

These caring family messages clearly articulate their frustration with a system of government that neither values, nor recognises at law that these families have rights in the same way that paid working families have rights, but alas those rights are not legislated, nor are they considered a "first order priority" for the government, which clearly leaves these matters out of the COAG reform agenda. As this submission will clearly show, there have been countless inquiries, research projects, plans and agenda's, none of which have made a significant difference to family carers because they have not translated into positive action and commitment of resources. [See- Are needs being met -addendum 1]

No natural justice for family carers:

"For families there is no "natural justice" or due process, there is no legislation or union to protect them from malicious complaints (made against the carer). However, it is the secrecy, no requirement for disclosure of complaints received enabling one a defense, that is so reprehensible, and an abuse of that person, by a process designed to protect the vulnerable. Well who is it who is vulnerable? Not only has my 'personal credibility' been destroyed in this process, but my professional integrity has also been impugned, and by people who make a very fine living out of my family's misfortune. These are people who hide behind the dictums of the Government bureaucracy, and policy that is formulated by persons who do not allow for a common sense approach to policy implementation, but expect complete adherence to a rigid and misinformed policy that allows no flexibility" **"**When discussion on the minimum adequate supports required for them to remain in my home failed, the result has been my formal relinquishment of my daughter and son into Government "care". "My daughter and son's lives were turned upside down – they were not going to familiar services with friends, the only family unit they had known no longer existed...... and as for me.... everything I have been for the last 27 years no longer exists". "My heart has been ripped out of me, and my soul destroyed" Single Parent Carer-QLD

In the case of systemic carer abuse as illustrated above, common sense did eventually prevail and this family is reunited, but this incident highlights the absolute necessity to provide family carers with Legislated Rights and Entitlements - if unpaid caring is to remain an option for the future of people with disabilities and frailties.

Carer on-line Quote:
"The sad reality is that most of those we are caring for are unable to advocate for themselves, and it is left to their carers (who often are starved of the energy needed) to continue with their plight for better conditions / support from our welfare system/ politicians.
Let's face it, those in government who are not faced with this hardship, do not lose any sleep over this issue. It's nothing short of a desperate situation for carers and our disabled relatives alike."
Cissy

Recognising carers' role means giving carers legislated Rights and Entitlements

Australia lags far behind in providing family carers with rights and entitlements. Whilst some state governments have introduced "Carer Recognition Policies" and some state governments have even legislated for Carer Advisory Committees to be formed i.e. Western Australia. These are far from uniform across the nation and are completely resisted in states like Victoria. The introduction of the Victorian Disability Bill in 2007, is a classic example of this. After three days of Legislative Council Review of the 'draft bill' and dozens of amendments seeking to have the role of family carers recognised; the state government voted out any reference to family carers, in spite of the fact that the CSTDA specifically names carers as recipients of support services. Only after repeated amendments, the government finally agreed to include recognition of the role of family as a last minute concession.

Australia, has no legislation that gives family carers any Rights' or 'Entitlements.'

The UK and Carer Legislation:

Services to support carers throughout the UK are provided by local government. UK Legislation to Support Carers is articulated on council websites across the UK, Wales and Ireland. One such council, Hartlepool Borough Council has this to say about UK carer legislation:

" In the last few years the Government has increasingly recognised the carer's role by introducing new rights for carers. The Carers (Recognition and Services) Act 1995 built on previous legislation and gives carers the right to ask for their own assessment. However, the right to assessment was qualified by two main factors:

- The carer must be providing "substantial care on a regular basis"
- The person cared for must also have an assessment of need

The Carers and Disabled Children Act 2000 (CDCA) expects agencies to consider the impact on carers' lives of their caring responsibilities. It gives the carer the right to an assessment even when the disabled person refuses an assessment. It also gives parents of children with disabilities the right to request an assessment and empowers local authorities to provide services. Having listened to the carer's view, the Local Authority must take into account the result of the carer's assessment when deciding what services to provide to the person who is being cared for. Many carers are probably still not aware of their right to a separate assessment. However, Department of Health guidance clearly states that local authorities should offer carers the right to a separate confidential interview i.e. it is not incumbent on the carer to ask.

The Carers (Equal Opportunities) Bill received Royal assent on the 22 July 2004 and became an Act of Parliament Under the new law, carers will have to be told about their rights; will have more opportunities for work, education and life-long learning. There should be greater collaboration between statutory services to help carer in their caring roles.

'Our health, Our care, Our say: a new direction for community services'. White Paper January 2006
The White Paper states that 'carers are a vital part of the whole health and social care system - we will give them more support', and proposes to:

- Update and extend the 1999 National Strategy for Carers
- Encourage councils and Primary Care Trusts to nominate leads for carers' services
- Establish an information service/ helpline for carers, perhaps run by a voluntary organisation
- Ensure that short-term, home-based respite support is established for carers in crisis or emergency situations in each council area.

Allocate specific funding for the creation of an Expert Carers Program to provide training for carers to develop the skills they need to take greater control over their own health and the health of those in their care.
[Hartlepool Borough Council UK Updated: 20th March 2007 View pages in this section]

Clearly the role and recognition of carers in Australia must include as a matter of urgency, the introduction of carer rights and entitlements legislation.

Families provide the vast majority of all cared accommodation

More than 93% of all cared accommodation for people with dependent severe or profound disability is provided by families. Unless and until these families are provided with rights and support which match their responsibilities, the future for unpaid caring is bleak indeed.

Family Carers Father Phil - Separated
Phil is a grazier and runs a 55,000 acre property in remote Australia. Phil is divorced. He was married for 26 years but his wife Maree left him 6 years ago. Phil and Maree have two adult children, a son, Aaron who is now 28 and Sophie who is 24. Sophie is married and lives in Melbourne, she has one child and her husband works for a large engineering firm that supplies rural services and equipment.

Aaron still lives on the family property. Aaron is a quadriplegic and Phil is his primary and sole carer. Aaron was severely injured in a single vehicle accident when he was 19. He is entirely dependent on Phil for everything - feeding, bathing and mobility. Maree used to do this while Phil ran the property but she found the burden of care for a young adult male more than she could cope with.

Due to successive years of drought Phil has had less to do on his grazing property and at 57 is considering selling up and moving into town but can't get enough for the property to make it worthwhile, so he will hold on for a few more years. Phil is lucky, his property has reasonably good water and a large part of his river flat is leased to a cotton grower. The income from this lease is the only thing that keeps the property business solvent, otherwise the bank would have moved in years ago.

Aaron's health is variable and he is very susceptible to chest problems. The closest town is 85 km away and the closest doctor is in a town 100 km further away. An appointment needs to be booked 3 to 5 days ahead but this is only because the doctor makes special arrangements for Aaron. Phil takes Aaron to the visiting specialist in the city every 3 months. It is a 700 Km round trip. A couple of times a year they have to travel to the state capital to see other specialists, this is a 3 day 1700 Km round trip.

Apart from visits to the local towns for business and to the city to take Aaron to doctors Phil has only been off the property twice since Aaron came home after his accident. Once was to attend his granddaughter's christening in Melbourne and once to conduct business in the state capital including a visit to a law firm about numerous matters including Aaron's situation.

Aaron's main source of entertainment is satellite TV. He spends most of his day watching TV but he is learning to use a computer with a head pointer. Some parts of a 55,000 acre property are 30 minutes drive away so Phil is unable to work much of the property. He has to ensure he is not too far from the homestead as Aaron is unable to do anything for himself.

Family Carers contributions and governments response

The allocation of increased funding of $1.9 billion over the next four years for disability supported accommodation, respite and other support services represents a mere drop in the ocean of unmet and under-met demand for alternative living options and support for people with dependent disabilities now living with families. Media releases proclaimed the news:

"State and Territory Disability Ministers agreed to deliver $900 million in funding, on top of the Australian Government's $1 billion commitment. The $1.9 billion is expected to provide around 2,300 in-home support places, 2,300 supported accommodation places, 9,900 individual support packages and 10,000 much needed respite places, in a range of forms, across Australia" (Ministerial Media Release 31March 08).

One only has to consider how few people receive a funded service to get some measure of the depth of unmet need:

- Only 5 per cent of people potentially requiring accommodation support get a service - 95 per cent miss out
- Around 13 per cent receive community support – 87 per cent miss out
- Less than 7 per cent have community access funding – 93 per cent miss out

And it is equally bad for respite and employment. *(Source: Table 2.2, AIHW 2007, Disability Support Services 2005-06, national data on services provided under the Commonwealth State/Territory Disability Agreement)*

The Carers Role is compounded by unmet and under-met support services need:

There are currently some 55,000 persons aged over 35 years with a severe or profound dependent disability still living with aged and ageing co-resident parent carers. These persons run the real risk of becoming homeless because the funding increases are failing to cope with even the growth in demand, let alone addressing the outstanding unmet need [customised data ABS/DAC survey 2003]

The number of persons aged 0-64 with severe and profound (S&P) disability is projected to increase to 752,100 (an increase of 34,600) by 2010. (AIHW current & future demand for disability services 2)

But, there are no definitive plans to ensure growth funding to meet this increased demand or the unmet demand that currently exists. Caring families bare the brunt of this abject neglect.

Emily – Primary Carer.
Emily is 35, the mother of three children and lives in a capital city. Karl is her eldest, he is 16. He was born with intellectual and multiple physical disabilities. He has very high support needs. Karl's physical disabilities cause him to have fragile health. He has two younger sisters and they are Rhiannon, 13 and Jacinta who is 7. When Karl was 5 Emily's husband left her when it became apparent how severe Karl's disabilities were and how demanding his care would be.
4 years after her separation Emily had a relationship with Mark who is Jacinta's father. As Karl has grown into a teenager Emily's time has been in higher demand by Karl. Mark had difficulty dealing with his partner being so occupied by her son and he left 2 years ago. Emily has no immediate family nearby and no other supports. She only has a few friends who she sees occasionally. She has no social life.

Emily has been a full time mother and primary carer since Karl's birth. She is not in the paid workforce and the family lives in state owned housing. Emily is devoted to her children and fights tooth and nail for services for her son. She gets a few weeks respite each year. Even then she supervises Karl's respite due to his support needs. On average Karl attends a special school 3 or 4 days a week, depending on his health.

Emily's days start early getting school lunches ready and cleaning the house or starting the washing. At 7am she gets Karl out of bed and bathes him and gets him dressed with clean clothes and a fresh nappy, this takes about an hour. Karl does not weight bear and weighs nearly 70 Kg; this is about 12 Kg more than his mother. Emily gets 4 hours per week of funded support. She takes this support for 1 hour four days per week to assist with bathing and dressing Karl. One day a week she has to do the whole job by herself.

The family sits down to breakfast at 8am and Emily feeds Karl. At 8:30 they all load into the van, a 1986 Toyota Tarago which is badly in need of a service and tyres. Jacinta is dropped at the local primary school and Rhiannon is taken to the High School in the next suburb. Emily then drives Karl to the Special school about 8 km away. At about 9:30 she returns home to clean up after breakfast and continue washing and cleaning.

At 1:30 she leaves home to return to the special school to pick Karl up and take him home. She changes Karl as soon as they get home. The girls get home about an hour later and Rhiannon usually feeds Karl if Emily is busy taking the washing in or doing ironing. Rhiannon also helps with preparing the evening meal.

At 8:30 she changes Karl for the night and puts him into bed. She then gets Jacinta off to bed also. Emily goes to bed exhausted at about 9:00 pm and sets the alarm for midnight. Rhiannon is left to close up and switch the lights off.
Karl's bedroom is adjacent to Emily's. If Karl doesn't first wake Emily then she gets up at midnight and again at 3:30 am to roll and reposition Karl. She may also change his nappy during the night if he is particularly wet. Karl can be very demanding and Emily is often up attending to him at other times throughout the night. Karl often requires suction to clear his airways, particularly in winter.

Emily spends most of her spare time worrying about the girls and how she has little time for them due to Karl's needs. Mercifully she doesn't get much spare time. She survives on an average of 4 hours sleep a night; it all starts again at a quarter to six in the morning.

The Senate CSTDA Inquiry Report Primary Recommendation

The Primary Recommendation of the Senate Inquiry Report into the funding and operations of the CSTDA 2007 was for: **'substantially increased funding to be made available by both Australian and state/territory governments'.** Whilst we acknowledge and welcome the $1.9billion increase in disability funding over the next four years, this can hardly be accepted as 'substantially increased funding.' When the increase in service user numbers as a result of this funding boost is added to those receiving a current service and expressed as a percentage the outlook is bleak for those still waiting for urgent support services.

- there is a 2 per cent increase in the number to get an accommodation support service, so 93 per cent still miss out; and
- there is a 5 per cent increase in the number to get a respite service, so 83 per cent miss out. *(Based on Table 2.2, AIHW 2007, Disability Support Services 2005-06, national data on services provided under the Commonwealth State/Territory Disability Agreement.)*

Considering that the Federal funding is being paid over four years ($124.5 million in 2008-09; $154.4 million in 2009-10; $252.6 million in 2010-11; and $369.7 million in 2011-12) the full complement of relief will not be available for another three years for the fortunate few.
Government acknowledgement that more needs to be done is cold comfort, when there is no appearance of 'more being done' by way of funding commitments, and little transparency around what is being done or planned to be done**.**
Moving the COAG program for people under 50 in residential aged care into the disability sector is akin to putting more deck chairs on the Titanic.

In order to appreciate the growing need to recognise the role of life-long family carers of persons with a dependent disability, we need to take a look at Aged care services and growth patterns as reflected in the size of the demographic and the funding provided for services both out of home and supporting carers of the aged.

Ministerial Media on funding for aged care makes this announcement:

*"Over the next four years, funding for aged and community care will reach record levels of more t**han $40 billion -- with $28.6 billion of that on residential aged care alone**.* The Minister said:
"Caring for our ageing population is one of the major challenges facing our nation this century - and as a Government - we take that responsibility very seriously," Minister for Ageing, Mrs Justine Elliot said. "No government in Australian history will spend more on aged care and community care than this one. We are proud our plans for aged and community care. "This is about planning for Australia's future and the challenges of the 21st century. "We want to ensure that older Australians can live independent lives and age in their homes, but also have the option to enter nursing homes if they need to," Mrs Elliot said. Australians now have the world's fourth longest life expectancy – after the Japanese, the Swiss and Icelanders.

Carers of people with dependent disabilities age less than 65 years may well ask why the same level of support is not forthcoming for aging parent carers and those for whom we care.

Discrimination exists between aged care funding and disability funding.

The comparison between aged care accommodation and support funding, and disability accommodation and support funding is stark. The report on Government services 2008 states:

"In 2007-07, 56.4 per cent of government recurrent expenditure on community services related to aged care services, 29.1 percent related to services for people with a disability, and 14.5 per cent related to protection and support services. These proportions have been fairly consistent from 2002-03 to 2006-07 (F.8)

It is vital that the committee understand that caring contributions by families are impacted heavily by the lack of support services. This is nowhere more evident than the disparity between funding for aged care services and disability services. The gap is wide and growing wider in spite of the current increased funding for disability services as discussed previously. To understand this disparity we need to repeat the statistics on severe or profound disability by age grouping.

- **427,000 persons aged over 65 years.**
- **706,600 persons aged less 15-65 years.**

Current government expenditure on accommodation and support services for each age group 06-07

- **$8.4 billion aged care**
- **$4.3 billion disability care**

(Report of government services 2008 F.8)

Per head of population funding for accommodation and support services of persons with a severe or profound disability in each age cohort:

- **$19,672 aged care**
- **$ 6,085 disability care**

When we compare the government expenditure on these services we can clearly see why it is that the imputed value of family care contributions is now over $41 billion annually. This must change!

Population based benchmark funding- a vital need for continued family caring

The NCC is at the forefront of the push for population based benchmark funding to be introduced to disability services. Our submission to the Senate CSTDA Inquiry discussed this proposal in detail, including a formula for implementation that mirrors the benchmark funding that has existed in aged care for decades.

We acknowledge the Gippsland Carers Association and Margaret Ryan, carer advocate, for their expertise and work in writing the benchmark funding proposal and formula subsequently included in our joint Senate CSTDA submissions.

Population benchmarks have been used to deliver aged care funding for decades and it is our contention that a similar formula can be used to deliver benchmark funding in disability services. The formula simply applies the incidence factor of severe and profound (S&P) disability in both aged care and disability groups utilising ABC SDAC data from the 2003 survey.

The S&P incidence Factor applied to Benchmark funding:

- The over 65 years age incidence rate, S&P is currently 22.5% of the total aged population.
- The 15-64 years age incidence of S&P is relatively static on 3.9% of the total population.

Comparing the over 65 years of age incidence of sever/profound of 22.5% with the 15-64 years incidence of severe/profound of 3.9% we create an incidence ratio of 5.7 / 1. That is 5.7 units or care packages for the 70+ population to every 1 unit or care package for the population age range 15-64. Furthermore, it is a logical step to look at the current planned aged care funding allocation of 108 units/1000 of the population aged 70+ and say this figure equates to 10.8% or approximately half of the severe/profound incidence rate of 22.5%.

This percentage allocation when applied to the people with severe/profound disability gives a benchmark of 18/1000, which becomes 1.8% or approximately half of the severe/profound incidence rate of 3.9% for under 65 year olds. This means that the disability services sector population benchmark should be 18 units of funding/1000 of the population aged 15-64 years.

Figure (i): shows the number of support packages to be applied to disability services utilising the 18/1000 benchmark as described above.

Fig(i). utilising ABS – DAC 2003 population chart-4430.0

Pop 15-64 (a)	% of total population	18 /1000 benchmark for accommodation or support packages
13,273,437 (b)	**67** (c)	**238, 914 places/ packages (rounded)**

(a) calculations based on a 2003 overall population of - 19,811,100 ABS
(b)Severe & Profound incidence rate of 3.9% (c) population aged 15-64 years

The current CSTDA delivers an accommodation support service to just over **33,700** persons. It can be clearly seen therefore that the application of comparative funding benchmarks to disability services would increase the number of recipients by over **205,000** care packages.

Fig (ii) Shows the number of service units with benchmark funding applying a 30% High care, 30% low care accommodation support and 40% community access support package formula and current average funding levels for existing services.

Fig (ii)

18/1000 benchmark of Pop 15-64	30%High Care support packages	30% Low Care Support packages	40% community Support packages	Total Recurrent
*238,900 (rounded)	71,670	71,670	95,560	
High Care $83,000 Per bed/package	$5,948,610,000			
Low Care $45,000 Per bed/package		$3,225,150,000		
Community Care $18,800 per Unit			$1,796,528,000	**$10,970,288,000**

- National average costs for CSTDA funded accommodation support services are as follows: Group homes: $83,098 per service user - congregate and hostels: $74,461 per service user, Community based support: $18,883 per service user (AIHW Minimum Data-set 03-04).

Benchmark funding commitments:

We acknowledge and thank the Rudd government for making the implementation of population benchmark funding for disability services a pre-election policy commitment for the next CSTDA. Labor Policy states:

Reform priorities will include:

- *Better measurement of current and future need for disability services.*
- ***Moving toward national population benchmarks for key disability service types.***
- *Making older carers a priority for all disability services under the CSTDA.*
- *Quality improvement systems based on the National Disability Services Standards for all CSTDA services.*
- *Improved service planning and strategies to simplify access to services.*
- *Focusing on early intervention, life long planning and increasing the independence and social participation of people with disabilities.*

However, we now know that population based benchmark funding has been sidelined by the CSTDA negotiations Ministerial group until at least 2012. Such decisions, which put-off the need to address unmet and under-met needs for support services, can only exacerbate the 'crushing and unreasonable burden' families are subject to.

It is a stark reality that many ageing and over-stressed carers will not survive another four years.

This strategy must only result in further collapse of the health and wellbeing of countless caring families sidelined by government in its 'first step' planning that puts aside the ever increasing problems of family and family carer breakdown.

Much is wrong with the support provided to family carers:

It is a reality that carers are suffering higher levels of stress related illnesses both mental and physical, than the rest of our community. “Carers have significantly worse mental health and vitality and higher rates of depression than the general population” *[xiii The Nature and impact of caring for family members with a disability in Australia- Australian Institute of family studies 2008]*

Carers Tell the real story - Rachael –Primary Carer.

Mother - Married to Brian for 31 years (fewer than 30% of all caring families are two parent families)
Brian and Rachel are a minority within a minority. The reality is that they are a caring family and a working family with a single income. They are both in their early 50’s. At the age of 25 Rachael left her career as a Manageress of an exclusive ladies apparel boutique to have a family. Brian works full-time as a public servant.

In reality they are both from big families and belong to a social circle of long term friends but are unable to participate in many social events that their friends do. The reality is that all of their friends and most of their siblings are “empty nesters”. They have 4 adult children, 3 have left home. Their eldest daughter, Claire is 25 and has a disability with high support needs, she is dependent for everything. She lives at home with her parents. Rachael is Claire’s full time primary carer. The reality is that Rachael will never get the opportunity to return to the workforce and resume her career.

Rachael is also carer for her mother who is in her early eighties and also lives with them.

Brian and Rachel own their home but have a large mortgage which has progressively increased over the last 20 years as they used their equity to put their other three children through school and help make ends meet. Recent interest rate increases have reduced their disposable income to nothing.

The family has never had a family holiday with duration of more than one week. Claire’s care is not easy away from home and support mechanisms. The reality is that respite is difficult to get and respite for longer than a week is non-existent.

Brian and Rachael are aware that their other three children have had to take second place many times as Claire’s care and health has had to take precedence. The reality is that Claire’s siblings are aware that they have missed out on many things that their cousins and friends have received or have done and that the only difference is that their cousins and friends don’t have a sister with a disability.
Claire has spent many weeks of her life in hospital due to chronic lung problems caused by her physical condition. Claire does not communicate so her parents spend 24 hours a day, in shifts, beside her in hospital. Most of her hospital visits have been for an average of 6 to 9 days.

Rachael starts her day by getting Claire out of bed at 7:30 am each day and bathing her, feeding her and giving her medications. Three days a week she prepares Claire to attend a day-respite centre. This is from 9:00am till 2:00 pm. Most weeks she takes either her mother or Claire to doctors or to hospital for out-patient visits. Rachael suffers from a stress related condition. The highlight of Rachael’s week is the two hours on a Friday morning when she goes ten-pin bowling with a friend.

Through contact with older carers at support groups Brian and Rachael have come to the realisation that in 15 years they will be approaching their 70’s and Claire will be 40. They worry about what will happen to Claire if they die or cannot care for her any longer for whatever reason. This is a constant concern and the time approaches when this will be their reality.

The current wave of so called “community Care” espoused by governments compounds the problems faced by family carers because it clearly sets out to mask the reality of gross under-funding and gross unmet and under-met needs for support services for carers and their dependents.

Policy and Impact on Family Caring

The ideologues who propound 'community living and inclusion' have no conscious when it comes to the undeniable fact that people with dependent disabilities and mental illness are not housed in their own homes but in the "family Home" making a mockery of the terminology of people with disabilities having the "right" to live in their own homes.

As a consequence of deliberate policy and strategy to place the responsibility of accommodation and caring for our most vulnerable citizens squarely and unfairly upon caring families we now see research making very different claims.

Key findings of a report on the 'Nature and Impact of Caring for Family Members with a Disability in Australia' by the Institute of Family Studies (recently released) say this:

"One of the key issues to emerge from this research is that carers and their families experience high rates of mental health problems. Carers had significantly worse mental health and vitality and higher rates of depression than the general population"

Similar findings were reported by Dr Robert Cummings in -The wellbeing of Australians – Carer Health and wellbeing 2007:

- Carers have the lowest collective wellbeing of any group we have yet discovered
- Carers have an average rating on the depression scale that is classified moderate depression
- In the general population the wellbeing of people who are separated or divorced is some 5 points below the normal range. The process of caring depresses this by another 16-19 points.

The result of these pressures on families in demonstrated in the following article from a Melbourne Daily newspaper.

Parents dump disabled kids - Herald Sun Report

DISABLED children are being taken to weekend respite centres and not picked up again as desperate parents reach breaking point. Forty Victorian children are living permanently in short-term accommodation after being relinquished by their families, according to the State Government. The Association of Children with a Disability said it could be as many as 100. A shortage of foster carers and complex disabilities mean it can take years to find these children new homes.

Some families struggle on at home for years waiting for foster homes. Two families in Cheltenham and Bulleen have waited four years for new homes for their children. Mother Anita Fejzullai has asked the Herald Sun to help find a loving foster family for her daughter Emine, 14, who has partial chromosomal trisomy, an intellectual disability and epilepsy.

She has spent the past two years at an interim centre in Coburg, which has been a good, stable base but not a home. "I just want someone who will look after her and love her like I do. She's a lovely girl and a very happy girl," Ms Fejzullai said. "But I'm by myself with no family and friends to help me and I find it very difficult to look after her."

Yooralla manager Marisa Harvey said parents failed to collect their children from respite care "only in extreme cases . . . but it does happen". "There are families who are very stressed and extra resources are needed to support them in terms of better access to respite care and other appropriate support services," she said. "There is a desperate need for committed families to open their homes otherwise these children will remain in supported accommodation for the rest of their lives."

Human Services department spokeswoman Jennene Rodgers said finding families took time, particularly when children's needs were complex. "We would encourage people to become involved in caring for children with disabilities, it's challenging and rewarding," she said. [Susie O'Brien, social affairs reporter 28 March 2005]

The Recognition and support needs of natural family Carers do not translate into entitlements thus forcing families to relinquish care. What we have in the above scenario is a comparator, between informal family carers on one hand and paid and volunteer carers on the other.

The Foster care difference:

Foster families as volunteer carers, have ‘rights’ and ‘entitlements’ that family carers can only dream about.

Research has shown us that foster carers receive direct payments that are **Means Test Free** and **Tax Exempt**. This indicates a gross form of discrimination against family carers for whom Carer Payment is Means Tested and Taxable.

Foster Carers also have access to up to 50 hours of family day care a week and can still do paid work without penalty. Foster carers as volunteers may relinquish care at any time without stigma or penalty. They will be covered by Workcover third party exemptions (in Victoria at least) with a move by states to make Workcover regulations uniform, will enjoy these benefits nation-wide.

Foster Care payment scales are similar in QLD, NSW and VIC at least. Without researching other states, we can comfortably assume national coverage as indicated in the tables which follow:

Foster Care Rates– extract from DHS Victoria – Children, youth and families website information:
Home Based Care General (Foster Care, Kinship Care, Permanent Carer & Shared Family Care rates-

Table 1.

Age years	0-7	8-10	11-12	13+
Fortnightly rate $	231	241	274	370
Per Annum Rate $	6,011	6,278	7,131	9,617

*(price adjusted on 2.75% CPI growth 05/06) are the most current figures available – *Fortnightly amounts are rounded.*

Table 2

Adolescent Community placement & Finding solutions Respite	
Fortnightly rate	$370
Per Annum Rate	$9,617

Note: When the young person is in receipt of income DHS contribution to caregiver is $234-295 per fortnight and person contributes $132 per fortnight.

Table 3-Home Based Care Intensive(SHBC & IHBC)

Age years	0-7	8-10	11-12	13+
1:Fortnightly rate $	234	256	307	431
1:Per Annum Rate$	6,093	6,653	7,989	11,195
2:Fortnightly rate $	279	306	368	517
2: Per Annum rate$	7,264	7,963	9,566	13,440
3:Fortnightly rate $	374	407	491	689
3:Per Annum rate $	9,725	10,578	12,779	17,926

Table 4-Home Based Care Complex (OTOC) Loading

Fortnightly rate	$1,047 – $1,168
Per Annum Rate	$27,225 - $30,378
Foster Care Allowances paid by State and Territory governments do not fall within the test for FBT and CCB purposes, as the ATO does not consider remuneration received by people who are volunteer foster carers to be assessable income- according to the Australian Foster Care Association. Visit www.fostercare.org.au	

Visit www.office-for-children.vic.gov.au for more information.

Volunteer foster carers also receive many other benefits, such as 50 hours of child care per week, a week-end per month respite and compensation for care costs for children in their care. (DHS Victoria – Children, youth and families website information)

Let us be very clear about what these voluntary foster carer entitlements are:
“Foster Care Allowances paid by State and Territory governments do not fall within the test for FBT and CCB purposes, as the ATO does not consider remuneration received by people who are volunteer foster carers to be assessable income” - (The Australian Foster Care Association)

Whilst the payments to foster carers are made by the states it must be clearly understood that Means Testing and Tax Exemption are the province of the Australian government. Family carers have no entitlements to ‘Means Test Free’ and ‘Tax Free’ remuneration for doing exactly the same work as foster carers!

It is clearly evident from the statistics on carers who receive financial remuneration from government via carer payment or carer allowance, that direct financial payment discrimination is a significant contributor to the failing health and wellbeing of family carers.

Carer Payment and Carer Allowance Recipients

The latest report on carer payment and carer allowance put the number of recipients as follows:

- Carer Payment recipients 105,058
- Carer Allowance recipients 366,960

(Year Book Australia 2007 7.13-p206)

The Means Testing of Carer Payment prevents thousands of full time carers from accessing this benefit because they are recipients of other welfare payments such as age/disability pension or who have a partner who is employed. This makes a mockery of the claim that the Carer Payment is a benefit for caring!

The SDAC statistical data on the numbers of family carers aged over 15 years puts their numbers at 2.4 million persons making it clearly obvious why family carers are suffering financial, mental, emotional and physical breakdown. Family carers have a right to expect that governments will not treat them less favorably that other carers doing the same or similar work.

Carer's pay commensurate with the degree of difficulty and the care provided

Most government support payments are gratis – payments with limited or few strings attached. The Carer Payment is the only government support payment that restricts the recipient, in lifestyle, in personal freedoms and personal choice. Carer payment recipients providing full time care often work for in excess of 112 hours per week plus sleepovers 7 days per week.

The 25 hour work/study/volunteering rule was initiated by government to control the hours of work, study and volunteering undertaken by unemployed workers or pensioners who are required to work no more that 40 hours per week to be classified as fully employed.

Centrelink Definition: substantial level of care

Substantial level of care is a criterion for determining whether a person is:

* receiving care in a care situation, OR

* providing community-based care, for a person in a care situation.

For the purposes of CP and CA, a carer is a person who provides constant care (CP), or care and attention on a daily basis (CA), for a child or an adult with a disability or severe medical condition (care receiver (1.1.C.21)).

"This includes circumstances where the carer or care receiver are absent from the care situation for part of the day, but the intensity of the care required and provided during the remainder of any 24 hour period is such that it roughly equates to a normal working day"

We submit that this places carer payment recipients in unfair disadvantage compared with any other welfare recipients who are not required to qualify for benefits by performing up to 24/7/52 unpaid work. These rules apply to no-one else. Carers should be either paid for services rendered or given the choice of services, such as accommodation services, accommodation supports, alternate long day care and meaningful respite funding that is more than a band-aid approach.

If carers were not forced into a black hole financially, many would choose to continue to care. Reasonable financial remuneration would assist families enough so that many would stop feeling so desperate, leading to the conclusion that the only way out of the pit of despair is by giving up the care role and joining the workforce.

There is justifiable cause to exempt carer payments and to stream carers' payments depending on the level of disability, whether it is dependent or whether the role is supportive and the time of life that the care role extends across.

Caring for a child grown into an adult and beyond basically removes the carer from the earning pool for decades and it has become obvious in the past years in reports and submissions to various inquiries that this role of 24/7 care is often not by choice but motivated by fear of what will happen to those you love if you say "I will not do this anymore".

The Centrelink regulations clearly state that the expectation for qualifying for carer payment is that the care is provided for such a period as equates to a "normal working day" or 8 hours per day.

Therefore the carer should be free to be employed for any number of hours exceeding eight hours per day. To avoid penalty for paid work then requires exemption from Means Test and Tax liability for carer payments.

Carer Payment and Carer Allowance Definition

For the purposes of CA, a CA (adult) is a person aged 16 years or more who has a disability (1.1.A.79) that results in care needs that qualify a carer for CA (adult).
1.1.C.310 Constant care (CP)

Definition

A carer is said to provide constant care if they personally provide care on a daily basis for a 'significant period' during each day. The care may be active, supervisory or monitoring. To provide care on a daily basis for a significant period, a carer should reasonably be expected to provide at least the equivalent of a normal working day in personal care, as the policy intent of providing Carer Payment is to recognise that the carer is not able to undertake substantial employment because of their caring responsibilities. This includes circumstances where the carer or care receiver are absent from the care situation for part of the day, but the intensity of the care required and provided during the remainder of any 24 hour period is such that it roughly equates to a normal working day.

Note 1: Where the care receiver is a lower ADAT score adult (1.1.L.130), the carer must be directly involved in providing constant care for the disabled adult but does not have to be directly involved in caring for the dependent child. The carer is said to provide constant care for both care receivers if the disabled adult is caring for the child and the carer is supervising the provision of that care.

Note 2: It is reasonable to expect that a carer (particularly a carer caring for a high care needs individual) will need to have a break from the caring role. It is open to the carer to utilise the 63 days of the temporary cessation of care provisions (3.6.4.40) for such breaks, and such cessation should not preclude the carer from being eligible for Carer Payment.

Example 1: Where the care receiver is a higher ADAT score adult (1.1.C.20), the carer is personally providing care on a daily basis for a period of time that is generally the equivalent of a normal working day, notwithstanding any employment or training that they may be engaged in.

Example 2: Where the care receiver is a profoundly disabled child and that child attends a special school, the carer is personally providing care on a daily basis for a period of time that is generally the equivalent of a normal working day.

If the carer also undertakes employment or training of not more than 25 hours per week, consideration must be given to the *carer's capacity to satisfy the constant care requirement*.

Aspects of the care situation that can be taken into account include whether the carer attends school with the care receiver, or whether the carer is 'on-call' while the care receiver is at school.

Example 3: Jane applies for Carer Payment. She is providing a high level of care each day including overnight. However, for her to sustain this level of caring, Jane has a scheduled break from 4pm on Friday until midday on Sunday, when other carers take over the caring role.

Jane is utilising one day of temporary cessation of care each week on a Saturday. She is providing substantial care on both Fridays and Sundays, so these days do not count as temporary cessation of care. In this scenario, Jane is said to be providing constant care and utilising the temporary cessation of care provisions.

If Jane were to exceed the temporary cessation of care provisions of 63 days in a calendar year, then she ceases to qualify for Carer Payment unless there are extenuating circumstances that allow an extension to the 63 days temporary of cessation provisions.

Definitions cont:

Where more than one carer provides care to the care receiver, each carer must meet the constant care provisions. That is, the carer is said to provide constant care if they personally provide care on a daily basis for a significant period, equivalent to a normal working day, during each day (unless they are utilising temporary cessation of care on particular day(s)) .

Example: Mrs Abbott and her adult children, Susan and John, each care for Mrs Abbott's husband, Sam. Sam has an ADAT score of 125 which qualifies him for more than one carer. Susan and John each take 10 hour shifts in caring for Sam. Susan cares for Sam from 5am to 3pm each day. John cares from 1pm to 11pm. Mrs Abbott provides care as needed over a 24 hour period. She cannot manage a lot of the care by herself and needs the adult children to lift and move Sam while she changes bedding, washes or massages Sam or changes his clothes. Both Susan and John meet the constant care provisions as well as Mrs Abbott, and because Sam's ADAT score is over 80, (of which 32 is attributable to the HPA) all qualify for Carer Payment. They are all providing care at least equivalent to a working day each day even when caring at the same time.
Act reference: SSAct section 198 Qualification for carer payment

The stringent carer payment regulations, means testing and the absence of any tax exemptions or tax benefits for family carers places them in an endless poverty trap cycle. This denies carers accessing paid work to relieve that burden. The impact of such draconian regulations is greatest upon single parent carer families.

UK Council told to pay family for disabled woman's care – D. Brindle (UK Guardian August 3, 2007)

A council is today told to pay a family compensation of almost £100,000 for failing to arrange suitable care for a disabled young woman, in a ruling that will sound alarm bells in town halls across the country.

Trafford council in Manchester is found by the local government ombudsman to have neglected the needs of Carly Wright as she grew out of services for disabled children and young people. In a strongly worded judgment, the ombudsman says the authority should retrospectively pay her family £1,000 a week for having been left to look after her - and should continue paying it until care is organised.

The ombudsman, Anne Seex, finds that the council made only two offers of residential placements, one of which had no downstairs toilet that Ms Wright could access. The other placement had been unable to answer questions about how it would meet her therapy needs.

Ms Wright's parents, Wilma and Peter, have a three-bedroom house but have two other, teenage children, a boy and girl. Mrs Wright said: "The thing that really got me was that we were told Carly was entitled to something ... and then when it came to it, nothing happened. We decided not to take it lying down."

Under Ms Seex's recommended compensation package, which has to be agreed by Trafford, the family would receive about £94,000 for care costs over the past two years, plus £3,000 for distress, anxiety and time and trouble in making the complaint, plus £1,000 a week until a placement is agreed. The council apologised for its "shortcomings" and said plans for a

'Australia lags far behind Mother England in supporting family carers with Rights and Entitlements'

If care needs to be paid for in order for a carer to earn an income, this cost of care must be paid out of the earned income of a carer of an older child or adult requiring care, which usually makes working financially unfeasible. There is not a 'pot' of funding that automatically comes into play to assist working carers. Nor are their tax offsets.

Financial Discrimination Case Study

'Nancy is a primary carer of an adult daughter with a dependent disability who works an average of 19 hours per week and uses up 5 ½ hours travel time to and from work. She is away from the care role nearly 25 hours per week.

Nancy earns 28,000 per year, which reduces the carer payment to $50 per week. To earn this money she must personally fund 10 hours of care each week, because her daughter's day program runs for just 18 hours per week. Nancy must drop her daughter off at her day program 1 hour late each day to fit in with the 25 hour maximum so as not to go over the 25 hour requirement. Her daughters 18 hours inflexible funded care (block funded 9-3) is therefore reduced to 15 hours per week. This additional care is unavailable, beyond a 3-hour week flexible 'respite' package so she must pay for it herself. She must pay for 9 hours of care each week from her wages.

She pays $17.00 per hour which is $153.00 per week including an inbuilt 'entertainment' element for 9 hours care each week that she has no option but to pay because her daughter cannot be left alone. 'N' cannot offset this payment before tax; it must come from her in-hand money. 'Nancy is paid $1,074.00 after tax per fortnight. $306.00 of this is her cost of care for a dependent adult that the Australian Government has deemed her to be socially, morally and financially responsible for. She has in her hand after care costs are taken out $768.00 per fortnight or just $384.00 per week plus $25.00 she still receives from Centrelink

The Carers payment was $273.40 + $50.00 low income rental subsidy – $323.80 Nancy has lost from her 'carers payment' $222.00 per week as well as her rent subsidy of $50.00 per week leaving her with just $86.20 extra for working 19 hours. She earns $30.00 per hour; imagine these it figures if she earned $17.80 per hour?
'Nancy was offered more hours which she had to decline because she could not afford to work as working more would mean bringing home less.

Nancy says "originally I was offered more work but had to actually ask if they could pay me less so that I could keep the benefits that I was receiving because I was aware that the loss of take home money after paying for care would make earning money meaningless without the add ons. My employer was shocked to the core when I explained this to him. They took me down to fewer hours to do this".

*This would have meant she could remove herself entirely from government carers payment but she cannot afford the cost of care to work these hours because of losing the subsidy benefits of 'carers' allowance costs, tax with no deductions for the cost of 'adult' care, health benefits etc.

Nancy says she works because of the importance to her of having interaction with others rather than the distressing and extreme isolation she feels as a carer. She says that her work allows her anger and the frustration that she feels to go into something positive. "My country has turned its back on us, mainly because governments use tricky language to hoodwink the average person into believing they are 'fixing' the problem". N says that she often cries in despair and thinks suicidal thoughts because it all seems so hopeless.
If Nancy worked 38 hours her personal cost would be an additional 30 hours of unfunded care at $511.00 more per week from her wage because the extra days would be 6 hour days (her daughters day program is just 3 days per week) + travel times. If Nancy worked full-time -38 hours, her Income would be $65,000.00, Tax paid $14,865.00 Care Cost $32,708.00 - Total earnings kept after tax and care cost $17,421.00 or $335.10pw –
This is $76.00 less than working 21 hours per week and $10.00 per week more than not working at all and staying on the full poverty level carer's payments…

Poverty and carer families

The fact is carers of adults with dependent disability are forced through penalty imposed by governments to live in extreme poverty even while earning a reasonable income. How can a wealthy nation justify this? No other familial group is expected to meet the costs of care of an adult for an entire adult lifetime, which is decade after decade of forced care with no provision made for free choice.

Parents of pre-school children are given offsets for the cost of childcare, school aged children offsets for after school care, yet these same parents when their child becomes an adult (if they have a dependent disability) are expected to carry the financial burden unaided, are supposed to succumb to total poverty, simply because doing so releases billions of dollars back into the economy so that the Australian deemed of having social importance can be delivered bonuses and tax cuts in order to 'buy' votes.

If 'N' was entitled to the same Means Test Free and Tax Free entitlements as a foster carer receives as a volunteer carer she would be able to work full time and pay for her alternate care needs which would of course be subsidized as family day care is subsidized!

There is distinct age discrimination at both ends of the care scale – families are not expected to pay the burden of costs for the first cycle of life, nor the last cycle of life.

The Commonwealth Government pays youth allowance and disability pensions because they believe that families are not responsible financially for children past a certain age, nor are they responsible for the choices and actions of their adult family members, government cannot then expect families to be responsible for care of an adult who cannot provide care for themselves.

The Commonwealth takes responsibility for all Australian citizens who are over the age of 65 who are in need of support systems and funds residential placements in every region of our nation in the form of retirement complexes, residential care, nursing care and community care.

Family carers have identified and informed government on many occasions, of a number of compelling issues affecting both themselves and those they support/care for.

These issues were clearly articulated in an issues paper generated by the 'National Family Carers Voice' and published on the ABC Four Corners Website in March 2005. Issues identified included the barriers and human rights inequities they face as citizens of Australia. The issues were also identified in the report on Balancing Work and Family and the report of 2007 on the Senate inquiry into the Commonwealth State and Territory Disability Agreement.

The failure of successive governments, both State and Commonwealth, to redress funding inequities has resulted in a severe resource (supports and services) deprivation for citizens with a dependent disability that places extreme undue pressure upon their unpaid family carers.

Necessity does not mean "voluntary" and the defined "temporary" nature of the role of volunteer certainly does not apply to unpaid family carers. For most family carers it is not by intention that they become carers, a role that is above and beyond the role they would normally experience as a member of a family, it is usually by accident and not by free will. However, unpaid family carers have more often than not been perceived to "choose" to undertake an unpaid role in the provision of supports.

Centrelink says:
Carer Payment (adult) is an income support payment for people *who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged.*

We contend that carers are *NOT* unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged but are unable to support themselves because of lack of funded supports and lack of tax credits that will allow an earned income to remain intact.

We contend that this has nothing to do with being unable to self-support and has everything to do with being able to afford to work given the Australian taxation system and the Commonwealth, States and Territory Governments implementation of disability policy alongside ludicrously low funding levels all colluding to deliberately and knowingly penalise families who care. After all a person totally overwhelmed by poverty, exhaustion and depression combined with loss of hope and the illnesses that are bought about by these factors, is highly unlikely to create serious political waves about their social and financial conditions.

We contend that this is a deliberate strategy by governments not to respond to the unmet need for services and supports for people who are dependent on the care of another, preferring instead to make working so economically unviable as to keep carers captives within the care role and captives of totally inadequate poverty level ‘social support systems’.

Current tax concessions

Australian governments have made a conscious and deliberate choice that families who give birth to children with dependent disability in Australia are to be ignored by the tax system as almost an entire group for decade after decade.

The only allowance within the tax system that benefits caring families is:

- A child over 16 is deductible by $745.00
- A parent or spouses parent is deductible by $1,489

The tax office has discriminated in their expectation of the care roles in the same way as the government with supports. It is saying that families who care for a dependent adult child deserve less of a taxation offset than those caring for a parent, even though the care of a dependant child continues over decades, while the care of an adult parent is time limited.

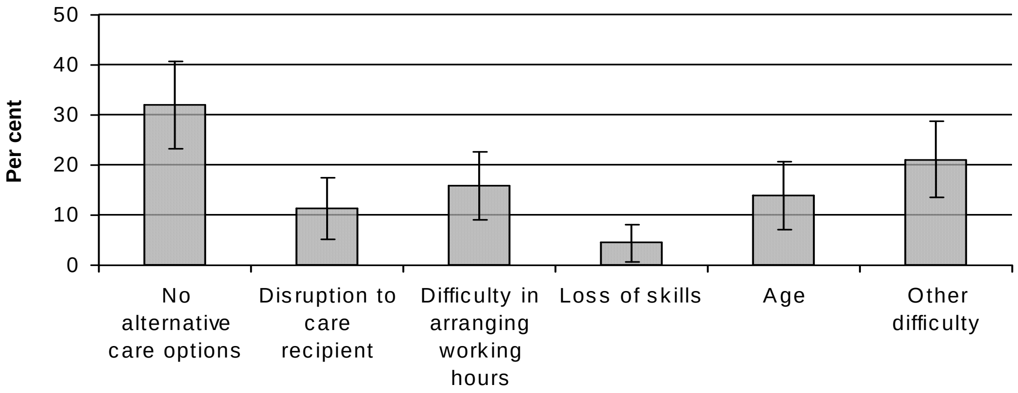
Australia lags dramatically behind mother England in supporting family carers. Legislated entitlements there give carers the right to an assessment of their needs as well as the needs of the cared for person and the right to receive a service that matches the assessment. (UK Carer Rights Legislation)

> *“A recent judgment in favour of a caring family was reported in the UK Guardian newspaper; “ A council is today told to pay a family compensation of almost £100,000 for failing to arrange suitable care for a disabled young woman, in a ruling that will sound alarm bells in town halls across the country.*
>
> *Trafford council in Manchester is found by the local government ombudsman to have neglected the needs of Carly Wright as she grew out of services for disabled children and young people.*
> (SocietyGuardian.co.uk © Guardian News and Media Limited August 3,2007)

Carers want government to implement the findings and recommendation 18 of the Balancing Work and Family Report in regard to carers. Recommendation 18 (8.42) The Australian Government consider allowing adults, who incur care costs for the care of elderly relatives or relatives with a disability, to have the choice of either receiving all current carers’ benefits or claiming these costs as a tax deduction where they can demonstrate that paid care was necessary to allow them to work.

How else can we assist carers who want to work?

What kind of choices are carers likely to make under the current system and is it really choice at all? Given that some 75% of 24/7 carers of sons and daughters with dependent disability are women, this is also questionable sexual discrimination. The table below lists the perceived barriers to carers accessing work opportunities, as you can see the alternative care option is the greatest barrier.



Estimates for 'disruption to care recipient' and for 'loss of skills' have relative standard errors between 25–50 per cent and should be used with caution. Source: ABS (2003c).

The Provision of after school care for adolescents with dependent disabilities, adult day programs extended to 5 days per week with hours of 8-6 for working carers and the cost of care for working carers to be offset before tax, even if it means that not one cent of tax is paid by the working carer must be a priority of this Inquiry if life is to be Better for carers.

Better support and recognition for Carers then means:

- Legislating rights and entitlements; and
- Legislating to provide "Means Test Free" and "Tax-Exempt" payments to family carers who provide a full-time equivalent (EFT= 40 hours per week) or significant care for a person with a severe or profound disability, regardless of the age of the recipient, where government funded accommodation and care would otherwise be the outcome for the person with a dependent disability.

What is a family carer's current status in their own home

The rise and rise of rights and entitlements for paid carers (who assist families in their care role) and the absence of rights and entitlements for family carers is placing untold stresses and pressure upon families.

This is especially true where the rights of paid workers put family carers at risk in their own homes. Homes that are now considered to be 'workplaces' in providing in-home support to families caring for severely and profoundly disabled kin threaten the very fabric of in home care where the family home is used as a surrogate supported accommodation service.

The following case study shows the threat to be real and indefensible.

Family left without a service

"Last week I was informed by phone that my service provider would no longer provide my 14yr old son with personal care based on his size. They said they would have to do an OHS assessment before putting the carer back in, but they must have been aware of the implications for me and my family by doing this. If I was to hurt myself, struggling with two children with profound disabilities where would they go? Into accommodation that doesn't EXIST? The Service Provider can't just cut out care when proper equipment is provided, based on complaints that the carers have tired backs after working with my boys for one hour 2-3 times a week, sometimes less. The service provider says they have a duty of care to the carers, what about the duty of care to me and my boys. I have covered some of the care with a more reliable agency and am struggling to cover the rest on my own.
Parent/slave of two wheelchair dependent profoundly disabled children – Victoria".

This carer was sued by the Victorian Workcover Authority as 'Third Party Liable' for a paid worker's injury alleged to have occurred in the family home.

The incident involving the carer above in a Third Party Workcover dispute, was tested out in the Parliament of Victoria, because the government had previously passed amendments to relevant Workcover legislation, which now exempts 'volunteers' working for agencies from 'third party liability'.

A new private members Bill sought to also exempt family carers, when it was learnt that the law did not recognise family carers as 'volunteers.' The private members Bill was shamefully lost on the majority vote of the Labor Government in Victoria.

The obvious conclusion to be drawn from the Victorian government's actions is that they confirm our own belief that family carers are not volunteers. Family carers are not employees either, so this therefore begs the question; where do family carers fit in Australian society? The answer quite simply is that we have no legal status of any kind and remedy is long past due!

Family carers require the urgent attention of governments to Legislated rights and entitlements to ensure that this ridiculous situation is resolved, lest carers decide not to allow any in-home paid help, making their care role untenable in the future.

External pressures for families to have both partners in paid employment will only increase the reality that unpaid caring is keeping carers in a poverty trap, which is compounded by increasingly onerous threats to their wellbeing. These threats come in many forms. They come from the absence of a nationally funded family advocacy system that unites caring families together at the grass roots of caring at the regional community level. They come from the fact that full time family carers have no pay, no days off, no sick leave entitlements, no annual leave and no superannuation – no future.

What is very clearly evident from all the research available to government, from submissions made endlessly by carers themselves, and as also attached in addendums to this document to this Inquiry by NCC, is that Carers have:

- No Legal or Ethical Rights
- No Government Legislated Entitlements
- No Family Carer Advocacy –
- No Voice in Policy and Planning; and
- No Protection under Australian law against Workcover third party claims by paid care workers.

Community Connectedness and Caring Families

Recent public events, in the media, reporting the abuse and neglect of children have resulted in comments on television, and in radio interviews suggesting that caring is a whole of community responsibility and encouraging community connectedness to ensure neighbors care about neighbors.

One such interview was with Neil Mitchell, Radio 3AW Melbourne on 27 June 2008, speaking with our Prime Minister, who made these comments:

> On the need for annual leave:
> MITCHELL: (relating to a public servants annual leave) Q: If you are on leave and a major crisis erupts, you come back.
> PM: Neil, I would appreciate the opportunity just to answer the question you asked me before, which is that any individual is entitled to have leave each year. And what we know in terms of the pattern of economic challenge over the course of the last seven months, there hasn't been any opportunity for this individual to take any significant leave whatsoever. Any individual to remain effective throughout the course of the year needs to take a break.

> On the need for care networks:
> MITCHELL: Several cases with neglected children in Adelaide and Canberra over the past few days which are just horrendous. I saw the parliament debating it yesterday with Jenny Macklin talking. Do you agree with Barnaby Joyce that neighbours have got a bit of responsibility here? If you see this going on, dob them in?
> PM: I think the whole community's got a responsibility. And to act sensitively and responsibly. I mean, I think the basic principle here is the protection of the most vulnerable. Little children together with our most aged and infirm Australians, are the two groups who are the most vulnerable. And I think, frankly, that's just a higher call. It sort of goes across everything else so that if you have a reasonable suspicion, or reasonable concern, that a young child is the subject of abuse, I think you've got a moral responsibility to act.

We contend that the government has a moral responsibility to <u>ACT NOW</u> to fund a disability family advocacy network to ensure that our most vulnerable citizens and their carers have links to the world outside of the family home where many are imprisoned by a failure to give carers a better and fairer deal.

Immediate action is required now to ensure that family carers are given legislated rights and entitlements that are long overdue. These must ensure that family carers are protected in the same way that paid care workers are protected from age discrimination, financial poverty, sex discrimination, injury, injury liability and isolation. The Role of Family carers must be recognised with:

1. National Legal Rights Legislation for family carers
2. Government Legislated Entitlements including fair pay for work performed
3. Tax and Means test Exemptions for carer payments
4. A funded family carer Advocacy network commenced from grass roots regions
5. An entitlement to a Voice in Policy and Planning
6. Protection under law from Workcover liability where paid care takes place in the family home
7. Implementation of population based benchmark funding as a matter of urgency

The carers stories highlighted throughout this submission cannot fail to bring home to the Committee the need for immediate action.

The Burden and Exploitation of Carers runs deep and is Clearly Evident

Rose: Carer- Daughter - Single
Rose is 49 years old and is single. Rose is the eldest of 4 children. She lives in a small town in a rural area 100 km outside a capital city. Her mother, Molly, has a progressive disability that she has suffered from since she was about 40; Molly is now 70 years old. Rose assisted Molly from her late teen's and never married. Rose worked part-time in the kitchen of the town's hotel for about 10 years. She has been her mother's full-time carer since that time. Rose gradually became her mother's primary carer as Molly became more debilitated by her disease. Rose cooked and cleaned for the family in the family home. She assisted her mother with feeding, bathing, dressing and mobility.

At 52 Rose's father Tom retired to assist Rose as Molly's primary carer due to his wife's increasing level of care needs. For several years Tom still did some part time work to support the family.

Rose's siblings have all married and left home. About 14 years ago Molly began to spend time in a nearby supported aged-care facility as her condition progressed. Tom died of a heart attack five years ago and Rose again became her mother's sole carer until Molly was confined to the care facility full-time due to the severity of her disease. Rose now lives with her youngest brother and is still caring for her mother when she visits her several times a week. Rose has Down Syndrome.

The Exploitation of children as Young Carers

One of the most abusive actions of governments in our 21st Century world is the glorification of children as YOUNG CARERS. It is totally wrong to fund special programs for 'young carers' because condoning the abuse of children as ' unpaid care labour' must never be tolerated.

Carers NSW, provide a raft of information about Young Carers on their website and it sadly highlights the absolute need for government to take the lead by condemning the use of children as unpaid carers. Carers NSW write:

"Young carers rarely have a choice about fulfilling their role; they often provide care because they are the only ones available. They are most likely to be providing care to their mother, often in a sole-parent household. Young carers often spend most of their time thinking about the person they support or undertaking caring tasks. This can involve providing emotional support, assisting with mobility, administering medications, cooking and housework. Often they assist with more intimate tasks such as bathing and dressing which can be inappropriate for their age or relationship.

The Impact of Caring Responsibilities on Young Carers
Many young carers come from low-income marginalised families. Their caring role can have positive effects such as developing skills and building strong relationships, but these are likely to be outweighed by the negative short and long-term effects on their Health and Wellbeing**.**

Health and Young Carers

- *Young carers' health is at risk from stress, limited sleep and the multiple physical and emotional demands on them*
- *Many young carers report constant feelings of sadness, guilt, anger, fear and worry which can contribute to impaired psychosocial development;*

Social Participation for young carers
Young carers do not have any 'spare time' or the finances for sporting, cultural, recreational or leisure activities. They are likely to have fewer friends and to feel isolated and lonely.

Education and Employment for young carers
Young carers frequently miss school and tend to leave school early without qualifying to go on. Distracted by worry and duties, young carers often skip homework and underachieve at school Career choices are often 'put on hold'; it is difficult to obtain and keep any employment at all; and
Transitions into Adulthood for young carers
Choices and opportunities are limited; young carers are often unable to leave home, gain employment and financial independence or maintain intimate relationships; and
The Future for young carers
As the incidence of disability and sole-parent families continues to rise in Australia, so will the number of young carers. Currently they receive little recognition, understanding or support from any sector of the community. Few programs or services target their needs and they face many barriers to accessing existing services. Above all, young carers deserve the opportunity to reach their potential through full economic and social participation with their peers in the wider community. ***Source:*** *Carers NSW Website – Young Carers Project. (Carers NSW website)*

Governments who replace in-home care and support services for people with dependent disabilities with funding to support children to care are condoning child abuse.

This is a violation of the 'rights of the child' to be a child and must be roundly condemned.

There can be no justification for using children as unpaid care labour.

The transition into and out of caring for all carers.

What kind of choices are carers likely to make under the current system and is it choice at all?
The husband of a 58 year old woman recently had a brain embolism that had burst and bled into his brain causing both short and long term memory damage. This had resulted in violent outbursts and aggressive tendencies. Just 6 weeks earlier, her husband had had major brain surgery and was now in need of intensive rehabilitation. The rehabilitation hospital placement had been arranged and on the day of his transfer between hospitals this poor woman was told that his place had been taken and he was instead being sent home.

Two weeks later she was verging on suicidal. Her husband had gone from a loving husband to a person with long term memory loss, short term memory loss and he was also having episodes of aggressive, challenging and violent outbursts. The only support and assistance made available to her was a therapist coming to the house to show her how to assist him with physiotherapy exercises. She despaired, she was frightened, she could not leave the house and did not know what to do, and her pleas for assistance had fallen on deaf ears.

After much discussion regarding the choices given to her, the time it would take to have her complaints reviewed and perhaps acted upon, she decided to take her beloved husband back to the hospital to have him re-admitted and then (from a position of power) to refuse to bring him home until he had undergone reasonable and necessary rehabilitation.

How can we view this as a transition into caring? The person in question made the only decision possible for herself given the circumstances, by transitioning herself straight out of caring. The expectation that such a great burden of care can be offloaded from the public sector to the family without skills training and without resources would have been as detrimental to the person being cared for as it was for the carer. If the carer is expected to become a 24/7 physical support service provider as well as the sole provider of the therapeutic services from a position of helplessness they will and do, burn out.

Currently if you are offered an accommodation service for your son or daughter (an extremely rare event) there is a transition period where the family share care until the person moving into a placement is secure enough to move in totally with just weekends or holidays with the family.

The truth is that most families with adult sons and daughters who want to transition out of the care role have just one option. That is to force governments hand by relinquishing the cared for person into respite care services so that government will make a place available within the supported accommodation program.

Families have tried waiting lists, but they rarely progress into the final selection. Previously families would join service provider charities and put in time, raising funds and supporting these charities, leaving their estates or encouraging benevolence within their social networks so that eventually their time would come and they would be offered supported accommodation for their children. Groups could once work together and their family members could develop relationships that led to compatible housing.

With the event of the vacancy management system, which over-rides belonging to these charitable institutions and gives all say in regard to placement with the Minister of the day, working for a place has become worthless. The vacancy management system has led to group homes which are not centered on client compatibility, violent clients are being mixed in with passive clients, vacancy has become a dumping ground for problem clients and the common thread which was once compatibility is now simply a spare bed. Such crisis management has led to assaults on housemates by housemates because no common bond or relationship is accessible and they are not often housemates anymore but all too often just co-residents.

In NSW most recent vacant places have been mainly filled with clients from the Department of Community Services (DoCS), with clients from the prison system and clients that have been relinquished by families, more often than not because of behavioral issues and very few clients come directly from the family home. Little engagement is happening in regard to behavioral modification before placement. There is now no way into the service system but by Ministerial pleasure. Charities have evolved into mainly government funded service providers instead of running a lot of their services on donations.

If the primary caregiver is diagnosed with a terminal illness it is more likely that no supports are made available at all until the state's hand is forced because of the carer moving to palliative care or actually dying. In a recent NSW case the government was made aware of the sole carers impending death 6 months prior to the event, yet they left her son with no transition plan at all but waited until after her death to pack him up and move him 40 kilometers from his community, his support base, his friends.

Transition plans into accommodation services must start as soon as the government is made aware of family crisis, aged carer stresses, terminal illness. Leaving a person with a disability unprepared for a different life, unprepared for the break between family care and ultimate loss of the most significant person in your life is cruel, uncaring, abusive.

Children's services

Australia spent 26.232 billion on primary and secondary educational level in 2004 and very little on specialist disability intervention services to prepare the most disadvantaged for school. (Source: Yearbook Australia 2007ABS) **37,800 students with disabilities attended un-graded classes.**

Children with disabilities are poorly treated in the education system that claims integration into mainstream schooling is best. Therapies to prepare them for school are close to non-existent or they have simply become a quick fix of telling the carer family what to do with little therapist to client service. Not all parents are ready to become 24-hour carers, OT's, behavioral psychologists, speech therapists, and physiotherapists without the hands on input of the trained therapist.

A mother recently wrote this:

> "They will say that the referral was open for a couple of years but in that time the Speech Therapist saw him only a handful of times - maybe about 6, he NEVER had any face to face therapy - it was merely handing me written information and "plans" - god they love their therapy plans! They NEVER actually did any work with Jack whatsoever - wasn't the service meant to be for him not me - and how ironic the referral was for communication and not once did the ever communicate with Jack!! Oh the irony of it..............Maybe these therapists need to first learn to communicate themselves?"

We need therapy services to once again become outcome based. These outcomes should be defined and agreed upon by the carer as well as the therapist. Therapy is an intense hands-on support service; it is not good enough to settle for just 'plans' instead of real and meaningful support.

Recently 'autism' packages were released – packages to a select group of children with disabilities. 70% of people with autism also have developmental disability/ intellectual disability - across all ranges. We are saying by this policy that only children with autism will have the therapies they need, even though many of these children will have as their overriding disability intellectual disability.

When the USA did this, the incidence of 'autism' diagnosis rose, because medical practitioners, psychiatrists and parents saw that the only hope for the majority was to have 'autism' associated with the intellectual disability to become eligible for support services.

Every child deserves the opportunity to flourish. The more opportunity supplied at a young age will make the child less expensive to assist as an adult and the less demanding for the carer. These therapies are vital to reduce the ongoing burden of care.

Respite Care

The total national budget for respite services in 2005-06 was a mere $223.6million of which the Australian government contributed just $4.8million This represents just 6.3% of total direct service expenditure – (Report of government services 07 T13A3 and 13.A4).

The CSTDA minimum dataset 04-05 reported the number of respite service users as 23,915 of a potential population said to be 219,848 families. In other words only 10.8% of potential respite users received any respite at all. Little wonder that depression is rife in caring families.

Utilising the dollars allocated for respite in 05-06 and the number of service users from 04-05, the average funding for respite per user was just $9,320.

At $28/hour for alternate care- this equates to just 13.8 days of respite per user per year.

The respite outcome outlined above for the most basic support service can hardly be considered an appropriate response to Australia's 1.6 million carers of people with a dependent disability!

A fulltime caregiver of a person with a disability is not eligible to access holiday respite until they are 70 or the person they care for is 65 or more under the Aging Carers Respite Initiative (ACRI)
It is irrelevant whether the carer have been caring for 30 years or 6 months. A stay in hospital qualifies as respite care and the allocation is for one week under this scheme.

Some respite care is available, but it is time limited and difficult to obtain. More recent developments have seen the rise of flexible respite care, an annual package that allows 2-3 hours per week of respite care for families caring for disabled kin under the age of 65 years.

Carers of people over the age of 65 may access the Centrelink respite days allocation of up to 63 24-hour days without loss of entitlements because facility based respite is offered in all aged care residential facilities in every major town and city across the nation if they ask for it.

On the other hand facility-based respite for people with disabilities aged less than 65 years are almost non-existent. Once again age discrimination rears its head. The age of the carer has nothing to do with aged care respite services but everything to do with the divide in services for the aged versus State funded disability services.

A 30 year-old carer of an aging parent qualifies, yet a 55 year-old carer of a disabled child does not. If carers are not given timely breaks they risk burn-out. This is partly why carers have such high events of depression, physical conditions and illnesses.

The Barriers to Social and Economic participation for family Carers

In Australia it is widely acknowledged and accepted that two incomes are required in today's society in order to provide for the family unit. It is also widely understood and accepted that alternate/substitute child care is required in order that families can enter/re-enter the paid workforce. Governments have accepted this need for substitute childcare as necessary for family participation in the paid workforce and responded with funding for childcare centres, school holiday programs, pre and after school care and have provided tax relief for substitute child care.

The type of substitute childcare provided is based on "ordinary expectations" of an "ordinary" child - the age and developmental stage of the child i.e. a baby will require assistance in all aspects of their life- protection, constant supervision and attention, feeding, changing because they cannot do this for themselves.

As developmental milestones are reached and skills of independence - such as speech, mobility, independent toileting and bathing, independent dressing, cognitive awareness and thought processing, likes/dislikes and the ability to express such choices, awareness of danger and the ability to discriminate- are acquired, there is a tapering in the intensity of care required culminating in a developmental stage of life where acquired skills of independence result in care where minimal supervision and direction is required. Access to the variety of substitute child care is based on developmental levels, and the dependency and vulnerability of the child.

In chronological adulthood, where all developmental milestones are presumed to have been reached, the expectation is that, ordinarily as adults, there should be no need for assistance from another person to provide support/assistance in the activities of daily living or in decision making.

For people with dependent disabilities the story is often very different with lifelong dependency upon others for all aspects of daily living a reality that cannot be ignored.

Community inclusion devotees would have the public believe that every person with a disability is capable of living independently in the community. This of course is euphemism for keeping all such citizens safely tucked away in the family home. Out of sight – Out of mind.

People with dependent disabilities and their family carers Role:

It needs to be accepted that in caring for a child/adult with dependent disabilities the parenting/ family role goes well beyond that experienced by "ordinary" families in the community. Parents/family members may be managing complex medical conditions and addressing developmental lags in reaching milestones with a variety of therapies where the family becomes therapist, doctor, nurse, teacher on a daily basis. The necessity for this level of out of the ordinary parental/family role can be intensive and lifelong. The impacts of this intensive support role on carers and their families are well documented and include:

- Prolonged parenting - their "parental care" role (24hrs/day 365days/year) extends for decades – 85 year old parents caring for sons and daughters with dependent disabilities aged in their late 50s and 60s
- Higher than the national average divorce rates in caring families, coupled with lowered re-partnering rates leading to prolonged single parenthood and lowered workforce participation rates
- Fractured and dysfunctional families – loss of extended family engagement, sibling impacts
- Over 40% of primary family carers acquire a disability as a result of their care role
- Many family carers experience depression, isolation, and suffer from stress related illness
- Mothers comprise the vast majority of single parents of children/adults with a disability
- Poverty – a significant percentage of carer families' income levels are in the lowest quintile
- Ability to enter/re-enter the paid workforce is dependent on availability of substitute care

Social participation:

For family carers in Australia there are **no legislated entitlements** to lifelong and age appropriate supports for people with a disability. Resources are delivered ad hoc, are scarce, hard to find, and it is considered "lucky" if supports are found and maintained. Families and the person with a disability are subjected to multiple assessments and in the allocation of resources, deemed to be needy or not needy, means tested based on family income, assets tested based on family assets – not on the income / assets and the support needs of the person with a disability.

Over the last three decades, this lack of support for people with a dependent disability, has resulted in parents/ families being placed in the position of being the prime provider of the supports required by their family member with a disability and the prime payer of the extra costs associated with a disability i.e. mobility aids, transport, medical aids and equipment, accommodation, heating and cooling, home modifications etc.

The impact on the family unit of becoming, by default, a substitute service provider affects all family members and limits the ability of all individual family members to be both individually independent and act collectively as a family. Any social participation by family members and the person with a disability revolves around the support needs of the family member with a disability: whether or not venues are accessible or appropriate in meeting support needs and the availability of substitute supports.

Any social participation must be carefully planned with support needs in mind. Spontaneity becomes a thing of the past and plans can change due to illness of the person with a disability or substitute support arrangements falling through.

The broader Australian community largely does not understand many of the issues involved in supporting a person with a dependent disability or the intensity involved in the provision of supports. As such social contact for caring families usually occurs with other families in similar roles as they understand the complexities involved in caring, the lack of supports available and are more than understanding when social engagements have to be cancelled at short notice.

Social participation is also strongly linked to economics. In coupled families one partner usually assumes the primary care role resulting in the family being reliant on one income and a very tight budget in order to make ends meet. The high divorce rate – and lowered re partnering rate- in families where a family member has a disability results in a single parent trying to juggle the competing needs of family members and the need for an adequate income to support the family unit. In many cases sole parents cannot combine work and caring and are left no option but to enter into the poverty trap of welfare dependency. In both cases there is little or no money available for holidays or social participation and caring families can become disengaged from the broader community. This isolation can result in stress, depression and related health problems making social participation harder to achieve. Whilst this affects carers, both of the aged and younger people with a disability, the length of time in the care role faced by parents of children born with a disability can, and does, span decades – a “cradle to grave” caring role. The average length of time spent caring for an elderly relative is six years.

The Barriers:
- Lack of substitute supports
- Lack of entitlement to supports
- The high financial cost of substitute supports
- The high financial cost of income loss
- The extra costs associated with disability
- Lack of community understanding
- Lack of opportunity for community engagement.

Economic Participation.

“Working Families” is undeniably the most promoted phrase in Australian political and government circles. The “working families” tag refers to families engaged in the paid workforce and is now used in place of the pejorative “Taxpayers”, succeeding in perpetuating the difference between those who can be in paid employment and those that can’t. As such “working families” are held as examples of need for assistance from governments – tax relief, mortgage relief, child care relief. Paid “workers” in Australia are protected by legislation that clearly outlines the conditions under which they will work, including the capped number of hours each day and a minimum level of remuneration.

Caring families receive no such protection from legislation, their homes are their workplace, the supports they provide cover 24 hours each day, week by week, year by year and they are still not regarded as “working families” as they do not receive payment for the support they provide.
Carers who receive a Carer Payment have had their hours of work clearly articulated by government – they can have 25 hours/week free of the care role (but must include their traveling time to work, study or engage in volunteer work). In other words they must be available to work, by providing support to the person they care for, 143 hours each week.

Whilst government states that carers can have 63 days each year free of the care role there is no funding attached, as an entitlement, to enable respite to take place through the provision of substitute supports to the family member requiring care. Primary carers in a partnered relationship have their payment assessed – not on the work they do – but on the income of their partner.

Substitute support workers are paid for the hours of work they do, which is the same work that unpaid family carers undertake, without any financial responsibility for the person they care for. However, this responsibility is blatantly expected of family carers for little or no remuneration at all.

The rising cost of petrol, food and accommodation in Australia affects all Australians but has a greater impact on caring families and in particular those pegged to a fixed welfare payment. There is no discount available for those families surviving on one income or a government payment/ pension - they pay the same amount for food and petrol- it simply means that a greater percentage of their income goes on basic living costs. It needs to be noted that many people with dependent disabilities cannot travel independently or use public transport – a vehicle is not a luxury – it is a necessity.

Whilst governments consider their options on our proposals for population based benchmark funding, carers have no choice but to continue in their unpaid role. However, the systematic exploitation of carers as unpaid labour and the toll it exacts on all family members has to stop.

Carers and those they support have become prisoners in their own homes – out of sight and out of mind. They are imprisoned due to financial constraints, overwork, ill health as a result of the over work. They are socially isolated. This is both shameful and a National disgrace.

Government needs to take a good hard look at the work family carers do and financially compensate them properly for that work. We have estimated that there is the need for an immediate injection of $11billion needed to address the present unmet need caused by decades of government neglect. Government should not be asking “Can we afford to do this?” they should instead be saying “Can we afford NOT to do this?”

Conclusion:

The National carers Coalition have maintained a very public sustained effort to bring to the attention of successive governments the plight facing family carers due to decades of neglect.

The National Carers coalition have made detailed submissions directly to government via COAG, the Senate CSTA Inquiry and the Federal Budget process, but nothing has changed to make life ‘better for carers.’

The National Carers Coalition exist because carers have mandated that we exist, yet a ‘deaf ear’ and a blind eye continue to ignore what is plainly known to government at every level, carers are being mistreated and ignored.

In spite of the fact that carers have made themselves available at Hearings, Reviews, Inquiries and Consultations for decade after decade, here we are again, once more telling members of parliament that carers are at breaking point.

We ask the committee to consider:

- How much longer must we go on?
- What will it take for some giant steps to be taken to ease the “crushing and unreasonable burden” endured by family carers ?
- Do you think that caring families will go on forever ignoring the increased costs, pressures and destruction of their lives?
- Do all caring families have to down tools and refuse to continue before government will hear our calls for justice and a fair deal?

We ask the committee to Do The Right Thing.

We ask the Committee to accept that:

It's time to help family carers financially, emotionally and systemically.
It's time to hear family carers and take action to give them their own funded advocacy voice.
It's time to give family carers the rights and entitlements they have so clearly earned.

It's time to put disability and carer support services onto the COAG agenda as a clear and urgent 'FIRST ORDER' priority of government.

We ask you to give family carers the legislated rights and entitlements you know they should have. We ask you to stand up for family carers as a matter of justice, and stand with carers because our cause is just.

Recommendations

That the Committee on Family, Community, Housing and Youth recommends:

I. The Federal Government immediately make funding provision for the implementation of a Disability Family Advocacy Network, commencing with grass roots regional bodies who will nominate their state and federal peak bodies as articulated in our submission addendum.

II. The Federal Government immediately legislate for Carer Rights, including the right to care or not care , the right to Carer Assessments and Entitlement to Support Services.

III. The Federal Government legislate for the introduction and funding of Population Based Benchmark Funding of Disability and Carer Support Services as a matter of First Order Priority.

IV. The Federal Government immediately legislate to ensure that all full time family carers have access to **means test free** and **income tax exempt** carer payments that will include a cost of care component with no 25 hour work/study/ volunteering rule.

V. The Inquiry by the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs into financial security for carers and seniors make a stand-alone report on financial security for Australia's 2.6 million carers to the Henry Commission Review of Australia's Future Tax System.

VI. The Federal Government ensure that service agreement negotiation with the states and territories foster the provision of long day care for older children and adults with dependent disability aged less than 65 years to facilitate paid work opportunity for carers and to relieve the burden of caring on stressed families.

VII. That the Federal Government ensure people with dependent disabilities have Legislated entitlements to assessments of need and access to accommodation and support services to meet those needs.

Addendum:

1. Are needs being met? – Margaret Ryan June 2008
2. Submission to the Inquiry into the Funding and Operations of the CSTDA –NCC July 2006
3. Australian Government Budget Submission – Disability Family Advocacy Network- NCC January 2008

Liaison members of the National Carers Coalition would appreciate your invitation to address the Committee at hearings to ensue that together we may forge "Better Support for unpaid family Carers"