

Submission 1291

(Inq into better support for carers)

Acc. 28/10/08

The Secretary of the
House Standing Committee
on Family, Community Housing and Youth

4 July, 2008

Dear Committee Members

RE: Inquiry into better Support for Carers

Please accept my submission for consideration by the Committee. I give permission for my name to be used in full on your website my address and other identification must of course remain private.

Young carer-families want to be supported in steering the life-course for their family. They want to make the choices that are in the best interest of all their children including their child with disabilities and they must be assisted in doing that. This is the case with all families providing care for a person with dependent disabilities.

No matter how disability occurs for a family member, when people become carers it is as if their world doubles in volume. They live in the "normal" world but must also inhabit a parallel world I call "Disability-ville".

In Disability-ville the rules can change minute by minute, there is no co-ordinated, rational approach to service access and/or service provision, every activity involves endless form-filling, circular phonecalls seeking help beginning with one phone number at the start of the exercise only to come full circle back to the number with which you first started. The fruitless search for help enervates and debilitates carers/parents, eroding their self-confidence, resilience and reserves.

In this rich first-world country, it is a shocking but shameful reality that parents in their late 50s, 60s, 70s, 80s and some in their 90s fervently pray each night that their son or daughter who is dependently disabled, will die before them. They do not want to die and leave their helpless adult children. Their stark and unpalatable reality is that no provision has been made for their sons or daughters with dependent disability to be cared for in community settings familiar to them, in appropriately supported accommodation by well-trained, well-paid-carers providing quality care. These people with disability and their elderly parent-carers are the *Forgotten Australians*.

Mothers and fathers, and now, too often, it is the ageing mother alone, have taken seriously the past exhortations of government, bureaucrats and disability advocates that the best place for the person with a disability is in the home with family. For decades they have nurtured, cared for, protected and provided for their family member/s with dependent disability.

The expectation of these parents was that in exchange for a quarter of a century or more of devoted care for their adult child with disability there would be prepared for them a living arrangement independent of their parents bearing in mind their certain mortality. Parents were led to believe that their adult child with disability would transition into supported living arrangements nearby providing continuity and family connection, that timely, humane and considerate transitioning would deliver a double benefit of independence and peace of mind for both parent/s and adult child with disability.

The reality is parents of severely disabled adult children have been thoroughly conned. Their expectation was that plans were in place and provision would be made. They saw the role of disability advocates as advocating for this supported living arrangement for their sons and daughters. They believed that part of the brief of disability advocates was advocating for the future quality care of their adult children with disability. The bitter realization of these ageing parents is that no such thing has been happening and the cupboard of supported living with quality care and service is bare

Other first world countries can and do provide – to its shame Australia has totally abandoned carer-families, the people for whom they care and people with disabilities in general.

I have made little reference to specifics with respect to Carer Payments, Carer Allowance and other monetary adjustments and benefits. I am still married after 28 years. There is no doubt our marriage has suffered and our interpersonal relationships have suffered significantly. However, I am very fortunate.

I dread to think, however, what life would have been like had I been alone as tens of thousands of carers are alone and it's almost invariably the woman who is in life-long lonely servitude.

I know many magnificent, intelligent women who live this lonely existence. It's fundamentally unjust. In my view this is the forgotten frontier of feminism. Carer women are ignored by everyone including feminists, where is the social justice for these carers?

Women as carers suffer enormous social injustice and it is the challenge for today's feminists to set that right, to enter this forgotten frontier and champion their cause. For whatever benefits are won for carer women are won for all carers, men and women.

Impoverished by their life-long efforts elderly carer-parents are powerless to change their reality, which is to age in place with much younger disabled sons or daughters ageing before their time, isolated and limited to the social interactions initiated by their ageing, enervated parents.

With good reason many carer-families are skeptical of the utility of this Inquiry because it traverses ground already covered in recent numerous and voluminous studies and reports: Some think it is a perverse compulsion to force families to re-live over and over their desperate situation, others think it is just a political exercise to engrass the Labor stamp on the issue.

Whatever the motive it is gives few parent-carers any hope that anything will change and they see it as further evidence of the "Busy-doing-nothing-to-ensure that-nothing's-done" Syndrome, a debilitating condition afflicting institutions of government, the clinical feature of which is decision-making paralysis.

If we could have a dollar for every worthy word written and uttered about disability and carers in the last 30 years there would be no need for "yet another" Inquiry into the immediate and longer term challenges faced by carers. Unfortunately over the last 30 years governments of every political persuasion have ignored the fact that the parent-carers of tens of thousands of Australians with disability would age and die. We live in hope that something better will be done by this government. Whether it's a forlorn hope is up to this Committee.

I would like to express my thanks for the opportunity to once again expose my private life to scrutiny by people I do not know for a benefit which is yet to be defined but the opportunity is nevertheless welcome.

Joan Tronto is professor of political science and women's studies at the City University of New York and author of *Moral Boundaries: A Political Argument for an Ethic of Care*. In her essay *Care as a basis for radical political judgments* she says that the ethic of care supports a "climate for good political judgments". Her definition of care is all the things we do to "maintain, continue, and repair our world so that we can live in it as well as possible" Care reflects the lived experiences of people and "entails a basic value: that proper care for others is a good, and that humans in society should strive to enhance the quality of care in their world."

It is the ethic of care that underpins the world of carer-families. It is a worthy ethic that should be applied to all areas of our human life.

Parents and families are the irresistible force that has shaped society for all time. It is love that fuels and drives their passion and if love were enough there would be no need for this Committee of Inquiry. But love is not enough. Families want to create the opportunities for their family members with disabilities, to try new things, to work outside the parameters set by professionals who are often jaded and out of touch. With support and in partnership with a government that trusts them they will have the freedom to do what they believe is in the best interests of the person with disability for whom they are responsible and for whom they have enormous love and respect for the unique qualities that are theirs alone.

My thanks for the Committee's consideration of my submission and I take the opportunity to extend my best wishes in its deliberations. If the Committee puts carer-families and people with disability at its heart then the outcome can only be recommendations and policy which is progressive, innovative and bold and which will respond to the enormous goodwill which carers have invested by making their submissions.

Term 1 - THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY AND HOW THIS SHOULD BE RECOGNISED

Part 1 - THE ROLE OF CARERS

Carers provide unpaid support and care to people with dependent disability, almost invariably it is a family member, whose needs arise from a chronic illness, mental illness, disability or the problems associated with onset of frailty.

Disability recognizes no socio-economic boundaries therefore carers come from every walk of life. Carers are mothers, fathers, husbands, wives, uncles, aunts, sons, daughters, cousins, brothers, sisters, neighbours and friends

There are 2.6 million unpaid carers in Australia and each and every year unpaid carers add value to the bottom-line of Australia's economy. Access Economics modeling has quantified this figure at \$31 billion.

The largest number of long-term carers are parents of young and adult children with disabilities. Carer-families are like every other family with the over-arching responsibility for a family member who, for whatever reason, is unable to care for themselves because of disability.

Carers are almost invariably family members who do not choose their role as a carer. However they undertake that task with love and devotion, often from a sense of duty and moral responsibility.

Long-term carers make enormous sacrifices in taking on this task.

Often their caring role comes about suddenly without warning or time for preparation.

Carers sacrifice personal relationships, career, career opportunities, opportunities for further education, travel, lifestyle, their individuality. Their lives are subsumed by their carer role.

Carers suffer significant financial hardships. Many life-long carers have no superannuation, cannot engage in remunerative employment, cannot asset build, cannot make future provision for their family member with disability because of financial incapacity brought about by inability to work and accumulate savings. Oftentimes carer-families do not own their own homes and often live below the poverty-line.

Restoring broken faith with Carers

Elderly parent-carers have lost faith in government. For over 30 years governments of every political persuasion has failed to plan and provide for the day when elderly parents caring for severely disabled adult children would die.

For decades these parents have diligently participated in countless surveys, Inquiries, forums, consultations, research and the like. All this busy work has delivered to them nothing in the way of peace of mind for the future of their sons or daughters with disability who will be left behind when they die

Carers want to see the recommendations of recent Inquiries implemented without further delay.

By calling this Inquiry the Rudd government has been criticized as dilatory on the issue of people with disability and carers. I feel this is a legitimate criticism given that it was Labor's Senator McLucas, who moved for the CSTDA Senate Inquiry to be undertaken and ***“argued that an inquiry into the CSTDA would 'give clarity to the way the Commonwealth and the States negotiate about people with disabilities and their services...[and] give clarity to people with disability about what the intent is of both parties so that they can understand what will be delivered'***

(Chapter 1 Introduction at 1.9 of the Senate Inquiry Report)

The House of Representatives Family and Community Committee's considerations will be well informed by the very recent studies and reports of just these last 2 years.

1. The Senate Inquiry Report into the operation and Funding of the Commonwealth State and Territory Disability Agreement released on 8 February, 2007

Hundreds of hours of evidence was taken from carers as to the difficulties that they face on a day-in/day-out basis and the crisis so many families are facing in terms of poverty, adverse health outcomes and relationship breakdown.

The Inquiry received over 115 submissions from family-carers and service providers. The recommendations of this report should be implemented immediately particularly the primary recommendation

Primary Recommendation - Recommendation 21

4.150 That Commonwealth, State and Territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.

If this recommendation were implemented forthwith much of the distress and crisis facing many carer-families would be immediately alleviated.

The announcement by the Rudd government on 30 May, 2008 will make little difference because the funding is not significant due to the decades of chronic and persistent underfunding which has created the critical unmet need particularly for supported accommodation of people with dependent disability.

2. The Taskforce on Care Costs Report released on 16 November, 2007. The Taskforce on Care Costs was supported by over 45 high profile business and non-government organisations. The Taskforce on Care Costs was established in 2003 to investigate the relationship between work and the cost of care, and propose sustainable and fair solutions to give carers choice. The Taskforce on Care Costs found that 1 in 4 workers is likely to leave the workforce because of the cost of care particularly in the coming decade.

3. The Special Report released on 15 October, 2007 titled the *Wellbeing of Australians: Carer Health and Wellbeing* produced by Professor Bob Cummins from Deakin University. This report builds on the Australian Unity Wellbeing Index and investigates satisfaction with economic, environmental and social conditions in Australia, as well as giving ongoing insights into our perceptions of individual well-being. Professor Cummins found that carers have the lowest well-being index he has ever seen for any large group in Australia.

4. A report released on 14 July, 2006 by the Australian Institute of Health and Welfare *Disability update: children with disabilities* Report show that 91% of all primary carers of children with disabilities were the children's mothers. Most primary carers of children with disabilities spent 40 hours or more a week directly caring for their child.

5. The House of Representatives Standing Committee Inquiry Balancing Work and Family Report released on 7 December, 2006. A comprehensive inquiry into how Australian families were balancing their work and family commitments. This Inquiry received over 220 submissions. Many submissions came from parents-carers of family members of people with disabilities. That report and those submissions are a valuable resource and will provide insight into the circumstances of carer-families and how they balance work and life. Most do it at the expense of their health, well being, relationships and marriages. It is a heavy price paid too often by a single parent, almost always the mother.

6. Carers are affected at every level including at cellular level. Australian Dr Elizabeth H Blackburn, is a cell biologist, and one of Time Magazine's "100 Most Influential People in the World," for 2007.

Dr Balckburn is a professor of microbiology and biochemistry at the University of California at San Francisco and an expert on telomeres, protective caps on the

ends of chromosomes and is published extensively with 119 pieces of published research in which she has collaborated. Dr Blackburn is credited with the discovery of the enzyme telomerase, and is the winner of the international awards 2006 Gruber and Lasker awards for medical research.

She has had a long career looking at the effects of ageing and has collaborated in a study investigating the effect of prolonged psychological stress on cell ageing. For the study two groups of mothers were looked at; one had normal, healthy children, the other had a child with a chronic illness. Physiological and psychological studies were done on everyone.

With the stressed group it was found that the longer the mothers had been caring for their chronically ill (disabled) child, the more they were ageing at a cellular level (less telomerase and shorter telomeres). It is no surprise that similar effects were found in women who were primary carers for partners with dementia

Part 1 - CARER RECOGNITION

Legislative recognition of the carer role

The United Kingdom which has enacted the following three pieces of carer-specific legislation.

- The *Carers (Recognition and Services) Act, 1995*. This Act recognises the role of informal carers and provides for the assessment of the ability of carers to provide care. This Act gave carers the right to an assessment of their own needs which are usually aligned with obtaining proper services and support for the person with dependent disability for whom they care.
- The *Carers and Disabled Children Act 2000*. This Act makes provision about the assessment of carers' needs; to provide for services to help carers; to provide for the making of payments to carers and disabled children aged 16 or 17 in lieu of the provision of services to them and for connected purposes
- The *Carers (Equal Opportunities) Act, 2004* The Carers (Equal Opportunities) Act 2004 . This Act gives carers new rights to information - Section 1 of the Act places a duty on authorities to inform Carers of their right to a Carers Assessment. Ensures that work, life-long learning and leisure are considered when a carer is assessed –

Section 2 of the Act means that when a Carer's Assessment is being completed it must take into account whether the carer works or wishes

to work, any courses the carer is taking or wishes to take, and any other leisure activities the carer undertakes or wishes to undertake. Gives local authorities new powers to gain the help of housing, health, education and other local authorities in providing support to carers - Section 3 states that if the authority requests another authority to plan services, that authority must give that request due consideration.

“Single-point-of-entry” Department of Disability

Carers need a “single-point-of-entry” Department of Disability to which carers can turn when there is a diagnosis of disability for a family member. A stand-alone, Commonwealth department with cross-jurisdictional access to “whole of government” services.

This department would work and co-operate with family-carers for the best outcome for the person/child with disabilities having regard to the needs of the family as a unit. This department would hold a centralized database accessible, with the consent of families, by agencies such as Centrelink and Medicare to reduce the necessity for on-going reviews when the disability is life-long and debilitating. This centralized database would relieve families of the waste of time and energy spent in filling out copious forms. This department would be the portal through which all service providers, with consent of parents/family, would access the central database: medical practitioners, therapists and allied health service providers. disability service providers, whole-of-government services.

Card Carrying Carers

The role of carers and the agency of carers for family members who are unable to self-determine and self-care must be legally recognised. The abovementioned “single-point-of-entry” Department of Disability would be authorized to issue carers with a Carer Recognition card given legal force. This card would be universally recognised and used to access services and supports and entitlements and exercise rights as carers and as agents of the person with a disability who may not otherwise able to gain access themselves because of their disability.

The need for this arises from my own experience when personally attending to submit Disability Support Pension application forms for my 16 year old son. The Centrelink officer asked me where was my authorization from my son. I told her he was severely intellectually disabled, could not speak, read or write due to his disability and that I was his primary carer and his mother. I was then asked was I his guardian which I am not I am his primary carer and his mother and he was still a child under Commonwealth Legislation to which Centrelink is subject. However that was not good enough. So my authority and legitimacy as a parent was totally ignored and in fact deemed illegitimate. If parent-carers are subject to

this kind of questioning when there might be a medical emergency then there needs to be registration of the interests of primary carers, nominated carers and persons responsible in order to ensure positive outcomes.

Such registration will recognise the notion of agency for those in the medical profession and allied care industry, hospital triage, government departments such as Centrelink and others. This is particularly important when the person with a disability has a significant intellectual or cognitive impairment or mental illness

The easiest way for the time being is to utilize the universality of the Medicare card. The Medicare bureaucracy already exists and can be used to register carers in long-term, short-term or temporary carer roles as the person responsible. This database could record such information as the "nominated carer" for people suffering mental illness or the person responsible for children and adults with disability who cannot self-determine or self-manage their care. There is also the capacity to upload medical information and the like which would provide ease of access and ease of admission to hospital etc.

Degree of Difficulty of Care

The degree of difficulty of care provision by family carers must be recognised by a sliding scale reflected in the Carer Payment and access to benefits such as in-home and centre-based respite. For example the level of care required of a carer for someone with severe and degenerative multiple sclerosis or motor neurone disease would be significantly different to a carer providing support to someone with mild or transient disability.

Term 2 - BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS

Part 1 - Social barriers

The universal barrier to carers and people with disability is access to the community. **Laws not lip service deliver ACCESS.** The poor implementation of building codes over the last 30 years has continued to restrict access to the community.

For the first time ever we have a dedicated Ministry of Social Inclusion. Ms Julia Gillard is the Minister responsible. Ms Gillard is also the Minister responsible for Education and Workplace Relations two enormous portfolios which take significant time and attention. Perhaps the best course would be for portfolio responsibility for Social Inclusion to pass to another member of government so that it is a stand-alone portfolio.

The concerns of carers are by no means selfish, their fundamental concern is the well-being of everyone in their family and this includes the person with a disability

who may be the least able to care for themselves. They want policy that gives access to community life to both carers and people with disability. If a person with a disability is excluded from access to the community so are their carers are also excluded. Part and parcel of community life are social, economic, leisure and cultural pursuits. Carers and people with disability want to be part of their community by having access to all those areas of community life.

Disability must be embraced as a mainstream legitimate state of being. That it is acceptable to be disabled because it is part of our human diversity. People with disability are still regarded as "other" or "less" not as "equal" and "as good as" in terms of value and respect. Legislation has played a part in changing community attitudes to disability but acceptance cannot be achieved by legislation alone. You cannot legislate for people to care. In partnership with legislation must be education and inclusion of people with disabilities, families and carers in the formulation of "whole of government" policy; i.e. health, transport, education etc.

Social inclusion has to be more than a buzz word. There are many areas of local, state and federal government in which this word is used, most especially with regard to people with disability. While you cannot legislate for people to care legislation can be used to mandate access to premises and employment. In this regard we need laws not lip service

Legislation is required to:

- Mandate universal access to public transport and newly constructed commercial premises, schools and other public places so that people with disabilities have the same capacity to access as non-disabled people.
- Mandate government assistance to fund access provision to people with disability to private premises such as schools and other institutions open to the public when the cost of modification would cause significant, unsustainable and undue financial hardship to those private organisations
- Mandate universal access to premises codes must ensure that people in wheelchairs come through the front door of all premises not in through the goods lift or through the back door like society's dirty little secret.
- Mandate universal access to the school and/or tertiary education curriculum for students with disability in whatever setting. In other words for students to be provided with the assistance to access the curriculum be it through technology/aids/teacher aides/student aides

- Mandate residential dwellings be wheelchair accessible and that all doorways be 920cm wide instead of 720cm wide. An opt-out option made available upon payment of a prescribed fee.
- Make it illegal to excluded students with disabilities from schools on the pretext of Occupational Health & Safety issues
- Make it illegal to exclude people with disability from securing employment on the pretext of Occupational Health & Safety issues
- Make it illegal to exclude people with disability from private or public housing estates on the basis of their disability

Our society will only be truly inclusive when the planning of our social and built environment looks to the inclusion of people with disabilities are a matter of course rather than as an afterthought

Part 2 - Economic barriers for carers

Carer-families are economically disadvantaged for the following reasons:

- one partner leaves employment or cannot participate in remunerative employment because of long-term care responsibilities
- single wage carer-families have insufficient funds to maintain a standard of living above the poverty line
- to avoid waiting for services carer-families often spend after tax dollars on medical treatments, therapies, physical aids and personal care, special dietary requirements and so on. Choice impoverishes the family because there is no tax deductibility for the investment made by family and no recognition that in choosing not to wait in line for services they are saving the government at both ends of the social spectrum. E.g. in autism - for every \$1 invested for a person at the outset will save \$17 on public expenditure if there is no investment.
- carer families often break into superannuation funds to meet the needs of their family member with disability which means they have less in superannuation in their retirements which reduces their quality of life and lifestyle, they will live in poverty in their old age.
- reduced economic capacity reduces the opportunities for social interaction and entertainment
- if a carer-family cannot afford a wheelchair accessible vehicle the entire family becomes socially isolated
- social isolation and economic disadvantage often impacts on well-being of carers and their family, there are higher rates of depression among carers

- economic pressures can lead to family breakdown resulting in single parent households,
- usually the single carer-parent is the mother who becomes totally isolated with little prospect of remunerative employment because of her caring role; she and her family live below the poverty-line in the formative years of her children's lives; without remunerative employment she will have no superannuation and must live on the old-age pension, which essentially means poverty-line existence; she will also be still caring for her disabled family member because there is no supported accommodation into which her family member with disability can transition.

Part 3 - HELPING CARERS SEEK AND SECURE EMPLOYEMENT

We are in a tight labor market. Australia is bringing workers from other countries to work under Section 457 visas when carers want to work but cannot work with the availability of care for school-aged and adult family members with dependent disability.

I commend the Committee to the findings of the Taskforce on Care Costs [click here](#) or at this link

[http://www.tocc.org.au/media/Final TOCC 2007 Report The Hidden Face of Care 16 Nov 2007.pdf](http://www.tocc.org.au/media/Final_TOCC_2007_Report_The_Hidden_Face_of_Care_16_Nov_2007.pdf)

The TOCC Report comprehensively deals with the issue of how the employment of carers is affected by workplace inflexibility. I also commend to the Committee the Submissions of the National Carers Coalition (NCC) which are comprehensive in detail and scope. Submissions to the Balancing Work and Family Inquiry, [Click here](#) or at this link

<http://www.apf.gov.au/house/committee/fhs/workandfamily/subs/sub199.pdf>

to the NCC's submission to the CSTDA Inquiry, [Click here](#) and Attachment 1 [Click here](#) or at these links

[http://www.apf.gov.au/Senate/committee/clac ctte/completed inquiries/2004-07/cstda/submissions/sub28.pdf](http://www.apf.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/submissions/sub28.pdf) and attachment at

[http://www.apf.gov.au/Senate/committee/clac ctte/completed inquiries/2004-07/cstda/submissions/sub28a.pdf](http://www.apf.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/submissions/sub28a.pdf)

the NCC's November, 2005 submission to COAG. [Click here](#) or See at this link <http://www.carers.net.au/COAGSubmission11-05%5B1%5D.pdf>

Submission to the Federal government's Budget 2008 for carer-family advocacy. (Enclosed as attachment)

The NCC's CSTDA submission was widely quoted in the Senate's CSTDA Report and in the Report on Balancing Work and Family in the Chapter relating to family carers and disability.

I also enclose as an attachment my submission to the Balance Work and Family Inquiry which provides a personal insight into our family life. Click [here](#) or at this [link](#)

BARRIERS TO EMPLOYMENT

Why can't carers seek and secure employment?

1. Inflexible workplace practices are a barrier to carers securing employment. Employers fail to recognise and make adjustments for carer responsibilities – it is imperative for workplaces to have regard to the needs of workers who are also caring for a family member with disability given that in the next 10 years 1 in 4 carers expect to leave the workforce to meet care responsibilities.
2. Highly educated carers of people with dependent disabilities are accepting employment well below their skill level in order to build in the flexibility they need to meet care responsibilities, which means less pay and less superannuation savings.
3. Highly educated carers of people with dependent with disability therefore work shorter hours and are under-utilised in the workplace in order to build in the flexibility they need to meet care responsibilities- which means less pay and less superannuation savings.
4. Highly educated carers are more likely to pass up the opportunity for promotion because of care responsibilities- which means less pay and less superannuation savings.
5. Lack of childcare for children with disabilities means that carers cannot work – Unlike for non-disabled children, for children with disability there is no before or after school care, nor is there vacation care for school-aged children with disabilities.
6. Unrealistic hours of day programs for adults with dependent disability. Piecemeal provision of day programs for adults with disabilities means that carers are unable to secure 9 - 5 hours of employment day programs for their disabled family member only run to a school-day timetable i.e. 9am to 3pm

Term 3 – THE PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS, INCLUDING KEY PRIORITIES

Part 1 - Practical ways to support carers

1. Provision of a “one-point-of-entry” stand-alone federal Department of Disability for new carers with cross-jurisdictional access to “whole of government” services and non-government services and supports
2. Carers with their detailed expertise be given partnership status with service providers, therapists, clinicians, educators and be part of all decisions with regard to their family member with disability if a child or unable to self-determine,
3. When the person with a disability is a child or has a significant intellectual or cognitive impairment or mental illness. The agency of carers be recognised in legislation in order to deal with confidence with the medical profession, hospital triage, government departments such as Centrelink and others.
4. Carer-families be given 100% tax deductibility for purchase of motor vehicles for the transport needs of the family and the person with disabilities
5. 100% tax deductibility for vehicle and residential dwelling modifications based on the needs of the family and the person with disabilities.
6. 100% tax deductibility for the investment in effective, globally recognised therapy services for the family member with disability.
7. Direct funding to carer-families to allow choice of services that best meet the needs of their family member with disability. Pilot programs show when directly-funded, carer-families and the people with disabilities use funding more effectively and efficiently often with outcomes are far superior than if funnelled through formal providers.
8. Australia pilot a project similar to the UK’s innovative “In Control” project, a regimen of direct funding providing positive outcomes with families much happier and distress much reduced. Choice is very liberating both for the carer-families and people with disability.

9. Out-of-school-hours care for school-age children with disability including before and after school care and vacation care.
10. Direct funding to families for out of school hours care for school children with disability to allow choice in the delivery of out of school hours care, either in a formal care setting or to engage a paid carer to help with afterschool personal care, homework help or some leisure/physical activity in out of school hours..
11. Trust the family- carers to secure services that are the most efficient and effective to help their family member with disability. Accountability is essential when taxpayer dollars are spent, however, “Gate-keeper” mentality and reviews of how funds are spent often cost more than what was spent at the outset
12. Freedom for carer-families to choose the service and support that will meet the need of their family member with disability. Choice and options are the hallmark of a responsive, well-co-ordinated system that recognizes and trusts families (with few exceptions) want a positive outcome for their young or adult children with disability, as long as the therapy/service/aid is globally recognised and outcomes are measurable and the person with disability benefits directly.
13. Carers want an education system for their child with disability to educate their children. At the moment education of students with disabilities the Australian education system is simply chaotic.
14. Carers want accountability, choice and measurement of outcomes for their family member with disability who is in school or tertiary education.
15. Ensure that when it comes to the education of students with disability the education of the educators is comprehensive. Teacher training must move with the times, teachers must be properly trained, properly supported and properly resourced in the classroom for better outcomes for all students.
16. Carers want trainee teachers to have more classroom time in classrooms where teachers are properly supported. Trainee teachers need to experience students with disability in various classroom settings.
17. Carers want to know that inclusive education is not captive to the “grab-rails” and “ramps” view of disability and that there is recognition of the subtle needs of individual students with disabilities.

18. Carers want to play a partnership role with teaching staff in planning the education of their family member with disability.
19. Carers want choice in schooling their family member with disability At the moment the funding arrangements in education do a great disservice to students with disabilities in all sectors.

Part 2 - Key priorities for action

– enabling the family enables the person with disabilities:

- A “one-point-of-entry stand-alone federal Department of Disability for carers with cross-jurisdictional access to “whole of government” and non-government services and supports
- Ensure that regular respite is given at least once a month particularly to families who have the most difficult caring task. Those providing the highest and most difficult level of care be provided with regular respite at least once a month as is the case in Canada, the US and the UK
- Ensure that there is a transition from the family home to supported accommodation for people with dependent disability in reasonably close proximity to parents and familiar surroundings.
- That there is choice to transition from the family home to supported accommodation and that transitional accommodation be available by the time the person with dependent disability is 20 years of age.
- Out of school hours care for school children with disability
- Day program hours for adults with dependent disability be extended to co-ordinate with timetables of families who work.
- Direct funding to carer- families to give choice for targeted services, therapies, aids and supports
- Tax deductibility of monies invested in services and supports for family members with disability which directly improve outcomes for the family member with disabilities
- Universal access to premises, transport and employment for people with disability

Term 4 – STRATEGIES TO ASSIST CARERS TO ACCESS THE SAME RANGE OF OPPORTUNITIES AND CHOICES AS THE WIDER COMMUNITY, INCLUDING STRATEGIES TO INCREASE THE CAPACITY OF CARERS TO MAKE CHOICES WITHIN THEIR CARING ROLES, TRANSITION INTO AND OUT OF CARING, AND EFFECTIVELY PLAN FOR THE FUTURE.

For my family the previous references have covered most of this term of reference.

The future

With respect to policy as a long-term carer I would like to see the following become part of the better future for carers

1. *A new funding formula for the funding of disability and home care services through the Commonwealth State and Territory Disability Agreement (CSTDA) with population-based benchmark funding for disability, mental health and aged care services, to meet the unmet need for services and support. Attached is a document prepared by Jean Tops, President of the Gippsland Carers Association which sets out the technical niceties of this funding formula. Basically it calls for population-based benchmarks for funding disability services for the target population between the ages of 0-65. Anyone in that target population can become disabled. After the age of 65 there are legislative entitlements to aged care.*
2. *Federal legislation which recognises the carer role, and legislation which entitles carers to support. As has been enacted in the UK.*
3. *Funding of Disability Carer- Family Advocacy on a Regional, State and Federal level so carers have a voice in the policymaking which defines their quality of life*
 - *Carers will support a Carer's voice through a funded advocacy organisation coming from grassroots carers groups.*
 - *Carers must be stakeholders in their national voice, representation must be democratic with representatives elected not politically appointed.*
 - *A Carer's Voice must be included to inform policy so that decisions are not continually made about us without us.*

(See attached National Carers Coalition for Carer-family advocacy submitted to the Federal Government for Budget 2008)

Action is the only way to relieve the stress and distress of carers now and in the future. For more than a decade the need for action has been critical.

On a personal level - the future for our carer-family – with a teenaged son with severe intellectual disability our overwhelming concerns are:

1. **Most immediate concern:** That his school will close because the lifeline offered by the previous government was not converted to recurrent funding which will keep his unique and valuable . The school community in partnership with families, the school authority and the federal government is reviewing the situation and we are hopeful for a positive outcome.
2. **Concern at the end of 2009 - His accommodation** – he deserves to be and wants to be with his peers, i.e. with young people like him in accommodation which is near to his family, will provide quality care, continue with his education about the world, where he will participate in activities/life-skills training to enhance his independence remembering that he is severely impaired and will always need assistance in his daily life

General concerns

1. The lack of certainty of day program funding and placements which are often not finalized until almost the very last day of the student's school-life.
2. The lack of transport to day programs if the parent is to return to full-time employment
3. The lack of realistic timetabling for day programs – at the moment they run on a school-hours timetable which is unrealistic and will continue to exclude the carer from employment
4. The lack of choice of respite, either centre-based or in-home for families who are in the caring role. When working and also caring for a large, vital, rambunctious energetic teenager respite is vital. Respite must be regular at least once a month as provided in Canada, the US and the UK .
5. Lack of actual physical places for supported accommodation as well as funded "placements". Respite and accommodation in NSW is chaotic due to dysfunctional vacancy management.
6. The notion of living "in the community" is meaningless if a person with disability is moved out of family into accommodation 50 or 60 kilometres away from parents, community and family. Service providers, who know

their clients best are essentially excluded from vacancy management resulting in inappropriate placements and distressing outcomes.

7. At the moment there is no comprehensive innovative residential options for people with disability which means there is no choice of accommodation models.
8. There be no prescriptive accommodation for people with disability. There be a wide range of accommodation options reflecting choices open to the general community in line with Article 19 of the UN Convention on the Rights of Person with Disabilities. Accommodation for people with disabilities should be comfortable, secure and safe providing quality care that meets the needs of the person with disabilities.

As a mother I want my children to be happy. My son with disability deserves to have a life in his community where he feels he belongs, where he is respected, protected, cared for and provided with activities that help him continue to learn about the world and to feel he is making a meaningful contribution no matter how small through the things that he does in his life. My son with disability has a value that few see at first instance but in knowing him as I do, I know his value is unique and sacred and my hope is in time others will see that too.