

noc 21/7/08

Submission No. 951
(Inq into better support for carers)

What have you done to our voice?

I ask every single one of you to *really* view our world, the carers world, and decide if this is the Australia that you would want for your sons and daughters if by an accident of either life or birth or an acute illness *your children* find themselves walking for decade after decade in our shoes.

The carers world is a constant battle for every service and support that we need to enhance the quality of life of those we love and in so doing perhaps also making our own lives a little easier. It is a world where our identity is lost. We are often isolated from family, from friends and community and are forced by both default and by the inaction of our governments into becoming non-entities, to become both the voiceless and the disempowered people of our nation.

This inquiry is playing yet another part in this disempowering, forcing us yet again to be non-entities. It has silenced our right to speak out as who we are, and that is citizens who have equal value to every other citizen who has been allowed to give voice in their own name to the myriad of government committees and inquiries that have gone on before this.

This committee has decided that we will not be free to be recognised as who we are before even one of our words is read.

This is an inquiry about carers where carers are being reduced to faceless and unidentified letters. This sadly is a continuum of the way we are forced to live our lives and says much about the way government has determined we should remain.

We who make submissions are not to be acknowledged as the writers, our complaints will remain faceless. This committee has gone for the final humiliation of reducing us to initials on a page. Every inquiry gives the option of withholding names, to allow people who do not want to be recognised by their name on their submission a way of speaking out while remaining anonymous. *This inquiry also has this option.* If we decided to remain recognised as the authors, you have decided to remove that right.

This inquiry is about us, but steps have been made to remove the only thing that remains democratic in our lives and that is our right to stand up, be counted and to be heard as individuals who are (were) allowed to participate using the right to free speech.

Removing our names without permission and without request is censorship.

You say on the website that our submissions will remain nameless "because our submissions are of a personal nature". I think the many carers who have told me that they have written to this inquiry deserve recognition for who they are, what they do and what they think.

This is the first time that I am aware that any government has gone to this length to deliberately devalue such a large group of people.

After submitting to this inquiry, we get a letter from the committee saying;

INQUIRY INTO BETTER SUPPORT FOR CARERS

Thank you for your correspondence dated July to the committee's inquiry into Better Support for Carers. It will be presented to the committee for consideration at its next meeting.

If your correspondence is accepted by the committee as a submission to the inquiry, you should be aware that the inquiry process itself is a public one. As such the committee usually decides to publish submissions and a copy will be placed on the committee website at:

The way I read the above notification, the Committee will decide whether or not the submission made is acceptable. What makes a submission acceptable? Content? Whose politics decides?

Our Lives

The Australia that carers live in may as well be a light year away from the one that you, our elected representatives inhabit.

Yours is the land of opportunity, *ours* is the land of opportunity lost.

Most Australians view this nation as the country of the 'fair go' but there is nothing fair about the way our government, the people who ask us to vote for you in the hope of creating a better, fairer and stronger nation, *a nation for all of us*, refuse to acknowledge the plight of so many people. We are denied opportunity, denied support and denied the right to be heard in a nation that prides itself as democratic.

As carers we unite in a cause that is not just for our own survival but the survival of those who are not so articulate, those who are so deeply weighted by poverty, by despair and all too often the hopelessness of their existence. Many carers live lives that have become totally overwhelmed by the crushing of their dreams and their spirits that they barely make it through each day intact.

It does not have to be this way. Every child born, whether perfect or not is a precious and wonderful gift, a life worthy of opportunity, a life worthy of compassion. Every family starts out in a similar vein, with hope, joy and expectation in their hearts, for the precious and beautiful life they are about to bring into this world.

For those of us whose expectation of giving life to the 'perfect' child who will progress easily through each and every one of their expected and eagerly anticipated milestones is not to be, it can become catastrophic.

Instead we find our beautiful special child needing 24 hour nurturing and guidance to reach their own 'individual' milestones and when we look around for support, compassion and guidance, we find door after door of resistance. Our entry into this foreign land, where every single day becomes a battle that is not of our own making, but the making of our governments is fraught with despair.

Every child is born with ability, the abilities of children with disabilities are just different, but it means that their needs are far greater. This does not mean that they cannot achieve, it just means they need help to do so.

Few children who have greater needs than most ever get the services they deserve to progress to their capabilities, because Australia offers very little in intervention services or therapies and what they do offer are a short term band-aid solution, doled out begrudgingly when families are in extreme crisis or at the end of coping.

Children whose parents are not articulate, who do not know how to battle bureaucracy, who do not have the ability or emotional strength to fight every inch of the way do not even get to access these less than adequate services. It is shameful and the pressure it places families under often tears them apart, which means instead of a battle for two, it often becomes a battle played out by one.

As parents most of us are determined that our children will achieve to their potential and that means, because few services are forthcoming, that we have to give up our own opportunities to ensure this will happen. Parents instead become untrained therapists, doing the best that they can. Every achievement becomes a diamond that people who are not in our position will never experience. The problem is that getting there takes a toll. It fractures our relationships with spouses, it drains us of the ability to give what we should to our other children and they often suffer greatly as a consequence. This means that our society

will also suffer as a consequence of the inability of the family to nurture all of our children in the way they deserve.

Often our sons will grow up without fathers, or our daughters without mothers. It drives families under, it steals spontaneity and it creates a different sub-class of people.

Such is the lot of the families who become carers in our wealthy but unwitting nation.

As our children grow into adults, little in our life, the life of the care provider changes. Opportunities are denied in every conceivable way. Parents who have become carers cannot become income earners because there are few services or supports that will allow the possibility of working and actually keeping the wage intact.

The band-aid system continues into adulthood, slapped on top of the ones that are festering from childhood. These are the band-aides of extremely poor service provision for all-of-adult-life.

Historically the family unit cared for sons and daughters with profound disabilities across their lifetimes, with siblings inheriting the care. The extended family stayed close, allowing both emotional and physical supports. Both the current and boomer generation have found that dad going to work and supporting the stay at home mother-nurturer was a social response of the past, it has come to pass that it now takes two incomes to feather a nest, and extended families scatter across a global world.

The stress of trying to live in a 21st century economy with a profoundly disabled child is nigh impossible and in its stead we have seen much stress placed on these families with divorce and fragmentation in around 80% of families. The outcome of this is social and financial poverty for the person left with the care role. The carer, isolated and bereft, realises they cannot go it alone and eventually seeks to either end the care role, or to demand a human response from our governments with services to assist.

It is a massive demand that someone will give their entire adult life over to another's needs with the only reward being heartbreak, uncertainty, fear and eventually death.

The siblings, many who have grown up in poverty and within fractured families, understand the strain and hopelessness their families endured and are not willing to accept the caring role as their ultimate legacy. Why would they when they see for themselves the government response? Who would choose isolation, divorce and hopelessness as their future options?

If Australia does not address the fact that we under-fund disability services by 300 - 400% and does not start to plan for the future we are going to reach a crisis of mammoth proportions in the next decade.

Governments have, by removing choice in whether to care, continue to care or not, have also removed from the caregiver their fundamental human right, of freedom of choice.

Every conceivable opportunity is denied to the person living with disability and because of that, they are denied to the carer who is forced by omission to take up the neglect of a nation.



**HOW OLD DOES MY MOTHER HAVE TO BE
BEFORE THE GOVERNMENT WILL HELP?
MY MUM IS ALREADY AN
AGED PENSIONER**

**She has been pleading for help for
A QUARTER OF A CENTURY.**

**What is going to happen to me?
My mum is all I have...**

**I am blind, deaf and intellectually disabled.
If she dies I cannot even call for help.**

Five people in every hundred who need adult accommodation services currently have them. This means that the other ninety-five out of every hundred eligible people are living their entire adult life with their unpaid carer (usually parent).

These parents need their own opportunities as well. Many of them are exhausted and at the end of their capacity to keep going. Many are poverty stricken, not because they would/will not work but because the service system and the taxation system conspires against them to ensure they cannot receive financial advantage if they do.

Every tax cut that is given to the broader populace is given on the backs of our vulnerable children and our own abandoned lives.

Many Carers have no assets, no retirement, no nest egg, nothing but a future of more of the same destitute level of barely surviving until death.

If you - our government are to have the expectation that families will provide decade after decade of free care that so handsomely rewards every other citizen of our nation, then you should see to it that your expectations and our efforts are rewarded with an income that keeps us above the pit of despair.

No country should expect so much, and yet offer so little in return

Professor Robert Cummins released his report into carer health and wellbeing in October, 2007 titled the *Wellbeing of Australians: Carer Health and Wellbeing*. This report verified that carers have the lowest well-being of any group of people in Australia in both a physical and mental sense.

Carers and people living with disability cannot be separated.

Carers need supports for people with disabilities and they need supports to assist them in the care role if the person they care for needs attendant services

Past submissions to a myriad of enquiries whose recommendations have all been ignored by successive governments tell the real story of government apathy to our plight.

What carers need is to avail themselves of the same opportunities as every other citizen of this nation. What carers need in order to do this is to have a choice in the direction of our lives and a clear voice at the policy-planning table.

There is so much data on carers and people living with dependent disabilities that no words that we can possibly speak are new.

In recent times we have had two major inquiries that cover the subject well.

The Balancing Work and Family report as well as the Inquiry into the CSTDA, both whose findings in relation to carers and people living with disability have been ignored. The Balancing Work and Family Inquiry has great social importance in what it is that Carers need in order to avail themselves with similar opportunity that is so freely given to other Australian families. These opportunities would allow us to participate in our own economic lives. The recommendations of this inquiry acted upon recommendations of what parents of trophy children needed, but ignored what parents who are forced by omission of services to be carers needed.



Every one complains about
WorkChoices

But are silent that caring families have

NoChoices

We have been abandoned
by all political parties

This excerpt from a radio interview with Nigel Scullion in May 2007 says it all. When government speaks about their priorities, they are *NOT* for humanely funding Disability Services in Australia.

Disability Services in 2008 are still tossed the dregs of every government funding allocation.

"The FaCSIA budget in the 2007/2008 Budget is a total of an additional \$4.5 billion, so it's a tremendous amount of money, and that's going to be used to further support families, children, people with disability, carers, indigenous Australians and older Australians. So that's quite a wide stretch across the FaCSIA budget, as you can imagine".

"But we're delighted - I can say that I'm certainly delighted that there's been such an injection. That's broken down into principally...as people would be aware, childcare has had a huge injection of some \$2.1 billion. There's been \$1.4 billion for seniors. There's \$406 million that's going to be for carers". (Carer's bonus).

There's an additional \$66 million for volunteering - and made an announcement actually yesterday, for completeness, for another \$4 million for volunteering".

Here is the clincher

"One of the most important initiatives, I think, is the \$128-odd million that's for disability services. I know already from the feedback I've had about the continuation of some of those services that it is very important in that sector.

* Transcript of interview with Nigel Scullion and Chris Ellison in May 2007 produced by The Captioning Studio

The conversation above allocates 14 times more for additional childcare for children less than 5 years of age than services for the disabled across an entire spectrum of ages from birth the 65. It is really saying that if you have trophy children, we (the government) will go all out to assist you so that you can continue having a social and economic life while your child is dependent.

Yet he (Scullion) dared to put his tongue in cheek and publicly call it (disability services funding) 'one of the most important initiatives'!

A huge reverse message was also sent to families whose children will always need attendant care support (0.3%) - by refusing to respond to the unmet need - the message comes across loud and clear - if your child has disabilities and needs lifelong support/care - we (government) don't give a damn - we might toss a few crumbs from the table of plenty, just enough to hoodwink the public that something is being done. Why? Simply because you (government) that it is still possible to get away with this because you believe we have no collective voice.

Nigel Scullion said in that interview that the lousy 128 million was very important to that sector.

WHY? Because the disability sector is given the least amount of funding for the unmet need of any public sector and is caving in from lack of resources.

This sector is under-funded by 3-4 hundred percent.

CARERS RIGHTS

The United Kingdom 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.

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

Australia offers no rights at all for carers. It expects a lot but gives very little in return

In the past few years, economists have increasingly looked beyond conventional measures of growth to the field of psychology and subjective concepts when considering wellbeing in society. However, the focus on happiness as it relates to utility in economic theory dates back to the 18th century, evolving from debates around the role of public policy in maximising utility across society as a whole.

Utility was defined as people's ability to meet their needs, and optimise their wellbeing. Conventional analysis has focused on income, which in turn reflects consumption possibilities, as its main determinant. In 2004, the Australian Government Department of the Treasury produced a Wellbeing Framework.

The framework draws on the early utility-based welfare economic theory that maximising aggregate utility corresponds to maximising societal wellbeing.

The Treasury's Wellbeing Framework comprises five dimensions: the level of opportunity and freedom that people enjoy (i.e. the capacity to choose the lives they want to live) the level of consumption possibilities (i.e. people's command over resources to obtain goods and services to satisfy their needs and wants) the distribution of consumption possibilities (i.e. the spread of all aspects of consumption across the population, including across different groups in society, across different geographic regions and across generations).

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How has it come to this?

It is simple, our governments has depended on carer social isolation to keep the status quo going, The introduction of the information super highway - world wide web, where information is but a few keystrokes away has removed any possibility of carers remaining isolated and not claiming their rights as full citizens of this country. Carers groups have popped up all over the country, uniting and growing and demanding that they be heard.

Carers have realised that their lives are firmly entwined with politics, that politics and politicians define their very existence. It is the lack of willingness of governments to listen to and acknowledge our ability to self advocate and our ability to see with perfect clarity the changes that are needed for our families to survive. This was the impetus for carers to form their own political party, the Carers Alliance.

Government is still under the misconception that it is still able to stop the rise of carers demanding an independent voice by handing disability family advocacy over to already formed government appointed boards – the Carers peaks, which are currently funded as government information support. This is too little too late and will fail because there will be no independence, it will be controlled and answerable to the government of the day. It is too late for this kind of tokenism, our voice must be our own, it must be formed through grass roots groups joining together to achieve true advocacy, advocacy that they both want and need.

Through carers own personal advocacy and social networking and the formation of our own collectives across Australia over the past few years, carers unfunded advocacy has achieved what decades of disability advocacy has not, and that is making the public aware of this shameful blight on our collective conscience, the massive under-funding of the sector...

YET... Government refuse to fund our voice. It refuses to fund Disability Family Advocacy that carers can relate to and be a part of. Government refuse to both fund our voice or to give acknowledgement to our great efforts in bringing this shame into the public arena.

Carers have told you that they need to develop their own grass roots democratic advocacy and carers have been ignored even though the National Advocacy Review has twice recommended this funding of a national voice for families who care.

Australia funds a myriad of 'peak' advocacy for Disability, the Aged, Mental Health and Chronic Illness but refuse advocacy for those who provide 91% of all services nationally, for the very people that government depends on to keep the system going.

WHY ARE WE EXPECTED TO SURVIVE ON PRACTICALLY NOTHING?

The Carers Payment (which is poverty level survival at best) is made not because carers cannot work or will not work but because governments penalize carers if they try to work. This alone is oppression and violates our rights to live a life that is not of our choosing and not constrained by poverty.

Carers need either services that allow us to work or compensation to assist with the cost of care.

This can be tax relief or payments to offset the cost of care. The Balancing Work and Family recommendations are a start. Carers should also be compensated commiserate with the amount and level of care required.

The Federal Government provides for families with young children –

**statistics taken from the ABS Yearbook Australia 2007*

Child care support

“To help families with children to participate in the economic and social life of the community, the Australian Government supports their access to child care”.

Child care services include centre-based long-day care, family day care, in-home care, before and after school hours care, vacation care, occasional care, and Multi-functional Aboriginal Children's Services. Flexible services that can combine various models of care are also available to meet the needs of families in rural and remote areas. To assist these families we also provided:

1. 522 billion Childcare support with a further increase in 2007/08

**(2.400 billion additional childcare dollars budgeted in for 2007/08)*

13.534 billion on family assistance payment (Part A &B)

6.048 billion on parenting payment

0.855 billion in maternity allowance

0.049 billion immunization allowance

4. 818 billion parenting payment

2. 101 billion youth allowance

2.869 billion disability and war widows' pensioners

8,256 billion disability support pensions

20.588 billion on aged pensions

2.824 billion on service pensions

40.7 billion on residential aged places

1.145 billion for programs for ageing Australians

1.409 billion for State and Territory contributions to programs for ageing Australians

**ALL THIS MONEY TO EVERY CONCEIVABLE NUANCE OF OUR SOCIETY AND
WHAT DO CARERS GET FOR CONTRIBUTING OVER 34 BILLION DOLLARS WORTH
OF 'FREE' CARE TO THE AUSTRALIAN ECONOMY?**

2.479 billion on carers allowance and carers payment

3.8 billion dollars per year for all disability services nationally to support the carer within the care role and to support *ALL* people living with disabilities who are aged under 65, who need support and assistance as a joint contribution from the Commonwealth and the States and Territories.

A PERSONAL EXAMPLE OF CRISIS CARE AND SUPPORT NSW STYLE

Timelines are not exact, as they are dependent on memory

- July 2004 unusual behaviours getting more pronounced.
- July 2004 Contact DADHC in regard to finding help.
- Asked for advise on professional medical/mental health services, was advised to take her to the Doctors
- August 2004 Discovered the existence of the Disability Clinic
- Told of 2 year waiting list, only one such clinic in NSW - burst into tears
- Arrange an 'emergency' appointment for November
- Contact DADHC and was told they new about the disability clinic – just 'forgot' to mention it.
- November 2004, run a series of tests and advised to see Disability psychiatrist.
- Appointment for March 2005, few specialist psychiatrists in all of NSW.
- December 2005 daughter becomes foetal, minimally responsive.
- Medical Practitioner suggests schizophrenia, medicates.
- Jan 2005 starts post school programs
- Difficulty adjusting due to illness.
- March 2005 See psychiatrist – diagnoses schizophrenia.
- March 2005 contact DADHC for behavioural support.
- July 2005 contact re behavioural support
- October 2005 contact DADHC for behavioural support
- January 2006 contact DADHC for behavioural support
- March 2006 contact DADHC for behavioural support, they sent info on day care programs for mental illness.
- Contacted programs and told that they are inappropriate for intellectual disability – no support – and dangerous to young girls like my daughter
- May 2006 DADHC comes around to take daughters name for accommodation support, they were starting a 'new' list (lost the old one?) And I thought that I should include her on it.
- Sends respite form for overnight respite, which is inappropriate to her current needs.
- June 2006 contact DADHC for behavioural support to discover name removed from list
- June 2006 Ring Ministers office screaming, told they will contact DADHC's office.

- June 2006 Contacted to say I will be contacted
- July 2006 meeting at post school program, SURPRISE DADHC psychologist at meeting.
- Told they were thinking of a program to teach intellectually disabled people about their illness.
- July 2006 That was it! Psychologist spent two afternoons observing Tess.
- 1st Sept 2006 Sent email to psychologist asking for a care package
- Told that Tess had been referred for case management she would chase me up.
- 5th Sept 2006 sent psychologist a detailed care program I had designed for the minimal supports I believe Tess and I need to make it possible to contemplate continued in-home care.
- Reply email asking if there had been problems that necessitated asking for this or did I discover this possible option and decide to apply!
- To date – 1st October 2006 I have heard nothing, and the psychologist is now on holidays.
- November 2006 Mental Health class begins – problem - it is designed for mild intellectual disability when my daughter has base moderate intellectual disability, she enjoyed colouring in the books though, understood nothing at all. Other people in the class were independent, some also chain-smoked – very unsuitable
- Therapist finished the 6 classes, Christmas break, therapist left DADHC
- February 2007 I rang DADHC to find out when I would get replacement therapist. Told that the service was closed, *my daughters' needs had been met. I outright refused to accept this and demanded she be re-instated as needing support – name back on the list.*
- August 2007 – Crisis again, behaviour difficult, mental health declining. Demanded support. Decided without support I could not continue the care role. Wrote to the Minister and said I was going to cease the day-to-day care of my daughter. A meeting was arranged and I was promised support.
- Meeting with DADHC and my daughter's advocate.
- August therapist called to say he would be working with her.
- Therapist visited home, discussed problems and decided to review her at her day program (only 2 days per week)
- Therapist visits day program a few times
- Therapist rings to say he is transferred
- Sept 2007 First respite weekend in four years
- February 2008 contacted therapist to demand to know what was going on. Told that services were transferred to another psychologist – he would contact me
- April 2008 contacted by new therapist. Told he would be reviewing daughter at day program
- May 2008 therapist started visiting day program to work out an action plan
- June 2008 therapist goes overseas for 6 week holiday
- July 2008 substitute therapist is reviewing while therapist is away
- July 2008 have to be forever vigilant, as my daughter of late has become Houdini.

CONCLUSION



I NEED HELP

It is really scary being me because
I cannot take care of myself.

The government ignores me. It must
be because *I have disabilities.*

My mum say's they must want me to beg.

**I would but I don't know
how...**

It has been 4 long years of heartbreak, fraught with difficulties for my daughter who is so very needy of assistance. In those four years we are still waiting at first base for appropriate assistance.

Sleeping fitfully is a thing of the past.

NOTHING MEANINGFUL AS FAR AS ASSISTANCE HAS HAPPENED IN THAT TIME.
In 4 years she has accessed 1 full week of respite care and 2 weekends
This year she has accessed a flexible respite package.

DISABILITY SERVICES ARE NOTHING BUT A LIST TO NOWHERE

DESPERATELY NEEDED SERVICES FOR ADULTS WITH DUAL DIAGNOSIS

NSW does not even offer appropriate mental health services for dual diagnosis intellectual disability/mental illness

** See mental health paper attached*

RESPITE CARE

The carer accessing breaks – time to recharge and refresh the batteries – or so says the government in media releases.

Respite care has now been reduced to 'flexible packages'. In plain English this means just three hours of assistance per week instead of centre based overnight stays.

A service that is hardly a service is now called respite so that governments can say they have provided X amounts of 'more' or 'new' respite packages when in fact it provides around 150 hours of support per.

*Even these 'respite' episodes are hard to come by they are a 30- 60 page application for a lucky dip.

My 'local' centre-based respite service is 15 km away. (even though we have 6 centre based day programs for hundreds of adults with a disability within a 5 km radius)

NSW calls respite – dropping the person you care off after 3pm and picking them up before 9 am the next morning and delivering them back again at 3pm to repeat this performance over the number of days allocated for 'respite'. The carer can still do nothing but remain 'on call'.

They also charge the daily pension rate for this less than adequate service, which means even while running around and doing their job for them, using petrol etc, they still expect you to pay for it.

The assumption must be that a person with a disability must not have to cover their rent while they are at respite care.

For families living on destitution level of benefits, it means the loss of rent component, electricity etc for those days as well – if they pay it – many refuse. Interestingly they only charge in some areas, not others. Discrimination based on where you live?

DISABILITY HEALTH SERVICES

Developmental disability health is in crisis

Policy and program development across the Australian Governments should ensure adults with an intellectual disability are availed the same right of access to mainstream health services, mental health services and disability services as experienced by the general population when in pursuit of reasonable quality of life.

Developmental disability should not mean poor health outcomes.

Urgent unmet need:

- Developmental Disability Teaching Hospitals attached to universities.
 - All N.S.W health areas should have a disability clinic
 - To provide assessments of complex need.
 - Specialist facilities
 1. Therapists
 2. Speech pathologists
 3. Physiotherapists
 4. Dentistry
 5. Nutritionists
 6. Psychiatric services
 - Travelling Clinics are necessary for remote centres
 - Funding of Specialist Practitioners training and ancillary staff training.


 - All health areas should have a Developmental Disability Mental Health care beds separate from the general populace and from behavioural disorders.
- These clinics should work in conjunction with government to develop suitable programs for best of all-of-life health and welfare outcome

SUCCESSION PLANNING

Many primary carers live impoverished lives accumulating few assets to leave to either for their child with a disability or their other children. The entire family can grow up in poverty.

Why would siblings volunteer for the same lives their parent/s lived for decade after decade? Many of our children are tertiary educated, paying off hex bills and developing careers. Yet it is expected by our governments that our sons and daughters will continue the 24/7 care of their sibling when the parent/s die.

If family members openly choose to provide care, that is one thing, but the current climate tricks family members into believing that this care role is just for a short time while government seeks or puts into place the correct accommodation service for the individual involved.

	<p style="text-align: center;">SIBLINGS SAY NO!</p> <p>I love my sister but I want the opportunity to have a family of my own.</p> <p>Governments expect siblings to <i>inherit the care role</i> so that they can continue to massively under-fund disability services.</p> <p>Government neglect of disability services saves a staggering 7 billion dollars. Paying the price are families - with their futures</p>
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SIBLINGS SAY NO!

**Governments cannot steal
OUR FUTURES**

Cost-shifting the free care and support of disabled
siblings across the generations is **IMMORAL**

DISABILITY TRUSTS

Governments have gone for the idea of succession planning in a big way. Last year saw the advent of the Disability Trusts.

Few families will use these trusts while they are under the auspice of the Protective Commissioner.

Why would they? The office of the Protective Commissioner is self-funded. If families have read the submissions into Elder People and the Law, they would seriously think twice about these trusts and instead form their own trusts making them impossible to break.



**How can I support a family of
my own if I am expected to
look after my high needs brother?**

**My brother deserves a better life
than I can offer him**

**GOVERNMENTS MUST FIX
THE BROKEN DISABILITY SYSTEM**

WHAT CAN AUSTRALIA DO?

HOW CAN GOVERNMENTS BETTER SUPPORT CARERS?

IS THIS A SERIOUS QUESTION?

We have had many reports and so many reviews and inquiries

THE FIRST THING IS THAT CARERS NEED RECOMMENDATIONS OF INQUIRIES, REVIEWS ETC TO BE FOLLOWED, INSTEAD OF IGNORED


Recommendation 1

Funding of grass-roots Disability Family Advocacy on a Regional, State and Federal level so carers have a voice in the policymaking which defines their quality of life

- Carers have been demanding a place at the policy-making table and are largely ignored.
- Carers will support a new voice through an advocacy organisation built from grassroots carers groups.
- Carers must be stakeholders in their national voice, representation must be democratic with representatives elected not politically appointed.

Recommendation 2

New funding formula with population-based benchmark funding for disability, mental health and aged care services, to meet the unmet need for services and support. Particularly the provision of both supported accommodation and accommodation supports

	<p>SIBLINGS SAY NO!</p> <p>If governments currently accommodate 5 of every 100 profoundly disabled people, where are the other 95?</p> <p><i>They are cost-shifted (using coercion) by governments across the generations.</i></p> <p>How fair is that Australia?</p> <p><u>Fix the broken disability system</u></p>
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Recommendation 3

Federal legislation, which recognises the carer role, and legislation that entitles carers to support.

Recommendation 4

Respite a right

- Expansion of centre-based respite to improve access and allow for greater flexibility in the way respite is tailored to family situations.
- A right to access centre-based respite.

Recommendation 5

Implement the findings and recommendations 18 and 19 of the Balancing Work and Family Report regarding 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.
- Recommendation 19 (8.53) The Department of Families, Community Services and Indigenous Affairs make access to its funding programs more flexible, including the \$19,000 per child per annum under the Inclusion Support Scheme, so that community groups and businesses can establish child care centres that have expertise in the needs of children with a disability and allow the development of after school hours care and vacation care for special needs children.

Recommendation 6

The Carer Payment and allowance should be streamed according to the whether or not attendant care is required commensurate with the weekly 38-hour wage of a paid care worker.

Recommendation 7

A specific tax levy to pay for disability services, potentially linked with either Medicare or corporate and individual taxes

Recommendation 8

Motability Scheme similar to the UK, with graded mobility allowances

Recommendation 9

Adult day programs to be 5 days per week with hours of programs running long day care hours - 8-6 for working carers

Recommendation 10

Implement the findings of the Senate Inquiry into the operation and funding of the Commonwealth State and Territory Disability Agreement with recommendation 21 implemented immediately.

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.

Recommendation 11

A one-stop point of entry for services and support when a family member is diagnosed with a dependent disability

Recommendation 12

Every child with a disability deserves intervention therapies and supports in a timely manner. Set up a voucher system which will allow children to access private therapists within their own communities

Recommendation 13

Ratify the UN Convention on the rights of the disabled person, but also to be signatory to the protocol. Without the protocol, the UN Convention on the rights of the disabled person is just pure tokenism.

Nell
Parent/Carer for 23 years