Australian
Productivity Commission

Disability Care and Support

Submission

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Submitted by: Gippsland Carers Association Inc
On behalf of family carers of persons with
Dependent Disabilities.

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Introduction:

The Gippsland Carers Association Inc is a wholly voluntary, self funded and self managed information, peer support, advocacy and dedicated family carer organisation, consisting of family and community members providing unpaid accommodation, care and support to persons with a disability, handicap or frailty.

The Association is representative of some 24,000 unpaid family Carers of people with disabilities and frailty throughout Gippsland in Victoria. However, our influence stretches far beyond the region itself. We are actively involved in networking with caring family groups across our state and nationally as a part of the National Carers Coalition.

A critical factor in the formation of the Association is the lack of commitment of successive governments, to ensuring that all families caring for persons with dependent disabilities receive support via their own grass roots funded family support and advocacy networks. By political design, this neglect occurs, despite the fact that families provide more than 92% of the supported accommodation and personal care needs of persons with dependent disabilities across the entire nation.

We were established in 1997 and rely entirely upon the support of caring families, local service clubs, local government, philanthropic grants and generous citizens.

Governments are continually looking towards academics, professionals, government departments, the funded disability services sector and the funded disability advocacy sector, when seeking to examine the delivery of services to disabled citizens and the families who care for them.

There is often open anti-family aggression from service providers and disability advocacy peaks that belittles the role families play in caring for our most vulnerable citizens. We have long sort for family carers; equality with disability service provider peaks and self advocacy organisations, which are funded at regional, state and federal levels by both tiers of government.

We draw your attention to comments made in submission 845, to the Better Support for Carers Senate Inquiry 2008 by the Australian Federation of Disability Organisations (AFDO) in relation to family caring, which said in part;

> "AFDO would like to see carers acknowledged for their contribution to society, but that acknowledgement should also include an understanding that the work of carers should actually be the work of paid professionals"

This is a back handed slap on the back for family carers, which says; but, we want you out of the equation and **only** paid professionals in the job. There is just one way that AFDO's desire to have only Paid Professional Carers in the disability care sector to be realised and that is to demand a national care and support scheme so huge that it will rid the nation of caring families altogether. That is clearly a ridiculous proposition for governments.

It is imperative therefore that the Productivity Commission understands how this neglect of unpaid family carers leaves vast numbers of families out in the cold in every consultation process.

A very real question to be asked by the Commission is 'how in the world the majority of unpaid family Carers will know about this inquiry when they have **no funded family/carer network voice** to widely distribute this information or to speak for their majority?'

We make the critical point in writing this submission that at least 50% of unpaid carer families, care without any links to services or funded organisations at all, as the findings of the ABS, Survey of Disability Ageing and Carers (SDAC 2003) clearly shows.

The wealth of data already available to the Commission demonstrates the undeniable fact that caring families '**as the major stakeholder'** in services provision to people who need assistance with daily living because of their disabilities; **are seldom listened too**.

The failed and failing state managed disability services system is clear evidence of critical neglect, indifference and discrimination in delivering to people with dependent disabilities the support they should have in a humane society. The real choices they have a right to expect under anti-discrimination legislation do not exist.

Customised data obtained from the ABS Survey of Disability Ageing and Carers (SDAC) 2003 estimates that the number of Victorians with a severe or profound disability aged over 30 years and living with co-resident aging parent carers is **13,600. These persons will all now be over ‘37 years old’.** There are “NO” Plans by the Victorian Government to address the issue of impending homelessness for all these citizens when ageing parents become to ill to care; or die. The following media story reflects this clearly.

Passing years, lack of options taking toll on ageing carers SARAH-JANE COLLINS – The Age - January 25, 2010

EVERY day Barbara Higgens helps her son Neil get dressed and ready for day care. She lays out his clothes, helps him brush his teeth and checks that he's cleaned under his arms.

At 72 Mrs Higgens has been caring for her youngest son for more than 40 years. In March Neil will celebrate his 41st birthday at home with his Mum and Dad, who now feel they are too old to keep up with his care. "Years ago you were healthy and you just got on with the job and you didn't complain," Mrs Higgens says. "But gee, it's got to the stage where your health fails a bit and small problems become big problems. I suppose that's age for you."

Intellectually disabled, Neil has epilepsy and asthma, as well as limited use of his right hand.

"It's the behaviour of what you get of a young child. He can't read and he can't write but he understands a lot of things," Mrs Higgens says. The Higgenses are one of hundreds of Victorian families waiting for suitable supported accommodation for a loved one.

A parliamentary report on the system released earlier this month found elderly carers were struggling with the demands of their role, and that there was insufficient accommodation available to fix the problem. For Mrs Higgens the biggest problem is that there is no solution on the horizon for when she and her husband, Neville, can no longer care for Neil. She says the Department of Human Services has offered Neil possible placements in Warrnambool, Terang and Colac but none were suitable because of the distance from the family home in Geelong. "Geelong is really where he's got his friends and I feel if you cut him off from the family and then you take all the friends away by sending him out of the area it wouldn't be good for him."

The parliamentary inquiry heard that Mrs Higgens' problem is widespread in regional Victoria. "There are inconsistent accommodation and support options currently available to people with a disability living in rural and regional areas," the report says. It recommends a redistribution of services in regional areas to better reflect unmet demand.

Opposition community services spokeswoman Mary Wooldridge said while welcome, the report did not reflect the desperation of elderly carers. "I have seen the tears of ageing parents who are too afraid to die for fear that their vulnerable adult child will not receive proper care and accommodation," she said. She called on Community Services Minister Lisa Neville to urgently act on the report. Ms Neville said the Government was making record investment in Victoria's disability and mental health sectors. But she acknowledged there were problems with ageing carers.

"The committee raised a number of areas that we need to have a continued focus on, including providing support to older carers [and] responding to the needs of an ageing population," Ms Neville said. Mrs Higgens, who's son has been on the waiting list for 7½ years, simply wants a solution. "It's just got too much and we're getting too old," she said. "You just get to the end of the road, and I just want something settled before I die, and my husband too."

The same extrapolated customised data as that used for Victoria, reveals that the national numbers of persons with dependent disability who would be in the over 37 years bracket and living with ageing parents in 2010 will be over **55,000.**

Latest figures released by the Victorian government reveal that as at December 2009, there were: 193 people statewide waiting for day time activities; 1,234 people waiting for support to live in the community; and 1,291 people waiting for supported accommodation options as recorded on the Disability Support Register (DSR).

Note: People with disabilities cannot access the DSR unless they have an immediate need for a service. This is DHS Policy since the introduction of the Disability Bill 2006.

The impending ageing carer catastrophe can also be said to be a catastrophe for all the families who with generous heart care for 92% of children and adults with severe or profound dependent disability and give up many of their own life chances in order to 'fill the obligation void' so obviously rampant in Australian government services.

This clearly shows that the state and territory managed disability care and support system fails in meeting their obligation to our most vulnerable citizens and therefore the obligations to a fair and just society today. The situation for many elderly and aged carers is obviously untenable at this very point in time as extracts from a state-wide newspaper article of last week show**:**

Disabled carers afraid to die - Herald Sun, Matt Johnston -Tue 20 July 2010

WIDOWS and parents in their 80s are being forced to remain full-time carers for their disabled children because of a lack of state-supported housing. Carers have told the Herald Sun they are ``afraid to die" because they don't know what will happen to their adult children.

More than 2700 Victorians have their cases waiting on the State Government's disability support register, up about 7 per cent in the past year. That includes almost 1300 people waiting for housing options. Marjorie Burnstein, 83, said her son just wanted to live in his own place. The pensioner says she is scared about what will happen when she dies.
``We are trying to get into a government-supported place but it's very hard," she said.
``I'm 83 and I'm not going to last forever."
Opposition community services spokeswoman Mary Wooldridge said "carers were ``crying out for help" but many had been left feeling abandoned by the Brumby Government. ``They are forced to wait in limbo for support they need and deserve," she said.

Marie Hell, who leads the group Disability Capability, said parents wanted more involvement in accommodation options. Ms Hell, who lost her husband this year, is now sole carer of her disabled son and says she will not give up until her calls for help are answered.
``People are afraid to die, they are just terrified of leaving their son or daughter to an uncertain future," she said.

The Government said about 280 extra supported accommodation places across Victoria are now being built. Community Services Minister Lisa Neville said the Government was committed to helping vulnerable Victorians.

It is clear from the response of the Victorian state Minister; that the commitment to helping vulnerable Victorians is a very pathetic and weak response in the face of the burgeoning disaster waiting to engulf our most vulnerable citizens.

A look at the 2010-11 state budget papers reveals that increased funding for supported accommodation over the next four years will deliver just 20 new shared supported accommodation places (capital and operating)

As the 13,600 ageing parent carers of the dependently disabled in Victoria become to frail, ill and die leaving all these vulnerable people without a roof over their heads who will cry out that this is shameful?

When adults with dependent disabilities find themselves dumped into a crisis driven and crisis managed disability care and support system; who will cry out that this is shameful?

It is our hope that this Inquiry into a **Care and Support scheme** will bring an obligation upon all Australians and will for the first time, make the dream of entitlement to a care and support service for people with dependent severe and profound disabilities **a reality**.

It is hoped that a Care and Support Scheme will be introduced in time to save at least some broken families from ill health, heartbreak and an untimely death.

Part one - Setting the Scene

What is this Care and Support Inquiry really about?

1. It is about getting rid of all the rhetorical arguments over why people with disabilities should not have free choices in 'where they live', 'with whom they live', 'how they live' and about 'what support services they need to achieve their goals to live normal lives.

2. It's about fixing an ad hoc system of state and territory government management of an under-funded and age discriminatory disability service system managed by a bureaucracy that is in love with itself and its own self serving policy dogma.

3. It's about removing 'funding scraps' off the budget table for disability care and support by disparate jurisdictions; jurisdictions across whose boundaries people with disabilities and their entire families cannot cross if they hope to take their support services with them. This clearly violates a citizen's Constitutional right to 'move freely across states boarders' in our nation.

Victorian Carer- "On face value I would have to agree with this (national care and support scheme) very strongly - the pain caused by DHS to us and our son (with severe challenging behaviour) - is "almost criminal" and when we finally found a suitable support service - **in NSW** - we have to jump through very high hoops to get the funding transferred (from Victoria) to NSW (ADHC). DHS insisted that the only way for cash to flow to the provider was that we had to transfer our son to NSW care ADHC (using the NIPP (National Interstate Portability Protocol). In the end ADHC (NSW) refused to have anything to do with the program - and we ended up with the service provider being paid a small amount just a few days before our son moved to NSW, times when no money was being paid to the provider and now, with them having to operate on "payment on invoice" ie payment after the fact - with up to 60 days payment terms. Such an arrangement is unsustainable, was unfair and caused us a lot of angst. Such an arrangement would also prohibit any reasonable business from ever wanting to start up something new! I would support going national as this would eliminate the need for such stupid so called "protocols" which don't work, and would allow people the freedom to move around Australia and choose service providers as they see fit. It might also bring all suppliers up to the highest standards,. it might also bring some down. So we must be sure to get the federal scheme to adopt best practice and drive bad operators out of the business - starting with DHS Victoria's own - Disability Accommodation Services."

4. **It's about questioning State and Territory governments who think it's OK to be the legislator, the provider of funds, the assessor of eligibility, the deliverer of services, the monitor of quality assurance, the keeper and controller of unmet and under-met needs and the dictator of policies that refuse to give people with disabilities any rights, real choices or entitlements**.

5. It's about taking the funding of disability support services out of the charity bin and into the realm of **rights and entitlements** in a society that claims it is **'fair'** to all Australians.

6. It's about rebuking a federal government that practices **'age discrimination'** in supported accommodation services; because it accepts full responsibility for residential services for frail aged persons over 65 years with a system of benchmark funding, but, does not ensure comparative benchmark funding for persons with a dependent disability aged less than 65 years in state and Territory managed services.

7. It is also about 'why it is the responsibility of all Australians' under our Constitution and under every 'human rights mantra' we pretend we believe in; to change the argument from charity to entitlement because it is wrong on every level of belief that we as Australians have in ourselves and our democracy. Some examples of this belief follow.

Australians and their national governments (through legislation and regulation) support and believe in:

- A welfare scheme that ensures no-one is without funds for basic sustenance
- A compulsory national health scheme that delivers health care to all Australians
- A national supported accommodation and care scheme for our frail elderly
- A superannuation scheme for all paid working Australians
- Insurance against accident for paid workers
- Insurance against motor vehicle accident for all Australians
- Insurance against inflicted injury by another
- A minimum wage for work performed
- A regulated paid work retirement age
- Paid maternity leave and subsidised child care for paid working families
- Compulsory education for all Australians
- Human rights and anti discrimination regulations and legislation
- And the list goes on and on……

So why don't we also have a National Care and Support Scheme for people who are born with or who acquire a dependent disability before the age of retirement?

We have to take a bold step into the future to stop the crisis in its tracks. It has been festering for a long time and every indicator tells us that the current system of unpaid care cannot be sustained.

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]

Unpaid Family Carers & their role in Disability Care and Support

The writer of this submission on behalf of Gippsland family carers is a hands-on and full-time carer over a time span of more that 47 years.

She has raised three children with disabilities, two sons with Phenylketonuria, and a daughter with profound disabilities as a result of the Rubella Virus. A life-time of care and positive parenting has led her two sons into contributing adult lives to the best of their abilities. Lives that include marriage, parenthood, paid work and community volunteering in Scout Leaderships, Fire Brigade and Charity Centres! These are lives, which would make any parent proud of their achievements in spite of their disabilities and handicaps.

Her daughter, now aged 41 years, is however an entirely different story. She is profoundly deaf, legally blind, intellectually impaired, and diabetic. She has a congenital heart condition, incontinence at night and is totally dependent on others for her survival. This is not her choice. She is apraxic and has no ability to initiate or communicate her needs. The writer has cared for her all of her life and still does, because the state care system has nothing to offer, and no plan for her daughter to choose to live in her own home.

Over the past four decades, the writer has involved herself fully in caring and contributing to the family income by working night shifts and weekends to ensure we could meet all the extra costs of caring and survival. Any spare time that could be managed was untilised as a volunteer in disability service provider organisations, and with many support groups; she is the founder of Gippsland Carers Association Inc.

Learning about how the system of care works, through participating in consultancies and discussion groups by the score, and persistently networking; a life-time of knowledge is accumulated making the writer an unrecognized 'expert' on the effects on persons with a dependent disability and caring without adequate supports.

This example of the role of the unpaid family carer in the lives of people with dependent severe or profound disabilities is repeated at least 706,000 times across Australia and the total number of caring families in the disability sector is at least 1.6 million.

Such dedication to family and friends with dependent disabilities contributes more than 92% of all their supported accommodation and care needs across the nation. As a consequence of this massive commitment to care, families have often placed their own health and wellbeing at great risk, because the system of supports is so sparse and almost a total failure for the many that still wait for any publicly funded assistance.

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 abundant research making very different claims about the impact on families, of failed supported accommodation and care policy.

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 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.***

Such pressure upon families is endemic within the current system of supported accommodation and care, which is clearly in crisis due to bad policy and inadequate funding.

Of all the inquiries we have given evidence too, the most recent took place in May 2010 at our regional Carer's Forum. It was to give evidence to the Victorian Law Reform Commission inquiry into Guardianship and Administration Law. The most critical of the issues raised by Carers is the fact that caring families feel and are intimidated by government departments, service providers and disability advocates alike. Some of the issues they raised were published in our recent quarterly newsletter (The Gippsland Carer June 2010) as follows:

Guardianship & Administration - **May Forum Review Discussion**

Carers were very vocal in their condemnation of the current legislation. Some of the issues for legislative change were:

- Participants said that the current system is not geared towards families and carers. The government strongly encourages family members to fulfill the role of carers but does not provide them with legal standing or adequate support.
- The G&A does not pay enough attention to what carers do. Provision should be made in the Act to recognise the carers role.
- Families are being treated as guilty and must prove they are innocent this must be changed; carers should be treated as 'innocent until proven guilty.'
- There is a strong need for carer support and advocacy with many local examples of how Guardianship can be lost to outsiders without direct support to families being given.
- It was believed by some that it is better to remain informal than to be caught up in G&A law and regulations that do not support families well enough.
- It was suggested that to deny plenary guardianship orders conflicts with the' least restrictive option.' i.e. if a person with a disability has some capacity they can appoint a family member as an enduring power of attorney!
- Some participants said that guardianship should be made ongoing where full-time care was needed and the person had limited capacity.
- It was suggested that guardianship is used as a weapon when carers have a conflict with service providers. Some carers have been threatened with orders if they did not comply with the wishes of service providers.
- Carers said that they felt pressured to take on the role of administrator when they do not want the role, some felt compelled under threat of appointing 'state trustees'
- In practical terms carers do act as administrators and they should not be required to undertake such matters as accounting as this is extra burden on over-burdened families.
- It was suggested that if a person with a disability lacks capacity and is cared for by family full time and their only income is a pension, family should be given an EPA and be exempt from annual returns because other pensioners do not have to account for their pension spending i.e. aged and others with capacity.
- Administration should only apply where large sums of money are involved.
- Carers stated that the alternative to full time family care was a group home that costs in excess of $125,000 per person per annum to taxpayers (because the state won't support anything else).
- Carers noted that there was a conflict within VCAT itself over the necessity for formal orders/ hearings are too formal and intimidation/country people do not have enough regional access.
- The OPA needs to be more accountable and respect the role of family in a disabled person's life. It was suggested that the OPA sides with services too much where conflict arises (between services and family).
- Services have a tendency to want to put people with disabilities into the community, but they take no responsibility for the associated risks. It was asked 'who are the people making decisions about dignity of risk?'

We have a plethora of carer stories from which these pleas for change come and were articulated to the Gippsland forum hearing. If we were to relate all these to this Inquiry we would need one hundred pages.

Perhaps the Productivity Commissioners would have a better understanding of the need for radical reform of disability services if we relate one of two of these stories here.

Carer Story 1- Only the names are changed to protect the family.

(a) James had applied for and was granted a Group Home placement for an adult with challenging behaviour in a specialist unit. It became a matter of concern to the parent that the adult child appeared to be suffering abuse at the hands of others. When seeking an alternative option failed, James felt forced to remove the adult from harm. Subsequent negotiations for a more suitable option failed at which time James was notified by the regional office of the Department of Human Services(DHS) that a Guardianship Order would be sought on the grounds that the parent was not acting in the best interests of the person with a disability because they would not accept a return to the facility described above . The Public Advocates Office sided with the DHS.

James was encouraged by our support group to make his own claim for Guardianship. To get help with this James approached the regional disability advocacy organisation for help but was told that 'they only advocate for people with disabilities not for families so they could not help'.

Note: a subsequent VCAT hearing found in favour of the Parent, but not before many months of stress and trauma were experienced by the family.

Carer Story 2-

(b) Agatha is caring for a multi-disabled dependent adult child in the parent home with access to facility based respite as an ageing parent carer. Some years ago the parent was asked to sign an 'indemnity form' to absolve the Department of Human Services (DHS) and all its agents from liability over the giving of medications in the respite facility.

Agatha declined to sign on the grounds that she did not have any legal authority to do so on behalf of her adult child who lacked capacity to sign. The parent was told that DHS would have to deny access to the respite house if the form was not signed. The responsible DHS officer made the outrageous threat that he might have to apply for a Guardianship Order so that the adult child could have access to respite.

Carer Story 3-

(C) Jemma carers for her two children with profound disabilities who are both wheelchair bound. She receives in-home help to care for them by a DHS funded not for profit organisation. Without any warning, or any awareness that there was an incident, Jemma received a letter from the Work Cover Authority telling her that she was third party liable to pay recovery costs for a paid care-workers alleged injury as a result of working at the family home. Jemma had not been told that the worker had claimed any injury or that she would be required to pay compensation to the Workcover authority for same. Jemma asked us to help her and we took the matter to the Media and the Workcover authority.

It transpired that Jemma was not entitled to an exemption under the worker regulations that exempt volunteers from liability and Jemma was told she could ask her House Insurance Liability to pay. Opposition parties joined forces to pass a private members Bill to exempt family carers from this legislation, but it was defeated by the government in the assembly of parliament. So much for valuing unpaid carers!

Carers Story 4-

> "For families there is no "natural justice" or due process, there is no legislation or union to protect us from malicious complaints (made against the carer by service providers and bureaucrats). 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"

We strongly believe that all families have a right to be protected by **legal recognition and entitlements legislation** if they are to be around for future generations of people needing care. Such attacks upon family carers, if allowed to continue, will certainly have a deleterious affect on unpaid caring both now and into the future.

We believe that people with dependent disabilities have a common law right (in the absence of a legal right) to have access to support services sufficient to give them living choices and a life that mirror those of the rest of our society. This is clearly not the case in 2010 in Australia because governments rely far to heavily upon caring families to carry the responsibility, with 92% of all cared accommodation and personal care needs being provided by families who feel coerced in a system deliberate government design.

We believe unpaid family Carers and those for whom they care are entitled to a decent standard of living, an adequate income and the right to enjoy all the benefits available to non-caring and non-disabled peers including the right to paid work and the right to retire from caring.

We believe that Family Carers:

- As citizens have equal rights to legal, financial, social and culturally normative lives free from discrimination, exploitation, isolation and prejudice.
- Have the right to access supports that sustain their ability to be fully participating members of society within the full range of choices available to the general community
- Are entitled to legislated recognition and rights, the utmost respect and full involvement in decision-making, including Policy and program direction and planning.
- Unpaid family Carers have the right to choose NOT TO CARE and the right to expect that age appropriate and normative alternate care will be provided to dependent adult family members for whom the family cease to have legal responsibility post 18 years of age.

We believe that people with disabilities:

- Are citizens with equal rights to legal, financial, social and culturally normative lives free from discrimination, exploitation, isolation and prejudice.
- Have the right to access supports that sustain their ability to be fully participating members of society within the full range of choices available to the general community
- Are entitled to legislated rights and the utmost respect with full involvement in decision-making, including Policy and program direction and planning.

Caring for a family member or friend should not be a burden, but it often is, because of the lack of support services that are available to help. It is wrong that parents in their eighties and nineties are still caring for adult sons and daughters who are themselves middle aged and even elderly.

The media has responded to families pleas for help for decades. From the time of demanding the closure of failed large scale state managed supported accommodation services to the present day. ……..

The Age - State failing to house intellectually disabled - Carol Nader - March 13, 2008

IF Ty Cuttriss could speak, he would probably utter words of frustration. His mother Yolanda says he has a great desire to communicate verbally. He just can't. He has had an intellectual disability for all his 28 years.

Mrs Cuttriss is frustrated, too, that her son has been waiting for appropriate accommodation for 10 years. But there is no place for him. Instead, he lives with his parents, which has put incredible strain on the family. Their plight is not unique. There are some 1370 people with disabilities in Victoria waiting for supported accommodation, according to a report by the Auditor-General tabled in State Parliament yesterday.

"Sometimes you get so fed up and so frustrated with the whole situation that it makes it very difficult," Mrs Cuttriss said. "He's always demanding our attention, and so mentally and physically for us it's very wearing. You expect to care for your children until they're 18, but after that they generally are able to care for themselves. But not so for people with children with a disability."

Auditor-General Des Pearson found the Department of Human Services had taken a "reactive" approach to disability and had failed to provide support for all those requesting it. Demand was rising by 4% to 5% each year but the department had not accurately quantified future needs. "As a consequence, residential service recipients will suffer and the system will continue to be crisis-driven," he said.

The report also raised concerns about the conditions of some houses. The department itself had identified about 200 of its houses as not meeting building or occupational health and safety standards. Work had progressed on upgrading those buildings, but the department has received just $44.5 million of the $123.2 million it needed to bring the houses up to standard. It said in the past four years, the Government had created 77 new facilities to replace unsuitable ones but had not increased bed capacity. Some houses had an "institutional" mindset that catered for residents' physical needs rather than operating like a home where they were encouraged to develop independence.

It cited instances of incompatibility in shared accommodation that had adverse effects on residents. In one case, a resident had a disorder that meant they were not suited to communal living but there was no option than to live with others. Staff had to manage the resulting conflict. It said positive steps had been taken to tackle some "long-standing system shortcomings", such as establishing a framework to improve quality of support and accommodation.

National Disability Services state manager Kerry Presser, part of the report's reference group, said it proved the system was driven by crisis.

This family impact occurs because the governments of our nation don't care about the 'burden' placed upon an elderly family carer who has no right to retire and cannot unless they abandon care to a failed and crisis managed accommodation and support system.

This impact also occurs for families with children and younger adults who have disabilities because the governments of this nation and the people who put them there don't care about the 'burden' this creates for young families caring for children with severe or profound disabilities. The burden has led families to breaking point:-

Three die in Rosebud murder-suicide – MORNINGTON PENINSULA 'LEADER' 17 Aug 2009

Eddie Travaglia, 54, and his two disabled sons, Leigh, 30, and David, 27, were discovered at Mr Travaglia senior's home yesterday. Mr Travaglia had recently told the Leader about Federal Court action that was pending in relation to the care of his two sons. Both suffered cerebral palsy and were deaf. Police investigations are continuing, but there have been reports that Mr Travaglia had recently been diagnosed with prostate cancer and may have been concerned about his sons' ongoing care. The men were found at a home in Kennington Rd, about 10am (16 August), a police spokeswoman said. Police said they were treating the matter as a double murder-suicide.

"Investigators are not looking for a fourth party in relation to the deaths," a police statement said.

Mr Travaglia lived in Rosebud and his two sons lived in a supported care home run by the Department of Human Services in Mornington. Devastated neighbours told the Leader they were deeply shocked and saddened to hear about the deaths. "I have lived here for 20 years and seen those boys grow up," neighbour Michael Montebello said. "I would see them being taken to school when they were younger. They grew into big boys. "I only saw them two days ago. I am so sorry to hear about this. "I would always wave and say hello as they went for walks down the street. "Mr Travaglia struck me as a lonely man."

Other neighbours were concerned about what had happened in their quiet seaside town street. "We saw all the police cars and fire truck yesterday. This is just terrible,'' another neighbour said. It is not known who discovered the men's bodies. Last month, Mr Travaglia told the Leader he made a complaint to the Human Rights and Equal Opportunity Commission after his son Leigh was taken to a lingerie shop by a former carer. The carer allegedly bought women's underwear that was framed and later hung in the man's room, he alleged. Mr Travaglia said his son Leigh did not consent to the shopping trip in 2006 or to being photographed with the framed lingerie. He also claimed that the staff member, who allegedly did not know sign language, "could not effectively communicate" with his son. Mr Travaglia had started action in the Federal Court after an attempt at mediation via the Human Rights and Equal Opportunity Commission failed. Police are preparing a report for the coroner.

The 2007 Senate Inquiry into the Funding and Operations of the Commonwealth, State and Territory Disability Agreement (CSTDA) made it clear in their Final Report that they understood this burden in the following statement of their report:

"The Committee was acutely aware during this Inquiry that evidence of sub-optimal organisation and provision of disability services underscores an immense personal, social and economic burden affecting hundreds of thousands of Australians" [4.143]

"The Committee recognises that the weight of that responsibility on countless families is a crushing and unreasonable one, and that much greater community assistance in that task is urgently called for".

The final Report of the Senate Inquiry was released on 8 February, 2007, the report identified:
Substantial new funding for disability accommodation and support services as the Primary Recommendation out of 29 Recommendations.

But, nothing has been done to provide the "Substantial New Funding" that was recommended. So, what is the purpose of these Inquiries if government fails to act upon primary recommendations in the face of such condemnation of the disability support system?

We emphasise, in this discussion about 'the burden of caring' that the person with a disability does not create the 'burden' the failed care and support system creates the 'burden.'
The failed support system for people with dependent disabilities happens because we as a society allow it to happen.

THE STAKES ARE HIGH FOR CARING FAMILIES.

We would like the Commissioners to know that the vast majority of families care for loved ones with a disability first and foremost, because we love and care for them. We also want you to know that we are very resentful of the fact that successive governments and the bureaucracy that rules our lives have taken extreme advantage of this fact.

The industry that prospers from delivering a support service to people with disabilities has a love/hate relationship with the very families who are the sole reason why countless thousands of persons with dependent disabilities have a roof over their heads at all to this very day.

Nothing is more painful for a caring family to abide, than the knowledge that our contribution to the welfare of our dependent relatives and our contributions to society are recognised only by lip service.
Lip service by governments, bureaucracies, academics, so called disability professionals, service providers, disability peaks and chosen advisors who tow the government line are killing the golden goose; the unpaid family carer.

Some examples of how the system takes advantage of family carers across Australia:

Carer Mother 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."

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!"

Our silence is engineered by "shutting us Out" of the Planning and Policy Processes and denying us the right to have a region-based and funded family carer voice despite our persistent pleadings and our majority contributions to accommodation and personal care of people with dependent disabilities.

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 "un-Australian." Shame, shame on them.

We make the critical point that the issues we raise have been repeated again and again and again to Inquiry after Inquiry, to consultation after consultation and review after review for decades after decade. We are exhausted by this process. We strongly believe such tactics are by deliberate design to dampen down demand and discourage descent.

The fundamental rights of people with disabilities must be the same as all other citizens but they are not. The fundamental right of our citizens of all ages must be that they do not suffer age discrimination but they do.

Discrimination in care and support choices is clearly why we desperately need a National Disability Care and Support Scheme that will forever reform the way that people with disabilities and their caring families are supported.

- Anyone at any time may be struck down with a disability.
- Anyone at any time may find they have a child with a disability as an accident of birth or illness.
- There but for the grace of god, go you and you and you!
- This is a whole of society issue and the whole of society needs to respond.

For far to long the decision-makers of our nation have ignored the very real consequences of failing to prevent the destruction of entire families struggling almost entirely alone to care. They do this because unpaid carers contribute $32 billion worth of unpaid supported accommodation and care to the nation annually, which allows taxpayer funds to be spent elsewhere.

The time for change is now.

Family carers are tired, stressed, dragged down by acquired illness and poverty because we care. We are the 'forgotten people' 'shut out' of mainstream family life; shut out of the right to paid work, annual leave, superannuation, days off, sick leave and equality.

The time for massive reform is <u>here now</u>, before unpaid care disappears.

We therefore ask the valid question of the Productivity Commission, will you ensure that the Australian Government will be 'Doers of Reform' and not 'Sayers of Reform' to ensure that care and support becomes a 'right' and an 'entitlement' to better support people with disabilities and those who now care for them?

Part 2: The Care and Support Scheme Key Questions

Who should be eligible?

People with a 'dependent disability' under the age of 65 years should be eligible for services under a disability care and support Scheme. That is to say, children and adults who have a severe or profound dependent disability, who rely upon therapy services, aides, equipment, home modification, personal care and support, supported accommodation, supported education, skills development services and supported community access activities, without which they cannot live a meaningful life.

Where families choose to accept the responsibility to provide supported accommodation and personal care they should also be entitled to be eligible to receive support services and respite.

Which groups are most in need of additional support and help?

As carers we know that the 'powers that be' in the state and territory managed disability sector have an agenda 'to make themselves look good' in the statistical numbers stakes. This leads to greater inclusion of those who have smaller or lesser support needs.

There is a current culture of trying to sidestep people with profound dependence and challenging behaviour, those with intellectual disabilities and those who's care and support will be for the term of their natural life. An example of this classic sidestepping by the bureaucracy as told by a caring parent is as he wrote it thus:

"My eldest son John (not his real name) was six when he was correctly diagnosed as suffering from Prader-Willi syndrome. In the last 11 years or so, my family have become experts on Prader-Willi. Indeed between us we have, collectively almost 44 years (not including John's own 17 years) experience of this genetic malady. Yet who decides what services John will have access to? Who decides where and how he will be cared for in the long term? Who decides what type of future he will have as a welfare dependant person? Perhaps someone who has, maybe, if we're lucky heard of Prader-Willi in a brochure somewhere. Who do you think is the expert judge of John's life chances? But who do you think will make those choices? I want to paint a short word picture for you. I hope you will get my point.

Some years ago, John's violent behaviour meant that it was becoming increasingly dangerous for him to stay in the family home. Physical restraint had become, often, the only way of managing his violence. Oh yes we had tried the chemical options but they either zonked him out or didn't affect him. So, finally, we organised a meeting of the various health professionals who would be able, or so we thought, to give us some guidance.

We met in their offices, over coffee. We chatted, but as many of you know, both from within the professional ranks and those of you who are now "customers", the chat was not really getting the results we had come to find. So, I finally said, and I'll never forget this moment. It will haunt me to my grave. I said, well if you don't find some form of accommodation for John my partner and his brothers will have to move out. It's too dangerous for them to stay. A momentary silence fell over the room. I saw a change come over the face of one professional and she said. So, you're telling us that John's brothers are in danger! I felt like saying - No I'm telling you the moon is made of green cheese!! Well, in that case, she informed us, they (the brothers) could be removed by court order if we weren't able to ensure their safety. If you can't guarantee their safety, then they could be removed. **Who is in denial here?"**

The above evidence is a typical departmental reaction to a family asking for a place for a child or adult child with challenging behaviours or profound dependence**. "We will remove the 'normal children' so that you can care for the one with the profound disability"**

This culture of denial of need must be removed entirely from a reformed system of care that is funded adequately by a national Care and Support Scheme with entitlements to assessment and appropriate services to meet the needs of the individual.

Those who have the greatest need for help and support are therefore, people with:

1. A severe or profound dependent disability whether from birth or acquired
2. Challenging behaviours
3. No, or poor decision-making capacity
4. Dual dependent disabilities
5. Adults over the age of 30 years still living with ageing parent carers
6. Children for whom early intervention will reduce the effects of disabilities
7. Aides and Equipment needs to assist independence/care support needs
8. Family carers who choose to provide supported accommodation and care for all the categories named above

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

Those who have a profound or severe dependent disability whether by birth or acquired as a result of an accident, or illness, or with a decision-making incapacity must have priority over all else. Only when all these needs are met will it be fair or equitable to extend "Care and Support" to those more able.

Fairness is in the eye of the beholder. Is it fair for one person to receive funding of say $130,000 to live in a supported group home setting whilst his peer living in the family home is likely to receive nothing or a great deal less, and his peer receiving one/one behaviour support around the clock costs four times as much. To ensure Equity and Fairness there must be:

1. National responsibility for the funding and delivery of a Care and Support Scheme to eliminate state/Territory based inequities of which there are many.

2. National 'benchmark funding' of service types designed with tiered levels of need bands, identified through a thorough process of checks and balances to ensure that a National Funding Scheme will meet the needs of a multitude of disability accommodation types, levels of support, aides and care services.

3. Population based Benchmark Funding to ensure all states, territories and regions have their needs met equitably by weighting of services to rural and remote regions.

4. A comprehensive national 'standard assessment tool/s' to measure the level of dependence and level of need of each individual person with a disability.

5. An 'entitlement to assessment of need' and 'the right to access funding and support to meet those needs' including an assessment of family needs where families are willing to provide a care service.

6. Complete freedom of 'choice' to access all accommodation options that are available to the rest of our community and the funding to accommodate the need.

7. A national and completely independent quality assurance system to ensure that services meet, 'optimum quality standards' with penalties for non compliance.

8. A separation of powers to ensure that the existing failed disability system is removed. The current system where the government is the funder of services, policy-maker, quality monitor, assessor of need and deliverer of services is a dual state and not-for-profit system that is divisive, competes on very unequal terms and fails.

9. A variety of funding models which will include Individual Funding packages, with the ability to choose self/family/administrator managed, brokered/ block funded and portable options.

Who gets the power?

Power is a complex issue when dealing with a National Care and Support Scheme that is to be funded to ensure that people with dependent disabilities will have their needs met.

There is a place for considering a 'Medicare type scheme' that will be built around the 'equity and fairness model' as suggest above. Such a framework would be delivered by an independent body charged with responsibility to manage and distribute the funds.

Power will vest with the federal government to ensure legislation is in place to safeguard the scheme and its managers, establish rights and entitlements for the person with a disability and where necessary the families as providers of services.

Power will also vest in the people chosen to establish the protocols, standards and the assessment criteria for the scheme. There are inherent dangers for the person with a disability and/ or their family if the usual practices of government are followed.

Traditionalists and bureaucratic controllers are often placed on panels to make reform decisions that are tarred with the failures of the past. This scheme will need to be swept clean with a new brush.
Academia, bureaucracy, service provider/disability peaks and hand picked individuals are a repeated theme of government policy-making to the detriment of non discriminatory service provision. These are often people who have vested interests or are far removed from the realities of care requirements and far removed from the wishes of people with dependent disabilities themselves who have most to gain or most to lose from this process.

History is littered with the failures of these methods to reach decisions about the lives of people with dependent disabilities and the families who care for most of them. The monumental failure of the institutional model of care for example, has nothing to do with the size of the roof of a building, as state bureaucracies would have us all believe. No, it has everything to do with the failure of successive state jurisdictions to plan, deliver, monitor and sanction itself for the failure.

The current move away from group homes as an option for community living are indications of a falling out of favour by states jurisdictions for the very same reason as there predecessors the large scale institutions, government mismanagement!

We repeat that the institutionalisation of people with disabilities has nothing to do with the size of the roof of a building and everything to do with the management of the service. The failures and responsibility for those failures rest entirely with the states and Territories who deliver the service.

No matter how one looks at the unequal power vested in states managed services for people with dependent disabilities, the supported accommodation services fail because they are self serving of a bureaucracy that is out of control and dictatorial in restricting choices and options.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

The power needs to be put back into the hands of people with dependent disabilities themselves; and for those who cannot speak for themselves, the families who have demonstrated their commitment by delivering 92% of all their supported accommodation and care needs on a daily basis.

People with dependent disabilities and/or their families should have the power and freedom to choose a variety of living options, such as stand alone housing, units, clusters, hostel style, village style, age appropriate nursing level of care facilities etc. In other words all the options that are available to other Australians, either throughout life or in retirement.

People with dependent disabilities and/or their families should have the power and freedom to choose a variety of funding methods including block funding or individual support packages, whether self managed, brokered by a service provider, managed within the family or by an appointed guardian.

With compulsory funding of a care and support scheme for all people with dependent disabilities the current scarcity of living choices will be eliminated. This will happen because the proliferation of customers seeking choices will create a demand for all the options currently banned by the discriminatory state and territory systems which must be reformed by national regulations.

With the right level of care and support, many families will choose to continue to provide supported accommodation and personal care, but equally people with disabilities who today have no choice but to live with families will be set free to choose their own path in life.

This means that the first steps in this process must be the establishment of funded region-based carer family networks and the reform of region-based disability networks to ensure that the voices of people with dependent disabilities and their caring families are put first in the policy and planning processes for the national care and support scheme.

This also means legislating for an independent, National Disability Review and Complaints Process that will be overseen by an **Ombudsman system** with the **'power to act'** where discrimination is found and complaints are upheld.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

This means legislating 'rights and entitlements' to assessments of need and access to the funding to meet those needs for both the person with the dependent disability and their families.

The Care and Support Scheme will establish population based benchmarks for the delivery of services, 'benchmarks' for the cost of each type of support service that will be categorized and be based upon an agreed level of tiers of support such as Intensive, high, medium, low need etc.

This will be decided by an expert team of end users and professional advisors established within the new and independent Disability Care and Support scheme.

What services are needed and how should they be delivered?

People with dependent disabilities have the basic necessity to have a home in which to live and the supports needed to live there. They also have a need to receive an education, skills development, employment where possible, access to their own community, the opportunity to have friends, recreation and leisure and links to family.

Supports should be provided in the least intrusive way possible by services that meet the identified individual needs of the person and their family where applicable.

The services will be delivered by non-government providers; both not for profit and private sectors should be included.
The standards, rules, regulations, accreditation, sanctions and grievance procedures will be a national responsibility.

Unless states and territories are willing to divest themselves of direct service provision and age based discriminatory practices, then the services should be devolved by the national government to local government or to local management committees.

What kinds of services particularly need to be increased or created?

As previously stated our carers association obtained individualised data from the ABS SDAC 2003, which identified some 55,000 Australians with a severe or profound disability, aged over 30 years still living with ageing parent carers. **These persons will now aged over 37 years.**

- **These all have a right to be living in their own homes of their own choosing – they must have urgent priority in supported accommodation choices.**

Contrary to the propaganda contained in many of the state departmental publications about people with disabilities living in their own homes in the community, these persons are not living in their own homes they are living in our homes.

The normal expectations that families have is that their children will grow to adulthood bursting with the desire to leave the parental home and establish their own homes and families. Very few of these adult children decide to remain in the parental home and then only by mutual agreement.

For adult children with severe or profound dependent disabilities this is seldom the case. Neither they, nor their parents have any say in the matter and that is what must change first in a funded national care and support scheme.

For people with this level of dependence living in their own homes requires a quantum shift from current policy and planning dogma. Providing real choices in living options means getting rid of all the hang-ups of bureaucracy about where, how, what and with whom they may live.

This means government involvement in providing bricks and mortar as well as support services because people who were born with or who acquired a lifelong disability do not have the resources or opportunity to acquire a home by themselves.

If all living options are to be put on the table to eliminate discrimination then every possible option both here and elsewhere must be investigated and supported by the community and the care scheme. This has to be a top priority of a new scheme.

There is clear evidence that the rationing of funding for support services has created a decades long generational void in meeting the needs and under-met needs of people with dependent disabilities and the families who care for the majority with little or no respite.

This shortage crosses over all facets of the service system and does not need to be repeated in answer to this question. The question is, how do we identify the gross shortage for everyone to understand? **This shortage in funding is why we have long supported a system of population based benchmark funding for disability services.**

We have over a number of years previously published a detailed proposal for the introduction of a **Population based Benchmark Funding Model for disability services** because there is already a Benchmark Funding System for our dependent elderly that provides over **233,000** supported accommodation beds and community care packages, of which **175,472** places are for residential service beds, but no comparative model exists for disability services.

It is a matter of gross neglect that we suffer a system that refuses to provide the same benchmark funding criteria for services to our dependent kin with disabilities who are less than 65 years.

This has given rise to the fact that governments only fund a mere **16,600** supported accommodation packages, for people with disabilities despite the fact that there are twice as many persons who are aged less that 65 years and who have a dependent disability that requires care. There is a simple formula that is based upon the severe and profound incidence rates in the population.

Benchmark Funding in aged care currently delivers **233,000** supported accommodation beds and community care packages derived by applying a population benchmark of **113 places per 1000** of the population aged over 70 years. This can be related to the severe and profound incidence factor.

The S&P incidence Factor applied to Benchmark funding:

- The over 70 years of age incidence rate of sever/profound population is currently 22.5%.
- The 15-64 years of age incidence rate of severe/profound population is static on 3.9%.

Comparing the above ratios we create an incidence ratio of 5.7 / 1. That is, 5.7 units or care packages for the 70+ populations to every 1 unit or care package for the population aged 15-64 years.

This means that the disability support sector population benchmark should be 18/1000 of the total population aged 15-64 years.
Furthermore it is a logical step to look at the current planned aged care allocation of 113/1000 of the population aged 70+ and say this figure equates to 11.3% per 1000 or approximately half of the severe/profound incidence rate of 22.5%.

When applied to the people with severe/profound disability the allocation benchmark of 18/1000 becomes 1.8% per 1000 or approximately half of the severe/profound incidence rate of 3.9% for under 65 year olds.

The Figure below shows the number of beds/packages to be applied to disability services utilising the 18/1000 benchmark as described above; to the Australian population of people with a severe or profound disability aged 15 to 64 years:

Australia:
Australian Disability Population Benchmark utilising ABS – population estimates July 2010 of 22,396,000 rounded

Pop 15-64	% of total population	18 /1000 benchmark for beds or support packages
15,005,320	67	370,240 places/ packages (rounded)

This figure of **370,240** places/packages compares to the current national allocation of a mere 16,600 supported accommodation places for people with severe or profound disabilities or 2.5% of an estimated 700,000 or more persons in this category .

This is clearly age discrimination, but Cabinet Ministers and senior bureaucrats shamefully allow it to continue year after year and decade after decade. Why?

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

By providing:

1. A National framework, national standards, national accreditation and national sanctions developed by an independent Care and Support Scheme that will be delivered by the non government and not for profit sector (with possible entry by the private sector)

2. Direct Service delivery will be taken out of the hands of state governments and be devolved to the non-government sector under government regulation and oversight.

3. Legislated rights and entitlements to assessment of need and funding to deliver the assessed services for both the person with a disability and the primary family carer.

4. Costs benchmarked over every freely chosen accommodation and support option based on a tiered structure of funding, upon assessed level of dependence and urgency of need.

5. Services benchmarked to include tired levels of funding graded according to degree of support required.

6. Day-time activities remodeled to include choices to retire from perpetual training, with leisure and recreation services geared to including older adults in community norm activities.

7. All supported accommodation and care options should be put on the table and delivered by free choice. This will reduce the supported accommodation costs through diversity.

8. Partnerships between government, not for profit organisations, for profit groups and families should be canvassed to encourage innovation, quality supports, cost benefits and coordination are optimal.

9. For Carers their rightful place at the policy and planning table – this means establishing; **as a matter of priority**; regional Carer Support Networks to provide peer support at the **grass roots** level and a direct voice to government and policy makers.
10. Carer services that include ‘long day care’ for adults with severe or profound disabilities to allow unpaid family carers to enter re-enter the paid workforce
11. Respite services for all families who choose to continue to accept the responsibility of full time care. This must include facility-based and holiday-length respite as a priority.
12. Supported accommodation system that ensure that all adults will have access to their own living accommodation before their family carers attain the age of 65 years and before the age of 35 years for the individual who chooses independence, whichever is the lesser age.
13. Therapy and support equipment (including home modification) upon assessment of need.
14. Personal care services that include assistance for children and adults to access education services in line with normal expectations of their non-disabled peers.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

All of the issues outlined in this paper are addressed by a Disability, Carer and Support Scheme that puts people with disabilities and their caring families squarely in the middle of all decisions with the supports required, as articulated in previous questions.

What should be done in rural and remote areas where it is harder to get services?

The introduction of full Population Based Funding of disability services will allow the new service system to rationalize funding to take into account rural and remote area management. i.e. These people could have their level of support funding raised to the maximum level for each category.

Housing may be more affordable than in the big cities, but remoteness may require extra travel funding etc.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

- Make the management of Disability Services a National Responsibility with Policy, standards, assessment standards, evaluation, complaints and sanctioning criteria that covers the nation.
- Make one reviewable Individual Support Plan to be utilised by every service provider including government departments
- Take government out of direct service provision
- Introduce a national service provision reporting system

Funding

A new scheme will need more funding, and people will need to be confident that funding will meet their future as well as current needs. How should a new scheme be financed?

There should be:

1. A compulsory National Medicare style Levy that is contributed to in a similar manner by all Australians.

2. Federal, State and Territory Governments should also contribute half the cost to the Scheme from existing taxes i.e. 50/50 federal/state contribution to half the cost of the scheme.

3. The introduction of Population based benchmark funding that will take into account the estimated number of people with a dependent disability to gauge current and future demand.

4. Benchmarks should be set to cover the broad range of service types that will be required including supported accommodation and nursing level of care services

5. User pays components of service – means tested - bearing in mind that adult people with a dependent disability may only have pension level income; and the parents of dependent children will need concessions due to the cost burden of care.

6. An immediate state and federal injection of substantial funding to alleviate current crisis management and remove high priority wait lists as evidence of intention to deliver a fair and compulsory system for the future.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

1. The Care and Support Scheme should be compulsory and operate in a similar manner to the Medicare levy as a stand alone independent agency of federal government.

2. The Federal and state governments should be required to pay at least half of the cost of the fund from existing tax collections 50/50.

3. The Federal Government should be required to pay at least $5billion from the future Fund into immediate alleviation of the current crisis.

4. $5billion from the future fund as a start up fund for the scheme to address ongoing urgent unmet demand.

5. There should be a Means Tested user pays system for adults with disabilities and for families of children with disabilities.

6. The State and Territory governments should continue to manage current services and urgent unmet needs under the current disability services agreements with the federal government **only until the new scheme comes into being**.

Organising and implementing a new disability policy

[A new disability scheme will change the way that people get services and how much they get. That will mean many decisions will have to be made about a new scheme, such as: the roles of service providers, people with disabilities, their carers and governments (eight governments are heavily involved in providing and funding current disability services)?]

This question goes entirely to why there needs to be a completely new service delivery system. It is clear that the current system has failed the majority of people with severe or profound dependent disabilities who require supported accommodation, care and support.

It is entirely feasible to have a national system of funding, rules and regulations that can then be delivered directly to people with disabilities, their families, service brokers, service providers, etc. (after all the aged care system is already managed wholly from Canberra and the health system is about to follow)

It is entirely feasible to have local governments manage the services in the same way the services are managed in the United Kingdom.

It is entirely feasible that disability services could be managed in a similar way to the local community councils the Health Reform agreements are planning at the present time.

It is entirely feasible that non government and not for profit groups could be funded directly from Canberra to avoid the wasteful bureaucracy that currently exists.

How risks and costs would be managed to make a scheme sustainable for the future?

This goes back to our argument about 'population based benchmark funding' and 'benchmark funding of each item of service provision'.

The more diversity that the scheme opens up in the way that services are delivered and in the choices that are made, **the more cost effective the system will be**.

Population growth projections will determine the level of increases that will be required to sustain the system into the future with regular assessment of effectiveness.

The writer recognises that there may be some people with a moderate disability who will have a need to access some support services under this scheme.

We equally recognise that not every person with a severe or profound dependent disability will want a home of their own. Some may choose to remain with agreeable families for long periods of time if both are happy and Carers are supported to remove the burden of care.

The writer also recognises that such options will be far more cost effective than most other living arrangements, however, **the exploitation of families as unpaid service providers must stop.**

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

- Take the bureaucracy out of determining for a person with a dependent disability where to live, with whom to live, how to live and what mode of housing to live in.
- Give the policy-decision-making power back to people with disabilities and their families.
- Allow people to choose their best mode of funding and planning strategy.
- Put practical people in the front line of policy and planning.
- Make the scheme simple to use and access.
- Create maximum diversity in living and support choices to reduce cost pressures.
- Take good care of carers; **they are your most precious and cost effective asset.**

How long would be needed to start a new scheme, and what should happen in the interim?

The scheme should take no more that three to four years to activate. The building planks should be kept simple if the Medicare Levy model of insurance is adopted.

The plan should be ready to put to the people of Australian before the next federal election in 2013.

We have already alluded to the necessity for an interim arrangement whilst this scheme is activated. The current crisis driven service system needs to be propped up until the new scheme comes into being.

The future fund should be utilised to provide an interim $5billion to the states and territories on a dollar for dollar basis.

This measure should:

- Be used to provide accommodation and support services to those on priority waiting lists and for emergency cases.
- Provide funding to divest state governments of direct service delivery as soon as possible.
- Establish regional Carer Family Networks that will ensure families have priority input at the policy and planning table.

The Care and Support Scheme should also receive $5billion from the future fund to commence immediate work on establishing the independent scheme as outlined.

Conclusion:

We are caring families. We care most about what happens to our loved family members who have a dependent disability. We would never have given up our own life chances if this were not true.

We believe we have a right to receive the full attention of the Productivity Commissioners in this Inquiry because we are delivering over 92% of all the supported accommodation for people with dependent disabilities across our nation.

The nation cannot afford a National Care and Support Scheme unless families continue to provide unpaid care into the foreseeable future.

How this freely given service is retained whilst giving caring families and their loved ones for whom we care the normal and decent lives everyone else aspires too is up to the Commissioners to recommend and for Government to legislate.

We would be pleased to discuss our submission with the Productivity Commissioners at a mutually agreeable time.

We commend our submission to you, to the various governments of Australia; and
to the people of our nation.