Australian
Productivity Commission

Draft Report Submission

Disability Care and Support

29 April 2011

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

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Overview

"Gippsland Carers Association Inc (GCA) is a dynamic, forward-looking Carer's support and advocacy organisation. We are entirely self-funded and managed by carers, former carers and community volunteers. Since our inception in 1997, we have provided peer support services, information, education and advocacy to thousands of carers within the Gippsland region, across the state, and indeed across the nation as a founding member of the National Carers Coalition (NCC).

GCA have a highly visible community presence through our shop-front premises located within the central CBD of Morwell, through region-wide forums held twice a year, the circulation of a quarterly newsletter, and more recently our own website www.gippslandcarer.org

We service the local carer community throughout Gippsland and beyond, we seek to influence the provision of services to the people for whom we care, particularly the provision of in-home support, long day care, flexible respite services and out-of-home supported accommodation services, aides and equipment; and for Carers, grass roots peer support, advocacy, recognition and entitlements.

We seek for these services to be driven by people's choices and not expediency, by rights and not welfare, by planning and not crisis management.

We are vitally interested in carer well-being, and the daily struggle faced by each and every family in caring for the vast majority of people with severe and profound 'dependent' disability in the family home with grossly inadequate resources, support or recognition.

We thank the Productivity Commission for their Draft Report, and for their very strong language in condemning the current failed disability care and support system.

We also express our thanks to the Commissioners for the opportunity to speak to the Hearing on the Draft Report recommendations in Melbourne on the 6th April 2011. This submission reiterates the matters raised at the Hearing and expands on those and other issues where time did not permit full discussion, with added detail and feedback.

There are a number of issues and omissions from the Draft Report and its many vital and overdue recommendations that we chose to address in the limited time made available to speak to the Hearing process. Matters discussed as priority issues included:

- **Current high levels of urgent Unmet Need for disability services**
- **The way forward in supporting family carers into the future**

Chapter 4 – issues

- **DSP - Carer Payments and the NDIS**
- **Transport and the NDIS.**
- **Mainstream education and the NDIS**

Chapter 5 – issues

- **NDIS assessments and the use of the 'reasonable' test**
- **Carer assessments as an entitlement**

Chapter 8 – issues

- **A quality framework for disability service providers**
- **Monitoring and evaluation of NDIS services**
- **An Independent Accreditation Process**
- **An Independent disability Ombudsman role**

Chapter 16 – Issues

- **Who should be covered by an NIIS**
- **Other Issues?**

Other Priority Issues!

- **Current high levels of urgent Unmet Need for disability services**

Due to gross neglect and endemic underfunding of the state managed disability services system over decades, the crisis has many caring families at the end of their endurance.

Carer health and well-being, financial resources, family stability and irreplaceable caring is now at great risk of collapse, a care role worth at least $30-$40billion P/A.

'Customised data' was purchased from the ABS-SDAC 2003 showing the number of people with disabilities who are living with parents who provide care and support. These numbers are shown in Fig 1. Below.

Fig 1. Customised Data for Australian's with disabilities living with a co-resident parent –ABS -SDAC 2003.

Persons receiving assistance from a Co-resident parent, by age of person	Profound Core Activity Restriction	Severe Core Activity Restriction	Total Profound and Severe	Total with a reported disability
0-15 year	74,400	77,200	151,600	198,800
16-29 years	20,400	33,200	53,600	112,000
30 years and over	***22,400***	***33,200***	***55,600***	***80,400***
Total 0-30+	**117,200**	**143,600**	**260,800**	**375,200**

Over 55,600 persons with a profound or severe disability, who were aged over 30 years in 2003 and who are now **aged over 38 years**, lived with **ageing parent carers**. This is grossly unacceptable for the people with disabilities and their Carers.

When the Government passes legislation to enable the NDIS to commence in 2014, it is likely that few of these 55,600 people who will then be over 40 years old will have their needs met until at least 2018 unless urgent measures are taken up front.

More than 3,000 Victorian people are on a waiting List for supported accommodation or accommodation support services. This list is called the Disability Services Register (DSR) and it only records those people who have an expressed need for a service NOW!

We accept that the Commission have recognised this issue, however we believe that the emphasis on the crisis that now exists, is not nearly strong enough and we urge the Commission to take a much stronger stand on the current crisis matters.

We need to save the many ageing parents and other aged carers from falling into any further irretrievable poor health, mental breakdown, or dying in despair. This is no way to thank unpaid family carers who have given up decades of their own life and aspirations to care.

The cost of alternate supported accommodation for just the 55,600 people now aged over 38 years who have a severe or profound dependent disability; and based upon your own estimate for an average accommodation cost of $61,000, this would require at least $3.3billion to be made available as an urgent injection of public money at the outset of urgent need.

We strongly recommend that the Productivity Commission, make more explicit and pressing statements of the need to inject *<u>considerable immediate Federal funding resources</u>* into the failed state-based disability support system to relieve the crisis in care NOW.

We commend to the Commission our submission to the Victorian Government Inquiry into Provision of supported Accommodation – Disability and Mental Illness - October2008, where these issues are discussed in detail. (Copy attached)

- **The way forward in supporting family carers into the future**

We acknowledge that the productivity commission has recognised that an NDIS will only be successful and sustainable with continued reliance upon unpaid family care into the estimative future.
However, the Commission seems to take little account of the fact that some 93% of accommodation and personal care services is provided in the family home by families denied adequate support and a structured and funded voice in the planning process.

We also note the Commission has recognised that disability advocacy is important and should remain a strong part of the disability support system for people with disabilities to be subsidised by the NDIS. However, yet again, the unpaid family carer is the poor relation within the recommendations that the Commission has made, because your findings fail to recognise or foretell of the need for advocacy for caring families.

The simple fact that funded dedicated advocacy for family carers is currently non-existent shows just how little our governments really value the enormous contributions carer families make to the welfare of people with dependent disabilities throughout the nation, contribution currently under-valued at $30-$40Billion a year and clearly taken for granted in the NDIS future plan.

Clearly these family carer gifts still do not merit an advocacy and support system for carers and the kin for whom they speak at least as widespread as that which less dependent people with disabilities currently enjoy! This is morally indefensible and unacceptable to caring families.

Countless submissions and reviews over decades have all strongly recommended the funding of disability family support and advocacy services. A Submission to the Senate Inquiry Hearing into ‘Better Support for Carers- 2008, by the Australian Federation of Disability Organisations said Quote: “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” unquote.(submission 845)

It is not only governments and their bureaucrats that insult and demean caring families, the disability advocacy sector itself heaps scorn upon our irreplaceable contributions. This poor treatment of family carers must not be allowed to continue into a future NDIS. There is an urgent need to provide an on-the-ground, grassroots carer support, information and advocacy service within regional settings, to give family carers the voice and the support they have a right to have.

An NDIS which leans heavily upon a continuing future reliance on unpaid family care, but does not take into real consideration the opportunity costs and risks to the scheme of not providing effective mechanisms that ensure future family care is sustainable, will be devoid of moral legitimacy, and as such will be at great risk.

Unless the Productivity Commission recognises, through its recommendations for the NDIS, that family carer support and advocacy should be placed into the centre of planning for people with severe and profound dependent disability, the percentage of unpaid caring will rapidly decline. Carer Recognition is not enough; you need to give Carers the on the ground support and advocacy services we have a right to expect, and to which we are entitled by virtue of our irreplaceable services to people with disabilities and to the national fiscal bottom line.

FYI, we are pleased to provide the Commission with our Carers proposal for funded Regional Carer Support and Advocacy Networks [as attached] and based upon our lived experiences.

A similar proposal to this was submitted to the Federal Government Budget Process in 2009 for the National Carers Coalition (NCC) and this submission was once again ignored.

We urge your strong recommendation that the NDIS fund such a scheme as a high priority.

Chapter 4 Issues –

DSP and Carers Payments and the NDIS

The Commission understands that the DSP should be outside the scope of the NDIS and rightly so as the DSP **is income support**. However, in this section, the commission makes the suggestion that possibly ***'other payments that are sometimes classified as income support such as carer payment and carers supplement , carer allowance , mobility allowance and child disability assistance payment are really payments for support of people with a disability, since they encourage the provision of informal care or address people's mobility needs'.***

This failure of enquiring minds to take account of the fact that family carers of people with a dependent disability are actually delivering an unpaid accommodation care and support service is yet another indicator of a dismissive approach to valuing the work of carers.

- The Carer Payment (pension) is INCOME SUPPORT for people who give up the right to paid work and/or have no other means of support.
- The Carer Payment is means tested and denied to carers who have a partner in work or who are in receipt of another pension such as aged or disability, etc.
- The Carer Allowance and carers supplement are paid to a family Carer for services rendered in caring for a person with a disability; therefore these must also be excluded from the NDIS scheme unless the **NDIS intends to provide family carers with a financial payment for caring services provided!**

The Carer Payment is 'income support' and must be excluded from the NDIS unless a means tested payment for caring is introduced.

The Carer Allowance is a token payment and must be excluded from the NDIS unless a means tested payment for caring is introduced.

The Child Disability Assistance Payment and Mobility Allowance could be considered as 'In the scheme' but only where the scheme provided the support services and adequate transport subsidy as a part of the persons ISP Funding arrangements.

Paying neighbours or friends to care, but not family members is specious reasoning and indefensible.

- *The Commission discusses the importance of people with disabilities having the option to manage their own individual support package, including the possibility of paying neighbours and friends to provide some of these support services. In so doing. It makes a clear distinction between the possibility of hiring a family member and/or paying the primary carer in similar circumstances.*

It is once again, extremely discriminatory to expect an unpaid family carer to continue to provide an around-the-clock care and support services without making it possible for such family members to be recompensed adequately. To suggest an ISP could pay a neighbour or friend to care, but ignore the poverty trap this continues to place on the family carer is an appalling affront to a family Carers dignity.

- Make the Carer Payment (what it's name suggests) a 'means test free payment' to all primary family Carers; and
- ensure the Carers Allowance is increased to a truly compensable level for work performed
- or; Recommend that the national disability insurance scheme, make a priority to ensure that personal care and support funding is made available to a family member, who accepts the primary care responsibility for a person with a dependent disability, aged over 18 years.

We strongly recommend that the Productivity Commission rethink their NDIS recommendations and take a second look at the possibility of ensuring that over-burdened family members are no longer discriminated against and exploited for their unpaid service by paying everyone but Carers.

Transport Issues and the NDIS

Transport costs to access education and adult learning services for people with disabilities in rural and regional Australia is high impact, often precluding access to any services where subsidised Taxi transport is the only available mode of travel for profoundly disabled people. We repeat the common issue here:

Kate (not real names) has two profoundly disabled sons, Jake who attends a special development school and the other Tom (having reached 18 years) now attends an adult day learning program. Both are wheelchair bound and require a vehicle with a ramp to travel. Kate's younger child is picked up by a private bus service funded through Education services. Kate sought access to the maxi-taxi service for the older child Tom, but was told that the service was so in demand that Tom could not be picked up until after 10am and would be returned home between 1.30 and 2.00pm as no other transport options were available. The cost of this subsidised taxi service would be $40 per day or $200 per week. Kate lives 20 km from the day centre. Tom stood to lose 2 and ½ hours of his program every day.
Kate asked DHS for help through individual funding and they suggested that Kate take Tom to school herself in her own modified vehicle. When Kate asked for an increase in funding to cover petrol costs she was told Tom had a Mobility Allowance i.e $83 per fortnight. It costs Kate $60 per week for petrol and an extra half hour of personal care for Jake, but the real cost to this Mother is far reaching in terms of commitment, stress and extreme burden.

- **There is a strong case for considering alternate modes of transport that may cost less than the very expensive Taxi program, especially in rural and remote regions.**
- **If the education department is able to fund private bus services for children with disabilities to access Special schools, a similar service should be considered for adult day programs.**

We strongly recommend that the NDIS include transport funding options where a person is assessed as having a profound disability and an unmet need for transport to access services.

Mainstream Education and the NDIS

4.5 – We believe there is a strong case for Mainstream education services to be overseen by the NDIS to ensure that children with dependent disabilities receive adequate personal care and Teacher aide support. This will be essential to optimize learning and relieve the burden on families who often contribute significantly to support in school for children due to the lack of aiding resources.

You do not have to look far to find many examples where children with disabilities have an urgent need for funding of teacher aides and personal carers to help them cope with school in mainstream and even special school situations:

Ellen Modra is suing in the Federal Court on behalf of her son Luke, now 21, under the Disability Discrimination Act. Ms Modra says staff at a school for autism in Melbourne conspired with a medical practitioner to prescribe her son, then about 12, with three times the recommended dose of antipsychotic drug risperidone. As a result Luke developed a neurological condition characterised by jerky, involuntary movements, she alleges.
She says he was also physically restrained and abused while in respite care and at school, including being locked for long periods in a courtyard. "The school was supposed to be there for people with autism, but we wound up in a situation where nobody loved him, nobody wanted him and he deteriorated," Mrs Modra told The Sunday Age. "They told us he was incapable of learning … the best they could do was try to contain him with drugs."
In May, Victoria's Senior Practitioner, Jeffrey Chan, called for a review of the increasing number of young Victorians in state care being "chemically restrained" with mood stabilisers and sedatives. Disability advocate Julie Phillips said she was helping several parents of autistic children whose schools had recommended medication. "Schools are increasingly making requests that parents consider medication, which is often linked with an inability to support the child in the class," Ms Phillips said. "They simply lack the resources to cope."

Another parent, who is considering suing the state over her son's treatment at a special school, said the school invited parents to a presentation on behavioural medications. "I was gobsmacked," she said. "They were essentially promoting drugs for our children. "Ms Modra said her son's school insisted he be medicated in order to attend, and that staff liaised directly with his doctor, who eventually increased his risperidone dose to three times the maximum recommended for autism. Extract from Sunday Age July 4, 2010

Schools telling disabled children to stay at home - Justine Ferrari, Education writer | *August 26, 2009* - Article from: The Australian

SCHOOLS are turning children with disabilities into part-time students by restricting their attendance hours in breach of anti-discrimination laws. Some school principals are limiting the time disabled students are in class to match the hours a teacher's aide or other assistance is available, Macquarie and Sydney university researchers have found. The study, based on surveys with principals in mainstream schools in city and rural areas of NSW, identified several practices that breach education and anti-discrimination laws.

The breaches included negotiating with parents to limit a child's attendance, sending children directly to doctors to obtain a diagnosis without parental approval and pressuring parents to enroll their children in other schools or support classes. The study also highlights the subjective nature of labelling children with behavioural problems -- responsible for a rise in the number of students with disabilities. One principal was quoted as saying: "Well, a behaviour problem at (this school) would be a child who just doesn't do what he's told."

Disability Discrimination Commissioner Graham Innes said the practice -- which advocacy workers confirmed occurred routinely in schools -- was in breach of the act.

"We had a little boy in Year 1 who absolutely refused to do what he was told," the principal is quoted as saying. "We came to an agreement that every Tuesday and Thursday, (the boy) stayed at home ... and he only came (to school) Monday, Wednesday and Friday. "We could only get funding for a maximum three days, no matter how bad he was, so that left us in limbo for two days." "The availability of time of a teacher's aide shouldn't determine whether or not a kid is at school," he said. "A child should be at school and receiving an education unless there's a valid educational reason not to be there, such as going to another facility or school. On the face of it, it's a breach of the law." Julie Phillips from Melbourne's Disability Discrimination Legal Service said the practice was routine in Victoria and she was aware of similar problems in Queensland and NSW.

We recommend that the Commission should include NDIS assistance services to allow children with disabilities to attend mainstream and special schools full time.

NDIS assessments and the use of the 'Reasonable' test.

Chapter 5 Issues

5.2 – The use of the word **'reasonable'** in assessing a person's needs for support is **very subjective** therefore the assessment tools used in the NDIS will need to be, not only rigorous, but should clearly define what is meant by the **'reasonable' test to ensure all factors are taken into account in assessments of need for NDIS support services!**

The reasonable test of what is expected from unpaid carers and the community is a matter for discussion here.

It is clear from the productivity commission's findings that the NDIS and therefore governments, will continue to rely upon unpaid family carers to ensure an NDIS is financially sustainable into the future, but for the family Carers in this report there is **NO QUID PRO QUO.**

WE commend the Commission for including Carers in the assessment process with an entitlement to assessment and support, however , the details of what that support might include outside of respite and referral for counselling seem to be absent from the discussion and recommendations and this now requires much further work.

We strongly believe that assessments for carers must take into account carer health, wellbeing and welfare measured against criteria that address the current research that "carer health and wellbeing have the lowest score of any sector of the community"

- This raises the bar in Carer assessments in relation to the support services offered to carers in response to their irreplaceable role and their own right to expect help with accessing the community in which they live.
- The proposal to allow care payment to neighbours, friends and untrained staff, but to exclude or limit any remuneration or increases in payments to family carers are wrong and will be rejected.

Gippsland Carers proposal that will support unpaid family carers in the regional networks where they live, thus encouraging their continued involvement in caring is a vital missing link in Carer Support Services.

A quality framework for disability service providers

Chapter 8 Issues

The monitoring and evaluation processes for NDIS funded service providers must include stringent measures based upon national standards and the penalties and sanctions for failure to comply should be stringent, and include the removal of funding where compliance is not clearly demonstrated.

- Gippsland Carers propose that there be **an accreditation process that includes an 'external agency' to monitor services and apply sanctions up to and including funds withdrawal**.
- The accreditation must include state and local government departments/agencies where direct service delivery is supplied under the NDIS.
- **We believe there should be an 'independent disability Ombudsman' to investigate complaints and sanction service providers where required.**

An NIIS and Chapter 16 Issues

There seems to be support for such a scheme within our region, however there are questions to be debated about the merits of the recommendations for such a separate NIIS.

Catastrophic injury can be attributed to an **accident of birth or early childhood, viral infections, acute medical conditions such as brain hemorrhage, etc,** where profound cerebral palsy, irretrievable brain damage and physical deformity occur and where physical abilities are all extremely harmed, requiring life-long care. **Questions to raise are:**

- How will the separate NIIS and NDIS ensure that equal support will be provided in each case where an NDIS and NIIS are implemented??
- Will an NIIS cover Individual, sporting, leisure and catastrophic accidents in the scheme, as well as victims of crime... etc.
- We would expect that all vehicular accidents whether car, water, air, train, tram, bus or commercial water vehicle, should be covered by transport accident insurance and the Insurance cost be attached to the purchase of a ticket or license where applicable.
- How would who is in and who is out of which scheme be determined?

There is concern that overlap will be an issue for the two separate schemes because life-long care will be required in many cases of disability from whichever source it may have been acquired. The collection of premiums (taxes) for both schemes appears to have caused some issues for further consideration.

The suggestion that the NIIS could recover premiums from Municipal Rates and land taxes is a very inequitable suggestion because:

- Municipal Rates and Land Taxes excludes people who rent , who live in long term caravan parks, or in SRS services, etc..
- Municipal rates and land taxes as a premium collector would capture the aged who are either excluded from the scheme and/or are in receipt of income support as are DSP recipients.

Gippsland Carers suggest that if accepted, the NIIS should be funded by an increase in the Medicare Levy and exclude air, rail, road and commercial water travel, which should be included under TAC regulations.

Conclusion:

We passionately support the Draft Reports recommendations for a ‘nationally funded disability insurance scheme that will be funded from general government revenue sources as a core business of our Federal government’.

We are generally supportive of the recommendations for the establishment of the national disability insurance agency and its proposed functions. However, we have articulated a number of issues that we ask the Commission to address.

We thank the Productivity Commission for the opportunity to express our real concerns over some of the shortcomings in NDIS DRAFT Recommendations.

To promote the ongoing involvement of family Carers under an NDIS we strongly urge the Commission to support as an absent Priority-

- **The funding of Regional Carer Support and Advocacy Networks that will :**

- **Provide carers with the same right to funded region-based support as service providers and disability self-advocacy services.**
- **Empower families to take control of the issues that adversely affect their lives because they care.**
- **Give family carers a grass roots say in policy and planning.**
- **Encourage carer participation within the local community.**
- **Support carers to enhance their wellbeing.**
- **Encourage family caring into a very uncertain future for unpaid care.**

Attachment 1: Gippsland Carers Regional Carer Support and Advocacy Network Proposal

Attachment 2: Regional Disability Family Advocacy Networks- NCC Federal Budget Sub-2009