Submission No. 1010

(Inq into better support for carers)

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Submission to the House Standing Committee on Family, Community, Housing and Youth

Inquiry into better support for carers

Carers play a vital role in sustaining Australia's current system of community-based person-centred care. However, they are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment.

Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- **THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY AND HOW THIS SHOULD BE RECOGNISED;**

Family carers save billions of dollars. **Some of these savings MUST be redirected to those family carers in** greatest poverty.

SOLE PARENT FAMILY CARERS of adult daughters/sons who have profound, severe and multiple disabilities are among the most financially disadvantaged citizens of Australia. That their ONLY income is the Centrelink Carers Payment makes them a particularly unique group. Please see, Attach#1: Letter to JM.

From Carers Aust website: CAA Sole Parent Carers 2003.pdf **(Control+ Click),** *FaCS/Centrelink advised that of single carers, caring for adults, it is believed there are about 6,500 caring for adult children.* This is a very tiny proportion of the overall "carer population"

In the AMP.NATSEM report - 'Who cares'.pdf **(Control+ Click),**it states, "*One third of primary carers are in households whose equivalent incomes place them in the poorest one-fifth of households nationally*"

It is essential that there be a review and a redevelopment of rates of the current payment for these carers.

To be in receipt of the Carer payment one cannot have the financial support of another individual. I.e. The person receiving a payment MUST be living alone and have no financial support from husband/wife/partner. ONE CANNOT RECEIVE A CARER PAYMENT IF ONE HAS ANY OF THESE!!!

As a comparison, FOSTER CARERS can receive government payments for the Foster care AND receive a Carer payment.

The financial support for foster carers is as follows: $232.02/ $257.80/ $275.50/ $370.86/ $501.82

With loadings of up to $1514 per child at 17 years of age as per: http://www.familiesandcommunities.sa.gov.au/DesktopModules/SAHT_DNN2_Documents/Download/633512999730364320/Ready%20Reference%20No.%201%20-%20New%20Carer%20Payment%20rates%20%2031_01_08.pdf **(Control+Click)...**

Foster carers can also claim the Carer Payment if un-partnered and there is no requirement for Foster Carers to declare the Foster Payment for Centrelink/Taxation/Public Housing purposes. Foster Carers can also have the financial support of another individual living at the same address. That person can earn as much as they like and are not required to declare their earnings.

VETERANS have a sliding scale of benefits which identify the level of incapacity. The scale currently can be found at:
http://www.dva.gov.au/pensions/rates/pension_incr_rates1jul2008summary.pdf **(Control+ Click)**

The DVA classifies some payments as **Veterans' Compensation. While family carers have not gone to war, they have given up much of their lives for the care and support of their disabled children and as such MUST be considered in a similar light.**

I have highlighted in yellow the additional types of payments in the inserted document: DVA pension_incr_rates1jul2008summary DKS.pdf .. **(Control+ Click)**, which veterans receive.

While not for one minute do I wish to challenge the right of veterans to such payments? What I am attempting to point out is that payments to family carers should be regarded in a similar way. There should be a sliding scale of the level of care and support that a family carer provides as well as the level of other support which that family carer might have available to them.

A similar sliding scale would do much to address the poverty of a Sole Parent Carer who is unable to work because of their daughter/sons extremely high level of disability. It could also be used as measure of the support that other family carers who although not as disadvantaged as the Sole Parent Carer needs additional financial support because they cannot go out to work either but DO have a partner who earns some sort of income

- **THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS, WITH A PARTICULAR FOCUS ON HELPING CARERS TO FIND AND/OR RETAIN EMPLOYMENT;**

Often it is not possible for a Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities to go to work at all. Even if enough funding was secured to support that person it would never be enough to provide home care for 24 hours per day. This could cost in the vicinity of $350,000 per year based on the amounts charged by "For Profit" support provider agencies, which are in this state anything from $30 per hour on a week day and up to $60 per hour on a weekend and more on public holidays?

Even with reasonable levels support funding the Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities will still not get a good night's sleep while having to attend to the needs of that individual and has all of the responsibilities that are shared by partnered families to tend to alone.

No help for around the house jobs, no help with the shopping, (that's if they can afford to buy food), no help with the maintenance of the vehicle, (that's if they can afford to buy one not to mention run it). No one to share their worries and concerns about their lives and the person for whom they care. No one to share the care when the person being cared for becomes ill frequently due to their disabilities. No one to help pay the bills, replace the furniture, whitegoods, pay the exorbitant power and water bills that accompany caring for a person with profound severe and multiple disabilities. No one to be there so that the carer can duck out for a few hours WHEN THEY FEEL LIKE IT AND NOT after IT HAS ALL BEEN ARRANGED. THERE IS NO SERENDIPITY IN BEING A SOLE PARENT CARER..... EVER.

The Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities is constantly reminded of the losses they have experienced and continue to do so. The gradual diminishing of friendships can be extraordinarily distressing. We watch as our friends and family go off the enjoy recreation and activities that we can only dream of. The inability to "keep up" financially not to mention time and energy constraints which that carer has to manage successfully slowly erodes the capacity to "keep connected".

That there is no one "on hand" to take over the care when the Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities is sick or is suffering from a chronic illness is another matter of great concern. This all has to be managed by the Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities ALONE! Often the personal and health needs of that carer are not met/ignored while that carer "keeps on keeping on".

WHO EVER DECIDED THAT OUR CHILDREN SHOULD BE SENT TO LIVE WITH A GROUP OF PEOPLE WHOM THEY HAVE HAD NO CHOICE OVER AND WHERE THEY HAVE HAD NO CHOICE ABOUT WHERE THEY WILL LIVE AND WHAT THEY WILL DO ONCE THEY ARE INCARCERATED IN THESE "PLACES"? THEN OF COURSE THERE ARE THOSE WHO COME INTO THEIR "HOMES" TO SUPPORT THEM... COMPLETE STRANGERS MOST OF THE TIME.

NO ONE ELSE IS EXPECTED TO LIVE THIS WAY FOR ALL OF THEIR LIVES. WHY SHOULD OUR CHILDREN BE EXPECTED TO????

Despite what some parents are saying many of us are quite prepared to care for our disabled adult family members. Often because we don't trust the "care" offered out there in "disability land". There is nothing normal in the congregate living arrange-ments which are in the main, the only type available for our daughters/sons to reside in.

Family carers usually are best placed to provide care and support because of their long term and intimate knowledge of their family member who has a disability.

Family carers usually provide the best care. Family carers usually provide the most appropriate care. Family carers usually provide the care with love and expertise above and beyond whatever an "agency" can.

While most of us don't expect the full amount, as indicated above, for the support of our daughters/sons, we should be entitled to know what it is that they can expect to be allocated and they/we should be able to have full control over the way in which that allocation is spent.

This should be while taking into account the principles and objects of the various Disability Acts and Agreement—where it clearly written that people with disability and their families should be supported to have full sovereignty over the way in which they receive supports and services).

See www.in-control.org.uk **(Control+ Click),**for an excellent example of the way in which Self Determination is supported in the United Kingdom..

The Centre for Self Determination, http://www.self-determination.com/principles/index.html **(Control+ Click),** has a simple but profound set of principles to guide us in our pursuit of control, choice and flexibility.

- **THE PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS, INCLUDING KEY PRIORITIES FOR ACTION; AND**
    - A key priority is to reduce the unmet need for supports and services for people who are being supported by Sole Parent Carer of an adult daughter/son with

profound, severe and multiple disabilities. This is urgent and essential. Take the strain off them by having enough funding per person.

- A key priority for Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities is that they are adequately compensated for the work that they do.

Highlighted in green below is how the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) defines the Carer Payment. http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-carer_payment.htm **(Control+ Click)**

Carer Payment ...*Carer Payment is an income support payment for people who are unable to participate in the workforce full-time as a result of their caring responsibilities. Carer Payment is subject to income and assets tests and is paid at the same rate as other social security pensions.* ***The payment ensures carers have an adequate level of income and maximises the opportunities available to carers to participate in their community***

That this statement is used to describe the most mean and miserly payment for the many hours per day of work that many parents perform in caring for their adult daughters or sons is one of the most ludicrous descriptions of what an **adequate income** is. This is about a payment which is below the Henderson poverty line and indicates the level of ignorance at government level around what is an adequate level of income, which would enable a Sole Parent Carer to "maximise" opportunities to participate in their community.

Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities *ARE THE ONLY INCOME SUPPORT RECIPIENTS who are required to be in attendance for at least 148 per week and yet they receive the same payment as the aged, and those who have a disability. As for it being "adequate" as per above how can anything below the HENDERSON POVERTY LINE be deemed adequate*

It is ridiculous to suggest that anyone let alone a Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities could have much change after paying for household expenses, to be able to go out and participate in anything!!!!

Let alone take sick leave, have 4 weeks annual leave, long service leave, Superannuation, purchase, maintain your own home, purchase/maintain a suitable vehicle, replace white goods, carpets, curtains, household furniture, heating/cooling. Go on a holiday, buy new clothes, go out to dinner and a show with friends, have a regular day/night out.

In December 07 the Henderson Poverty line for a Sole Parent Carer pensioner was $321.55 pw, the Carer payment, was at the same time $268.85.
http://www.melbourneinstitute.com/la bour/inequality/poverty/Poverty%20lines%20Australia%20Dec%202007.pdf

It is essential that the poverty of Sole Parent Carers is addressed at the earliest opportunity. An amount of at least double the Carer Payment should be the highest level of payment. It is also essential that any increases to payments to Sole Parent Carers of daughters/sons with profound severe and multiple disabilities is not added to the Carer Payment, rather that any increases are added to the Carer Allowance so that it remains non taxable, non declarable and not assessable for any purposes such as Public Housing authorities.

I have been living in poverty since the day I gave up my career and removed my daughter from the group home/institutional accommodation arrangement, which failed her so terribly. She was at serious risk of dying because of inappropriate and incompetent support arrangements. It took me 18 months to nurse her back to a reasonable level of health. I don't regret having her back home, I do regret the lost opportunities that have occurred since I did.

Stop comparing us with carers of the aged! There is a huge difference between a person who receives the Carers Pension for what is usually a short **"time/end of life"** commitment to an ageing parent , when compared to the **"all of life"** circumstance for many parents who will have the care of their daughters/sons particularly those who have profound severe and multiple disabilities from the day they are born.

- A key priority is for the federal government to take over the disability arrangements and develop an Australia wide system so that everyone knows where they stand.

- A key priority is a form of medical insurance which enables them to access medical services without the wait and with no gap to pay. This SHOULD be available to Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities

I have lost several friends who were Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities to illnesses that might have been avoided or even prevented if they had had the time AND MONEY to go for and pay for treatment.

In the recent few months I have been subjected to the vagaries of the public health system. While I was fortunate that my malignant melanoma was discovered early enough to give me a good prognosis, the fact that I had to do a huge amount of strong self advocacy to ensure that arrangements could be made for the care of my daughter to coincide with my couple of terms of hospitalisation was particularly unsatisfactory. This should be automatically acknowledged and support be given for this to occur.

I have had to wait for over 2 years to get dental treatment during which I have had to cope with persistent toothache.

I have further need of medical intervention regarding a cartilage problem to one of my knees but there is an extraordinary long waiting period for me to get to the radiologist for an MRI let alone for the probably required arthroscopy and rehabilitation. Some sort of guaranteed cover would go a long way to rectify this.

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

It is essential that individualised funding, which is person/family centred and able to be self managed is made available as a choice for all.

If the person with disability is individually funded with an adequate level of funding there is encouragement for the family carer to use funding to develop and maintain person centred, long term quality support arrangements. This has the potential to foster long term relationships that can be carried on after the family carer live, or ceases to provide intensive support.

When a parent can recognise that a future can be planned due to ongoing and assured levels of funding much of the worry about the future can be alleviated. While we can never be absolutely sure of what the future may hold for our daughters/sons, we will at least have the chance to have an involvement with their future plans and make our wishes known.

- **IN EXAMINING EACH OF THESE ISSUES, THE COMMITTEE WILL ALSO INQUIRE INTO THE SPECIFIC NEEDS OF PARTICULAR GROUPS WITHIN THE CARING POPULATION INCLUDING NEW CARERS, YOUNGER CARERS, OLDER CARERS, INDIGENOUS CARERS AND THOSE WITH MULTIPLE CARE RESPONSIBILITIES.**

I note with some concern that there is no mention of Sole Parent Carer of an adult daughter/son with profound, severe and multiple disabilities —I hope that this submission might go some way to change the focus toward that of the most disadvantaged of all carers!!!

Thank you for once again giving me the opportunity to speak for myself and others like me as I did for the Senate Enquiry into the CSTDA. I hope that as much attention will be given to this enquiry as was given to the CSTDA and that something positive will result form it.

I have attached to this document a copy of a letter which I sent to Jenny Macklin regarding my personal situation which goes a long way to explain my passion about the poverty of Sole Parent Carers of an adult daughter/son with profound, severe and multiple disabilities. I am trusting that that letter will be kept confidential with no identifying information made available to anyone except the members of the Enquiry?

Yours sincerely

Delphine