

AEC 28/7/08

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's *Inquiry into Better Support for Carers*.

The following comments/ideas I believe will help the Committee in seeking a better understanding of the situation for Carers in Australia

1. Role & Contribution of Carers in society and HOW this should be recognised

I am almost 70 years of age and I care for my disabled child - who requires almost constant attention - at home, with the aid of the restricted assistance I can get from the government. My contribution to Australia is that, as a Mature Age Carer (MAC) I am the one still carrying on that task.

The value of the MAC's long years in caring is the untold \$ saved by the Government re payment for such care, together with the low level drain upon community resources for many years - ie MACs of children with intellectual disability have "done it tough" for year upon year - *without* help and often *at cost to Carer's own health and wellbeing*.

(In recent years, early intervention and support have been available to younger Carers in Australia.)

Therefore *Financial help* and *Support* are major factors in the recognition of the MACs contribution to the community.

2. The barriers to social and economic participation for Carers

Problems being faced include:-

- a) After 44 years of caring for my child, the most stressful problems I face all stem from the fact that the quality of whatever assistance is available, *is less and less*.
- b) Knowing that the Government has billions of dollars of surplus locked up in "future funds" without the opportunity being taken to seriously address the grass roots issues of those who will never be able to fend for themselves.
- c) The fact that the government-sponsored mantra of "if they are treated like normal people they will become normal people" has been, and is, the single biggest cause of life-long distress that every carer, whether related by blood or not, has to cope with in the care of intellectually disabled people.
- d) The fact that normal people do not have the faintest inkling of what it is like to live

with a significantly disabled person! Words can never convey the breadth and depth of those problems - but try to comprehend the impact of living with even this, 24 hours per day, every day of your life, irrespective of where you go during the course of a day: a 44 year old female who, for all sorts of fundamentally unresolvable psychological reasons, cannot maintain her personal hygiene satisfactorily without supervision.

3. The practical measures required to better support carers, including key priorities for action

I cannot fully participate in social life because a social life is what 'normal' people have where they are able to take a break from the cares of world -- and it is something they can do quite regularly, even once a week or so. They don't have to wait for a Respite week, which is supposedly about giving the carer "a break".

A social life is not possible when by the last day of a Respite week, you are just reaching the point where you have recovered enough energy that the idea of actually doing something like "enjoying yourself" is an option which could be considered in the next day or so, only to instantly realise, that it isn't going to happen.

a) If a Carer cannot go out without one's caree, such often presents an "automatic" barrier to attending certain social functions -- meetings -- CIT courses.

To arrange care for even a short time of **non-workplace** hours involves

- (i) the cost of the support-person per hour -- is it affordable within this week's budget?
- (ii) the time factor re the difficulty in finding reliable, caring, support
- (iii) the extensive preparation necessary re explanations of caree needs, medications, etc

so that -- very often -- due to an MAC's own personal needs at the time -- an MAC will feel all the extra effort so involved it is virtually insurmountable -- and risks further isolation accordingly.

b) Financial difficulties --

The fact that I -- and so many carers - are financially struggling, indicates that the government appears to have little understanding of the economic reality of just how much *cannot* be achieved living on an age pension a Carer Allowance.

i) I have not been successful in obtaining ISP funding for my daughter, despite several applications and I see this as "competitive misery"! Despite my being an MAC, it seems that we are not seen as a high priority for funding.

My daughter's needs are increasing -- in terms of both her own ageing and re preparing her for the necessary transition from living with me fulltime - to living independently from me.

ii) everyday costs include finding activities which may suitably support the caree plus the often extensive costs re caree's needs -- ie medical, plus the reliable, caring support worker.

iii) there are insufficient medical professionals/specialists well versed in Intellectual Disability difficulties, often necessitating interstate travel and accommodation in order to

obtain the best care available for the situation,
i.e. GPs, psychologists, psychiatrists, medical clinics (ie. Continence Clinic)

Support difficulties

It is very difficult to find the necessary support to care for my daughter due to several major factors:-

- i) lack of properly trained staff at agencies – *due to unattractive rates of pay.*
- ii) lack of experience and reliability in working with, and understanding, people with intellectual disabilities.
- iii) the dedicated few suffer ill-health or burn-out as their efforts are not backed up with the necessary supports of (i) and (ii)

I worry about my future because

I know that when I am no longer able to care for, and fight for, my daughter's needs, no-one else is going to do it with the same attention to all the necessary details. The increasing realisation of that inevitability of such scenario distresses me more and more every time the quality of the assistance which is available slips down another notch.

- a) As an MAC and without adequate support - both financial and agency - I cannot obtain the training necessary to enable my daughter to make the transition from full-time parental home-care to living with 2-3 others independently of me - before I become incapacitated due to age or death.

Full time support is necessary for **non** workplace hours for medical reasons.

During 12 years of group living, wherein as the level of money decreased so did the level of care – alarmingly so. Due to poor supervision, my daughter

- was scalded on two occasions
- was hit by a car on 3 separate occasions
- suffered loss of most scholastic skills achieved
- had clothing and possessions stolen
- was subjected to extreme verbal abuse.

I do not wish to see these conditions occur ever again – therefore, satisfactory funding and support are very important factors.

The things that stress me the most about being a Carer are -

- i) Having to “bite every cent twice” to decide which item gets priority!
- ii) The whole system is geared to assuming the Carer will always be available and in perfect health. The Respite care is supposed to be to give the carer respite from caring -- but there is no provision for a Carer falling ill or needing hospitalisation. Every worker in the country gets sick leave provisions -- even employed carers, but not live-at-home Carers. The live-at-home Carers have to either give up Respite nights or compromise their financial resources even further to find some other way to cope.
- iii) The stress of having to re-apply for the carer allowance if the Respite quota is exceeded despite the medical evidence of the case in hand. The stress of the attitude that “one size fits

all” and that “all recipients of government assistance are malingerers and miscreants”, makes dealing with the government agencies under circumstances such as re-applying for the Carer Allowance, demeaning in the extreme.

iv) There are insufficient medical professionals well versed in intellectual disability difficulties in the ACT

ie GPs, psychologists, psychiatrists, medical clinics (ie Continence Clinic)

v) Dealing with the constant disappointment which comes with every single supposed determination by "the authorities" to "fix things up this time" that ends up in yet another reduction in the quality of the services provided. Surely there has to come a time when someone realises that the same questions have been asked from every possible angle, that the answers are always the same, and so it is time to actually do something that will make a meaningful difference.

I need help with my advancing age (70) – and feel that receiving *adequate support hours* and *reliable, caring support* from support agencies – plus ISP funding for my daughter - would be ideal solutions for me.

a) Limited help is available to MACs because - although the need is so acute in the ACT - properly trained, reliable staff are just not available – *due to* the low rates of pay not attracting suitably responsible, caring people.

b) For example, the person having difficulty in obtaining any other employment, who takes on a Carer’s role in the “casual” capacity, rarely has the necessary commitment – let alone experience - re the detailed knowledge so important and necessary – often on a daily basis - *particularly as* our intellectually disabled folk become older.

c) Carers – especially MACs – need *reliable, trustworthy, truly caring* support-workers – not just some bod who wants to be paid for some “baby-sitting” – our carees are real people, with real problems, real experiences and real needs – and they need to be properly recognised and treated accordingly.

d) Professionals – just having a piece of paper doesn’t make a professional – in the Care/Disability fields such requires – compassion, understanding, experience, sense of humour.

For example, an intern psychologist has relatively NO experience except for a few hours of a day’s appointments and the text books. This is frustrating to an MAC with long years of experience – who is running out of personal “oomph” and needing help re challenging behaviours. A 6-months stint for an intern may help the intern but such does absolutely *zilch* for the MAC carer and the caree.

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4. 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.

I think the Government can better help Carers by injecting more money into the disability sector which will help to educate staff, support workers and the individuals with an intellectual disability - thus enabling us to have improved choices and flexibility.

a) Time and again we are told that Ageing and Disability cannot go together! I would point out that -

in every instance of a Mature Age Carer caring for a family member with Intellectual Disability who is also ageing - that Ageing and Disability **can and do go together** -- not only every day/night but year after year! That is FACT.

b) As a Mature Age Carer caring for an ageing child with an intellectual disability, I think that a combined Aged and Disability accommodation area would be the best solution for me to help my child cope with my declining ability to care for her. This means: to have - within the community -- areas of housing where units of Disability are "interspersed" with units of Ageing -- "separate but close" (geographically) -- which would also enable a number of support staff to be satisfactorily utilised both strategically and thus economically.

i.e. various houses -- some Disability houses/units -- various houses -- some Ageing units/houses Such would allow a more "normal" integration within the community of the disabled and/or ageing people

c) **Solution:** to have (and I repeat) - **within the community** -- areas of housing where units of Disability are "interspersed" with units of Ageing -- "separate but close" (geographically) --

This would enable the intellectually disabled person to strengthen the "uncoupling" from the aged carer -- i.e. by enjoying the measure of independence whilst able to visit the Aged Carer every so often, without the problems of distance/transport which make such visits too hard for those caring for the disabled person - so that when the separation is completed by total incapacity and eventually death of the Aged Carer, the "break" is not so devastating to the intellectually disabled person.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Australian Carers.

Yours sincerely

Mature Age Carer