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NNAAMI

*The National Network of Adult and
Adolescent Children who have a
Mentally ill parent (s. Inc.*

Submission No. 1243
(Inq into better support for carers)

Doc 18/8/08



Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
Fax 02 62774844

**Submission to The Inquiry into Better Support for Carers
Standing Committee on Family Community, Housing & Youth**

29 July 2008

Dear Members IIBSC,

Thank you for your invitation to make submission to your important Inquiry.

Thank you for your preparedness to receive a late submission.

NNAAMI (is a peak body and) provides support for children young people and others who manage the burden and demands of a parent with mental illness, one of the most hidden, neglected and traumatised groups in our society.

For further information regarding this group please view articles stories forums and statement of best practice on our NNAAMI website www.nnaami.org

It would also be most relevant for your Inquiry members to read our Youth Link Submission which was submitted to Federal Government which outlines ways to reduce the impact on this vulnerable group, including our submission to the Senate Select Committee Mental Health.

The lateness of this submission is indeed indicative of the complete lack of support and lack of relevant resources from federal government to address the expressed needs of young people and others who manage a parent with mental illness 24/7. NNAAMI has reached hundreds of thousands.

NNAAMI's efforts now reach people world wide however the following statement remains true to this day " *No one who has not come from this life experience could ever begin to understand what we go through coping with a parents mental illness every day* " nnaami member

" Young people want their own organisation funded, we want our own voice heard and respected, not to be placed in with the disability area or a generic carer service for people who are looking after people with physical illnesses, the government from my understanding have never really read our stories or submissions or seen NNAAMI, website. They just don't get it,... we need to be funded to support each other, That would be cheaper and much more effective, you would think ?"
nnaami member

" We are not carers, I don't feel like one, and will never call my self one" nnaami member.

Should your Inquiry / committee be interested to discuss the enormous need of these young people and adults, please contact me directly Paul on 0407 857465 to make a time for us to provide further explanation of this groups vast need.

The cost of supporting and managing a parent with mental illness is not like other caring relationships and it has little relationship to the proximity of the parent.

" Your parents are your parents where ever they live I'm managing the situation just as much even though I'm not living at home now !" nnaami member

" We are the children breaking the silence "

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NNAAMI has vast experience and knowledge of the needs of children young people and adults managing a parent with mental illness. We have trialled a range of best practice support. With reference to Your Inquiries Terms Of Reference please find our brief answers and suggestions to redress the plight of this vulnerable group.

• **The role and contribution of carers in society and how this should be recognised ?**

1. Recognise NNAAMI and the work of our members 24/7 role coping with the unremitting demands of managing a parent with mental illness, parents who are often not receiving treatment or easy to manage. They provide this support and management without any government assistance or funded representation at all.
2. We believe The group NNAAMI represents is the, most vulnerable extremely isolated and hidden the most ignored and the most at risk and at risk of stress, suicide, trauma, poor health, heart disease / heart attack, have been caring longer than others without support or funding
3. Recognise NNAAMI Fund NNAAMI Network of support and see below,

• **The Barriers to social and economic participation for carers with a particular focus on helping carers to find and /or retain employment.**

4. First you need to fund and Support Network NNAAMI organisation, otherwise you can't get to reach them or support them to a stage where they can have the luxury of economic benefits afforded to others in our society.

We run our own support without money now ! WHY IS THIS SO ? What will government contribute ?

5. Everywhere, every child, young person, adult who manages a parent with mental illness, does it while at risk of extreme stress and high risk to their emotional and psychological and physical health.

“ Where do you get time to work if you have a MAD parent ? “ *nnaami member*
 “ She phones me every day all the time even at work ” *nnaami member.*

**First things first provide support RECOGNISE WE EXIST NNAAMI
 FUND our NNAAMI SUPPORT and a better level of emotional health and education attainment
 will follow and employment too.**

And

6. When a person / carer / manager of a parent with mental illness, needs time off work, **fund the employer with a bonus**, via Drs certificates or stat-declarations the gross wages of the person per day. Many have lost their employment as they are fearful of taking carer leave or not having sufficient or flexible carer leave available.

• **The Practical measures required to better support carers Including key priorities for action.**

7. “ Not another government strategy policy inquiry we had The Burdekin enquiry, The national mental health strategies, The health policies, the Promotion. Prevention and Early Intervention for Mental Health National Consultation, The Second National Mental Health Plans, Mental Health Promotion and Prevention National Action Plan. Senate Select Committee Mental Health Mental Health..... all talk but no action..... No More Plans Thanks.
Nothing delivered actual funding or appropriate support for this vulnerable group”
nnaami member

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8. Just have a NNAAMI Network Of Support funded, Its Basic.
Actual Federal Funding that is Open and Available,
and not prescriptive (or predetermined or presuming about what this group needs, or it having to be in
partnership with or in competition with, or under the management of, others),.

That is available to apply for, for this Charity / nnaami who is already doing the workAustralia
wide.

A Fund. Funding to Help to make and manage existing and new submissions to federal government not
multiple state governments.

9. So NNAAMI can further develop our vital support, internet site services, web-based support,
telephone counselling, advice and referral support, mutual support systems, structured and
group work support and monitor forums while consulting and providing advice to government.
and reach those most at risk.

and See below

- **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 changing roles, transition into and out of caring and effectively plan for the future.**

Government can Apply above strategies, and

10. Government read our website. Our submissions, See our Best Practice statement fund it and
apply it.
11. For the Federal Government to Manage State Taxes and for the Victorian Government
Not to Tax NNAAMI (indirectly Via Land Tax) !. and
12. Federal Government must Fund NNAAMI tailored support and advocacy around Australia ie
NNAAMI counselling, email counselling, telephone counselling and support programs, mutual
support, peer support and its tutoring educational support services. Fund our tools program, our
Jacks Toy Boxes for hospitals and toys program respite camps and discussion group programs.
13. To have Choice and Planning would be a luxury ! The above would go along way to supporting
this for these individuals.
*You can't stop your parents being your parents that easily especially when your parent is really like a
child anyway and many are caring for their siblings as well because there is no one else. Something
goes wrong you are the first person to be called. nnaami member.*
14. Recognise and pay carer payments to persons caring for a parent with mental illness where ever
they live. (If you spend 12 hours in an afternoon evening on and off the phone supporting a
parent it should not make any difference if you live with a parent with mental illness or not, the
exhaustion level is the same). Most of these kids don't get a carer allowance they should at least
get access to their own network a nnaami service.
15. Stop government funded advertising spending taxpayers dollars on mental health advertising
until you fund and support advertise and resource is nnaami the most vulnerable carers, who manage a
parents mental health 24/7.

" Seeing advertising on TV and Radio about mental health and a focus on mental health now only
makes us family members feel more isolated and that no one really cares about us, what we are like
invisible ? "

"What about an add that says Employ the underprivileged who have damaged lives from a parents
unremitting mental illness Invest in our youth or something they have already invested in their parents !."

LETS GET REAL Potentially more than one in five people have a parent with mental illness and they Vote.

- **Particular Needs of NNAAMI sub groups**

Further to above,

Further Sub groups identified by NNAAMI are

1. NNAAMI members managing a parent Ageing with Mental Illness
2. NNAAMI members of all ages who have a mental illness and are managing a parent with mental illness.
3. NESB CLAD community NNAAMI members managing a parent with mental illness we have produced a film in this area see our Youth Link Submission to view.
4. NNAAMI members managing a parent where the parent refuses treatment.
5. NNAAMI members who manage two (both) parents with mental illness.
6. Inadvertently The message government has given to young people by ignoring NNAAMI is,

WE DON'T CARE about you. This can only have a compounding detrimental impact on an already hard to reach, deprived and neglected group.

You Can Ask the Prime Minister Mr Rudd to write to these kids and explain when he will assist them / nnaami ?

*" I hear the statements in the media about carers.... WE DON'T NEED OTHERS SPEEKING ON OUR BEHALF..... and I think,..... you bullshit artists what about us.
You don't even know we exist you only know about people in wheelchairs,
But the problem is by government ignoring us and ignoring nnaami you create the next generations stress and health problems compounded time and time again. Forget climate change Live with a parent with psychotic mental illness and see if you can survive" nnaami member*

THE BENEFITS of funding NNAAMI and for NNAAMI users.

- Increase access to specialist support of nnaami, and to other relevant appropriate support.
- An Organisation run by and for the affected group, means taxpayers dollar goes further as you reach the target group straight away and they feel understood from the beginning (there is no middle man its then at a wholesale price) and not have to search around looking for people who really understand getting passed around from one organisation or professional to another.
- Advice and counselling, that's relevant to the affected group. and Advocacy that is fully representative of the affective group that is relevant and promotes self advocacy. Advocacy that hits the mark where relevant so children and young people feel understood by mental health and education providers and employers and other organisations are given ways to work in tandem, and young people and adults empowered while assisting this group of young people better reach their potential.
- Advocacy, that may increase the chances of a parent receiving treatment once a child or young person has their own needs met and advocacy that empowers children young people and adults to communicate with a parents treatment services / health professionals.
- Help seeking, promoting positive help seeking of isolated at risk children and young people and adults.
- Prevention of mental illness, and Prevention of suicide,
- Prevention Reduce burden on child welfare system.
- Referrals. Promote relevant referrals to child and adolescent youth and aged services for at risk children.
- Decrease risk of suicide, psychological dysfunction, and stress. Increased Healthy outcomes.
- Decrease stress, cardiovascular disease and Heart Attack
- Increasing professional understanding, rather than alienating children young people and adults who have a mentally ill parent.
- Increase Job/employment satisfaction and reediness for work, as in crisis they have an appropriate and relevant avenue of support,(with a range of support levels available).
- Decrease poverty among this group.

" Just knowing you are there has really helped me but I want to be able to call NNAMI at any time and know I can speak to someone who has been there and knows what I'm talking about and knows what it's really like" nnaami member

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" I was on the verge of attempting suicide, giving up packing it all in, finishing it all, no more had it all planned out, until I saw the NNAAMI site by accident. I now know I'm not alone I cried and cried the whole time reading those stories, not much different to my own"

nnaami member

- Increase network of support.
- Increased understanding of mental health system.
- Increased acknowledgement of the role of children young people and adults in caring for and managing a parents illness.
- Increased shared sense of concern.
- Increased shared strategies of managing a parents behaviour and increasing sense of self confidence and wellbeing.
- Increased family acceptance from boarder family members aunts uncles if around.
- Increased expert understanding and further exploration of special needs.
- Increased social connectedness and community connectedness.
- Increased connection and engagement with education and employment. Etc etc etc.....

If NNAAMI was not there, tomorrow the connection between these young people would fail,
And so would the only help for this vulnerable group.

To move a person up out of a wheelchair can take seconds with the right equipment.

To move a person out of psychosis or depression can take more than a life time of full time Management. You are Totally Working and Managing Another Persons' Life As Well.

**But managing someone who looks normal
but is truly ' MAD As A Cut Snake ', is something else.,**

And if that is your parent the odds against your survival suddenly increase.

The emotional and psychological abuse and trauma that is experienced far exceeds that of anything imaginable.

All we asked for was our own organisation funded.

How will government recompense these life time Managers ?

What part of our NNAAMI 'Youth Link submission' to Federal Government do you think should be funded ?

We know you can help us.

On behalf of these children young people and adults I look forward to your phone call
I can be contacted on 0407 857465.

Best Wishes in your endeavours with your Inquiry.

Yours Sincerely

Paul McKillop

Convenor

NNAAMI