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

Royal Commission into Victoria's Mental Health System
PO Box 12079
A'Beckett Street
VICTORIA 8006

**Submission to, Royal Commission into Victoria's Mental Health System**

**For all MHRC Commissioners, Personal Attention.**
**Date:** 4 / 07 / 2019
**From** Paul Mckillop and Family **ph** [redacted] **email** [redacted]

**Dear Commissioners,**
I am the convenor of the above organisation network representing children, young people, and adults who manage the constant every day burdens and demands of their parent with serious major mental illness across Victoria Australia and internationally. One in five has a mental illness however potentially equal to that or more will manage a parent with mental illness.
I have also worked for many years in mental health as a counsellor and educator in psychosocial rehabilitation across government and non- government organisations at the forefront of mental health. This work based in Victoria also reached across Australia and internationally. With others I have been involved in helping to change the shape of mental health from its previous focus on institutionalised care to one more centred around, rehabilitation, community and recovery. Victoria at this time grew to have one of the best reputations in mental health and innovation in Australia and I along with others were able to attract experts from around the world to have valuable input into developing our services. I still believe as I did then however there is a long way to go in mental health treatment and care before we can say our system is of best practice. Sadly some people remark to me these days that Victoria has fallen away somewhat since these times from its once respected even sometimes revered position.
I will briefly comment on and provide recommendations for you on the following including providing comments in this formal submission to your questions below,

- Children, Young People and Adults managing a parent with serious mental illness. (prevention, early intervention, and suicide prevention.)
- Aged Persons with Mental Illness. The following personal account of abuse of my [redacted] Highlights wide spread systemic failure to properly RESPECT, treat and support a person with mental illness and their family across various government and non government agencies operating in Victoria.
- Access and treatment support in Hospital Emergency Departments and mental health inpatient units. (Increase safety)
- Psychosocial Rehabilitation Recovery of persons with mental illness. (Day Centres)
- NDIS. (Access for persons with mental illness and their families)

**Contact Convenor Mr Paul Mckillop,** [redacted]
[redacted]
**Internet site : www.nnaami.org**

I would be happy to provide any clarification you may require regarding this submission and recommendations in person or by phone.

**Response to MHRC Formal Submission Questions**

1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

- Include family's needs in media community education about their huge support role for people with mental illness as well as consumer's needs. Include children of parents with mental illness in this in consultation with nnaami. (Stigma is not always the main issue).
  Let people be honest and not hold back about the real difficulties. Glossing over problems or the hard stuff of various mental illnesses does not wash for people who have been there. People can become more accepting when they get a gimps of the struggles people are really going through.

- Promoting Acceptance of a wide variety of people with mental illness and their families and individual diversity can be good. However focusing on major mental illness and specific conditions is also important.

- All the advertising in the world does not work the end if the mental health system is still broken.

- Treat Family of persons with mental illness with respect in all hospitals and services, this then has a positive flow on effect in the community.

2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

Workplace awareness and training programs are good value.

More training for GPs about mental illness, and the
Need for family inclusive /sensitive practice and
Being inclusive and respectful of family support and,
To give longer consultation times for people experiencing emotional psychological or mental health problems.
Doctors being prepared to refer to other specialists and
Engage in collaborative practice with other services and allied health professionals with patients permission.

Having GPs being aware to sensitively encourage people with mental illness where possible to bring in family or trusted friends to talk as well at times with the patient where appropriate. So people with emerging, mental illness, are less likely to get turned away unnecessarily just because the GP has not yet witnessed symptoms in the surgery.

See below 3

## 3. What is already working well and what can be done better to prevent suicide?

A. If government are interested in suicide prevention would be supporting those who represent groups with the high risks of suicide such as the needs of children, young people and adults, who have a parent with mental illness nnaami.org Please see our comments in section question 6. and 11.Below.
B. Workplace mental health and suicide prevention education on looking at how to support work colleagues and treat people with respect and looking out for each other is a good area and has merit.
C. Education, promoting anyone experiencing signs of isolation or depression to talk to friends colleagues or family or professionals and to persist till they get answers on if they should seek treatment.
Just promoting help seeking all the time may increase a sense of blame or further isolation could somehow increase stigma for them and be further isolating for some people, as they can often feel there experience within a broken mental health has not stacked up to their expectations of obtaining suitable treatment or support., Till the system is more equipped to respect consumers and family. Education about promoting people to access treatment before system repair can some ways be putting the cart before the horse.
Supporting Suicide Education which promotes statements like – 'that things might look different tomorrow /in the morning next month etc' can be good and using illustrations of people who have got through suicidal thought imminent intent and talking about what they found helpful as support for them can be good and helpful in prevention education for those imminently contemplating suicide.

- Possibly sensitively consider including particularly the perceptions of children's attitudes toward a parent's intentions to commit suicide, in education media about suicide prevention alongside other lived experience statements of family and consumers may be useful at times with nnaami support and proper evaluation.

**D. Day Centres and Regular Community Lunches.**
In the MHRC forum I attended many consumers and mental health workers stated that the demise of day centres somehow going out of favour or not seen as trendy. Has had a detrimental effect on many consumers. Having a place in the community to go and to be respected (without having expiations placed on them) is really important for people experiencing mental illness as a protective factor through increasing social interaction / inclusion and on suicide prevention and this was seen as positive for them irrespective of if they were receiving treatment or not at the time. Some reported it was the only place they would ever go and feel safe when extremely depressed. They would make the extra effort to go when all else was falling apart around them and they had even cut themselves of from many other.

Funding for existing daycentres should be enhanced increased and promoted.
Access and Attendance at a day centres should not be conditional on having to do particular activities.
More day centres need to be funded.

Funding for day centres should not be conditional on meeting funding targets or expectations on participants or dependent on other mental health programs or funding targets or NDIS funds. They Should be Open for anyone to attend. The more normalised the better.

Funding should be available to support existing day centres Churches /religious organisation and Community groups /volunteer organisations, to assist with operational costs, building alterations, and for any such organisation wishing to start and operate a day centre or continue community luncheons.

I have witnessed the positive change in a number of people experiencing extreme loneliness and also those experiencing emotional and mental health difficulties and those experiencing severe mental illness attending a regular free community lunch with others which is open to all operated by

volunteers in local community not far from me by a local church.
This social connection is invaluable.

- This is an excellent one it attracts a wide range of people from all walks of life for coffee and lunch. I would recommend it to anyone it is on Thursdays 12-1pm at St Paul's North Caulfield. My [redacted] also enjoys going to this one immensely.

E. Ongoing Support and advocacy for every one with mental illness seeing NDIS funding.
" I put in my application for NDIS it was refused
I put my application in again with a supporting doctor's letter. It has Just been refused again"
It's remarkable NDIS failure. This man suffers extreme depression his support worker has moved on to other employment from his mental health support program and was not replaced for some time.

He has suffered long term chronic depression was unresponsive to increased medication treatment for quite some time, with the need to be treated with recent admissions for courses of ECT. This had god benefit and has helped him manage his condition better with medication.
If someone like with his man with this condition with severe chronic depression is not eligible for NDIS who is ? !!!!

F. NDIS should be available for all new applicants irrespective of age. Many people still require support services and treatment after the current cut off age restrictions.

G. Consider a flexible individually agreed /negotiable age transition from adult mental health to aged mental health services, as the aged pension age has increased and as we have an ageing population and although people with mental illness and others have particular issues in ageing. That people do not age at the same rate. All have individual needs some may be more appropriately treated within the same adult service for longer while others may require earlier admission to aged mental health programs as need or condition arises. This should be based on consumer and carer negotiated preferences.

4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

At a MHRC consultation session I heard of a young man's account of attempting to access mental health treatment while experiencing a mental health crisis having presented himself at an a general hospital Emergency Department. He was extremely fearful of reports of drug affected patients in the hospital. Others report being turned away depressed at extreme risk of harm to themselves and others. I've heard of many families receiving people home after relative's presentation to EDs without any treatment or appropriate referral. See above.

Enhancing Better ED hospital Departments Safety is paramount for persons with mental illness and their family. If necessary consider having a police resident office in EDs to better support security and hospital staff from drug affected patients.
Consider having more short term immediate counselling allied health staff in ED's so people going through emotional or mental health concerns have a variety of counselling options immediately available to them on site, reducing stress on doctors medical trainees / hospital ED staff and for referrals with tangible realistic follow up support or treatment options.

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Social Isolation see response to question 3. And also See above response to 4.

Access to bulk billing is vital across all geographic areas and lower socio economic areas. Provide free counselling and welfare or social work support (with specialist mental health support education back up to these counsellors) in metropolitan lower socio-economic areas and in rural and remote area GP private practice (where GP clinics or local councils are prepared provide rooms) for these workers to work in collaboration with GPs. 4

6. What are the needs of family members and carers and what can be done better to support them?

- (1.) Children, Young People and Adults managing a parent with serious mental illness.

Despite the 'Burdekin Report' and many National Mental Health Strategies and plans which acknowledge the high stress (and concerns of) children managing a parent with mental illness. Virtually nothing has been provided or achieved by government to assist NNAAMI or deliver the necessary tailored support and peer supported counselling, group support and online service or outreach requested by the hidden group we represent. and.,

**Although research shows that young people managing a parent with mental illness have nearly an eight times greater risk of suicide as a result of the burdens they endure. It is remarkable that no assistance has been provided to NNAAMI from government in our endeavours to emotionally support and advocate for this large vulnerable at risk group.**

' No one outside this life experience could possibly understand what it is like dealing every day with your own parent with mental illness or a parent refusing treatment, psychotic, manic, or with deep depression" *nnaami member*
The support needs of this extremely isolated group are distinctly separate from other family of the mentally ill parent or existing mental health services. Their needs are also distinctly separate from their parent's needs. They don't necessarily require teaching about mental illness or clinical language or how to be better for their parents, because they know what mental illness is and how it presents (from very close intimate observation of the effects of a parent's mental illness). Support for this group must be fully managed by the affected group separately away from existing services or youth / adult mental health or welfare services to avoid potential or perceived conflicts of interests and to ever effectively reach the most isolated of this hidden group.

"It's like walking on egg shells all the time 24/7 looking after my mother"

While largely ignored by mental health professionals, (they) children, young people and adults managing a parent with severe mental illness have the face to face, day to day lived experience and should be respected as experts in the way their parents particular mental illness affects their individual parent. Some have developed a host of supportive measures and self protective measures to survive themselves and to help enable their parents everyday and rudimentary functioning. There role however should be valued and respected in healthy ways by mental health professionals.
The larger majority for whom we represent report their parent has a major mental illness where the parent does not get adequate treatment, receive any treatment or is not sufficiently compliant with medication. We believe support for this group should not be contingent on their parent's connection or not with the mental health system.

Our work when properly funded can also be highly effective in reducing stress and psychological problems for this group, as well as effectively contributing to mental illness prevention, early intervention, and suicide prevention. Because research shows " those that coped the best had an empathetic relationship with a caring adult someone who shared their life experience coping with a mentally ill parent "

Yet through no fault of their own these young people constantly carry the brunt of the burden in managing 'some else's', their parents mental illness. Most as a result of their life experience are far ahead of their years and carry on in daily life. The psychological and emotional burdens can be great. Their hugely undervalued supportive role with its associated emotional stress is often unrelenting. Due to family disintegration or separation and other issues, they will likely be managing their parent for longer durations across their lifetime than other family members of the mentally ill.

" I would be late for school because of her ranting and paranoia and ripping shreds off me, telling me 'it's all my fault, her illness' no one would know at school or anywhere what she its really like. The consequences of anyone knowing are diabolical. Can't take any friends home, but she expects me to get the dinner ready because she does not come out of her room she is still crying because she says again they are all against her." "She sees the doctor only when she can hold it together, but he believes all her stories when she says there is nothing wrong with her that she is coping. It's everyone else's fault she says to him the way she is. Constantly keeping her emotionally afloat um supported is exhausting. There has never been times of fun for us." "You are the first person I have felt I could trust to tell you with this stuff because I can see you have been there you know what it's really like and the problems I face, how could I trust someone to talk to who has not got a mentally ill parent them self" nnaami member.

Please read articles documented life stories of young people and others managing a parent with mental illness on our website nnaami.org

## Recommendations

**If there were a target for each child young person adult managing a parent with serious mental illness from the Victorian government what should it be?**
Tailored support for the affected group ie provide organisations fully representative of the lived experience of this vulnerable group with,

- A dollar figgure guarantee for appropriate emotional support, tailored support, outreach, counselling, on line support, community education and advocacy for each child, young person and adult who has a parent with mental illness in Victoria, managed by the affected group. What are they worth?

  Spend $100. $200. $300. $500. $1200. per annum for each person managing a parent with mental illness in Victoria on above.

  Then, once there are adequate funded support for this group, provide additional funds for,
- Community education and Education for mental health professionals regarding the huge need for RESPECT for all family members of people with mental illness and consumers,
- Including the separate group nnaami represents managed by nnaami.

### 7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?

See above

Have a large mental health budget component for Innovation, programs and projects.
Respect staff by including them at all levels within mental health organisations and by having flatter management structures and less paperwork. Ensure managers have a day a month doing the lowest on the scale type work, and all workers being involved with some management tasks.

Dissolve the us and them culture ie professionals vrs consumers or family.

Empower staff to look after their own mental health and wellbeing.

Change the culture Engender High value RESPECT for families and consumers in every professional interaction. Create collaborative inclusive practice with families everywhere. Reward professionals for doing this.

Create workplace environments that address challenge and change negative power imbalance in the medical model which work against good consultations and best practice.
Support managers in mental health to find ways to increase workers RESPECT for each other with greater focus on team development.
If pressure on beds is a problem create more and more alternatives to admission and post admission.

8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

See 'The Waverley Mates program' it's an on ground amazing supported employment program for people experiencing intellectual disability and many have long term mental illness. They are supported to do lawn mowing, ironing and cleaning in a supported environment in a local community many of their customers are elderly people at home, churches, community centres. Started by a group of parents from a disability special school who were concerned their kids would never get to have a Job other than sheltered workshops. They gain skills to mow lawns look after their equipment and their customers. Participants all take pride in their work and they are involved with participation in their committee of management's decisions.
Increase other mental health support programs café employment programs (and others) offering supported employment but without unrealistic targets to meet expectations or disincentives of losing their disability benefits., because mental illness can often be episodic life –long for many and also it can take quite some time before people are confident to do even a small part time unsupported work outside this type of program.
Create more programs that support people with chronic long term mental illness part time in existing businesses and workplaces where there is no threat of their pension or benefits being taken from them.

9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

- 1\. Patronising attitudes toward Families and Consumers must be non-existent, it must go.

- 2\. Ensure there is a focus on ' RESPECT ' for all family members in mental health policy and practice and,

- 3\. Ensure there is a focus on collaborative treatment with family inclusive sensitive practice.

- 4\. Help NNAAMI so there is appropriate support (as mentioned in this document) and also individual advocacy available for young people managing a parent with mental illness that can include assisting young people (where relevant) to be supported to effectively advocate for their parent for better treatment and support.

  5\. See section 11. below

- 6\. Increase provide (develop better) family sensitive education for staff , family inclusive practice and collaborative practice education to all of the medical and Mental Health

Workforce and Allied Health workers government and non government agencies organisations.

- 7. Develop a voluntary register in Victoria of all persons seeking treatment or support for mental illness and their family members / interested persons. With a sensitive follow up reporting review system on questioning, have they got any part of their necessary treatment or support yet? To help determine priorities forward resource planning and innovation in mental health.

- 8. Re treatment and support One size does not fit all.
  The Wide variety of treatment and program options the better. 7
- 9. See Innovation above (without it there are some programs of psychosocial support would never have been developed not everything should have to be evidence based).

- 10. More supported housing models for people with mental illness and innovative homeless shelters for people with mental illness with support. Also Even transportable tiny houses locatable on a needs basis to areas where land in metro areas might be available and in rural and remote supportive communities. Giving homeless people with mental illness an immediate roof over their head makes a big difference in a first step toward gaining and retaining increased social connections and better more consistent mental health treatment. *Perhaps support small and large rural towns and isolated communities who want to get on side and support the process, with incentive assistance such as civic infrastructure projects like community halls, sports or recreation facilities or the like.*

- 11. If we want to decrease stigma of mental illness. Have a focus in mental health to (dramatically reduce) <u>eliminate homelessness in Victoria</u>. Because for many people needing to seek mental health treatment or becoming unwell (from whatever socio economic background) the potential outcome of homelessness and, the high rate of persons with mental illness who are currently homeless, must be a huge additional worry for them.

- With the right programs, providing homes now, and cost affordable homes now and low rental cost homes however small, could also help stimulate the Victorian economy. With the right supportive programs we could engage and support some homeless people with mental illness in the process of building them. You need an address to get a pension then with the right support you might even be able to contribute to the actual building or rental of your new small home. What target does Victoria have to eliminate homelessness of persons with mental illness ?

- 12. Programs that divert people away from hospital EDs and minimise time in ED. Create programs in ED that minimise doctors and staff paperwork time. Provide a range of time limited crisis counselling options via allied health staff on and off site and increase appropriate referrals with follow up.

- 13. Programs that divert and refer drug and alcohol admissions to secure areas of a hospital or other services and refer to new 24 hour drug and alcohol community crisis treatment centres.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

    1. As above,... inclusion of Innovation expenditure in mental health budgets.

    2. Provide advocacy to people with mental illness to gain appropriate levels of support, psychosocial rehabilitation support and or via NDIS with follow up to ensure they have gained this and review.

11. Is there anything else you would like to share with the Royal Commission?

- Aged Persons with Mental Illness. The following personal account of the serious abuse of my [redacted] as attachments which highlights wide spread systemic failure and abuse across mental health to properly respect, treat and support a person with mental illness and their family across various government and non government agencies operating in Victoria.

- This has huge relevance I believe to your work as MHRC to ensure best practice is enshrined in mental health policy and legislation across all relevant government and government funded agencies that are likely to come in contact with persons with mental illness and their families.

- My [redacted] with mental illness and family were traumatized and abused by professionals in Victorian organisations and by the very laws policies and staff that are charged with protecting [redacted]

In Summary it involves.,

(Copy from Personal Account speech & submission to ACRC amended for MHRC)

Below

**Royal Commission into Aged Care, COPY for MHRC**
**GPO Box 1151, Adelaide SA 5001**

Statement to Commissioners Lynelle Briggs and Richard Tracey 3 May 2019
Submission By Paul Mckillop To ACRC at Community Forum Maidstone VIC
[redacted]

Dear Commissioner Brigs and Tracey,

**There are many really good services and dedicated people providing aged care support.** [redacted] **(having experienced chronic major mental illness all** [redacted] **life)** has had 16y of wonderful (aged care) home support workers after being diagnosed with dementia till one day,

**<u>Our recent experience</u>**

- Without supplying evidence there was vindictive malicious misuse of Aged Care Mandatory Reporting practice. This was done knowingly by a HCP Provider Team Leader to divert attention away from their own **Misconduct** and abuse of an elderly client **with mental illness** and family. A serious spate of further intolerable abuse followed.

With current Mandatory Reporting Aged Care Policy, Procedures and Legislation
**If this below can happen to my** [redacted] **with a 'Home Care Package', it can happen to you as well**.
This should never happen to anyone again - We believe you can prevent this from happening again.

My [redacted] ([redacted]) was,

1. **Intimidated - Unprofessional conduct by HCP Team Leader and her manager** <u>(without proper consultation with family or mental health).</u>
2. [redacted] **Abused by Locum Home Visiting Nurse**
3. **I was Assaulted by Police and thrown into the street.** (Incited by a HCP team leader and her boss) [redacted]
4. [redacted]**Abducted from** [redacted] **home and**
5. **Admitted to hospital without need or evidence,** or cloths nightie or a toothbrush.

6. **The same police** came (with a HCP provider case manager we had never seen before and her boss) without any prior questioning or investigation at our nearby family home few doors away in same street (witnessed by neighbours) **Threatened and Intimidated myself for making a complaint about police that evening.**
7. **Family prevented by above police to visit, contact or see my [redacted] in hospital.**
8. **Community Police** two days later (after one of the Commissioners of police heard of the case) then confide / admit **stated "no evidence found" and stated to my [redacted] and I "please help us close the case immediately..** please go see your [redacted] in hospital tonight asap".
9. **Client has fall on concrete floor in hospital (before family arrive)** and was sedated.
10. **Case manager applied for urgent VCAT hospital hearing against family without HCP case manager VCAT application or aledged evidence, ever being supplied to client or family** (as required by VCAT) but after application by family later this was never supplied to family by VCAT either. **Order made against family for appointment of OPA temporary guardian (retaining family as EPA EMPA) - VCAT Presiding Hearing Member Never Acknowledging [redacted] As A Person or read our 32page family NNAAMI submission.** [redacted]

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11. **Dr in general hospital** stated to me a day before the above hearing **" you have done nothing wrong" and "you don't seem to know what goes on here - they all go into the VCAT hearing room beforehand I see it all the time, and discuss all the cases, make their decisions before I can get in there to speak, it's all wrong…** I'm going to try my best to get in there as early as I can when the hearing starts, you need to as well, be early. I agree with you [redacted] should go to the Aged Mental Health hospital now because they (our hospital psychiatric registrar) messed up [redacted] medication and is not listening to me I will advise them of this imminent hospital transfer to another hospital aged mental health unit for your [redacted]."

12. [redacted] **sent to an Aged Mental Health unit** because hospital had not consulted with family earlier and had changed [redacted] medication (due to police action preventing family attendance at hospital).

13. **Further abuse,** client found in the Aged Mental Health Facility (when I returned from a break) **with mattered hair incontinent, not dressed, and not prompted to wash or shower** (as per written management plan by family). I visit every day now and take [redacted] out for lunch as well as morning or afternoon tea.
14. [redacted] **left without cloths on weekend in non-fitting pyjama pants (to small and tight to pull-up / covering shoes flapping on ground ) creating high falls risk as if [redacted] were in a straight jacket for [redacted] legs**. Staff oblivious of above attempting to assist [redacted] many times in toilet by lifting up the back of pajamas with out any clue these were completely the wrong size. Staff claimed later patient had no cloths. After much questioning by family. Cloths were found locked in patients room. In following weekend patient found again in the same situation. Not sufficient sleeping medication given. Many other patients claimed "your [redacted] is awake all night" "we have to take [redacted] back to [redacted] bed you know, it's happening most nights, the staff do nothing"
15. **Other staff in above facility confided "Not sufficient staff on at weekends"**. This was obvious every weekend and as the staff stated each time to me. "Are you taking [redacted] out" pleading "please take [redacted] out again we are short staffed thanks thank you for doing this". *(In a previous admission a year before staff pleaded with me on the weekend " please help medicate [redacted] now as [redacted] is pacing up and down without medication I was glad they called me though. They were frantically stating in reply to my questions " We can't get a Dr to see [redacted]. We have no one to call even though as you say there is a hospital next door, we are not allowed to call on them. Please come now as we are frightened [redacted] will break [redacted] hip if [redacted] doesn't get help with [redacted] medication straight away." On this earlier*

*admission I was told the psychiatrist was on holidays and no one is covering for her. Remarkably* [redacted] *has only had 3 admissions there in total ever over 16 years)*

   a. **[redacted] had a fall in this facility on a concrete floor**.

16. **All Staff in aged mental health unit claimed "we can't talk to you as [redacted] has a guardian".** **([redacted]**
**[redacted] [redacted]**

17. **Family not consulted or invited to Discharge planning meeting by OPA guardian or by any hospital staff.**
18. **No Dr or Psychiatrist consulted family** the whole time of a 4 month admission. Psychiatrist became very annoyed when I questioned her how can you assess anyone appropriately without also talking to the family / carers. This changed slightly when the social worker arrived back from leave. **OPA guardian ran a subsequent discharge planning meeting and [redacted] discharged home by OPA guardian.**

19. **HCP Package provider and Service provider all stated " We can't talk to you or listen to you because [redacted] has a guardian"**

20. **HCP package provider charged for services [redacted] never received for the whole duration while [redacted] was in hospital** (eventually package reimbursed months later after many emails from us to them)

21. I stayed with [redacted] after discharge at [redacted] home for support. **I was not permitted by OPA guardian to leave the house without [redacted] at any time not even to walk the dog or get a loaf of bread at the milk bar at the end of our street.** Draconian directives were constantly issued to us by the OPA guardian. [redacted] was now continent independent with prompting with relatively good ADLs. However workers at [redacted] home were now inappropriately Hovering and Standing over [redacted] in the toilet and bath! Not the regular workers but those under instructions from the guardian to report anything they could find it would seem as an issue back to the guardian. **HCP Service Provider managers engaged to provide personal care worker staff for [redacted] would not talk to us / family about how any service worker was to interact with [redacted] at home or what was their plan of support (or what [redacted] or us saw as appropriate support).** Soon [redacted] however bathed and dressed [redacted] each morning before they arrived due to their intrusiveness. One APATT nurse even made a habit of looking through my personal diary when he came on home visits and helping himself to look in [redacted] medication box. [redacted] needs for sleeping medication were refused (I eventually complained about his actions).. **It seemed we were somehow under House Arrest by the OPA guardian and HCP provider** (incl *aged mental health APATT)* ***(Set up to fail).*** **[redacted] was not allowed to go out with family for dinner. [redacted] was not permitted to go to our holiday home or to go to Church or see friends there. OPA Guardian also stated [redacted] was not to have HCP home help lawn mowing or cleaning services, claiming "this was a ruling under Aged Care Policy" because I was there. The HCP provider complied with this without question.** It was obvious there had been no advocacy in support of [redacted] or family rights by OPA guardian quite the opposite. **[redacted] had no Choice [redacted] had to have the same HCP Package Provider at discharge that had abused [redacted] earlier in the year**.

22. **HCP Package Provider Account Statements reflected constant overcharging for Services already quoted. A Day Outing once per week of $100.**

**was Charged at $120. p/w and this service provider** (a wonderful supportive service who knows [redacted] well) **still not paid by HCP provider for 9 months.**

23. **OPA public Guardian Eroded [redacted] HCP Funds using the highest cost home nursing service leaving virtually nothing left for any other support.**
    Good Neighbours and friends and wonderful care workers, and [redacted] new HCP package nurses and service providers workers were in disbelief. All started writing letters of support for [redacted] and us and complaints again to OPA and later to VCAT.

24. **We felt we could not complain to anyone ourselves because they had [redacted] Hostage at every stage** above. **Every agency management stated "We can't talk to you because [redacted] has a guardian!"**
    **( [redacted] .) which also addresses this particular issue. and Revoked their own original order of March 2018 reinstating myself as guardian for [redacted] and retaining family as EPA EMPA.**

    **VCAT Statement of reasons were highly critical of services and non consultation with family carers.**

I stated during my speech to ACRC .,

***" I want you to imagine my tie is through my mouth tied behind my head and my hands are tied and bound behind my head how do you think I feel ? ……..we feel muted …… and held hostage. If I feel like that and my family feel like that.,...... How do you think my [redacted] with (mental illness and) Altzheimers dementia feels?***

[redacted]

Revoking their own VCAT Orders and highly critical of OPA and Aged Mental Health., **which has implications for all mental health services and other Victorian agencies** on how people with mental illness and Alzheimer's / dementia and their families should be better respected.

[redacted]

**MHRC Commissioners, Please read all this in full in [redacted], along with the following recommendations for urgent action.**

" When you support a parent with mental illness and they are ageing you have very little time for yourself "

"Aged Mental Health culture sometimes looks out of step with the rest of adult mental health they seem still at times to be back in the institutional era of mental health and not even up to date with adult mental training on psychosocial rehabilitation or recovery or today's Age Care Policy or Standards"

People with mental illness have particular greater needs in ageing they seem more vulnerable to a mental health system willing to push them prematurely into congregate aged care and vulnerable in aged care.

Greater Advocacy thrust and support is needed to assist people with mental illness in ageing maintain their best quality of life in the least restrictive environment.

The following urgent mental health recommendations are provided for you for the MHRC

POWER IMBALANCES in MENTAL HEALTH

## Recommendations

- Aged Mental Health units need better allied health staffing levels and innovation funding to reduce patients loneliness inactivity and boredom and increase a sense of wellness.

  **There are some good examples of best practice** in Aged mental health or programs one of these is - The St Vincent's Volunteer Services Dept and their -Angel program and - pet therapy program, are I believe good example of best practice. However,

**Power imbalances in the mental health system have the potential to cause serious harm.**

## Recommendations for Action

- Person Centred Training and Training regarding RESPECT for and the needs of Families of persons with mental illness, must be mandatory and reviewed and monitored and regularly updated by government for every staff member in aged mental health hospital service / agency and for all doctors and workers across mental health, including all aged care package and service provider staff operating in Victoria. (Also please see policy recommendations for changes to Mandatory reporting in Recommendations to ACRC below & re mental health services).

- All aged care providers above in Victoria also require mandated training regarding the needs of people with mental illness and Respect for and the needs of Families of persons with mental illness in all staff of aged care home care package and service providers and for residential and nursing home care.
- With quality assessment review follow up via independent quality consumer and carer satisfaction surveys mandated in all services.

- Service quality and complaints assessment should be mandated to be publicised on a state-wide website available to all consumers and family and interested persons. ( I have never been asked to do a customer survey in mental health as a family member ). Fudging this could be easy for agencies and hospitals. Services should require signatures for these questionaries to increase accountability.
- All complainants to funded mental health government and non government agencies should be given a complaint number for each complaint and lodged in a complaints register identifying the subject area of the complaint..

This may help reduce reprisal actions by staff or at least to monitor it better.

- It would be good if this is properly mandated and standardised across Victoria. With the subject of and number of complaints recorded for each year placed on the agencies website and annual report. With this information in an online register of all aged mental health and mental health complaints across Victoria (and for all mental health services) Available for anyone to view so consumers and the public are more aware of levels of concerns regarding any agencies performance and their willingness to improve service or resolve concerns or not.

  Unfortunately much of what you read here goes under the radar as there is much risk for consumers and family to complain to anyone in mental health. I have been told by the aged mental health service just prior to [redacted] discharge that "if [redacted] comes into hospital again you know it will be the last time [redacted] sees [redacted] home again" I was also told by staff at the Chief Psychiatrists office " you can't talk to the Chief psychiatrists about complaints because they don't get themselves involved in any complains matters they won't talk to you." Surely it would take someone in high authority other than complaints bodies to help remedy this systemic abuse.

- Police There are many wonderful police in Victoria. I have personally witnessed police of good character with practical knowledge of the needs of people with mental illness and their families
  'Some police and ambulance officers assisted my [redacted] some time ago on the side of the road with the highest degree of patients, tact and respect, when we could not drive any more as [redacted] was in crisis, as they felt it was most important for us to get home safely and to avert unnecessary hospital admission.

- However, many Police require better mental health training about the needs of people with mental illness and their families and more training in de-escalating emotional situations particularly where it is suspected mental illness is a factor or contributor.

- Community policing staff are excellent an highly professional. However I believe community policing should be skilfully expanded to include civilian welfare / counselling and mental health personnel to work in tandem alongside and within community policing teams. To assist with on site assessment and referral and assist community police in formulation of their work - responses to the public and responses to / call outs.
  That this sort of community policing team should be more widely utilised (once expanded as above) particularly to assist and be available or take the lead where it is known or becomes known to police that a person has a mental illness or dementia, and alongside existing PACER responses respectfully.

- That Police and Ambulance staff and Aged Care Home Care Package and Service Providers operating in Victoria are educated more thoroughly about the inappropriate admissions to hospital of people with mental illness or ageing or dementia, (without proper consultation with family or carers, doctors), or relevant evidence of a need for admission and the inappropriateness of admissions without proper police interview / investigation or appropriately involving family.

- Good Policy should ensure if Police or Ambulance have any doubts after this. They should have at their disposal (in non-violent situations and where risk is minimal) the ability to request from the person or the family a home locum Dr on call medical assessment that reports to police (or if relevant obtain a verbal report or otherwise from the family GP within 72 hours).
  **There can be many unwarranted repercussions of unnecessary admissions to hospital for aged persons and persons with mental illness or dementia**. It can be unsettling traumatic and detrimental to the person and their family and an unwarranted impact on their conditions, setting the person back in their progress, apart from the unnecessary increased cost to the hospital system and unnecessary pressure on beds. Many conditions are more appropriately treated at home in the community.

- <u>OPA</u> require a detailed independent review and investigation into their practices in regard to how they manage people with mental illness (or disabilities) and their families. Their knowledge of the needs of people with mental illness and their families and of the needs to RESPECT and be mindful of rights of aged persons with mental illness, on how they supervise and provide training to their staff, its quality, 15 and their staffs knowledge and practice in respect of ‘the UN Convention on Human Rights’ of which I understand Victoria is a signatory.

- <u>Aged Mental Health</u>.
  I have met some wonderful aged mental health staff however.,
- Family should be provided with a questionnaire early on during hospitalisation of a family member with mental illness in aged mental health about their perspective of the circumstances and needs of the person with mental illness.
- Families should be provided with ways to have written input into case histories.
- Family emails should be Acknowledged (particularly when they involve request to place VCAT Order or statement of reasons in case history)
- Doctors and Psychiatrists and staff must be mandated to consult with family when family request this. (see VCAT statement of Reasons)
- Family meetings around big board room tables with multiple large numbers professionals should be a thing of the past, they are intimidating for consumers or family. Alternative much smaller size meetings need to be available for families.
- Second opinion requests should be available and not ignored.
- APATT should have more allied health staff component working within their teams.
- Aged Mental Health Inpatient Units require more allied health therapy staff and individual support staff available to take patients out in the community during hospital stay.
- Domestic and nursing staff requires more basic training on person centred care and quality personal care and on self directed care.

- Aged mental health has become more risk averse in some ways rather than person centred. Policy in this area needs to move forward toward promoting a person's capabilities and interests, Away from a focus on disability and more on a focus about ability of aged persons with mental illness and away from a fatalistic attitude toward dementia.

- VCAT need to have a detailed independent and regular review of their services and hearing member staff with regard to how they conduct hearings and hospital hearings and in relation to how they respect the rights and needs of people with mental illness (or disabilities) and their families in hearings. To ensure that the written submissions of people with mental illness or disabilities and their families are actually read by Presiding Members in VCAT Hearings before they make Judgments, Orders or Determinations concerning people with mental illness their family or carers (which clearly did not happen for my [redacted]'s first VCAT hearing - *this can cause huge stress and trauma for persons with mental illness and their families*). To also ensure that VCAT staff understanding knowledge and practice in respect of the need of people with mental illness and their families are of the highest quality and that they are cognisant of the UN Convention On Human Rights, of which I understand Victoria is a signatory.

  It should be noted that while there are many wonderful people with the highest respect for people with mental illness and their families, in the above organisations. Better 16 VCAT staff selection, supervision and support mechanisms and strategies I believe may be required to ensure that burnout amongst presiding members is minimised and to ensure that vulnerable and innocent people are not wrongly penalised punished or victimised.

- I understand that the Victorian government have been presented with an

  **'Access Justice Review'** which recommended the implementation of services for self represented litigants at VCAT., as well as other jurisdictions. Unfortunately and remarkably to date, no funding has been provided at VCAT even though other courts have pilot services. The non-representation of persons with mental illness or their family carries with it major risks and serious trauma for these people as was the case for my [redacted] and our family.
  This proposal utilised pro-bono services which are highly cost effective and you would think would help to swiftly clarify case presentations and reduce hearing times. It's remarkable this program has not been employed as yet by VCAT.
  NNAAMI strongly supports this proposed project in principal and urges you to ensure it's delivered immediately for all persons non-represented with mental illness or disability and others required to attend VCAT hearings.

**COPY**

**Recommendations To ACRC and amended for MHRC re Mental Health**

- **Amended with a (Bullet and or MH below) indication of what also relates or highly relevant to need for change in Aged Mental Health and Mental Health Practice.**

Quality and Safety

- **MH**

1. All Carers should be highly respected.
   Amend aged care policy (**& MH policy)** and procedures for HCP Package Providers and Service Providers to include all relevant family and primary carers in communication regarding aged care clients irrespective of if there is a guardian, power of attorney or not.

   Amend aged care policy (**& MH policy)** and procedures for all **(MH hospital & services)** aged residential facilities to include all relevant family and primary carers in communication regarding aged care clients irrespective of if there is a guardian, power of attorney or not. The risks in not doing so are huge.

   [redacted] and

- **MH**

2. Regarding Mandatory Reporting in residential aged care **(and Mental Health).** There are policy and procedure statements for aged care providers **(and Mental Health)** like, **.** "take reasonable measures to protect the identity of any staff member who makes a report and protect them from victimisation."
   For the protection of aged care **(and Mental Health)** staff regarding Mandatory reporting. 17

   However there does not seem to be any protections for families / carers wrongly reported or Victimised by staff of any government funded aged care organisations or agency. **(Or MH)**
   There does not seem to be any consequences for staff providing false or misleading reports or for appropriately addressing the ongoing abuse or victimization of others they have created.

   - Provide Maximum Protection for Family / Carers under any Mandatory Reporting Policies Procedures for all aged care **(and Mental Health)**, provides with Penalties for misuse of Mandatory Reporting.
   - Policy and procedures surrounding Mandatory Reporting by Aged Care package and service providers **(and Mental Health)** about family carers - Must include a recorded Investigating component with the accused (Not merely Just based on Suspicion).
     - (A) Face to Face Family consultation must be included where ever possible. Serious allegations must be handled by a Senior member of the service face to face (where possible) so Families carers are given the opportunity to provide information, make complaints, counter claims or arguments.

- (B) Where Police are involved Police procedures and protocol across Australia should include that all Police question the accused or family before proceeding. Otherwise above scenario is potentially highly damaging for persons with **(Mental Illness)** dementia being removed from their familiar environment without reasonable reasons and

  (C) Primary carers should always be consulted by police face to face regarding persons with **(Mental Illness** ageing**)** dementia (as is the case in using family or advocates when questioning people with disabilities) before they take action or not on any (suspicion or) allegation.

  (D) The proposed 'Strengthening protections for Older Australians – options for a national aged care serious incident response scheme' 29 March Document. Must be adapted / expanded with appropriate safeguards for families / carers regarding introducing any Mandatory Reporting by Home Care Providers with consideration of the above horrific scenario. **(and, This must include protection for people with Mental Illness and their families)**

  Complaints from families regarding Home Care Package or Service Providers or Vv, or in **(MH Mental Health Hospitals or Services)** should never be diverted using the excuse
  " I can't talk to you as there is a guardian" and allegations of physical or sexual abuse of an elderly person **(or person with mental illness)** in their own home should include an examination option by a home visiting doctor as first option. Rather than inappropriately removing a person with dementia **(or mental illness)** from their home.

3. I've heard quite often Home Care workers state,

   " They don't tell us anything about what you want us to do. What does your [redacted] need us to do for [redacted]? They (HCP service provider) tell us nothing "

   Aged care Home Care workers need information and where needed basic training regarding the individual needs of clients they are going to care for,

   [redacted] went into respite in a nursing home once some years ago. The staff were amazed I had given them a list of [redacted] abilities and care needs.
   They stated,

   " No one has ever given us this information they just leave the older person and go, we have to find out all this stuff later for our self."

   a. **Potential Risks can be alleviated** if Nursing homes providing respite had a basic tick sheet or proforma form for aged persons and their carers / relatives to fill in about the persons Abilities Preferences and Care Needs. (with a space for relevant comments) no one should be working in the dark about this stuff.

   b. Home Care staff need the same basic information as well to do their Job properly. However too often privacy or time constraints get in the way of common sense care.

4. Family Carers often have expert knowledge of the person including their support needs. Families (including adults, young people and children) of people with mental illness and major mental illness deserve and require greater respect from **(MH services)** HCP and Package and Service providers. Regular training regarding this should be provided to all workers across aged care **(and MH).** Police also require better training in this regard.

5. Family carer input into all Package and Service provider records for the person they care for.

   a. Some Home Nursing Agencies have changed to electronic record keeping effectively excluding vital family carer generated notes input.

   b. Families and all Carers must have at all time easy access to provide input notes documentation on Package and Service Providers or Home Nursing Agency Electronic or Paper Client Notes / Records.
   Otherwise aged persons health and welfare is potentially placed at risk.
   ( Sometimes the family are the only people who become aware of the need for an important care practice or medication change for a client at home)
   **Families should also have easy access to provide input into MH mental health records as a carer. (Having your concerns ignored or misinterpreted by busy over worked or non respectful mental health professionals can have dangerous consequences.)**

6. Transfer of HCP to New Providers Must Be Streamlined and Standardised.

   Home Care HCP package providers should have standard short time limitations on how long they take to wrap up a persons aged home care package accounts and hand over accounts to a new provider. Two or three months is far to long. Two weeks should be ample.

   Exit fees must be abolished. These fees have an unjust and unnecessary negative impact on an aged person’s home care as they eat into an elderly clients HCP funds and can dramatically limit vital services.

7. OPA Vic **(and MH staff)** urgently require education and training regarding Aged persons rights and aged care best practice standards and mental health best practice and standards and consumer and family rights.

8. Some providers remain in a risk-averse culture and need training and better policy frameworks from government to be more person centred and family friendly

inclusive., **(inc MH).** Providers Not including or listening to clients or family concerns or complaints due to perceived risks of liability or only seeking praise from clients or family is counter intuitive to good service improvement.

9. Choice is important for consumers. Potential Clients and family need at a glance basic information when choosing a facility
   Nursing homes and other service providers should be encouraged or made to advertise on a board at the front of their facility - how many staff they have, staff to client ratios, mix of staff and types of staff available and have this compulsorily constantly updated in real time online Australia wide via a government hosted website.
   Some facilities could offer more nursing services, while others more personal care support, while others may advertise more mix of a variety of allied health hours.
   Presumably everyone wins in this type of arrangement.

10. Increasing person centred HCPs the variety of Home Care options would be best practice and most cost effective in the immediate future for aged persons in Australia.

11. Self Managed HCPs and the number of these cost effective competitive HCP providers should be encouraged stimulated by government and increased. Many clients and families are competent enough to do the management of their own care.

12. I believe there is a need for flexible short term more homely respite in a normalised setting for two or three days or a week. rather than nursing homes dictating longer durations. So if a carer has to go to hospital they are assured their relative is in a smaller more normalise setting with adequate tailored care similar to what they have at home. **(MH Vic should also consider providing this separately for people ageing with mental illness).**

13. Choice of staff_and continuity of home care staff is paramount at times for aged persons experiencing dementia Client Ownership by a HCP must be banned. Staff told by HCP Service Provider “you are not allowed to notify the (aged) clients what agency you are moving to. They are our clients you cannot see them ever again ever or we will go you / sue you” (the workers believed this was done so clients can’t easily know where they are going next to work to make it difficult for clients to request them from a different agency). Later the home care worker found out when the client wanted to know what had happened to [redacted]. The HCP service provider had lied to the client told the client she (the worker) had retired and was no longer working anywhere.
    Clients should not ever feel owned - by any one or any agency! **(Also in MH)**
    These are aged People not Slaves owned by a HCP Service or package provider.

14. Quality is not always doing things for some one.
    It can be faster this way but not always quality. Assisting prompting empowering people to complete what they have ability to do at any level is often far more satisfying in the long run for the client.

Aged care Policy **(& MH policy)** needs to be more about Maximizing Aged Persons Opportunities and Capabilities and potential in all areas of aged care, **(and MH services)** in Home Care and Congregate care settings.

However Quality is not always about high quality training It's about promoting workers good attitude and respect for aged persons **(&MH).** A person with little training can do great things and be a wonderful support for an aged person with the right sort of leadership.

15. Family and carers experience should be seen and recognized as part of the wholistic care and support of an aged person **(or MH service).** A balanced person centred and family sensitive team work approach should be emphasised as best practice in aged care **(&MH),** involving the aged person's interests alongside carers family knowledge.

16. A Federal funded media Education campaign about the value of Australian unpaid carers of Aged Persons **(from vic gov for MH carers)** and those with dementia at home is much needed.

17. Ownership Who owns the elderly person? Family Exclusion Why?

To often Traditional Daycentres or HCP providers feel they know what's best for the aged person. lording it over aged persons and family carers by projecting an façade of higher knowledge or power.
There are Hugh Power Imbalances
One family in a rural area I know stated to me.

*" The nursing home are doing everything to keep my [redacted] and not ever let [redacted] go*
*I bring [redacted] home each week from there,*
*it's a one and a half hour drive to get there and come back.*

*[redacted] would be better with me and [redacted] family close by.*
*They are using [redacted] dementia as an excuse not to move [redacted] This is not right.*

*[redacted] has a great time when [redacted] is at our home and the local nursing home here is only around the corner from us and they are happy for [redacted] to come to our town. [redacted] could visit us much more every day then if [redacted] wants."*

[redacted]

[redacted]

[redacted]

[redacted]

**Yours Sincerely**

**Mr Paul Mckillop**

**Convenor**
**NNAAMI**