Mental Health Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

- Submitted online -

Brighton, 4 April 2019

Dear Madam/Sir

Submission to Inquiry into the economic impacts of mental ill-health

I am grateful for the opportunity to provide input into this Inquiry. I have been involved with Carer Support Groups such as ARAFMI and Carers QLD for the last four years due to the diagnosis of a loved one.

I have trouble identifying with the labels 'informal carer' and 'consumer', however, these are not the main concerns of my submission and hence, I'll use these terms in the following.

On the first page of the issues paper, under the heading "What is this inquiry about?" the authors state:

> "Despite a plethora of past reviews and inquiries into mental health in Australia, and positive reforms in services and their delivery, many people are still not getting the support they need to maintain good mental health or recover from episodes of mental ill-health."

Why is it that "many people are still not getting the support they need" "despite a plethora of past reviews"?

I am wondering whether that is because the issue of mental ill health cannot simply be managed with a 'neocortex – focused' logical problem solving approach of providing 'functions' and 'services'.

The issue of mental ill health can present itself as

- "serious problems with thinking clearly, emotions, and knowing what is real and what is not"[1] or
- "unusual ups and downs in mood and energy, which can be extreme"[2] or
- "a mental illness that makes a person feel sad or unable to enjoy anything for weeks at a time"[3] etc.

the issue of mental ill health cannot simply be managed with a 'neocortex – focused' logical problem solving approach

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[1] https://www.yourhealthinmind.org/mental-illnesses-disorders/schizophrenia
[2] https://www.yourhealthinmind.org/mental-illnesses-disorders/bipolar-disorder
[3] https://www.yourhealthinmind.org/mental-illnesses-disorders/depression

Mental ill health is 'amygdala – stuff'. It is about 'fright', 'fight', and 'flight' reactions. It is about 'beliefs' that cannot be influenced by logical reasoning but only by taking a 'detour' through working with the emotions and moods of a person and the experiences they made that led to that belief. As Mark Tyrrell says: "We know that people might die for their belief, so watch out!" and "And as you have probably noticed, no amount of arguing will change this belief – it may even make it stronger!"[4]

Providing problem solving recommendations, such as 'seek treatment' or 'get help' or 'seek therapy' doesn't cut it, because: why would one enter into problem solving mode when one's mood says that 'nothing can be done anyway', 'life is not worth living' or 'nobody will understand what I'm going through anyway'. Providing a recommendation to seek treatment challenges the 'belief' of the ill person that nothing can change for the better and will get them to argue even stronger that nothing can be done or no one understands.

> *why would one enter into problem solving mode when one's mood says that 'nothing can be done anyway'?*

The suggestion to seek treatment proves to the mentally ill person that the 'helper' has no idea what the ill person is going through. These well-meaning problem solving recommendations make us, the carers and helpers feel better that we have 'done something', 'supported someone'. – But it is *about us*, that *we* feel better; and it later leads to frustration when the ill person – not surprisingly – does not take up the recommendation, because it did not respond to their needs.

Please don't misinterpret what I am saying above: We as carers and our mentally ill loved ones **do need** all the treatments, therapies, services etc. that have been developed through the problem solving approach. However, we (ie our society) just have not found the right way yet on how to 'deliver' them to those who need them in such a way that they truly make an impact.

The issues paper speaks about a 'wrap around the person' approach. What could this look like?

How to find a new 'wrap around the person' approach?

If the Western rational problem solving approach is only partially effective, because we are not just dealing with rational logical issues, but with emotions, mood and irrational behaviours, we might need to call on different delivery and interaction methods and measures that have been found effective in this context. By way of example, I list below a few proven approaches that I have been researching and using:

- Dr Xavier Amador, author of the book "I'm not sick, I don't need help", prominent American psychologist who fathered the inclusion of anosognosia (='denial' as a symptom of the illness) into the DSM (Diagnostic and Statistical Manual of Mental Disorders), has developed the approach of LEAP – Listen, Empathise, Agree, Partner[5];
- Lifeline applies the CFRED model: Connect, Focus, Relieve Distress, Enable Coping and Decide next steps, based on Unconditional Positive Regard, Empathy, Non-Judgemental Listening and Appropriate Helping Style;

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[4] Mark Tyrrell, A Helping Hand – How to Build Self Esteem in Others, Oban 2014, pp 27 and 45
[5] https://leapinstitute.org/board-of-directors

- The Centre for Motivation and Change[6] teaches CRAFT - Community Reinforcement and Family Training, which includes:
    - Understanding a loved one's triggers to use substances
    - Positive communication strategies
    - Positive reinforcement strategies – rewarding non-using behavior
    - Problem-solving
    - Self-care
    - Domestic violence precautions
    - Getting a loved one to accept help (a question we as carers are most battling with!)
- Sue Koningen, a Family Interventionist and Peer Support Specialist[7] teaches LEAD – Listen, Empathise, Ask and Detach. In her practice, she also develops strategies with her clients to successfully free ourselves from the Karpman or Victim Triangle[8]. This is a basic must if we want to truly connect with all our loved ones and the broader community (not just mentally ill people) in an effective and productive way instead of staying caught in the daily struggle of 'Victim', 'Rescuer' and 'Perpetrator'. This knowledge is used extensively in psychological and broader interaction training practice, only not in those contexts that we get involved in as mental health carers.
- Mark Tyrrell[9], a psychologist in the UK, has published extensively about the issue that belief cannot be changed by simply contradicting it. As mentioned above, it rather makes it stronger. For example: "Canadian researchers found those with low self esteem actually felt worse after repeating positive statements about themselves. They said phrases such as "I am a lovable person" only helped people with high self esteem. Wood, J.V., Perunovic, W.Q., and Lee, J.W. (2009). Positive Self-Statements: Power for Some, Peril for Others. Psychological Science, 20(7):860-6. DOI: 10.1111/j.1467-9280.2009.02370.x" However, this is still what some CBT (Cognitive Behaviour Therapy) practitioners get their depressed clients to do and it is recommended by some treatment services. Tyrrell suggests other 'gentle' ways of using reframes, stories and metaphors to open his clients' minds[10].

using the above approaches has led to behaviour changes on the side of the carer, which in turn led to improvements of the consumer's mental health

In my experience, using the above approaches (particularly through the guidance of Sue Koningen) has led to behaviour changes on the side of the carer, which in turn led to improvements of the consumer's mental health[11]:

- Becoming aware of the victim triangle and consciously trying to avoid Victim, Rescuer and Perpetrator behaviours. This might mean to review many ways of how

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[6] https://motivationandchange.com/outpatient-treatment/for-families/craft-overview/

[7] http://www.susankoningen.com.au/index.html

[8] https://www.lynneforrest.com/articles/2008/06/the-faces-of-victim/

[9] https://www.unk.com/blog/working-with-low-self-esteem/

[10]To just provide one example of many on his website: https://www.uncommon-knowledge.co.uk/articles/uncommon-hypnosis/talking-thoughts-or-talking-feelings-does-it-matter.html

[11] Are the approaches listed above evidence based? I am aware that the LEAP foundation (Amador) and Unkommon Knowledge (Tyrrell) can provide scientific evidence, while the others refer to anecdotal evidence on their websites. If we want to use more of these approaches in the future, it will not be difficult to present more evidence.

we deal not just with our loved ones, but with all our relationships on an every day basis.

- Taking responsibility for our own agendas, anxieties and fears. How often do we try to get the loved one to do something that *we* consider the solution but they do not. Thus, we exhibit behaviour that might undermine the consumer's self-confidence and trust.
- Remembering the love or unconditional positive regard for our loved one and expressing it to them from the heart. Thus, we can help ourselves and the consumer to see their beautiful self within themselves instead of focusing on problem behaviour. This provides the basis for a strength based and self-confidence increasing approach.
- Stopping to lecture what 'they should do' (problem solving behaviour!) because we know it'll only lead to them getting upset about us (plus they 'know' it anyway).
- Becoming aware how we have been guiding them into 'learned helplessness'[12]. Best is to apologize about that kind of carer behaviour and stop doing it. This does not mean that helping is not allowed, it means to discover the true art of helping others to help themselves.
- Becoming aware of the difference between Care-taking and Care-giving[13] and managing our own emotions, anxieties and rescuer behaviours accordingly.

Going into more detail about these approaches and what I learned from them, lies outside of this submission, but I'd like to highlight though that nearly all of the above approaches include the element of 'Listening'. True and non-judgemental listening is the only way to find out what drives the consumer and it is the basis for inviting them to consider a 'service' they might be intrigued about enough for some reason only they know about.

all of the above approaches include the element of 'Listening'

What Listening can mean is beautifully expressed in a poem that I have provided as an attachment. It can be frequently found in peer discussions and support groups and in the attachment I provide a number of websites that provide a link to it. Despite the fact, this poem is quoted so often and in very different contexts, the experience as a carer or consumer in the Mental Health System, proves the opposite: there is never enough time to effectively listen from the heart, express empathy, agree on common goals and partner in achieving them. Instead, all participants jump to recommendations in the short consulting time provided, which simply won't be implemented (except for depot injections) because the ground work in the realm of emotions and mood in challenging the wrong beliefs and delusions has not been laid.[14]

All that said, I, hence, fully agree with the thrust of this inquiry as stated on the first page of the issues paper:

"By examining mental health from a participation and contribution perspective, this inquiry will essentially be asking how people can be enabled to reach their potential

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[12] https://positivepsychologyprogram.com/learned-helplessness-seligman-theory-depression-cure/
[13] http://mhr4c.com.au/coping-strategies/caregiver-vs-caretaker/
[14] Or, when true listening does happen (as in the meeting that I attended with my loved literally just half an hour ago), we leave without any recommendations or actions. So in this instance I feel that a problem solving attitude would have been necessary to wrap up the meeting and not leave everything (including the low mood my loved one had talked about extensively) out in the open….

in life, have purpose and meaning, and contribute to the lives of others. That is good for individuals and for the whole community."

To contribute to the 'participation and contribution' perspective, I will, in addition to the above, share my experiences as a 'carer' in the mental health system in the following. I will share experiences where people were not "enabled to reach their potential in life", not to badmouth the mental health system, but to draw the attention to where the devil lies in the detail of human relationships. I'll then attempt to provide recommendations or at least ask questions that could lead to working out alternative solutions.

I'll use the questions posed in the issues paper as a guide to presenting my experiences.

QUESTION ON ASSESSMENT APPROACH

● **What suggestions, if any, do you have on the Commission's proposed assessment approach for the inquiry? Please provide any data or other evidence that could be used to inform the assessment**

Substance use disorders

The Royal Australian & New Zealand College of Psychiatrists states:

"Remember
- Addiction is a health condition, not a lifestyle choice or weakness.
- Get help early. There are many options, from online counselling to inpatient rehab.
- Expect recovery. The majority of people who have an addiction will recover.
- Relapse is normal. Treatments work best when you expect to relapse and plan for it."

Leaving 'substance use disorders' out of the inquiry would in my opinion question the merit of the whole inquiry

Most cases of schizophrenia I have met in my carer involvement are drug induced. Leaving 'substance use disorders' out of the inquiry would in my opinion question the merit of the whole inquiry.

Not just substance use disorder leading to mental illness should be considered, also 'addiction as an illness' in its own right needs to be included. Not being listened to and the victim triangle (mentioned above and in footnotes) are at work when people turn to drowning their emotional issues in alcohol and drugs. The whole ICE epidemic and ICE induced mental illness tragedy leads to 'perpetrator' behaviour on the 'victim' side (the ICE user) as well as on the treatment side (the carer knowing nothing better than threatening what they'll do if 'conditions' are not met …). It is an issue of societal relevance and warrants research into how to 'heal' all parties involved instead of just raising more domestic violence orders and criminalising those who should be seen as the victims in this tragedy.

In-Scope/Out of Scope definition:

Psychosis, Mood and Anxiety disorders etc. are considered in scope according to Table 1 in the issues paper. However, the focus of the inquiry is suggested to be on people with a mild

or moderate mental illness according to the listing on page 5 in the issues paper. Is this a contradiction?

Also, no definition of mild, moderate, severe and complex mental illness has been provided.

The paper mentions the episodic nature of mental illness. It might be necessary to lay open the assumptions behind these definitions of severities of mental illness leading to the suggested stepped approach. For example:

- Do people with severe problems need to go to hospital, mild can be treated at home? However, this would not take into account the episodic nature of mental illness.
- Are these categorisations derived from the need to manage and plan budgets? Ergo: if we can treat people 'in the community', we can save money because we need less hospital budgets.

If the definitions are based on underlying considerations such as budgets, we might not achieve what's best for the mentally ill.

Effective and efficient use of budgets

I hope the inquiry is testing to what extent the 'saving of resources' (eg less FTE (full time equivalent positions), closing of step-up, step-down houses, closing of adolescent facilities etc.) leads to increased expenditure of resources to be spent for those who 'pick up the pieces': eg carer ill mental and physical health, overuse of hospital acute patient services, homelessness services, neighbour disputes, police call outs etc.

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QUESTIONS ON STRUCTURAL WEAKNESSES IN HEALTHCARE

 ● **Why have past reform efforts by governments over many years had limited effectiveness in removing the structural weaknesses in healthcare for people with a mental illness? How would you overcome the barriers which governments have faced in implementing effective reforms?**

Developing a 'wrap around service' would need a "structural" change where the behaviour of the treatment teams, the carers and their relationships to consumers is targeted towards a new approach to Listening, avoiding the victim triangle and working with the beliefs of the people involved. As long as 'structural' means collocation of services or new buildings for more services or more plans with more 'integrated' goals, without providing the actual human beings in a number great enough to having time to practice a new behavioural approach, nothing will change.

need a "structural" change where the behaviour of the treatment teams, the carers and their relationships to consumers is targeted towards a new approach to Listening, avoiding the victim triangle and working with the beliefs of the people involved.

Only implementing a changed behaviour of all players in the mental health system will lead to better relationships and achieve continuity of care, instead of frequent case worker changes due to burn out or carer fatique. All players in the mental health system need meetings that allow sufficient time to practice the LEAP or similar approaches, because the mentally ill person needs this to 'discover' recovery. This would present a true 'structural' change.

The "stepped model" of mental health care mentioned in the issues paper, does not allow to cater for the episodic changes of some mentally ill people. This is another 'structural' issue. 'Primary care in the community' and more 'specialised mental health services in community settings' and 'emergency departments' for the acute and severe care does not cater for *all people* involved with mental illness needing *highly specialised training* in listening, empathy, interaction strategies etc. in order to avoid the more costly professional services. This is a different understanding of what 'highly specialised training' means.

It would not be particularly costly, but a highly effective investment for bettering the 'structure' of relationships leading to better interaction, less violence and more effective health care.

QUESTIONS ON SPECIFIC HEALTH CONCERNS

● **Should there be any changes to mental illness prevention and early intervention by healthcare providers? If so, what changes do you propose and to what extent would this reduce the prevalence and/or severity of mental illness? What is the supporting evidence and what would be some of the other benefits and costs?**

Yes – As above

● **Which forms of mental health promotion are effective in improving population mental health in either the short or longer term? What evidence supports this?**

At my last visit to the Mental Health Outpatient service I picked up a brochure about suicide prevention services: 23 pages of services one can call – and yet the issue paper says that suicide numbers are increasing. Why is that? It seems to me that 'offering services' is not enough, those needing the services need to use them.

Alas, why should someone who says "I can't go on like this" call someone for help if it will just result in 'more talk'? The person in need of help might be too depressed to believe in change or they might just want someone to magically appear and change their life circumstances. One could say about this example: "Oh, so the mentally ill person applies problem solver thinking themselves?" Well, yes, that's the issue our society is faced with; and problem solver approaches are not wrong in themselves; it just depends when and how we apply them.

If we want to make mental health 'services' effective, we need to 'dig deep' and change the paradigm of how we approach the Mental Health area of societal relationships. It's the same question again and again: How do we overcome the barriers that the illness itself puts up against being treated? Effective treatment will have to include patience, time, non-judgemental listening, unconditional positive regard, etc. Approaches that are being re-invented time and again.[15]

the same question again and again: How do we overcome the barriers that the illness itself puts up against being treated?

Back to the question of how we get the people who need help to call the appropriate service. This question is mentioned frequently[16], however, no easy answers are attainable – not surprisingly as I try to demonstrate in Attachment 2 at the end of this submission.

What does the research say?

How many people who think of suicide actually do call help lines? How many help seekers who call suicide lines just call because they are lonely – or because of mental health issues that they are left alone with? How can we improve the promotion of these 'services' if we don't know whether they actually cater for those they are targeting? To what extent is our problem solver rationality so deeply ingrained

How can we improve the promotion of these 'services' if we don't know whether they actually cater for those they are targeting?

in the help seeker and the helper that they can't listen to each other and thus, can't find the appropriate solution to the problem? It seems obvious though that the means leading to the crisis cannot be used to solve it.

• **What changes do you recommend to healthcare to address the specific issues of suicides and comorbidities among people with a mental illness? What evidence is there to support your suggested actions and what types of improvements would you expect in terms of population mental health, participation and productivity?**

Change the approach as discussed above;

Create settings where staff have the time to provide the new approach in a 'wrap around' service.

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[15] These approaches also are contained in leadership training; eg
http://www.blanchardinternational.com.au/solutions/skill-training-modules/listening-skills-module;
http://www.georgekohlrieser.com/the-power-of-words-dialogue-and-negotiation-to-influence/

[16] This is what a quick Google search brought up (none offered the golden bullet!) – also refer attachment 2:
https://www.psychologytoday.com/us/blog/crazy-life/201608/4-steps-help-someone-when-they-dont-want-it; https://www.psychologytoday.com/au/blog/struck-living/201110/convincing-the-stubborn-accept-mental-health-care; https://www.nami.org/FAQ/Family-Members-Caregivers-FAQ/My-friend-family-member-doesn%E2%80%99t-want-medication-or; https://www.sane.org/families-carers/39-refusing-treatment; https://au.reachout.com/articles/what-to-do-when-someone-doesnt-want-help

● **What overseas practices for supporting mental health and reducing suicide and comorbidities should be considered for Australia? Why? Is there formal evidence of the success of these practices, such as an independent evaluation?**

There are most likely many more than the ones that by way of example I have referenced above, such as Amador, CMC and Tyrrell.

QUESTIONS ON HEALTH WORKFORCE AND INFORMAL CARERS

● **Does the configuration and capabilities of the professional health workforce need to change to improve where and how care is delivered? If so, how should the workforce differ from current arrangements? How would this improve population mental health, participation and productivity?**

The following example is based on the experience of a carer. Imagine you are trained in suicide calls and your loved one with a mental illness sitting next to you calls their mental health case worker because she's hit 'rock bottom' and needs help but does not want to go to hospital because the last experience was such that she does not expect help nor well-being there. The case worker is on leave and the intake officer asks in a cheery voice how the caller is. When your loved one tells the intake officer about her suicidal thoughts, the intake officer in her chirpy voice asks whether the consumer just has suicidal thoughts or plans to actually harm themself. The help seeker hangs up and turns to the carer saying that the Mental Health Care team is not taking her seriously and laughing about her.

In this experience, the trained professional knew nothing about basic crisis supporter skills

In this experience, the trained professional knew nothing about basic crisis supporter skills that every Telephone Crisis Supporter in Lifeline can practice in their sleep. If a Volunteer Telephone Crisis Supporter would exhibit such behaviour their colleagues would want to shamefully hide behind a rock.

So, that is one example where training for mental health staff seems in need. However, it might also mean that more time is needed for mental health workers to be able to do their job, which means a lesser case load put on their shoulders, which means more staff is needed with the right training etc.

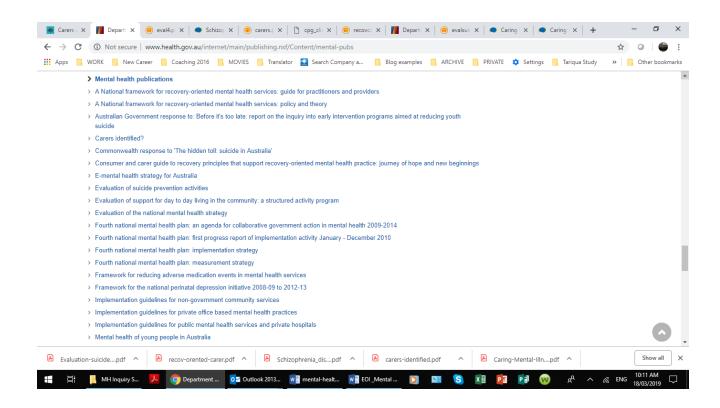● **What could be done to reduce stress and turnover among mental health workers?**

Give them training (in LEAP or LEAD or whatever we call the new paradigm approach that we'll come up with) and time; lower case loads. More humane interaction approaches like the ones described above.

● **How could training and continuing professional development be improved for health professionals and peer workers caring for people with a mental illness? What can be done to increase its take up?**

Stop writing more and more plans and more and more implementation plans and guides and other integration and structural reform documents and thus stop distracting people who want

to work with people away from just that, finding better interaction forms that are effective and make an impact for those who need it.

Aside from providing training in skills that support better interaction and in a new 'wrap around' approach (on which we yet need to agree), we could _use_ the documents that we've already got! The following screen shot only captures a fraction of what is out there:

Imagine, how much it would have helped if in the last four years the treatment teams I interacted with had actually applied the knowledge from documents such as:

- "Carers identified?"
- "A National framework for recovery oriented mental health services guide for practitioners and providers"
- "A National framework for recovery oriented mental health services policy and theory"
- "Consumer and carer guide in recovery principles that support recovery oriented mental health practice journey of hope and new beginnings"
- Etc.

use the documents that we've already got!

Yes, we do need some of these documents, but much more important is to practice a different interaction approach, to listen, listen and listen, and behave like human beings with a soul, not like robots who want to improve the 'machine of government' in an area where 'machine' does not work – and maybe lower case loads, so that professionals have the necessary time to apply these new skills.

- **What changes should be made to how informal carers are supported (other than financially) to carry out their role? What would be some of the benefits and costs, including in terms of the mental health, participation and productivity of informal carers and the people they care for?**

carers need help with their own anxieties about a loved one having a mental illness

A great support for carers would be if everyone working in the mental health system would be aware that we are dealing with issues outside the logical problem solving world and that carers need help with their own anxieties about a loved one having a mental illness.

One of the main issues for carers is that they are dealing with someone who has been diagnosed somewhat similar to this:

- "serious problems with thinking clearly, emotions, and knowing what is real and what is not"[17] or
- "unusual ups and downs in mood and energy, which can be extreme"[18] or
- "a mental illness that makes a person feel sad or unable to enjoy anything for weeks at a time"[19] etc.

As a carer you 'think' you know what the loved one 'should do' (rational problem solving mode), but the loved one doesn't live in the same reality (belief – not accessible through rational logic). You would expect that the 'professionals' would know how to deal with this situation, but they apply problem solving: medication. In many cases that works to the extent, that the consumer is back in reality, but now depressed.

Meanwhile the carers emotional stress and anxiety increases: not knowing how to deal with this, not getting the help one expected from the professionals due to different reasons; frustration that problem solving mode is not being accepted by loved one. And then the following behavioural pattern sets in: Rescuing attitude: pay their bills, give them shelter, but not receiving any acknowledgement back for that from the loved one. Victim behaviour: crying, have had enough. Perpetrator attitude: arguing, setting conditions, potentially resulting in conflict, maybe even violence. Domestic Violence Order is raised; loved one put in PICU (Psychiatric Intensive Care Unit) against their will etc. Consumer so fed up that does not consent for carer to be informed anymore. Carer still picking up bills, wants to talk to treatment team, but they refuse to provide information because no Consumer consent given.

The above scenario can have different players; for example:

- A drug user (first illness) who is psychotic (second illness); neighbours complain; police turns up and the 'consumer' in their delusion of being attacked harms the police. Has previous history of similar events. Is brought into the watch house; stays in the watch house for a week (while I think a psychotic person should be in a hospital); from there is brought – not to the hospital – but to the prison.
  From the 'system perspective' no carer exists, because the consumer has not given consent for a carer to be informed. However, there is a mother who cries her eyes out about the inability to communicate with her loved one, about the lack of skills, capability and preparedness of the treatment team to help her with that and facing

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[17] https://www.yourhealthinmind.org/mental-illnesses-disorders/schizophrenia
[18] https://www.yourhealthinmind.org/mental-illnesses-disorders/bipolar-disorder
[19] https://www.yourhealthinmind.org/mental-illnesses-disorders/depression

the risk of her own mental health going down rapidly.

The mother is the 'carer' in this scenario. It's obvious that she needs a lot of support from different 'players' in this example: treatment team, police, justice system etc.

- A couple: the husband is showing more and more signs of dementia[20]. He beats up his wife regularly. She has called the police. The money for the DVO fine comes out of the joint account, which is not plenty. The wife calls for an emergency assessment. The assessor does not listen to her, only to him who does not want to leave home and presents well. The wife keeps getting beaten up because she cannot afford more DV fines.

  The wife is the 'carer' in this scenario. Support for the carer would be to see her distress as the victim of domestic violence generated by a loved one with a mental illness and 'problem solve' in a way that does not leave the victim worse off and works reaching the potential of both carer and consumer.

- A mentally ill young adult living with a relative. His disorder is such that he hoards all significant household items in his room. The relative needs to operate with lots of locks for being able to keep items. The young adult has not been assessed and does not want to consent to an assessment. The relative cannot bring himself to call the police in order to have the person assessed. The carer suffers severe distress. Support in this scenario would mean that calling the policy for a love one who is sick and potentially violent should not be the only option provided to the carer.

- The question "What changes should be made to how informal carers are supported (other than financially) to carry out their role" does not address the issues presented in the above scenarios adequately. While I do appreciate that this inquiry asks this question at all, I find it unhelpful that Carers and Consumers are seen just as 'cogs' in a 'system' of 'goods and services' where every part has its 'role'. As long as this is how we approach the mental health 'services' question, issue paper will be written that lament that not much has changed to help those living with a mental illness improve their lives.

My answers to the question how carers could be support more effectively, not surprisingly, are:

- Try the LEAP and CRAFT and LEAD approaches for every person involved in the mental health (including addiction) system; train every carer as a Crisis Supporter etc.;
- Help carers deal with their own anxieties about the situation in a way that addresses the conundrum of dealing with belief and logic at the same moment in their interactions with their loved ones.

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[20] I am aware that "mental illness associated with a terminal condition, such as dementia" is excluded from this inquiry, "given that the Commission has examined end-of-life care in an inquiry on human services". However, the respective report: "PC (Productivity Commission) 2017a, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report no. 85, Canberra" does not take into account how dementia can lead to domestic violence and what this means for the carer's role.

- Find a more 'enabling' approach to the conundrum that a carer as an ethical person wants to uphold the value of "Nothing about us, without us", however also needs to deal with someone who has a different (sometimes unhealthy) perception of reality, and is dependent on the consumer's consent to be involved.
- Define the mental health system as a place where we want to improve human relationships, speak from the heart and exercise unconditional positive regard, so that all roles (from mother to psychiatrist to police and/or prison officer) are about "*how people can be enabled to reach their potential in life*" (p1 Issues paper) in the most ethical and inspiring way.

Define the mental health system as a place where we want to improve human relationships, speak from the heart and exercise unconditional positive regard

QUESTIONS ON HOUSING AND HOMELESSNESS

● **What approaches can governments at all levels and non-government organisations adopt to improve:**

● **support for people experiencing mental illness to prevent and respond to homelessness and accommodation instability?**

Don't release them from mental health wards when parents and other carers cannot take them anymore because they have become mentally ill themselves.

● **housing support for people experiencing mental illness who are discharged from institutions, such as hospitals or correctional facilities?**

Human, clean, professionally supported, LEAP inspired, supervised accommodation facilities that still allow independence.

QUESTIONS ON SOCIAL SERVICES

● **Are there significant service gaps for people with psychosocial disability who do not qualify for the NDIS? If so, what are they?**

Please be aware that over the past years, the mental health sector has tried to adopt a recovery focused language instilling hope and flexibility into how people achieve their potential. The NDIS uses 'disability'-language, thus promoting negativity and stigmatisation. I don't think that the NDIS extension to 'psychosocial disability' is helping the mentally ill persons in a substantial way. It will have to be discovered by the NGOs (Non-Governmental Organisation) funded directly the only way of Thus, we have the carer cannot the NDIS is could also turn who previously were by the government as getting financial support. created a system, where ask for support because consumer driven. It into a system where a

we have created a system, where the carer cannot ask for support because the NDIS is consumer driven

person diagnosed as having trouble discerning reality is convinced to ask for more services than needed to improve their life because it's the only way how the system allows the service provider to ensure their financial existence.

● **Is there evidence that mental illness-related income support payments reduce the propensity of some recipients to seek employment?**

It would be great to have some data backing up whatever the answer is to this question. Otherwise, this question smells of stigmatisation? It could be that the assumption behind this question is that people 'pretend' to be mentally ill so they don't have to work? In my experience that is stigma. The mentally ill people I know would love to work if they were able to, because it provides purpose and a motivating environment, which in turn increases happiness. Who would not want to have that? Most people who are unable to work most likely find it very, very painful not being able to work.

● **How could mental illness-related income support payments better meet the needs of people whose capacity to work fluctuates over time?**

Very, very important question and very tricky to answer in an ethical way; ie by not just jumping to the conclusion: force them to volunteer in social or environmentally relevant projects. How could one create a safe and inspiring environment of community and support? This question can only be meaningfully answered after a lot of listening has been practised in finding out from those who need it.

QUESTIONS ON SOCIAL PARTICIPATION AND INCLUSION

● **In what ways are governments (at any level) seeking to improve mental health by encouraging social participation and inclusion? What evidence is there that public investments in social participation and inclusion are delivering benefits that outweigh the costs?**

The issue paper states:

> "Social participation and inclusion are inextricably linked with mental health and wellbeing. Good mental health supports participation in social and community activities. Conversely, participation in social and community activities correlates with improved mental health. Social inclusion, in the context of mental health, is about how communities engage and include people living with a mental illness and whether those with a mental illness feel connected, valued, accepted, or positive about the communities in which they live. An important part of enabling social inclusion is ensuring that aspects of people's lives that are important to them — such as indigenous or cultural values — are included in the way communities engage." (p 22)

I do agree that it is important to further social participation and inclusion of people with mental health issues. Many carer support group meetings talk about the frustration of carers who describe that their loved one does not go out, cannot summon the energy to engage with others, is totally dependent on the carer they live with or lives in seclusion, alone and lonely. Social inclusion, working and volunteering create purpose and human beings need purpose and social interaction to thrive. How do we get them to interact?

The description of this issue in the issues paper, however, has a very narrow or rather idealistic understanding about "how communities engage". This sounds like there was 'a' community out there who cannot wait to engage. For example when the hospital decides that a patient can be released into community care, it sounds as if there was the community waiting outside the hospital grounds to receive our loved one with open arms. Far from the truth. It just means that the person can go home and if lucky the case worker will check on them within the next week, or two weeks or sometimes four weeks. (The example above about the ICE user ending up in the watch house for a week is an example of "cared for in the 'community' ".)

There is no community as such 'out there' who engages. There are different communities: the sporting club, the school, the church, a group of friends having a picnic in the park, a religious or cultural or environmental group, a party, a choir, a business community, a city council, an NGO, a consumer or carer peer support group, a community centre run by volunteers or paid people if they can devise an income stream, a book club etc..

There is no community as such 'out there' who engages

However, seeing that there are these groups and that it would be great if mentally ill people found engagement with them, there is no golden bullet how to facilitate this.

● **What role do non-government organisations play in supporting mental health through social inclusion and participation, and what more should they do?**

It comes down to the same question raised above: if someone has the belief that engagement would not be worthwhile or they are not capable of engaging, how do you communicate and live with them in a way that they are motivated and inspired to do so?[21]

I actually called a depression helpline to find out what I am missing and how to convince loved ones. The psychologist on the phone was very empathic, had good listening skills, but could not answer this 'million dollar question' himself. "I wish we knew". He recommended that I call the NGOs who provide peer support, and ask how they get the consumers into their workshops.

I would be curious to know whether there is research data that could fill in some blanks here?

QUESTIONS ON JUSTICE

● **To what extent does inadequate identification of mental health and individual needs in different parts of the justice system increase the likelihood, and extent, of peoples' future interactions with that system?**

Violence due to psychosis punished as violence will lead to more psychosis spurned violence.

Drug pusher forcing other inmates to use drugs (as observed by a carer who used to work in the prison system) will lead to more addiction, which in itself presents a mental health issue.

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[21] I am not saying it is not possible. I am just saying it is only possible, if the carers live by the different approaches that I listed above and it would help a lot if the treatment teams would do that as well.

● What are the main barriers to lowering the over-representation of people living with a mental illness in the justice system and what strategies would best overcome them?

A different concept of dealing with offenders that is not based on punishment. I am sure there is a lot of literature about this and I hope that a fellow responder would bring it up.

Find a different way of dealing with DV caused by mental illness instead of handing out DVOs that criminalise the loved one when it happens again, leading to family conflict and throwing people out of the family home into loneliness and drug infested social housing.

QUESTIONS ON GOVERNMENT-FUNDED EMPLOYMENT SUPPORT

● How cost effective have the Australian Government's Disability Employment Service (DES) and Personal Helpers and Mentors service (PHaMs) been in enabling people with a mental illness to find and keep a job? Have the DES and PHaMs been targeted at the right populations?

During my four years of active engagement as a mental health carer, I have never heard about PHaMs.

Carer experience with the DES was as follows:

- A young man engaging with a DES organised through an Early Psychosis Team. The young man had had two run ins with police during psychotic events, one in a night club setting and one in a residential setting, and was released with good behaviour bond. The DES got him to be trained as a security officer and the first job he was supposed to accept was for crowd control on New Year's Eve. Given his history and previous experience with the police, this led to such anxiety that he turned down the job. Mature decision one would think, alas he did not provide the context of his decision.
When he told his parents that he had not accepted the security job, they thought he had better plans for New Year's Eve and got angry. This led to him getting angry and him being excluded from Christmas celebrations until he would apologize for his rude behaviour. Never would his parents have dreamed of the possibility that a Disability Employment Advisor would send this young man into New Year Crowd Control. They thought he was too lazy to get bored in an empty warehouse on New Year's Eve. However, these are the security jobs that only experienced security officers are selected for.
When the parents found out and talked to the Early Psychosis Team (EPT), they were informed that such decisions were outside the control of the EPT.
Another example that shows that 'integration' lies in the attitude of the people involved and the willingness to a different approach on interaction and working with the consumer. The DES officer just seemed to be doing 'their job' of offering any job whatsoever with no consideration for the suitability of the job for a mentally ill person.

- A consumer allowed the carer to come along for a meeting with the DES. No listening took place. The consumer was offered choices with no real discussion and then told what would be chosen. How does this align with 'finding your potential'?
- The idea of providing DES is good, however, the practice does not seem to be very effective for the benefit of the consumer. I think a good way to change this would be to review the Key Performance Indicators of the DES workers and think of some that really lead to the outcome of consumers 'reaching their potential in life'.

review the Key Performance Indicators (…) and think of some that really lead to the outcome of consumers 'reaching their potential in life'

● **What alternative approaches would better support people with a mental illness (whether episodic or not) to find and keep a job?**

Listen, Listen, Listen. Find out what they are capable of doing. Get them to talk, so you can listen.

Listen, Listen, Listen (…) Slowly built confidence based on little successes.

Slowly built confidence based on little successes. Don't expect big steps.

Check the Key Performance Indicators (KPI).
Are they about how many people were offered a job or about finding well suited jobs for the job seeker?

● **To what extent has the workforce participation of carers increased due to the Australian Government's Carers and Work Program?**

This is the first time I hear about this program in four years involvement.

The relevant website shows: There are 13 locations of the 'Carers and Work Program' across Australia with 3 in QLD. Consequently, one cannot expect that there would have been a huge increase in workforce participation?

● **Which State or Territory Government programs have been found to be most effective in enabling people with a mental illness to find and keep a job? What evidence supports this?**

Very keen to read the answers to this question.

QUESTIONS ON MENTALLY HEALTHY WORKPLACES

● **What types of workplace interventions do you recommend this inquiry explore as options to facilitate more mentally healthy workplaces? What are some of the advantages and disadvantages of the interventions; how would these be distributed**

between employers, workers and the wider community; and what evidence exists to support your views?

Cater for the capabilities: short attention span, episodic well-being, short shifts, great people to work with, if you treat them well, just like any other employee.

QUESTIONS ON FUNDING ARRANGEMENTS

● **How could funding arrangements be reformed to better incentivise service providers to deliver good outcomes, and facilitate coordination between government agencies and across tiers of government?**

Pay attention to the KPIs – on every level, down into the detail. Do they reward quantitative measures of functions and services in problem solving mode or qualitative interaction successes towards 'wrap around services' and the individual's potential?

Do they reward quantitative measures of functions and services in problem solving mode or qualitative communication successes towards 'wrap around services' and the individual's potential?

QUESTIONS ON MONITORING AND REPORTING OUTCOMES

● **Are decision-making forums for mental health receiving high quality and timely information on which to base strategic decisions?**

During my four years involvement with Carers QLD, ARAFMI and PHN mental health support and/or integration groups, as well as Brisbane Metro North and South Education events, I have not witnessed any contact of the carer representative on the National Mental Health Consumer and Carer Forum with carers towards including the views of a broad representative group of carers into decision making. Consequently, I am wondering whether the decision making or advising forums really work on providing the relevant information.

What does improved participation, productivity and economic growth mean for consumers and carers?

This could mean truly achieving 'recovery', expressed for example as:

Recovery is a unique and individual process that everyone goes through differently.

- "(…) a process whereby a person reclaims their right to a better life, whether or not – and this is the key point – the symptoms of mental ill-health are present." (Mind Australia)
- "Recovery is about the whole of your life, not just your symptoms. It involves:
  - finding hope, and developing your self-esteem and resilience
  - having a sense of purpose and meaning in your life
  - building healthy relationships with people in your community
  - gaining independence in your life." (healthdirect.gov.au)

- "From the perspective of the individual with mental illness, recovery means gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self." (health.gov.au)
  - "Recovery is a unique and individual process that everyone goes through differently. However, there are some common emotions that many people may experience.
  - Shock at having to deal with something difficult and scary that you have no prior experience of.
  - Denial or difficulty in accepting having a health problem, particularly one that many people find hard to understand.
  - Despair and anger at having to deal with the condition and its related difficulties.
  - Acceptance of having a condition and the changes it brings, and accepting how others see you and how you see yourself.
  - Coping by finding new ways to live with and tackle these changes and challenges.

  Recovery goes beyond focusing on managing distressing symptoms but about having choices and being able to create a meaningful and contributing life." (Beyond Blue)

What outcomes should be measured and reported on?

Those outcomes should be measured and reported on that contribute to achieving recovery and the individual's potential in life. How can they be identified? Maybe by developing a program logic and a theory of change[22], as happens for other government departments?

Thank you again for the opportunity to participate in this inquiry. I am happy to elaborate on my experiences and thoughts as it is most likely that further clarification might be needed.

Yours Sincerely

Stefanie Roth

Incl.: 2 Attachments

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[22] Eg https://www.aes.asn.au/events-archive-nsw/1589-workshop-program-logic-and-theory-of-change-sydney-27-march-2019.html

Attachments

Attachment 1:

Please Listen: A Poem
By: Leo Buscaglia

*When I ask you to listen to me
and you start giving me advice,
You have not done what I asked.*

*When I ask you to listen to me
and you begin to tell me why
I shouldn't feel that way,
you are trampling on my feelings.*

*When I ask you to listen to me
and you feel you have to do something
to solve my problem,
you have failed me,
strange as that may seem.*

*Listen! All I ask is that you listen.
Don't talk or do – just hear me…*

*And I can do for myself; I am not helpless.
Maybe discouraged and faltering,
but not helpless.*

*When you do something for me that I can and need to do for myself,
you contribute to my fear and
Inadequacy.*

*But when you accept as a simple fact
That I feel what I feel,
No matter how irrational,
Then I can stop trying to convince
You and get about this business
Of understanding what's behind
This irrational feeling.*

*And when that's clear, the answers are obvious and I don't need advice.
Irrational feelings make sense when
we understand what's behind them.*

*So please listen, and just hear me.
And if you want to talk, wait a minute
for your turn– and I will listen to you.*

Found on the following websites to name just a few:

https://www.familyaware.org/listen-poem/

http://www.sarahwaldin.com/listen-a-poem/
https://static1.squarespace.com/static/5a58c50ff6576ed6668f17af/t/5a7a1f2de2c48358c69cf570/1517952813879/listen+poem.pdf
https://seapointcenter.com/real-listening-skills/
https://www.healingracismpv.org/files/8814/4735/8130/HRIPV_Listen_Poster.pdf
http://www.andreaharrn.co.uk/when-i-ask-you-to-listen/#sthash.lG0UHjzR.dpbs
http://aurora.umn.edu/sites/g/files/pua3546/f/general/listen.pdf

A*ttachment 2:*

What if your loved one does not want to seek help?

I'd like to make some quick comments on some of the recommendations I've found to the above question that I touched on a couple of times in the submission:

- Sane website: "*If there is outright resistance to the idea of getting medical help, talk to the doctor yourself to work out a plan. The doctor may be able to visit the person at home to make an assessment.*" (https://www.sane.org/families-carers/39-refusing-treatment)
  Sounds sensible and is what you would hope you could do. In the current environment, the doctor is not allowed to talk to me about an adult loved one. How often did I try this with the Psychiatric treatment team and was told to back off. (Not always, though, I must admit!)

- Carer gateway website – Some excerpts of "What to do when someone refuses help"

From Carer gateway[23]:	My comments:
"There are many reasons why someone rejects your help:" o *Denial; lack of insight as part of a medical condition* o *feel ashamed* o *feel frightened* o *make their own decisions independently* o *may not be able to express why they feel this way*	If "we" (ie the 'system') know the reasons why loved ones might not seek help, why do the treatment teams (ie the professionals) not prepare us carers for this situation and help us to cope with it? Why can we read in reports to the Mental Health Tribunal (that reviews Treatment Authorities) that the consumer does not work with the treatment team or is not interested in engaging in coping strategies or therapies? Shouldn't it be up to the professionals to turn that around?
Some tips for having a conversation with the person you care for: o *Choose a time and a place when you are both relaxed and calm.* o *Plan what you're going to say beforehand and talk in a calm, quiet voice.* o *Mention your concerns and any new symptoms you have noticed.* o *Tell them that you are interested in finding practical help for them.*	The answer will often be "Why don't you leave me alone." - even if the carer followed all the tips on the left…. The question rather is: how do we build the trust with our loved one, to have these conversations?
o *Allow the person to talk. Be prepared to listen and let them know they have been heard.*	What if they don't talk? How do you get them to talk? - Nobody is trying to 'entice' them to talk, even the professionals are not, rather write in reports that the consumer was not open to therapy ….

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[23] https://www.carergateway.gov.au/what-to-do-when-someone-refuses-help

From Carer gateway[23]:	My comments:
o *Be compassionate but make sure you set boundaries to take care of yourself.*	This is an art! It needs a paradigm change in how we behave to be successful in being compassionate and boundary setting at the same time.
o *Be as patient as you can. It may take many conversations before they agree to seek help.*	Easily said for someone who is not in the situation of watching a loved one deteriorate…..
o *If you get frustrated, they will probably stop listening to you.*	Oh so true!!
o *Make it clear that you are offering to support them. There might not be an immediate solution to the problem.*	… and the consumer might think: "I know she is meaning well, but this is so annoying and won't change anything anyway…."
o *Offer to make an appointment for them and to go with them if they like.*	That could lead to anger on the consumer's side….
o *You might have tried to have this conversation many times. Sometimes this can lead to power struggles and a lack of trust.*	True!!!
o *maybe it's time to consider whether you are the best person to try to help them*	The carer is most likely <u>not </u>the best person to help, because they are invested too much emotionally, however, often the carer is the only one left standing!!! The treatment team won't even have time to read through all these recommendations and plan out a good interaction strategy because they need to hurry to the next patient…. – and in my experience do not consider it they their task to guide the patient to recovery.

So what does help?

What has helped in my experience, are behaviour changes based particularly on Sue Koningen's approach on the side of the carer, such as:

- Become aware of the victim triangle and consciously try to avoid Victim, Rescuer and Perpetrator behaviours. This might mean to review many ways of how we interact not just with our loved ones, but with all our relationships.
- Take responsibility for your own agendas, anxieties and fears. How often do we try to get the loved one to do something that *we* consider the solution but they do not and thus exhibit self-confidence and trust *undermining* behaviour.
- Remember the love or unconditional positive regard for your loved one and express it to them from the heart. Thus, help yourself and them to see their beautiful self within themselves. (Seriously, write a love letter or even an eulogy …)
- Stop lecturing what 'they should do' (problem solving behaviour!) – it'll only lead to them getting upset about you, plus they know it anyway….
- Become aware how you are enabling them in 'learned helplessness', apologize to them about it and stop doing it. This does not mean that helping is not allowed, it means to discover the true art of helping others to help themselves.
- Become aware of and change from Care-taking to Care-giving.