Australian Government
Productivity Commission

PRODUCTIVITY COMMISSION

PUBLIC HEARING INTO MENTAL HEALTH

PROF STEPHEN KING, COMMISSIONER
MS JULIE ABRAMSON, COMMISSIONER
PROF HARVEY WHITEFORD, ASSOCIATE COMMISSIONER

TRANSCRIPT OF PROCEEDINGS

WESLEY CONFERENCE CENTRE, 220 PITT STREET, SYDNEY
ON TUESDAY 26 NOVEMBER 2019

INDEX

PROF KING: Good morning. Welcome to the public hearings of the Productivity Commission inquiry into mental health. My name is Stephen King and I'm the presiding Commissioner on this inquiry. My fellow Commissioners are Julie Abramson, who has moved along way, away from me and - - -

MS ABRAMSON: It's to deal with the table legs, Stephen, it's not personal.

PROF KING: And I use Palmolive Gold, so. And Harvey Whiteford. Sorry, you need to be old enough to have seen a certain ad on television back in the seventies to - - -

MS ABRAMSON: It's now on the transcript, so.

PROF KING: I'd like to begin by acknowledging the traditional owners of the land on which we meet today, the Gadigal of the Eora Nation. I would like to pay my respects to Elders past, present and emerging. The inquiry started with reference from the Australian government in November 2018 and the purpose of this inquiry is to investigate the mental health system in Australia and make recommendations to government about how we can improve that system. We have talked to representatives of the Australia State and Territory government service providers and their peak bodies, unions, academics, researches and individuals with an interest in the issues and held round-tables throughout the inquiry.

We released an issues paper in January this year and have talked to the range of organisations and individuals. We have received 573 submissions since our issues paper came out. We are grateful to all the organisations in individuals who have taken the time to prepare submissions and/or appear at these hearings. A few weeks ago we published our draft report and purpose of these hearings is to provide an opportunity for interested parties to comment and provide feedback on the draft report to facilitate public scrutiny of the Commission's work and to get feedback on the draft report.

Now, we like to conduct all hearings in a reasonably informal manner, but I would like to remind participants that a full transcript is being taken and for that reason comments from the floor cannot be taken however at the end of day's proceedings I will provide an opportunity for anyone who wishes to do so to make a brief presentation. If anyone does wish to make a brief presentation please just let yourselves known to Henry and Ros, the two staff members at the back there.

This is the seventh public hearing for this inquiry following this hearing. Hearings will also be held in Broken Hill, Rockhampton, Brisbane, Launceston and Adelaide. We will then be working towards completing a final report having considered all the evidence presented at the hearings and in submissions as well as other formal discussions. For those planning to lodge a public submission with their feedback on the inquiry draft report eh closing date for submission is 23 January of next year.

The final report will be submitted to the Australian government in May. Participants and those who have registered their interest in the inquiry will be automatically advised of the final reports released by government which may be up to 25 parliamentary sitting days after completion which I think means August because someone had actually worked it out last night which was very impressive.

Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions. These proceedings will be livestreamed to the Commission's YouTube page. All participants who have registered here at this hearing have confirmed their understanding that they may be visible or audible online. If anyone has queries about this or does not wish to be visible or audible online please approach one of our inquiry team members here today or free feel to leave the hearing now.

The transcript will be made available to participants and will be available from the Commission's website within a week of this hearing. Submissions are also available on the website. If there's any media representatives attending today there are some general rules. Please see one of our staff members for a handout to explain the rules. Participants should also be aware that any media representatives present may be using Twitter and other internet mechanisms to convey information online in real time including participant's remarks and I note there are a few other people tweeting as well so for someone who's not on Twitter, go for it.

MS ABRAMSON: In 140 characters.

PROF KING: In 140 characters, that's true. To comply with the requirements of the Commonwealth Occupational Health & Safety Regulation you are advised that in the unlikely event of an emergency requiring evacuation of this building, there are exits there and there are exits out the way you came in and the assembly point is St James - no in Hyde Park near St James Cathedral. You can tell I'm not a local, I almost got them backwards.

In your opening remarks if you can try and keep them to no more than five minutes. We do have a fairly packed agenda today and then would like to follow up with question on your remarks. If at any time you are feeling distressed we have psychological support on hand so - Leanne, there at the front. And if there's any additional information that you'd like to convey we have team members here who are happy to talk to you.

So let me start today by asking Emma Spinks if you could join us down the front. If you would be able to say your name, if you are representing an organisation what the organisation is and any opening remarks for the transcript. So the two sets of mikes means that these ones are for amplification and the other ones are just for the transcript.

MS SPINKS: All right. Am I in the right spot here?

PROF KING: Yes, I think that's fine.

MS SPINKS: Okay. My name is Emma Spinks. I'm not in line with any organisation. I'm addressing the Commission, thank you for the opportunity. As a mother, just a mother, I'd like to give a personal account of my family's experience of problems within the mental health system which I believe have contributed to the death of my daughter.

My daughter was a loving and caring wife and mother, she had many friends. She had no history of consultations for anxiety or depression. Before her death she had been very sick for over a month suffering from nausea, recurrent diarrhoea, chronic fatigue, significant weight loss and difficult sleeping. Pathology tests identified the case as hyperthyroidism and iron overload. An ultrasound of her thyroid gland had been ordered but was not carried out due to a pre-arranged family holiday which had to be cut short because of her illness.

On her return she visited the same medical practice because she was still feeling unwell and another general practitioner gave her a completely different diagnosis telling her that the chemical imbalance in her brain was causing her problems and anxiety. He prescribes Zoloft, and SSRI antidepressant which he said would rebalance her system but would take two weeks to work. He made no mention of side effects instead telling her that this draft was 'as safe as houses'.

Dr Peter R Breggin is as Harvard trained psychiatrist and former consultant to the National Institute of Mental Health. He has been a legal consultant for over 170 case in the USA and has had extensive access to drug company clinical trials and data. In his YouTube videos he reports that the chemical imbalance in the brain theory was initially proposed by drug manufacturer Eli Lilly. It has since been used by other drug companies for marketing purposes. Dr Breggin states there is still no medical evidence that is able to prove any chemical imbalance (indistinct words) anyone who's not taken psychotropic drugs.

He advises that selective serotonin reuptake inhibitor antidepressants work by preventing the brain's reuptake of serotonin and making it (indistinct words) between neurons. This is supposed to create more serotonin but Dr Breggin warns there is much evidence to suggest that the brain doesn't like this and responds by 'lessening' the production of serotonin and becoming less sensitive to it. He also warns it can be extremely dangerous to suddenly stop taking these drugs without medical advice and supervision. The GPs use of the chemical imbalance theory as a diagnostic tool appears to be in direct conflict with the Royal Australian New Zealand College of Psychiatrist's clinical guide for the treatment of mood disorders.

On p.20 it states:

> *Understanding and piecing together the various factors provides a more comprehensive picture of why the individual has developed the mood disorder in the first place. It also acts as a forerunner to considering which interventions are most likely to be of benefit. In addition to understanding the individual, their strengths, vulnerabilities and their predicament, it is important to bear in mind that there may be alternative explanations and that different psychiatric diagnoses and general medical causes may ultimately be responsible. Psychiatric assessment should involve a medical examination and investigations as indicated. These tests need to be conducted on a case-by-case basis and tailored to individual needs*

As the RANZCP state, 'general medical causes may ultimately be responsible' and in my daughter's case pathology tests ordered by another GP at the same medical practice two weeks earlier had been able to confirm that my daughter was suffering from hypothyroidism which has been medically proven to cause anxiety and iron storage disorders. Both the GP and the pharmacist who dispensed her prescription failed to warn my daughter about the risks associated with Zoloft, the possible side effects that include suicidal ideation and self-harm.

The Food and Drug Administration of the United States of America states on their website that:

> *'All patients being treated with antidepressants for any indication should be monitored appropriately and observed closely for clinical worsening, suicidality, and unusual changes in behaviour, especially during the initial few months of a course of drug therapy, or at times of dose changes, either increases or decreases. The following symptoms, anxiety, agitation, hostility, aggressiveness, impulsivity, akathisia, hypomania, and mania, have been reported in reported with patients being treated with antidepressants*

The FDA also notes that:

> *Families and caregivers of patients should be*
> *advised to look for the emergence of such symptoms on a day-to-day basis, since changes may be abrupt*

The Food and Drug Administration of the USA have also forced manufacturers of SSRI antidepressants to place a black box warning, their highest level inside the packets of these drugs, for at least ten years. The governments, Canada (indistinct) European countries also require warnings to be placed in SSRI antidepressant drug packaging. In Australia the Therapeutic Goods Administration has no such requirement describing practitioners are instructed to warn patients and dispensing pharmacists who are supposed to provide a product information sheet with prescriptions.

In my daughter's case both these safety measures failed. As family we had absolutely no idea there was a prescription drug that could cause possible side effects of suicidal ideation and self-harm in anyone who hadn't even suffered from a mental illness. If a warning had been included in the packaging we would have been able to save my daughter's life. I know that if my daughter had been warned of the slightest risk of possible side effects of suicidal ideation and self-harm she would never even contemplate taking Zoloft.

I believe that the fact she received no warnings constitutes and extreme violation of her basic human Rights. No mental health care plan was provided for my daughter. The website of the International Union of Basic and Clinical Pharmacology advises that practitioners can 'never' be certain that a drug will be effective or safe for an individual patient so they must recognise the need to monitor the outcome of their prescription. They define an adverse drug reaction as actual harm that occurs to a patient when they are taking a drug. When psychotropic drugs are prescribed a mental health care plan is absolutely essential because of the possibility of adverse drug reactions such as akathisia.

In his YouTube videos Dr Breggin reports DSM-4 states that akathisia leads to suicidal ideation and self-harm. A mental health care plan would include: giving patients information about how to take their medication as safely as possible and especially warning them not to suddenly stop taking it without medical advice and supervision; making sure patients tell their carers to monitor them closely for any changes in mood or behaviour, suicidality or worsening of their anxiety and depression especially in the initial few months of therapy or around dose changes either increases or decreases; a follow-up phone call by the practitioner to check the patient's mood for any signs of the development of adverse drug reactions such as akathisia.

Dr David Healy, an internationally respected psychiatrist, psychopharmacologist and scientist reports on the RxISK website that significant symptoms of akathisia occur in around 20 per cent of people taking an antidepressant and at least 50 per cent of people on low doses of an antipsychotic. He also states healthy volunteers as well as patients are at risk and that a healthy volunteer trial of Zoloft in 1983 had to be abandoned before the end of the first week due to 'every' participant displaying signs of akathisia.

Symptoms of akathisia provided on RxISK's website by Dr David Healy are: anxiety or agitation, restlessness, feeling emotionally uneasy; dysphoria (feeling bad or depressed), difficulty sleeping; distress or panic attacks; difficulty sitting still; feeling the need to keep moving - for example, pacing back and forth; the feeling of wanting to jump out of your skin; dark and unpleasant thoughts; intense emotional turmoil and mental restlessness; strange and unusual impulses often of an aggressive nature; suicidality and homicidality. Sufferers often find it very difficult to explain exactly what is wrong even though they may be in unbearable distress.

The following account is taken from my daughter's husband's report to the police after her death. It describes the onset of akathisia symptoms and demonstrates that because they were not warned they were unable to recognise them. She took her first table on Saturday morning. After taking it she felt nauseous, quite anxious and uneasy to which she was surprised as she wasn't told about side effects.

Later that evening she called the chemist that she got the medication from to ask them if she would be able to take the tablets at night hoping that the side effects would be only while she slept and she was told, 'Yes, that would not be a problem'. That night she took the table before bed and it kept her awake and made her feel jittery all night. I noticed that the tables made her withdrawn and not herself as she was always so bright and bubbly and always wanting to be with and play with the children but she was feeling uneasy and unable to do so.

On Monday we were discussing the effects of the medication and she was telling me that she did not like it and the way it made her feel. As we didn't know much about it and didn't know how severe the medication was we decided that as she didn't like taking it and it was making her feel worse then she should just 'stop' taking it.

On Tuesday morning my daughter drove her car to the top of the local multistorey shopping centre car park and fell to her death. Her poor body was so broken we were never allowed to see her again. The note that she left said she could not stand this pain any longer. On the RxISK's website Dr David Healy reports that David Foster Wallace who was suffering from symptoms of akathisia before his death was quoted as saying:

> *The person in whom its invisible agony reaches and unendurable level will kill herself the same way a trapped person will jump from the window of a burning high rise. The terror of falling from a great height is still just as great. It's not desiring the fall, it's the terror of the flames. You have to personally have been trapped and feel flames to understand the terror beyond falling*

I complained to the New South Wales Health Care Complaints Commission that the GP appeared not to have followed the guidelines to justify the Royal Australian New Zealand College of Psychiatrists in making his diagnosis and he hasn't given due consideration to the physical causes of my daughter's anxiety that were identified by her pathology tests. They dismissed my complaint because they stated, 'There were features of depression'. Their only recommendation was that the GP should have described Valium together with Zoloft for the first one to two weeks to mitigate the known early side effects of worsening anxiety associated with this category of antidepressants.

The NSW HCCC appear to be unaware that increasing anxiety 'may' indicate the onset of an adverse drug reaction such as akathisia. On their website drugs.com advises that Valium has possible side effects that include anxiety, agitation, aggressiveness, irritability, hallucinations, psychosis and insomnia. When I phoned the Health Care Complaint Commission the officer handling my complaint told me that they currently had a number of cases that were similar to my daughter's and that she felt antidepressants were prescribed far too often.

A coronial inquest was held to examine the circumstances surrounding my daughter's death. No family members were invited to attend. The expert witness statement provided to the coroner by the GP reported that my daughter presented with an irritating cough, anxiety for months, depressed mood, (indistinct words) and not excited by things anymore. He also stated she was specifically asked of any suicidal feeling and that she clearly denied this. The exclusion of family members from the coronial inquest meant that no evidence was provided to the coroner about the fact that my daughter had been very sick for over a month before she died suffering from nausea, recurrent diarrhoea, significant weight loss, chronic fatigue and difficulty sleeping and that pathology tests had found her to be suffering from hyperthyroidism and iron overload. So the coroner's report gave the cause of death as 'The injuries she suffered from the fall and depression'.

I have read that a screening process is currently being conducted for all New South Wales primary school children to check for early signs of a mental illness. I am extremely concerned about the growing number of children who have been described SSRI antidepressants as Dr Peter Breggin warns on his YouTube videos that young children and adults under 24 are at an increased risk of side effects that include suicidal ideation and self-harm. He also warns that prescribing psychotropic drugs, including SSRI antidepressants for children, make expose their developing brains to the risk of permanent damage.

In conclusion I believe the main problems that contributed to my daughter's death were: (1) my daughter received no warning about the possible risks of side effects of the SSRI antidepressants which include suicidal ideation and self-harm; (2) despite the fact that the regulatory agencies in the USA, Canada, Britain European countries have forced manufacturers to provide a warning in the packet for over ten years the Therapeutic Goods Administration still does not require manufacturers to provide this additional safe measure for Australian citizens; (3) the use of drug company promotional material is a diagnostic took rather than the clinical guidelines for the treatment of mood disorders provided by the Royal Australia and New Zealand College of Psychiatrists; (4) no mental health care plan was provided for my daughter to ensure that she was informed how to take her medication as safely as possible and was monitored appropriately to check for the onset of possible adverse drug reactions including akathisia, suicidal ideation and self-harm; the general practitioner, the dispensing pharmacist and the New South Wales Health Care Complaints Commission appear to show a general lack of awareness and knowledge regarding the risk and symptoms of adverse drug reactions such as akathisia that are associated with the use of SSRI antidepressants.

Considering all the risk factors associated with the use of SSRI antidepressants both myself and my family feel they should be reserved for the treatment of severe and treatment resistant depressives disorders. A report by the Australian Commission on safety and quality and healthcare dated June 2017 entitled, 'Medication Safety in Mental Health' states that 86 per cent of psychotropic medicines are prescribed by general practitioners and that antidepressant use has increased tenfold since 1990. We believe that general practitioner should be allowed to concentrate on diagnosing physical illnesses and that the diagnosis of mental health disorders should be left to practitioners such as psychiatrists and clinical psychologists who have received an extra five years of training in the diagnosis and treatment of mental illness.

PROF KING: Thank you very much, Ms Spinks, and thank you for coming in and sharing your story with us today. Just to clarify before I pass over to my colleagues, so as I understand the pharmacist who filled the prescription as far as you're aware there was no offer made by that pharmacist of the consumer product information sheet associated with the medication.

MS SPINKS: No, and in fact when my daughter rang up and spoke with one of the pharmacists she was advised that it was - you know, even though she was saying she was having reactions she was advised she could just take it that night, that would be fine, she would have the side effects while she slept. The pharmacist displayed no knowledge or akathisia or adverse drug reactions whatsoever. I did complain to the Pharmacy Board she has been counselled apparently but still it's very disturbing that this knowledge of adverse drug reactions seem to be very, very limited amongst, you know, generally the practitioners who are working in it and I believe, you know, in the Medication Safety and Mental Health Report they give quite a lot of instances where polypharmacy is practiced and the adverse drug reactions are not recognised so when somebody say presents with psychosis then they get another drug for psychosis on top of the one they're already taking and they're not recognising maybe an adverse reaction to the drug that they'd first been given. It seems to be a big problem.

PROF KING: Yes, and the reason why I stress that consumer product information, you may be aware of it from other medications, it's basically a white sheet but it lists out the various side effects and risks associated with the medication.

MS SPINKS: That's right, she was given nothing and this is my contention that, you know, as a safety measure there should be a warning in the packet and all the other countries have done that because you can't always rely on human beings to remember. You know, I mean, it might have been a busy day for the pharmacist who knows, you know. I mean, it's just - - -

PROF KING: But there should be safety measures.

MS SPINKS: - - - a safety measure that I can't understand why the Therapeutic Goods Administration is not providing it, I really can't. It doesn't make any sense.

PROF KING: Yes okay.

MS ABRAMSON: Thank you. On behalf of the Commission, Ms Spinks, can I acknowledge your loss, we are sorry that that has happened and coming today is a constructive thing to talk to us. I want to talk to you about a very small aspect of it and I've understood what you've said about the drugs and I'll ask my colleague, Professor Whiteford. The coroner's report, so on what basis were you allowed to appear (indistinct words)?

MS SPINKS: We were just never invited, we were never invited. In fact, you know, it took quite a while for me to even get the report about her death and they didn't seem to need to include family members, we weren't included at all. It was only when I asked at pharmacogenetic testing that I got the doctor's expert witness statement that he provided and realised that, you know, the information wasn't - you know, wasn't what we saw, you know, in my daughter who usually is very well but had just been so very ill.

MS ABRAMSON: Thank you, Ms Spinks.

PROF WHITEFORD: Thanks for telling us this story. It's, you know, an example of the tragedies that occur in the mental health system. Just one more question about the pack that your daughter got. So there was no provided information inside the packet or there was no - - -

MS SPINKS: No, nothing.

PROF WHITEFORD: It's unusual because that's a requirement that that goes in those packs and why it was removed in your daughter's case is something - - -

MS SPINKS: When I went and checked with Chemist Warehouse and got a - you know, said, 'Packet of Zoloft, is there a product information sheet contained within it?' and she got the packet out, no, there wasn't, no.

PROF KING: And even though you'd asked that question the pharmacist did not give you a separate consumer product - - -

MS SPINKS: Well, I wasn't prescribed Zoloft so I was just asking her. You know, I was asking because I wanted to check that out. Was it just my daughter or is this - you know, and since I've checked and in Australia apparently there's no requirement for this.

PROF KING: Okay.

PROF WHITEFORD: Thank you, we will take that. So the other question I suppose is the issue you raised about medications being given for mental health problems too liberally or when non-pharmacological treatments would be more appropriate or where there are physical illnesses which might initially manifest some symptoms that could be seen to be a primary psychiatric (indistinct words) for us. One of the things we have made is a recommendation on this to try and increase access to non-pharmacological treatments and so for busy GPs perhaps the temptation is to prescribe medication when other kinds of psychological treatments would be the first line of treatment versus College of Psychiatrists (indistinct words) recommended so picked up on that information and recommendations that have been made to us and we've tried to put provisions in the recommendations that we've made about the system to increase the options available to general practitioner.

MS SPINKS: And could I just say that when you say somebody has a chemical imbalance in their brain and that a medication will fix that chemical imbalance there's absolutely no point in going for psychotherapy if you think there's something actually wrong with your brain. It's a very - takes away hope for a patient to tell them that and in actual fact there's no evidence been found for it so I just feel that that tool for diagnosis is really harmful in so many ways and it really is a very simple explanation for what is a really complex problem and it's really sad that it's on the adverts, you can see it on the Zoloft ads in the USA, can get them on YouTube, you know, that's what they're promoting but - you know, and then Dr Breggin has had access to their drug company trials and records which, I mean, I know they do their own trails and evaluate their own products so, I mean, he's had access to that and he says there's no evidence to support that.

MR THOMPSON: Could I just say (indistinct words)?

PROF KING: Because of a transcript, if you hold on I'll ask you to come up just at the end of Ms Spinks, yes.

MS SPINKS: My daughter's brother.

PROF KING: Okay, yes, so I'll ask you to come up just in a minute.

MR THOMPSON: No problems.

PROF KING: Any other questions for me? Thank you, Ms Spinks. If you wouldn't mind coming down and just your name for the transcript.

MR THOMPSON: Yes, Your Honour. So my name is Ian Thompson so I'm the son of Emma Spinks and Jackie's brother. So just one extra point I wanted to raise there about what you raised. To me the doctor didn't even make the right mental diagnosis. She wasn't depressed, she had anxiety. And every interaction we had with her towards that stage she demonstrated that anxiety from her illness, from her physical illness, so if the doctor hasn't even had the chance to properly diagnosis her mental condition I agree with what you're saying and, you know, it went to a solution too fast when it should have gone through alternative therapies and a proper diagnosis of where she was mentally because if you don't even know what disorders you've got how can you treat it?

PROF WHITEFORD: So I think you're just reiterating what I said (indistinct words) consistent with what you fed back to us so clearly the appropriate course what we are recommending would be that an appropriate diagnosis is made and that includes the identification of any physical illness which is presenting with psychological symptoms and then secondarily if there is a primary mental health problem, that non-pharmacological treatments should be the first line of treatment for most of those and as Ms Spinks said that pharmacological treatments should be only used when they are the necessary treatment and shouldn't be provided prematurely when they're not the first line of treatment that should be recommended.

MR THOMPSON: Agreed, yes, thank you.

PROF KING: Thank you.

MR THOMPSON: Thank you.

PROF KING: Next, Daniel Comensoli and Lucy Abbott. And if you could state your names and any organisation you're representing and any opening comments like you'd to make.

MR COMENSOLI: I am Daniel Comensoli and I'm the policy and research coordinator at the Alliance.

MS ABBOTT: And I'm Lucy Abbott, I'm the director of programs and development of the National LGBTI Health Alliance.

PROF KING: Thank you.

MS ABBOTT: Firstly, I'd like to acknowledge the traditional owners of the land on which we're meeting today, the Gadigal of the Eora Nation, and to pay my respects to Elders past, present and emerging and I think the Commission for the opportunity to speak here today. The National LGBTI Health Alliance is the national peak health organisation in Australia that provides a national focus to improve health outcomes for LGBTI people through policy, advocacy, representation, research evidence or capacity building.

We welcome the release of Productivity Commission's draft report and its recognition that LGBTI people are a priority population for consideration and action. It's also reassuring the see the Commission recognising the need to improve access to appropriate services and to have a well trained workforce to provide high quality and culturally safe services to LGBTI people. However, if we are truly going to improve our community's mental health and wellbeing we need to go much further and talk about and address the causal factors.

Therefore we would like to use the limited time we have today to talk more broadly about the structural and societal barristers that contribute to LGBTI people being more at risk of poor mental health and suicidal behaviours. We know that these poorer health outcomes can be attributed to the impact of minority stress. Minority stress is the chronic stressors that LGBTI are uniquely exposed to as a result of the social stigma associated with sexuality, gender and bodily diversity. This includes experiences of discrimination, social exclusion, harassment and physical violence. Responding to these determinants is complex and is made more difficult when we live in the shadows of government processes and legislation that seek to entrench discrimination in society more broadly as well as within health and other much needed wellbeing and social services in schools.

We note the draft report's recommendation for routine data collection and its acknowledgement that significant knowledge gaps remains. One of those gaps is the census. Currently the census does not capture data on sexual orientation, gender identity and intersex status of the Australian population. This exclusion means that vital data indicators will remain excluded from important datasets that are used across community, primary and tertiary healthcare services and programs. Asking appropriate questions on sexual orientation, gender identity and intersex status in a census is crucial in fostering an evidence informed environment for health and economic policy service planning and understanding health and social service utilisation.

This is essential if we are to better manage the mental health of LGBTI people in communities. The welcomed focus on working toward zero suicides relies on good data; data linkage, access to current data such as coroner's data to assist in preventing suicides will not benefit our communities. We have higher rates of suicide and we need to benefit from good data. The only way to achieve this is by including these questions in the 2021 census as is in the case in New Zealand and the UK so that they can then be included in other datasets with consistency. We are seeking to have the same playing field that others have to work with to reduce the number of suicide attempts in our communities.

Australian and international researches consistently show that LGBTI people underutilise health services and delay seeking support due to actual or anticipated discrimination or stigma from service providers. In private lives, for example, in private lives too - 34 per cent of LGBTI Australians reported usually or occasionally hiding their sexual orientation or gender identity when accessing services to avoid possible discrimination and/or abuse. The Trans Pathway study found that 42.1 per cent of trans young people encountered mental health and other medical services who 'did not understand, respect or have previous experience with gender diverse people'.

Further, 60.1 per cent of study participants experience feelings of isolation from these services which was found to be linked to higher rates of self-harm, suicidal thoughts, suicide attempts and diagnosis of PTSD and anxiety. Alarmingly a recent study undertaken by La Trobe University in partnership with Lifeline Australia, QLife and ACON reported that 71 per cent of sexuality and gender diverse people choose not to use a crisis service support during their most recent personal mental health crisis to beat that 71 per cent.

35.2 per cent reported barriers that prevented them from accessing a service and 21 per cent felt unsafe while accessing a service. Healthcare research has demonstrated that disclosing your sexuality and gender identity to your regular GP is conducive to increase positive health outcomes therefore its vital need to work with LGPTI people in a culturally safe way. Fear of discrimination such as withdrawal of a care may lead LGBTI people to have difficulty disclosing even where they believe these issues are directly relevant to the detriment of their care.

It is also important that LGBTI people are able to be their authentic selves when accessing healthcare services so we can access holistic healthcare. The disclosure of being LGBTI, for example, will alert the practitioner to a number of considerations, for example, mental health given our disparities. The government's proposed religious discrimination bill entrenches discriminatory access barristers to healthcare for LGBTI people by allowing healthcare practitioners to conscientiously object to providing much needed healthcare to our communities.

The Bill will have the undesirable consequence of deterring governments efforts to reach, for example, its ambitious goal of zero suicides in Australia as well as the other priorities that are outlined in numerous health and wellbeing national strategies. We are also concerned that the healthcare provisions have the real likelihood of adding to the determinants that already place LGBTI people at a higher risk of suicide than their non-LGBTI counterparties.

There needs to be a nationally coordinated approached to LGBTI health to ensure that money is better invested into our communities to effectively respond to the significant health disparities we experienced. Currently there is no national coordination of goals and targets outlined in the national health and wellbeing strategies where we are identified as a priority population. We also need national coordination of LGBTI research in this country as we have a somewhat siloed approach.

The Alliance is attempting to bring all LGBTI health researchers together and our capacity to do this is hampered without the resources to do this. Other bodies are able to undertake this important work as well as other importation national peak functions because of core funding. Peak funding for the Alliance would enable us to undertake much needed coordination in LGBTI health as well as meet the demands of members, governments and other stakeholders that rightly reach out to the alliances of the national LGBTI health peak body.

There is also a vital need for greater investment at the national level to ensure LGBTI people could contribute and engage in robust and constructive participation in developing policies, initiatives and programs relevant to their own mental health. It is important to also acknowledge that at the jurisdictional level there is a need for greater investment in LGBTI health so that there can be sustained and equitable access across Australia to community controlled peer based programs. There's not one of the Alliance's full members who are all LGBTI health organisations that are properly funded to meet the mental health needs of our communities. This includes, for example, across ageing programs, general health and wellbeing services, drug and alcohol, social inclusion and safety and access to general services.

Overall the Alliance believes that a strategic and coordinated approach which considers meaningful change (indistinct words) community and social level is needed to address the health disparities that exist between LGBTI populations and the general community. This will require an effort across multiple sectors beyond health including education, employment, social services, housing and justice. A paradigm shift that decentres heteronormativity and embraces sexuality, gender and bodily diversity coupled with a connection of quality and robust (indistinct words) evidence will help increase social inclusion and reduce stigma and discrimination in the lives of LGBTI people. These measures will result in a more supporting and accepting societal environment that will act as a protective factor for the mental health and wellbeing of LGBTI people. Thank you.

PROF KING: Thank you. Can I start by asking - so we've looked at some issues of stigma and discrimination but for stigma and discrimination associated with mental illness rather than sexual orientation. I agree with you that to make a difference we need, you know, to be working across health education, work, justice, increase social inclusion. I guess everyone agrees - well, I hope most people, well not everyone, but most people agree with the goal how do we get there, I guess. So what do you want us to recommend to government next May that will make a difference?

MR COMENSOLI: Well, like Lucy alerted to you earlier the census would be a great start because as we say the census (indistinct) LGBTI indicators in the census is the key to the door to other datasets and what the census does is it provides the broad overarching data indicators that can be then be embedded in other datasets of the mental health services, drug and alcohol services and other health services. And also to the service provider level as well, without explicit inclusive policies, structures and data collection practices LGBTI people - all clients remain fearful, fearful of being discriminated against and in order to protect themselves they then hide and modify their identities, their experiences, their histories and that renders themselves invisible basically and then that can lead service provides to then assume that they don't have any LGBTI clients and therefore they don't need to consider them in service planning or service provision and so you see this cycle of invisibility that is occurring and what is key to sort of breaking down that cycle is good data and currently we don't have good data for our populations and because at a higher policy level we don't have - there is little to no data of LGBTI populations, there is limited evidence (indistinct) that would need for mental health services and that means that LGBTI operations are excluded from policy creation, implementation or valuation and - - -

PROF KING: Can I follow that up, so I think that is a really good idea at a population level but you also mentioned, you know, in a sense data collection at the individual level.

MR COMENSOLI: Yes.

PROF KING: Do there need to be sort of safeguards in there? I mean, in some other areas there's talk about data ownership, data rights, and so on so do you think if, you know, there's procedures put in place, for example, so that GPs, for example, regularly collect information on a patient's sexual orientation but there'd need to - well, do there need to be protections in there from the consumer's perspective so they feel comfortable to - - -

MR COMENSOLI: Yes, I think so. And, yes, the key to that I guess when questions are asked usually they're not appropriate and they're not accurately capturing the population that they're trying to capture so there just needs to be collected in a meaningful and appropriate way and that is in collaboration with LGBTI communities.

MS ABBOTT: So, for example, we heard recently at the AusPATH trans health conference that it's broad practice that GPs of trans people getting prescriptions for hormones, they're subject to genital examinations; completely not required, you know, traumatising and potentially abusive and we found that's a common practice.

MR COMENSOLI: There also, just one example as well, like in 2016 the ABS tried to be inclusive or within the sex question they asked, 'Are you male or female?' and then they had the third response option which was 'Other' and then in order to disclose another identity you had to ring up a separate phone line and then get a separate form printed out and the ABS has acknowledged that that approach didn't work and there was significant underreporting of trans populations in sex populations so it's sometimes better to not ask at all than to ask in a potentially harmful way so, yes, I guess it has implications for local health districts (indistinct words) who are crying out for this start-up.

We had recently an example where one of our member organisations engaged with local health district in Sydney, the priority population's in it actually, when they were writing their report on priority population LGBTI-type people weren't identified even though that district has one of the largest LGBTI populations on Australia and their reasoning was that, 'Well, the foundation for that report was based on 2016 census (indistinct) and because we weren't counted in census (indistinct) we weren't identified as a priority population which than implications for service planning and policies.

PROF KING: Yes, good.

MS ABRAMSON: Thank you very much for appearing today and hearing a well conversed submission from you with some practical recommendations as to what you'd like to see. We've had quite a strong vote for rural and regional Australia and getting services to (indistinct words). You've spoken about stigma and difficulty within urban - I mean, I'm making an assumption here - but urban settings with (indistinct words) you referred to; what more can we do in terms of supporting people in rural and regional Australia?

MS ABBOTT: I think the expansions of perhaps services that do target those areas and I think some of the biggest issues in rural remote areas are confidentiality and privacy so the Alliance coordinates and provides national support for QLife which is the telephone and webchat service. We know from our data from that that in the country areas people prefer webchat than the phone and that could be a connectivity thing so there's IT issues for telehealth and all those things that people need in rural remote areas compounded with privacy and confidentiality issues and then access to proper services so if your life is chronically - you know, half of our calls go answered because chronic, you know, funding issues.

I mean, it's not just about funding but it's about wraparound services for people and the fact that Lifeline refer to QLife, you know, those kind of instances where you've already got a very well funded national service and it's referring on to a service that is very poorly resourced and isn't a crisis services because it's not 24 hours. So it's kind of we need (indistinct words) services but we also need mainstream services to be more aware and to be trained, particularly the medical world.

MR COMENSOLI: Yes, I was just going to say that. Within a skilled and knowledgeable workforce who are aware of LGBTI issues and that's made more difficult in regional and rural areas where their services are scarce. I lost my train of thought, but - so just like the proposed Religious Discrimination Bill we have a provision in there that will allow mental healthcare practitioners to refuse services based on the personal religious belief and that has an impact in our communities and - especially in regional and rural areas where there are not that many services so - like, in a publicly funded health system we should be aiming towards improving access to health services and not winding its back. I mean, there are fundamental structural barriers in place already for LGBTI people and we need to be working harder to break those down and not entrench them in legislation.

MS ABRAMSON: On the lines services, because the Commission has such a strong focus on it, what you just said with Lifeline is very interesting for us because we've also heard that there's for some CALD communities Lifeline is not necessarily a good option so practical recommendations that you've just outlined to me is - and it would very helpful, thank you.

MS ABBOTT: I mean, one things in terms of the workforce and I think in relation to the bill, it's for the government to build confidence of the community. Like, the community do not have confidence in this government for a lot of reasons. There's historic reasons, there's a long, hard horrible history of discrimination and abuse but if you're looking at things like the community benefitting from something like My Health Record - like, our community are not going to register for My - they are opting out at high rates because they don't have the confidence in the government and when you've got Bills like the Religious Freedom Bill, the marriage equality vote, those things do not build confidence in communities then you're being kind of having to work extra hard to kind of - it's a bit damage control isn't it.

MS ABRAMSON: Can I ask you before passing you to my college to take something on notice as we're a little bit pressed for time. Workplaces: we have a very strong focus on equally healthy workplace and a number of companies have a range of policies which say that they will behave in a certain way and in some cases that's not the experience of the people in the workplace so (indistinct words) your recommendations around that would be - - -

MS ABBOTT: Great.

MR COMENSOLI: Thank you.

PROF KING: One quick question about data. So I know that consideration is being given to a question in the upcoming census, 2021 census, and I know from just checking my mind that there was a question within a social survey (indistinct words) survey in 2014.

MR COMENSOLI: Sexual orientation from my understanding, yes.

PROF KING: Right. And there is a new ABS survey (indistinct words) will be going into the field late 2020 so it would be, I think, useful to check the question that was in the survey in your view about what it was appropriate to cover the issues (indistinct words) and then also says whether the ABS would put a question in the (indistinct words).

MR COMENSOLI: Yes, that's a really good point. Like, the Alliance has been engaged now in a sensitive consultation process with the ABS which has been really great and that's been in collaboration with the Australian Rights Commission and Intersex Human Rights Australia, it's an interesting point that one of you raise about the general social survey because that's kind of put out there as, 'Oh, well we're collecting it in this way so why do you need it in a census?' so the general social survey only does ask about sexual orientation but what the census is that it manages to collect data at the small geographic level which the general social survey doesn't and that's really important in sort of directing investment and targeting services to those smaller areas so that's why we need those questions in there in 2021.

MS ABRAMSON: Thank you.

MR COMENSOLI: Thank you so much.

PROF KING: Thank you very much.

MS ABBOTT: Thank you.

PROF KING: Next, Matthew Fitzpatrick. And if you are able to state your name, if you're representing an organisation the organisation and any opening comments that you'd like the on the transcript.

MR FITZPATRICK: My name is Matthew Robert Fitzpatrick and I'm 61 years old. I have been diagnosed with a number of different mental illnesses that I don't have, right, of course most of them being schizophrenia which is a common one and bipolar as well. Now, I'm not on any medication at all at this very moment, not even non-psychotic medication. Okay, and actually I've spent 24 years in the army. I joined in 1980 and was discharged in 2004, okay, so all these diagnoses come late in life. Now, what's happened is that I have over time suffered from depression that through my recent research I've come to the conclusion that that's all about sleep due to the fact that I've never been a good sleeper so if there's problems going on then I'm not getting sleep for days, so. And since then I've come to the conclusion that both diet and exercise is much more important than what people realise and what I previously realised as well so I've got a 29 inch waist, I got to 37 inches, that's not pant size that's with the tape measure and I managed to bring that back to my 20 year old self - - -

MS ABRAMSON: I'm looking with great interest at you.

MR FITZPATRICK: All right. Okay, where were we. All right, yes so anyway one of the biggest problems that I find is the accuracy of the data, okay, and therefore the accuracy of the diagnosis and I also feel there's two different types of psychiatrists, there's the mainstream majority and the minority of progressive ones that are forward in modern thinking and the mainstream it's all about medication, getting people on medication as quick as possible and that's it.

But the other situation with this accuracy of data - and that's the reason why I believe that all psychiatric interviews should be audio video recorded because I feel that that would promote them to record more accurate, to listen more carefully and to pay attention to what's going on.

PROF KING: Can I just acknowledges a question about that? Should that be at choice of the consumer, of the patient?

MR FITZPATRICK: Well, I think, yes, it would but I really don't see that many people would have a problem with it. For example, it's acknowledged that there's this situation where people with mental illness on medication are more likely to be in the court system and the gaol system. Well, the court system they're recorded anyway so you haven't got a choice for this audio video recording.

PROF KING: Sorry, I interrupted, so sorry.

MR FITZPATRICK: No, no, that's all right. And as well as that if you look on YouTube you will find recordings of psychiatric interviews on YouTube going back to black and white from the fifties or whatever as well. But also there's this crime situation because you often hear on the news that someone that's been charged with something is suddenly claiming mental illness as well. Actually very recently someone that got a non-sentence for assaulting an ambulance officer, it was appeared and now the person's been diagnosed with schizophrenia after it was appealed whereas when he was sentenced he wasn't diagnosed with schizophrenia and now they're saying, 'We're appealing it' then he's diagnosed with schizophrenia so I'm not saying he's not schizophrenic but I'm saying it looks very sus.

So there's also that aspect and as well as that this would give you - there's this debate starting to happen about the safety of this medication as to, 'Does it cause suicidal thoughts, homicidal thoughts?' and I'm with the people who say it does, all right, so in that situation there just say someone does commit suicide if you've got all the full recordings, audio video recordings, of the interviews with the psychiatrists you can then go back and do a very comprehensive assessment of, 'Should the person have been on the medication? Could we have done things different?' and that sort of thing but at the moment we've only got what are called 'self-critiquing' which is the psychiatrist self-critiquing their medication prescribing skills because they're the ones that are judging themselves because there's no test.

It's not like if you went to the doctor with blood tests and then - for example, high blood pressure. If someone's got high pressure they're put on medication and you come back, they do a test and they can tell whether the medication is working or not from that test. There's no test, it's just what the psychiatrists record and I think some of the exaggeration that's being put in there is actually to protect themselves because they're prescribing these dangerous medications by exaggerating the situation and saying, 'Well, this person should be on the medication' because they're riding in a way that suggests that the person should be on the medication but that may not be the case.

PROF KING: Okay.

MR FITZPATRICK: All right, now the other thing is I'm concerned about this screening children for emotional wellness checks because my view of a psychiatrist diagnosis it's a bit like fishing with a net. Yes, you're going to catch the people but you're also going to catch - there's going to be collateral damage, you're going to catch others as well like other fish and plastic and marine life when they're fishing and it also depends on the grid of the net as to what you catch and so what I'm saying with that is different psychiatrists, it's basically in a different grid in the net because they can't all be exactly the same standard and views on this - yes, anyway, so for that reason I think that I'm alarmed by this because I think there's going to be people who get involved in the mental health system that shouldn't be and the other problem is that parents probably not wanting to hear that they're doing something wrong especially like with the diet because I think everyone would agree that- well, most people would agree that the diets are getting worse and worse and worse.

I mean, you've only got to travel on a train around when school's finished to see what kids are eating. They've got a can of V - like, an energy drink or something like that and they're 14 so, yes, so - and the problem is is that parents don't want to hear that there's some sort of medical reason for their child not feeling well, misbehaving, so there could be a tendency for the parent to actually want medication when it's not necessary as well. The child's brain's developing so you're giving this chemical imbalancing drug to a developing brain and also you're giving them stimulants so there has to be a tendency for them to be seeking out stimulants like ice when they're a teenager, when they're older, because they've taking as a child, the stimulants, so I'm alarmed at that.

I haven't sort of checked too much into it so I won't say anymore on that.

PROF KING: That's fine, yes.

MR FITZPATRICK: But, anyway, I am alarmed on that. Now, on page 64 and 397 there's a reference to GPs managing the drug side of things. The problem with that is that it doesn't really say anymore but that's just going to be with another medication because that's generally how side effects are managed. Now, in my - on my online submission, was number 358, in that submission I actually tried to say as little myself and left it to more professional people because I haven't got any medical background at all except for first aid training.

Now, one of the documentaries I put in there was 'The Hidden Enemy' and it's to do with basically the American military and psychiatry but there's other military people talking about how bad psychiatry is as well and in particular the drugs and how bad the drugs actually are. Now, - - -

MS ABRAMSON: Mr Fitzpatrick, I'm sorry to interrupt you but you can take it that we read that submission so you can take it that we are aware of those things.

MR FITZPATRICK: Yes. Yes, all right. But what's actually happened in there is that there's been young soldiers that end up on over 20 medications so they're given a medication side effect and then more medications - well, they've actually - well, you've got young healthy people dying from having over 20 medications in their sleep and they're taking it as prescribed so, yes, so just saying that a psychiatrist prescribing a drug and then saying, 'Well, it's up to the GP' it seems like it's palming the problem off to the GP with the side effect situation. But anyway - - -

PROF KING: I think you wanted to - I'm just aware of the time I think you also wanted to talk about non-drug treatments not being available.

MR FITZPATRICK: Yes, yes, I actually do. In that submission I showed where fasting was tried as a treatment starting in the Soviet Union and Japanese study has backed it up, okay. Well, since then I've actually, with not seeing a reference in it, I've actually seen more on that. Now, what I've actually - and for me, I've gone gradually gone to the one meal a day diet so I'm only eating once a day so I have to eat fairly well so I'm fasting for - so it's called a 'practising intermittent fasting' and every now and then I do a five day fast so that's me, and that gradually come in, but since I've been I've found that this has actually been tried and these are recent articles. This one here is 21 January 2019.

PROF KING: Did you want to pass them up, or?

MR FITZPATRICK: Sorry?

PROF KING: Did you want to submit the articles formally, or?

MR FITZPATRICK: Well, what might be better if I email it in.

PROF KING: Yes, I think that's best, yes.

MR FITZPATRICK: And in the printing of this this has actually skipped some lines so this is the one here on the ketogenic diet - - -

PROF KING: Yes, probably best if you can email us the links rather than going through the article.

MS ABRAMSON: Excuse, Mr Fitzpatrick - - -

MR FITZPATRICK: Yes, I will actually be doing that and here's another one - sorry.

MS ABRAMSON: Sorry, can I just summarise your evidence to assist you. Really you're saying there are other treatments that are available and diets (indistinct words).

MR FITZPATRICK: There is definitely and I can't understand why - well, I think I can understand but it's conspiracy type stuff to say why psychiatry is ignoring this. Now, this other one here - and they've actually given examples - exercise and fasting leads to brain detox. So - - -

MS ABRAMSON: What we would welcome, Mr Fitzpatrick, is if you'd like to put them into a formal submission and we'll certainly have a look at them but you've brought a point - we understand what you have very helpfully said to us about other treatments. I did want to ask you if I may about mental health tribunal because I understand that you wanted to speak in respect of advocacy (indistinct words).

MR FITZPATRICK: Right, I'll just quickly finish on this first because it goes a little bit deeper and then I will get on to that. Here's another one here, 'Chronic schizophrenia put into remission without medication'; this is the keto diet. Now the similarities between the keto diet and fasting is that you start burning ketones so they're both similar in that way so this is further evidence of fasting will cure schizophrenia.

Now, the other thing quickly. My experience in the mental health hospitals is that there's an extreme sugar consumption around people who are mentally ill. Now, I'm talking about having like ten more teaspoons of sugar in a coffee, there's extremes. Well, what I've found is that insulin resistance is a hallmark because these are all recent articles. This is 4 April 2019, 'Insulin resistance; a hallmark of schizophrenia'. As well this says, 'Abnormal insulin levels founds in first episode of schizophrenia sufferers' so I'm starting to conclude that sugar could actually have a causal effect in this happening as well but not only sugar it's also processed carbohydrates as well.

PROF WHITEFORD: Mr Fitzpatrick, sorry for interrupting. Well, what the clinical information we'd have to take from (indistinct words) we're not a clinical group here so a recommendation is more at a certain system level so can I just stop you there and ask you one question before you finish. In the interactions you've had with the mental health system is there any recommendation about, not from the clinical point of view, but from a service point of view that would have made it a better outcome for you?

MR FITZPATRICK: Well, the first problem is they start to medicate you from day one - - -

PROF WHITEFORD: Okay, so let's stay with that. So without now not going to the medication or drug therapy as the first choice but looking at options first?

MR FITZPATRICK: Well, there are no other options.

PROF WHITEFORD: Psychological treatments?

MR FITZPATRICK: Well, I'm not aware of that. My experience is that they're wanting to drug me from day one.

PROF WHITEFORD: Right, okay.

MR FITZPATRICK: The other huge problem is the delusional issue because you can be held in a mental hospital having delusions alone so that's a problem there because when you go - and the recordings in their file, they don't even have to record what the delusion is so they can just right down, 'Delusion - - -

PROF WHITEFORD: So are you saying under the system you weren't given an option for non-pharmacological treatment, just like you just said to me; is there anything else about the treatment system which we could take onboard to try and make it improved?

MR FITZPATRICK: Well, the problem is with these mental health review tribunals they've already started drugging the person before the tribunal. The other thing is that I don't know whether this my words, the targeted report thing, but they right a targeted report, the psychiatrist, and they won't give you any information on you so you're turning up for this mental health review tribunal not knowing anything or what's going to happen in there or being said so - - -

PROF WHITEFORD: Yes, we've heard there have been some recommendations given to us about how those tribunals could work better so we'll certainly be taking that onboard. We're about to run out of time. Is there one last comment you want to make before we finish?

MS ABRAMSON: And we've all read your submission.

MR FITZPATRICK: Right. Okay, well the complaint system is not - the Health Care Complaints Commission is the Health Care Coverup Commission'; that's my view because they are just so bad. Like, they use this, whatever they call it, by saying, 'We've only got 13 staff to deal with 6000 complaints. We can't do a better job on the complaint' but what they want to do is let as much as possible slide in favour of the psychiatrist and what they'll actually do is they'll actually change the nature of the complaint in their letter back so the classic example - and when you've put in a number of complaints you see a pattern.

Putting in one complaint you can't see a pattern. It's only when you put in a series that you're going to see a pattern so I've seen a pattern from that. They'll actually change the nature of your complaint so what they'll say, and it's in their letter, 'We understand your complaint. There's this' and in my case it was - because what happened was that - like from complaining about a public servant who was corrupt to medical health workers they actually had me admitted for that because they didn't like me doing that. I know this sounds strange but they were hell bent on having me admitted so what I did is I put in this complaint about how they knowingly misrepresented what I'd said because my life is actually - if you go deeper into you will find out that it's definitely like a movie. So in saying about my life being like a movie they made out that they actually believed that I was delusional and thought that my life was actually being made into a move at this time and used that as evidence to have me admitted, all right, and - - -

PROF KING: Right, eventually - - -

MR FITZPATRICK: Yes, and so what they did is they turned around and said, 'We understand your complaint. This worker', because I won't mention any names, 'misunderstood what you said' and I used the word 'misrepresented' not misunderstood.

PROF KING: Yes, I understand what you're saying.

MR FITZPATRICK: So they'll actually even change the nature of your complaint just to let it slide in favour of the other person.

PROF KING: All right. Well, we'll - - -

MR FITZPATRICK: But as well as that, quickly, on the complaints system, it's a fractured complaint system as well because not only do you have the Health Care Complaints Commission you have the Privacy Commission and they can actually fine you for putting in a complaint.

MS ABRAMSON: Mr Fitzpatrick, we've heard what you've said to us. It's important evidence. We're just mindful that there are a number of people who want to talk.

MR FITZPATRICK: All right.

MS ABRAMSON: But we will absolutely read your submission.

PROF KING: Yes, so if you can put in a submission with those links that would be fantastic.

MR FITZPATRICK: Part of the problem is I don't consider myself a very good writer, I'm better with my hands so it takes a lot of work but with the Privacy Commission thing, they're there for complaints on accuracy but if they believe that your complaint is frivolous or there's no substance in it they can turn around and charge you for putting in this complaint.

MS ABRAMSON: Mr Fitzpatrick, we will read it, thank you.

PROF KING: Thank you, Mr Fitzpatrick.

MR FITZPATRICK: All right.

MS ABRAMSON: Thank you.

MR FITZPATRICK: Okay, thanks.

PROF KING: Next we have Jeni Diekman.

MS DIEKMAN: Thank you.

PROF KING: And if you could state your name, any organisation you're representing and any opening remarks for the transcript. Thank you.

MS DIEKMAN: Thank you, Stephen, and thank you for allowing me to speak today. Yes, my name is Jeni Diekman. I'm a community pharmacist and also the carer of family members with severe mental illness complicated by drug and alcohol abuse. I really commend the report, the detailed examination that (indistinct words) mental health services in Australia. I've (indistinct) many of their recommendations but I'll have some comments about some of those recommendations that hopefully will lead to an improvement of the coordination of services for the consumer.

However, I think there was a significant gap in the report as it related to community pharmacy. The report says that pharmacists dispense and give advice on drugs and I want to demonstrate to you what I do in my pharmacy to show you the value of a network of community pharmacies and the pharmacies that are at the coalface in primary health care and argue that their current funding arrangements in community pharmacy does little to encourage the delivery of the type of care that people with mental illness deserve and as we've seen today with Emma, I'm very sorry to hear about the essence with one my colleagues, but I think that that will probably support my case for the way in which the funding of community pharmacy at the moment.

So what I'm going to do is I'm going to show what I do in my pharmacy with people that present at the various stages of the stepped care model. So if we start with the health information stage. I speak to people - for instance, they might come in with a sleeping problem. Now, it's very easy just to say, 'Okay, I can give you a Restavit. I don't do that. I like to find out what the sleeping problem is, I let them know that sleep deprivation can lead to mental illness and that there are various things that they can do before they need to take an over the counter medication like relaxation techniques, there's a whole thing they can do with sleep. We talk about weight and nutrition, smoPROF KINGessation and drug and alcohol misuse that might be contributing to those problems.

So we can give a lot of wellness information. It's not just about illness. Then in the early needs stage where you are putting the use of the digital health agency, that's where pharmacists - I recommend regularly for people to use the Head to Health website and we can promote it. We also provide written resources such as the Beyond Blue booklets on what works for anxiety or what works for depression and also the information resources that are available for consumer and the family. I can refer to the NewAccess program (indistinct words) health network, I've only just found out about that though.

And where my pharmacy is we have a lot of university students and we recommend that they can seek out headspace however I've had a recent instance where I have a 12 year old boy who had very complex family issues who was being bulled at school. Now, he did have a counsellor at school but the counsellor only came every three weeks but with these complex family issues he was developing extreme anxiety and I was trying to get him into headspace. Headspace referred to the CESPHN, PSS, or whatever it's called, then they decided to refer it back to headspace. It's now five weeks later and he's still not had management of his anxiety and he's now not going to school because he fears being bullied.

Then with low intensity mental ill health and I'm just going to mild, direct and low intensity where by that stage the person is usually seeking the help of a psychologist or a general practitioner and the person would come to the pharmacy usually for prescription medicine. Now, in my pharmacy they do receive a consumer medicine information sheet. In many of the generic medicines they don't have consumer medicine information sheets and my staff are trained to offer the consumer medicine information sheet with every patient and we print it off and we sit down with the person particularly if it's the first time they've had the medicine and explain the sorts of things that they might expect and sort of mornings.

I have argued with PSA and with government bodies that really with the dispensing fee that we are paid there needs to be some way to recognise whether the CMI is being given out with the medicine and the payments should be related to that but it isn't at the moment. We also give lifestyle advice and again ask if the person has had access to Head to Health or whether they use a psychological service because the evidence is that really the medicine doesn't work on its own often and the best evidence is with both psychological support plus the medicine.

Then with high needs patients, we see a lot of patients with high needs. First of all we do dispense the medicines and we often pack them in a dosage administration aid to help them with adherence and we provide advice about the side effects. For those that are at risk of misuse, I have several patients that come into my pharmacy. They ask us to stage supply their medicines because they are frightened of suicide, they are frightened of overusing their medicines and they'll come in daily so my staff are really important in the way in which they manage their illness because they have someone to talk to and give them advice about the medicines.

We also provide needle exchange and we ask about the general health of the patient. We ask them whether they have had their Hepatis status done. We might recommend that they have their new prescription opiate that they can use intranasally or we can ask them if they're ready to give up and they're ready to go rehab and that we can refer them. We provide opiate replacement services and the frustration - with a person that has high needs, particularly if they have a drug and alcohol problem, they have mental health problem and they now have some of the physical problems, they'll see a general practitioner, they'll see a psychiatrist, they'll see a drug and alcohol person, each time they have to go to a different place and someone with complex mental health needs it is very difficult and very demanding on them and I do note that you recommended a coordinator and I'll talk about that later.

Then of course there are the people with severe psychosocial needs. I have one patient that was in my pharmacy this week crying because he has been homeless for over a year. We tried to get him into a place, he has his own mental health problems where he gets aggressive and they kick him out and he's back on the streets and he lives under number six archway under the light rail regularly and he just said to me - he was crying, the tears were dripping down the chair and he said, 'Look, I think I've got to go back to gaol. It's the only place I can get a roof over my head and food'.

We often develop a long term relationship with our severely mental ill patients. They often check in with us daily by phone or in person and as I said it provides a sense of security for them particularly at their most vulnerable and so I just want to show you about a recent episode where one of these high needs patients used to call us every day three times a day just to report in, ask about their medicines, but then this one day the patient rang and abused my pharmacist, it was highly abusive. This the pharmacist that would speak to him three times a day. He was so abusive the pharmacist had to say, 'Look, I can't listen to this anymore. I need to hang up' so then he rang me and started abusing me and I said to him, 'Look, this is not you. This is really not you. You really need help'.

Now, this was a patient who was in his sixties, he was a Vietnam vet, he had had alcohol and drug problems and he'd had serious abuse issues as a child. He had never seen a psychiatrist. He didn't want to see a psychiatrist. He'd never sought - and he had a very good GP but he hung up - and the GP had tried to get him to see a psychiatrist for many years - so he hung up on me and then ten minutes later he rang back and he agreed that this time he really needed help and that was because the young pharmacist - - -

MS ABRAMSON: Do you want to just take a moment?

PROF KING: Just grab - yes.

MS DIEKMAN: The young pharmacist had always been so kind.

MS ABRAMSON: You just take your time.

PROF KING: Just take your time, yes.

MS ABRAMSON: It's no problem.

MS DIEKMAN: And for the first time in the 40 years history he felt that he needed to see a psychiatrist so because of what my pharmacy had done - God, I can't believe I'm doing this - - -

MS ABRAMSON: Do you want take a pause for a minute - - -

PROF KING: Just take a break. That's fine. Just take a moment. Seriously, just take a minute, relax.

MS DIEKMAN: Thanks. They're fantastic staff.

MS ABRAMSON: It's absolutely not a problem, you take your time.

MS DIEKMAN: Basically because the pharmacist had been so caring of him, always taking time out, he made (indistinct words) his life but he sought the help this time. So the current funding model for pharmacy doesn't encourage this kind of service. It basically - it pays you for a dispensing fee, it rewards dispensing fees. There are some for sitting down with the patient, there's some money but it's miniscule compared to the dispensing fee. So the incentive is to pay the - is to dispense the drug as fast as possible, use as few pharmacists as possible and have the pharmacist check. And online pharmacy gets the same remuneration per dispense as a full service community fund like the sort of things my kids do.

And the young pharmacist today are trained to be experts in medicine management as well as in primary healthcare and by paying them to be dispense monkeys, as I call it, the government is wasting a highly trained resource. Basically those that dispense, as I've said, dispense the most prescriptions as fast as possible get the largest slice of the PSS pie and I'm really not happy about that particularly - sorry, for my most distressed patients.

I also believe that pharmacy registration should be contingent upon mental health first aid certificate and any pharmacy that's providing drug and alcohol services like needle exchange should also do comorbidity guidelines so I'm now going to lead into comorbidity, that's drug and alcohol and mental illness. You mentioned in the report that people with mental illness often abuse drugs. You know, either they can abuse drugs before they had an undiagnosed mental illness and they find substances early because certain illicit substances are great at calming the anxiety but then of course they get into the addiction and they can be going in and out of rehabs but my experience with this is that in and out of rehabs they don't necessarily look at the underlying mental health condition so if you've got someone who's clean for a week, their anxiety comes back, they're back on the drugs. They're not dealing with the mental health issue.

And it can be the other way around. They can be abusing drugs and then develop a mental illness as a result of drug abuse so our system is not developed so that you have a separation of drug and alcohol services and mental health services and it's really - that isn't appropriate, you ask in your report, 'Should drug and alcohol services be with mental illness?' and definitely, yes, I think that they must. The Matilda Centre, I'm not sure if you've had a presentation from them, I think they did do a submission but they have produced a wonderful online training program called 'Comorbidity Guidelines' and I recommend that every health professional that's dealing with people with drug and alcohol problems and/or mental health should be completing these - they have a training program and, yes, drug and alcohol services must be co-located for mental health services. At the moment there's only one dual diagnosis clinic in Sydney and from people that have used it it's been very helpful particularly if you can get young - - -

I'm not going to go into the different recommendations that you've made. Now, with draft recommendation 10.1 that digital records should facilitate information sharing. I could not agree more. However, my experience with the mental health system, in particular mental health hospitals, are that people with mental illness are asked/recommended to opt out of a My Health record. Now, these are often people who are the most vulnerable and being able to see the My Health record across the various provides, because they're all in siloes, they are going to be most helpful. However, there's discrimination against the person with mental health and even the mental health service provides are recommending people opt out so I agree that we need to have that integration but I'm - yes, anyway, that's for you.

The My Health record is not being used. Most of the people that use the My Health record are the pharmacists so all their drugs are being loaded up and the discharge summaries from hospitals but many doctors, in particular specialists, are not - and I don't even know whether they have the software to be able to load up their reports onto the My Health record - so that's a frustration of mine when I try to look at the My Health record to see what is really happening across the various providers for the person. For the pharmacists the My Health record if it was complete is fantastic because we can now see what's happening with the person, we can see their levels for instance and adjust those as creatinine levels, for instance, and adjust doses et cetera.

Your draft recommendation 11.2, increase the number of psychiatrists. If you're going to recommend that please recommend that more of them do drug and alcohol. There are not enough psychiatrists that also specialise in drug and alcohol, it's all a bit hard because those patients are not as reliable (indistinct words). Then draft recommendation 10.4, the care coordination services. That is what's needed for those that are severely ill, they need someone who can look across the various silos and bring everything together.

Now, I know in the rebuild plan you have said that. I can't see how the money is going to work for that. I really didn't understand whether the way that you're recommending the finances be allocated would lead to a coordination of services.

Now, I want to give you an example. One of my patients has a friend in The Netherlands and she had asked for this patient to go and live with her in The Netherlands. The patient had had a psychotic episode, had drug and alcohol problems, and so the person in The Netherlands said - and I said, look this patient of mine is going to need a psychiatrist and someone to deal with the drug and alcohol problems and the person in The Netherlands said, 'I can't get you a referral to a psychiatrist. It's not how it's done here. What happens here is they go into a centre and they - it's a wraparound service. So they have someone to organise their housing, someone to organise their mental health problems, someone to organise their physical needs if possible', and that's how I would like to see the mental health services delivered in Australia, and if that's what the rebuild model is going to do then that's great. Thank you.

PROF KING: Thank you very much for that. Just to summarise, because - so one of the things that I take from your presentation is that clearly the role the pharmacies have to play in the mental health system - can I summarise it by two bits. Firstly that you feel that there's more of a role that pharmacies should play - - -

MS DIEKMAN: Definitely.

PROF KING: - - - and I want to understand, because I suspect there are differences across pharmacies. Some pharmacies would like to play that role, some wouldn't. So how do we distinguish between those. And the second part is that we talk about many doorways, so the doorways through school, early education and so on. Are you also saying that in a sense pharmacies need to be an effective doorway for the mental health system broadly defined?

MS DIEKMAN: Yes, I am, and we are often - well, that's what I'm finding in my practice, because people come in with say a sleep problem or a lot of students are stressed before an exam and how can we sit down with them - - -

PROF KING: But do you think that would apply to all pharmacies, or is all pharmacy unusual, because that's what I'm trying to get at.

MS DIEKMAN: No, I don't think my pharmacy is unusual. I think you particularly find in rural areas it is - and it's definitely not the way the young pharmacists want to be able to practice. So I guess - I mean I will say something pretty outrageous here probably, and that is that the licence for the PBS licence should really go to those pharmacies that want to deliver that whole of care, because at the moment the incentive is not to do that, and that means that people are missing out for instance - not here, but, yes, because that CMI should have gone into that box, and anyone who gets their first prescription should have been sat down with the pharmacist - - -

PROF KING: In the consulting area or - - -

MS DIEKMAN: Yes, and discussed what's happening, and I would also recommend that there should be a minimum number of pharmacists for the scripts dispensed, and I don't think that an online pharmacy delivery of a medicine, particularly a first prescription mental health medicine should really happen unless there is - unless you have a Skype interaction.

MS ABRAMSON: Ms Diekman, first of all I think that your patients are very lucky to have someone who cares about them so much. I wanted to ask you about pharmacy training, because in a number of other areas we've said that - you know, with GPs, with other health professionals there needs to be more of an emphasis on training in mental health. So would you have some comments about pharmacy training.

MS DIEKMAN: No, definitely. The guild has just recently done some excellent training on the person with mental illness. The reason the pharmacist also - they need training about the person and they also need training on how they can deal with the person, for instance my patient that rang up and abused the pharmacist, because the young pharmacist often when the person with mental illness is screaming and ranting and raving at them is because of their underlying anxiety, but the young pharmacist tends to take it personally. So until the pharmacist can understand that, no, this is part of the mental illness, I don't need to get defensive, and so how the pharmacist deals with the person with mental illness there probably should be a bit more training. There is mental health first aid, but I don't think - I have done two of those courses, but they're not aimed enough at what actually happens in your pharmacy. Look, we get spat upon, we get all the sorts of things that you see with people with mental illness. It is part of their mental illness and understanding that is really important.

MS ABRAMSON: Thank you.

PROF KING: Thank you very much.

MS DIEKMAN: Thank you.

PROF KING: Next we have Mitchell Peacock, and again if you could state your name, if you're representing an organisation the organisation and any opening comments that you'd like to make for the transcript.

MR PEACOCK: So I am Mitchell John Peacock. I work in a counselling organisation just to clear the air on that one, and one of the things I've noticed with the draft is that while it's fantastic - I'm just jumping straight in.

PROF KING: Yes, please.

MR PEACOCK: While it's fantastic that it's taking a very holistic approach in caring for the mental health of the public there is a shortcoming of the role of counsellors in there. I did notice that the (indistinct) was mentioned, but it was not mentioned as something that was overly considered.

The reason why I think that we're not tapping into what I would consider to be a vital resource for the community is quite concerning on my part. The reason why I think that is a lot of counsellors focus in mental health. The draft itself - I've made notes, but I'm kind of just going off the topic already - the draft itself does talk about data and data sharing, and I think all that is fantastic, but as counsellors they're an unregistered profession at this point and they wouldn't have any access to that. So if we're looking at better ways to capture more effective data, especially when it comes to interventions, we should be able to have access to whatever data that they're holding onto and whatever they're maintaining, because that helps deliver more effective treatments. Best practice comes into results, and as previously mentioned by someone else we're not really evolving with the times. So the more we have the better it is for everyone.

I also want to talk about the cost to the public in terms of counsellors not having a rebate, as well as how it stems into the public willingness to seek help. So from a counsellor's perspective because we don't have any rebates accessible to us outside of private health (indistinct), which comes with being unregistered of course, clients might see that as a larger out of pocket expense for them. If we could look at having a rebate then we can have more people treated.

One of the things that we talk a lot about is that people aren't getting the interventions when they're required. People are leaving it far too late, and they think this out of pocket expense is one of the reasons why that's happening. Maybe they can't afford the services. In the instance of comorbidity absolutely, if they're spending a lot of their resources fuelling an addiction that's something that's going to stop them from seeking further help. In comorbidity, because they did sight out in the drug and alcohol sector, it's interesting because for those to offer free services you get a lot of people coming in - I guess mention the places I have worked in - but they were running off government grants as if that was the only way to essentially get their funding, and you could see a lot of people engaging with those services, but outside of that when it becomes an out of pocket expense you don't get as much of it, and I think that by having that rebate for enabling the public.

It also creates a level of public awareness that (indistinct) of seeing a counsellor or a psychologist is definitely not as it used to be, but by having more people have access you further reduce that, and all of a sudden it stops being you see a counsellor or you see a psychologist, what's wrong with you, to everything else of, okay, you need this service and that's fine because it's more mainstream.

Going back a little bit to comorbidity as well, because I've written down a list of severity, because we're looking at the Stepped program. By having those early engagements and enabling people to seek help if they want to seek the help we end up having - we tackle it before we get to the high extreme. So counsellors might have their (indistinct) focus more to the low to moderate, and because I can speak from my experience I don't have a medical degree, I can't vouch for a pharmacist, I can't vouch for a psychiatrist, and I don't think that they're of not value, because they absolutely are, but I think there is a role for everyone to play, and counsellors do specialise in that face to face intervention, face to face therapy, which even a draft rec rises as effective, as well as online therapy. I have got more, but it's - - -

MS ABRAMSON: (Indistinct) a written submission if you want to make one.

PROF KING: Can I ask one question though on the data side. (Indistinct) of Productivity Commissions supported what's called a consumer data right, so the idea that - and it can be data about health, it can be data about banking, or whatever, but the consumers have rights to their data and have rights to be able to provide that data and require that data to be provided to whoever the consumer wants that data provided to. So the banking example, if you've got data with one bank about your credit history and so on you can actually say as a consumer I want you to give that data in a readable form to one of your rivals because I might want to get a loan from them. In health do you think that same sort of right might help overcome the issues that you have come across where there's data out there but you can't get access to it, and more importantly the consumer can't say, no, I want you to have access to it and that must be provided because that's my choice.

MR PEACOCK: Well, I think it goes both ways. It's not about just always providing data - well, it's not about having access to it, it's also about providing it. Our current state if the clients want us to provide data to an external source we need to have handwritten consent from them, because of course privacy and confidentiality. If that were to change I don't actually know what that would look like, though I am imagining this new system would be that there is a registry, certain people will have access to it. Clients could then confirm what they do or do not want to be uploaded to it, the same way that the current New South Wales Health works.

PROF KING: Okay. Thanks.

PROF WHITEFORD: Just one question. So the lack of registration has meant that there's not a lot of information about the, I guess consistency of counsellors across the country, so many people from different experiences, somewhat different qualifications, but I do understand there has been attempts by Australian Counselling Association and PACFA to try and look at standardising people who are members of those organisations. Can you say anything specific about that or your experience with that?

MR PEACOCK: Actually interesting you say that because it did remind me of one of the points I wanted to mention, but I will answer your part first. In terms of having a registration, yes, there are people who have different qualifications, but this point in time anyone who walks in off the street can claim to be a counsellor because it is not regulated. As a result that's very detrimental to not just the profession but anyone who might be seeking help who goes to someone who's not qualified.

I myself am a member of the Australian Counselling Association, so I can see exactly where concern would lie if you're going to someone who has gone through all of the education for it, because then we're (indistinct) due diligence onto the client who's seeking help who might not be thinking what do I need to do, how do I check this person.

One of the things that I did want to mention earlier was about rural areas where help might be needed more. If we enable an entire extra profession such as the counsellors to be more of assistance to people if there are any incentives or what not we would bolster the numbers of professionals in those areas. So I think that would also be a great help.

PROF WHITEFORD: Thank you.

PROF KING: Thank you very much.

MR PEACOCK: Thanks.

PROF KING: Next Ron Spielman. Thanks, Ron, and if you again can state your name, if you're representing an organisation the organisation and any opening remarks that you would like to make for the transcript.

DR SPIELMAN: I'm Dr Ron Spielman, and I'm not representing any organisation, although I've listened to the presentation by the college yesterday and I endorse everything that was said, but I'm going to hope to offer perspective from a clinician who's worked (indistinct) with individuals.

My hope in appearing before this hearing is to speak from the perspective of a now retired psychiatrist with some 40 years of clinical experience, and a psychotherapist and psychoanalyst.

My own clinical career developed from running a therapeutic community-based on group therapy principles through a few years as a director of drug and alcohol services for a population of approximately one million, to recognising that in none of these was I sufficiently well trained to understand the complexities of the underlying severe personality disorders which my patients were suffering.

Now, not every mental health clinician can have the privilege of this intense training, but I do consider that the mental health services need to assure greater competence in understanding and managing complex mental disorders that exist at present. In the course of this experience I came to understand that severe personality disorder has a mortality rate of at least 10 per cent. Severe personality disorder could present as any of the so-called mental illnesses through anxiety, depression and psychotic symptoms. Too early prescription of psychoactive medications risks driving the underlying issues even more deeply underground only to reappear repeatedly on later occasions. Any condition in physical medicine with such a mortality rate would attract far more attention and research funding than does this most lethal of psychiatric diagnoses.

I would like now to express some points from the vantage point of my own decades of clinical experience. I commend the Productivity Commission on the amount of thought and effort which has resulted in the draft paper. On reading the draft report my concern was that economic considerations, understandably in this instance, dominate considerations of the development and maintenance of mental health in individuals. A capacity for work is indeed a pillar of mental health, but so too are a capacity to love and to play. These three capacities contribute to a balanced personality. The current mental health system does not provide for adequate in-depth assessment of individuals and families who present to the system in a wide variety of manners and to a wide variety of service facilities.

Best attainable interventions at first presentation will save considerable future costs to individuals, their families and to societies as the result of development of chronic conditions. This requires the optimal training of all mental health professionals, and importantly their continued support by senior clinicians, who are too often lost to the public sector mental health services. Ways must be found to retain the experience gained by a long career in mental health services in the interests of staff morale in a highly stressful field of work. We have had an example of that this morning, I commend Jeni on her presentation and illustrating what it's like to be at the coalface. How important it would be to have the help and support of a consultant who can help the younger clinicians through these crises.

Mental health clinicians put themselves on the line in working with highly distressed and highly disturbed patients. All of us in the mental health services have our own issues, as do we all, and so need and deserve mentorship and supervision from senior experienced colleagues when such issues are activated by working with highly troubled patients.

The regrettable statistics outlined in the report in regard to suicide are the tip of the iceberg of the failure to adequately address the considerable levels of psychic distress in our community. The importance of severe personality disorder has contributed to most of the main economic drains incurred in the mental health field. For instance suicide, drug and alcohol dependence, eating disorders, domestic violence, child abuse and neglect and so on is vastly underestimated in our society. A heightened awareness of this important fact alone would focus policy development on issues underlying the most costly effects of mental ill health, and inform more costive effects at primary intervention.

Finally, an adequate understanding of the psychodynamic principles of infant, child and adolescent development, together with an appreciation of family dynamics underpins all aspects of management of mental health issues and their potential prevention. All mental health clinicians should be as competent as possible in this regard.

PROF KING: Thank you. Just a couple of questions to start off from me. So one of the things that is almost coming out as a topic this morning, I'm not sure how much of this morning you've been in the room, but a number of the presentations this morning have suggested that perhaps medication occurs too early, that there's too much of a churn them through and medicate them type of culture, that other alternatives need to be considered, non-pharmacological alternatives need to be considered, at least equally at the same time or potentially before medication, and you touched on it as well. So I'd like your views on it.

DR SPIELMAN: I have done more than touched though. Absolutely right. It was illustrated here this morning, the two individual cases that presented their own unfortunate encounters with the health services, and Jeni's excellent presentation as well shows that there is much underlying, and the rush to medication is partly due to - Jeni said there are too many incentives to write prescriptions and go and have brief consultations, but there's also a reluctance to touch on the deep distress and psychic pain that people are presenting. It's much easier to write a script than to take time to listen, and I think in both of the presentations here this morning where individuals presented their own distress you get a taste of complexity.

You are sitting there on behalf of the Productivity Commission, imagine if you were a clinician and had to deal with this in your consulting room. It would take more than one consultation, it would take several to get to the bottom of what is really underlying the distress of these individuals, and perchance I have just heard two and on a day to day basis this is what the health services are encountering. All tragedies that we hear in the newspapers of suicide, domestic violence, goodness knows what, there's always been an opportunity to do a more in-depth assessment and evaluation long before the tragedy hits the fan so to speak.

PROF KING: So in that situation incentives are something that we can deal with, although a movement away from ten minute GP medicine may be revolutionary, but we can't necessarily make - you can't change people's willingness as a clinician to sort of say, well I don't want to hear that story, it's easier to prescribe. Do you have any suggestions for practical recommendations that we could make to try and help avoid the overmedication. I understand the incentive side, but anything else?

MR PEACOCK: I've (indistinct words) to run the health services.

PROF KING: There's a chance.

MR PEACOCK: What one must do is train people to listen better, and sadly most of the trainings don't do this as well as they could. I've had a lot of high level training, some of which I paid for myself, but the point is it's being supported by peer groups and it's being supported by senior clinicians all the way. I'm now one of those senior clinicians, albeit retired. So I do think you can change people's willingness to listen as long as they're adequately trained and adequately supported and they need to have a venue to go to, a peer group for example, to talk about their difficult encounters and share experiences with peers, and this is time consuming and costly in itself, but if we're looking for a genuine solution to this serious problem then we've got to look to more time consuming and costly staff intensive methods and put less pressure on service delivery and throughput. That's just a brief answer to a very serious question.

PROF KING: I understand. Thank you.

PROF WHITEFORD: Thanks very much. A quick question related to one of the recommendations that has come up this morning, the issue about trying to intervene as early as possible to especially I guess deal with what later may become a personality disorder. One of the recommendations in the report has been to include a socially emotional wellbeing check we've called it at the time that GPs or us do the 3 year old health check, physical health check. Obviously that's a bit of a blunt instrument in some respects, but any comments you'd make about the intent of that recommendation to try and not wait until there are clinical symptoms emerging, but trying to deal with the early issue which you did mention that might be causally related to a trajectory which is going to result in development of a mental illness later in life?

DR SPIELMAN: I think it's commendable, and the check list idea is not something that I have much faith in, but at least it's focusing on early infant development. I've spoken to kindergarten teachers who say that they can pick the children in their classes whose families are in difficulties. If we could find some way of offering services to the kids that those people identify - it's a family dynamic problem. I'm not trying to allocate blame, but when kids are in trouble it's because the family is in trouble, and the parents are already beyond primary intervention, they need secondary or tertiary intervention. But anything that's going to focus on the kids has got to be worth doing and spending a lot of time fine-tuning it.

My last point about family dynamics and depreciation of development it's got to be part of training not only mental health professionals, but also kindergarten teachers and school teachers, because kids who are in difficulties will demonstrate it at school, and that's one place of picking them up, and of course in general practice and pharmacies, and it's a daunting task. I don't have any ready solutions, but I've appended to my submission 18 a proposal that I wrote years ago for what I call a psychodynamic consultancy panel where each state health system should have available to them a group of clinicians trained as I have been trained in-depth and willing and able to deal with complexity to help them work through some of the aspects of programs that they're wanting to develop. I mean sadly I'm retired, but I really would like to still feed back to the system what's taken me 40 years to learn, and I still think I'm young enough in that sense. So we need to tap a lot of the experience that has been gleaned. It's not as if we need knew methods, we need to develop methods that are known to work in a long term psychotherapy field which means involvement at depth and at length.

PROF WHITEFORD: Thank you very much.

PROF KING: Thank you.

DR SPIELMAN: I haven't had the opportunity to say that in public before.

PROF KING: Thank you. Scarlett Franks, and if you could state your name, if you are representing an organisation the organisation and any opening comments you would like to make for the transcript.

MS FRANKS: My name is Scarlett Franks, I'm a 26 year old dissociative survivor of complex trauma, which is to say that I am living with a legacy of disempowerment through child abuse and neglect, domestic abuse and coercive control, sexual and domestic violence, as well as the betrayal of the psychiatric, criminal justice, child protection, welfare, public housing, NDIS, victim services systems, which prolonged my disempowerment.

I am here today because I'm really excited about the Commission, but I was really disturbed to see that in 118 pages of the overview the word 'trauma' appeared three times, and I urge the Commission to follow the United Nations in their declaration that mental ill health is about power imbalances, not chemical imbalances.

The Blue Knot Foundation, the National Centre of Excellence for Complex Trauma estimates that 1 in 4 Australians are living with the legacy of childhood trauma, and that this kind of history is the single most significant predictor of contact with the mental health system. I encourage the Commission to look at Blue Knot's submission to this inquiry.

We have a paradox in this country when it comes to complex trauma. High prevalence on the one hand and yet scarce recognition, awareness and allocation of resources, and as a result many people are inappropriately labelled with things like bipolar disorder and treatment resistant depression, disorders of a psychosis spectrum and the so-called personality disorders.

The lack of recognition and evidence-based intervention into complex trauma set me up four years of re-traumatisation. I urge the Commission to look out for a forthcoming report based on a two year ANROWS funded study by Salter and Conroy and colleagues at WSU and UNSW, which looks at Australian women's experiences of complex trauma, and what their broad finding was that trauma is indeed marginalised in our country, and that treatment is skewed towards men's experiences of trauma, despite the fact that PTSD and complex trauma are more common among women.

A recent study by Dr Marianne Cape of UNE and her colleagues found that dissociative disorders are about as prevalent as mood disorders like depression, about 11.4 per cent of the population, which matches on to rates of multiple childhood traumatic experience at about 12 per cent, and yet despite this prevalence there is only one inpatient program for dissociation in this country at Belmont in Brisbane. This issue is almost entirely relegated to the private system, which makes it very inaccessible to the people who need it most.

So my recommendations are as follows: firstly, that housing and financial security are fundamental to mental wellbeing and ought to be the foundation of any Federal suicide prevention policy. It was not until I finally got victims compensation and the DSP nearly six years after the rape that led to my PTSD diagnosis that I was able to do anything more than crisis management in therapy. All nine of my suicide attempts and all of my involuntary hospitalisations occurred during this period of insecurity and debt. I urge the Commission to recommend raising Newstart and the DSP and to abolish the deliberate bureaucratic barriers to these entitlements.

Secondly I urge the Commission to consider as we have just heard the marginalisation of psychodynamic therapies in Australia and the impact this has on clinicians and clients. As a nation we have overinvested in the techno centric trifecta, drugs, CBT and apps. All of these tools can be of some use to people managing their mental ill health, but when we rely solely on cognitive behavioural interventions we leave survivors feeling irreparably damaged when these modalities invariably fail to make inroads in their underlying attachment wounds and do little to improve their safety and wellbeing.

As (indistinct) Koslow testified yesterday it is uniquely difficult to train as a trauma therapist in this country and very difficult to make a living. Complex trauma is relational and is healed in relationship, but rather than giving survivors the opportunity to cultivate attuned relationships with an appropriately trained therapist we are condemning them to a revolving door of psychiatric admissions.

Thirdly I want to stress to the Commission that the biomedical model sometimes does more harm than good. As others have testified we ought to think about moving away from models that individualise mental distress, altered states and troubled behaviour, and instead move towards critical and peer led models and consider alternatives to prevailing diagnostic systems like the power threatening in-frame work developed in the UK and endorsed by Beunot. This will force us to start treating child abuse and neglect, domestic violence and coercive control, sexual exploitation and violence, ongoing colonial violence and austerity as the public health crises that they are, and we must invest in prevention and response across all sectors.

Finally I would echo the testimony given yesterday by Irene Gallagher for Beam that co-consumer - consumer co-design, co-production and leadership must be the foundation of any policy making proposed by the Commission, and this includes the funding, the training and the work of consumer researchers such as myself so that it is more than a tokenistic advisory board.

Finally I'd just like to share one quick thing about my experience with suicide and recovery that I think will highlight what I've said. So in one of my favourite survivor memoirs by Susanna Kason, she wrote that suicide is more complicated than wanting to die. It is about wanting to exile a part or parts of yourself, the parts of yourself that hold terrifying sensory fragments from the past and are stuck, unable to metabolise the rage, fear and collapse they bear, the parts of you that carry shame and the parts of you exhausted from carrying the shame, intense muscle and lockjaw.

I recently celebrated three years without a suicide attempt and this ten year personal best would not have been possible without the therapeutic relationships that have supported me to embrace these young traumatised parts of myself, parts that like many people I tried for decades to exile to unconsciousness through cutting, through starvation, through suicide. Attuned Relationships allowed me to greet these parts of myself gently and with curiosity so that I can find out what their needs are and learn to soothe them. It is through Attuned Relationships that I have been able to experiment with new ways of relating to myself as a safe reliable person I needed when I was younger. My recovery has been about learning to return to my body after having to vacate it for so many years, and about learning to be soothed so that I don't have to try and exile the parts of myself in need of soothing, and so they don't need to intrude upon me so dramatically and destructively, but I could only begin this recovery when I had stability and when I finally got trauma specific affordable psychotherapy, something we woefully lack in this country.

PROF KING: Thank you. Where did you eventually get the relevant trauma oriented psychodynamic therapy, how did that become available to you?

MS FRANKS: After the seventh suicide attempt I made it to the top of the triage for the peers, the Early Intervention Recovery Service for Youth out of Cumberland Hospital, and it was through that that I got onto a two year wait list for the fantastic Westmead psychotherapy program, which provided two years of twice a week conversational model therapies specifically designed for people with structural disassociation.

PROF KING: Thank you.

MS ABRAMSON: Thank you very much for coming today to speak with us, and it's obviously a courageous thing to do. So thank you for that. Following up a bit from Commissioner King I'm just interested - we have got a lot of recommendations around the school system and early intervention, and what would have made a difference at an early stage in the issues you had to deal with?

MS FRANKS: Sure. What would have been a difference would have been trauma literacy and a trauma informed school culture. Yes, I agree with the previous testimony that check lists and psychometric testing isn't always that fruitful, but I was often sent to a school counsellor as early - I was sent to the school counsellor in preschool because I was tearing my hair out at the age of 3, but when I was sent in primary school to the school counsellor for some kind of disturbing behaviour they almost always said, right, we're going to call your parents, there's something going on at home, which only exacerbated the violence at home.

PROF KING: Thanks for coming and being prepared to take us through that. I guess for us it's also good to hear someone who's managed to get through, well enough to sit and tell a story as well as you just did. I guess going back to the question I asked Dr Spielman is clearly the issue is - it's great that you got the treatment you did when you did, but you should have got something a lot earlier, in fact you should have got something a lot earlier. So coming back to the question about, do we screen every, you know, kindergarten teacher in Australia because they're the best to pick it up, or do we try and screen every 3 year old because they go to a GP for a check, and you could do that - it has to be a population level screen and so you're down to some standardised instrument which have all the criticisms that we know about trying to standardise it, and maybe you don't have the answer to this, but you were identified by somebody when you were very young as a young child that was in difficulties, and yet nothing seemed to have been done apart from tell your parents that you were a difficult child or something, which made no difference in your - - -

PROF WHITEFORD: Made it worse.

PROF KING: It made it worse. How could we intervene earlier, so maybe not at 3, but at 5 or 7 or before it became clear that you had a diagnosis and were referred to some sort of mental health - - -

MS FRANKS: Yes. I don't have the answer, but I know that there's a lot of great literature, especially from the United States about establishing whole of school trauma informed systems, and that's been experimented with to great effect in some places, and that is sort of more informal, the cultural version of just testing and screening everyone. The other thing I would say is that the marginalisation of trauma literacy in this country is there's kind of epistemic injustice against the survivors themselves, because when survivors get a bit of psycho education about the neurobiology of trauma, about attachment and things like that they are then able to - and I can only speak for myself, but I am thinking of all my closest friends that I all met in therapy or hospital - that, you know, I didn't start receiving the help I needed until the age of 24, but I had been fighting for it since I was 14, because from the very moment I learned a little bit about trauma suddenly I made sense and everything that I was experiencing and everything that I had been through wasn't delusional or irrational or crazy, it makes sense, I'm living with these adaptations.

So I think while the ultimate answer is prevention of the kinds of social injustices that create so much complex mental ill health, I think in the meantime becoming - if we became more trauma literate as a country, and I want to specify that we can't call everything trauma, we need to - we can't, you know, make it devoid of meaning, but we need to be specific about what we mean by trauma, but if we changed a conversation in the country from sort of awareness and medicalising very common experiences of distress then I think perhaps both teachers and the people with a duty of care to these young people, and the young people themselves, would be better able to advocate for what they need.

PROF WHITEFORD: Thank you very much.

PROF KING: Thank you very much. Perhaps if we take a break for lunch now. So 35 minutes or so and we will recommence at 1.20. So thank you.

LUNCHEON ADJOURNMENT

RESUMED

PROF KING: Let me restart after the luncheon break. Karen, if you could come down and state your name, any organisation you represent if you are representing one and any opening comments that you would like for the transcript - and I should have checked, transcript's ready? Streaming is ready? All right, thank you.

DR SPIELMAN: Thank you very much. I'd just like to acknowledge the traditional owners of the land on which we meet and acknowledge people here with lived experience, their families and carers and respected health professionals and service providers and thank you to the Commission for your work and for the opportunity to comment on it.

My name is Karen Spielman. I'm a GP and I have about 20 years' experience in normal general practice but I have a special interest in mental health in adolescents, in young people, and specifically I do a lot of work with people with chronic complex medical conditions and mental health issues including eating disorders and trauma. I've also established a general practice as headspace, Bondi Junction, in the last four to five years but I would like to stress that I'm here as an individual despite my associations with headspace and as well as being a member of the RACGP and an organisation called ASPM which is the Australian Society for Psychological Medicine.

I felt compelled to appear today as my every day work involves many of the issues which you raise in your report. I'm very grateful for your work in examining the limitations of the current system and your comprehensive attempts to explore the alternatives and I'm very aware that there's no easy answer to the very complex situations and conditions that we're dealing with. I wanted to speak as a frontline clinician rather than a manager or an administrator and I wanted to just restrict my comments to a few issues.

Regarding headspace I know that you've had other people from headspace, their appearances yesterday, and so I'll keep my comments brief but I have been aware of this concept since it was raised probably about 12 years ago and, as I've said, been involved in the establishment of my local centre at Bondi Junction. It's a wildly popular centre in a very well resourced area which shows that it's an acceptable and very well utilised service by young people and I think that the benefit of the headspace model is its excellent responsiveness to local community needs with its local consortium partnerships and the federally funded components making a very, very good partnership which leads to very specific local responses.

I understand that it's a very expensive model but I believe that it's accessing young people who would not otherwise be receiving good services because it's very acceptable and recognised by young people. I feel that the comments in your report with propose more conditions on the funding feels very frustrating and counterproductive to the delivery of very good services. The statistics show that young people love the service and certainly my experience at Bondi Junction supports that and we feel that they come back often and they get better and that this is an incredibly positive thing in this incredibly vulnerable age group and I feel that this service should be supported and enhanced.

I think that the stepped care model works very well there but I believe that we're seeing many more complex young people than the model has been set up for which is more early intervention and that that may go somewhere to explaining why the data isn't as impressive as it feels like it should be. We talk about the missing middle of young people with more complex chronic conditions and I think that the centre is not well enough resourced to deal with these young people. I do believe that GPs are very well placed to work in centres like headspace and that we're well placed to enhance the management of mental and physical wellbeing for young people and I have been working locally with the centre and with the national office to try and encourage better structures and support for GPs in headspace and it would be lovely to have that supported at a higher level as well.

Regarding GPs I believe that many very GPs are very well trained and well placed to management of health issues but at varied levels depending on their experience and their context. I do support GPs with specialist training and experience being recognised and resourced in order to assess, diagnose, refer and in appropriate cases deliver treatment and for GPs also to be co-located in other services to enhance the management of complexity in multidisciplinary settings such as headspace.

I'm very aware of the limitations of the system including mental health care plans and very varied accessibility of ongoing psychological and psychiatric support. I think there's a gap between the Better Access funded services which are quite limited and people who are more highly at risk that may need more intensive care. Especially care coordination there are gaps between providers, financial barriers as we've heard can be enormous and difficult to overcome, community mental health services can have quite limited referral criteria and as GPs that can be frustrating and difficult to access the plans and psychiatrists, as we've heard, can be very difficult to access, psychologists can be too expensive and the services like PHN provided services can also be very limited depending on the area and this is inner city Sydney so I can't imagine how difficult it is in regional and remote areas.

I think the issues that the current Medicare system does not support long appointments and this is extremely counterproductive for mental health. Short appointments, which are more remunerated, mean that thorough assessments cannot be done, treatment can be appropriate targeted and services are misused. I think one of the most important things I do is match my patient to the right therapist and that takes a lot of time and particularly with high risk conditions it's important to follow-up and to take a lot of time to listen and understand the patient before making appropriate recommendations for care. So, yes, part of that might be recognising GPs who are more able to do this and supporting GPs to coordinate and communicate with multidisciplinary teams.

And just briefly regarding mental health care plans which I think it was very exciting when they came in but it's been an interesting thing to watch. I do think that it should be reviewed and the system could be done better. I think the plans themselves could be improved and the number of sessions and the way that people make referrals could be done differently as well. It's very challenging to support more complex patients who require services with only ten sessions.

I know you've made some comments about combined care plants which I think is an interesting idea and something which could work towards supporting collaborative care. I'm also very aware of the new numbers for eating disorder management and I think that's a very good model. Again it would be very interesting to what how it goes and I'd be keen to see that happen and also to maybe consider if there was something similar that could be for either diagnoses and for more moderate or complex comorbidity. I think I'll leave it there for your comments, thank you.

PROF KING: Thank you. Let me start off and then I'll pass it over to my colleagues. I suspect we have similar issues or questions that we want to raise but let me start off with headspace and it's great to hear how well it's working in Bondi. But do you think that the headspace model is an appropriate model everywhere in Australia so in all locations or in all geographic locations, so I'll ask that first.

DR SPIELMAN: Yes, absolutely, because I think each location is quite unique and it's part of how it's structured that each location responds to the specific need of its community and that's a very, very big positive with the model. I have been involved in headspace national and I have been to national conferences and I have spoken to different centres and I've been an advocate for GPs within the centres and I always thought Bondi Junction was absolutely wonderful, magnificent, and when I turned up to the national conference last year there were about another 100 wonderful anaesthetist centres but they're all unique and they all respond to who's part of the consortium, what the particular needs are, what the community is made up of and I think it's a terrific model.

PROF KING: Yes, can I understand that a bit better because my understanding is that headspace is a franchise-type model so talking with the national office my understanding is is that they actually put constraints, very significant constraints, about what headspace can offer in different geographic locations but you're seeming to say the opposite which is that there's a whole lot of flexibility.

DR SPIELMAN: No, it's not the opposite, it works together so there's a - it's called hMIF, the headspace Model Integrity Framework, which gives constrains to the way services are delivered, the way assessments are done and the kinds of services and the kinds of people who make up the service but each centre is able to enhance or work that into the community so the brand is very recognisable to one people. Like, one of my favourite stories is a patient who drove passed the centre, saw the sign, pulled in, was actually suicidal, came in to see me and, you know, got through the front desk, got through the first assessment and we were able to provide an immediate service which down the track she was able to say it, hopefully, made a huge difference certainly in the time that I was part of her care. I thought that was a brilliant example and she wouldn't have done that if it was a hospital or general practice, it was the recognition of the brand.

PROF KING: If the brand.

DR SPIELMAN: So that's something that's very standardised.

PROF KING: So given the benefits that you've mentioned for headspace, it is funded in a very unusual way in that it is essentially central funded by the federal government formally through PHNs but PHNs have no discretion on whether or not they set up a headspace in their region.

DR SPIELMAN: Yes.

PROF KING: I mean, given the regional benefits and the flexibility that you've discussed, would we want a situation where we say, 'Look, every PHN if it wanted to have a headspace' but equally if they don't think a headspace is appropriate for their region they shouldn't be required to have one. Is that a reasonable approach or not because at the moment some PHNs are required to have them?

DR SPIELMAN: That's an interesting point. I've worked in general practice in inner city Sydney for about 20 years in a normal practice but I've worked in many different settings in my youth health expertise and so my journey has been trying to understand how young people best access primary care and there is no one size fits all so some of my patients at my practice will see me there, others wouldn't set foot in headspace but the ones at headspace wouldn't set foot in the normal general practice or they're seeing a different model of GP and getting a different kind of care which isn't meeting their needs at the time because it's not youth friendly practice so headspace facilitates youth friendly practice in a way that Medicare funded direct services do not and we're missing in general practice a very highly vulnerable cohort and particularly for young people the WHA talks about the second chance in the second decade and we've spoken about early intervention which is clearly the way to go and, you know, economically where you put your money but we do have a second chance for young people when different issues do come to the fore to have another go at - well, not early intervention but early intervention for the young people to - - -

PROF KING: Early in the course of illness, yes.

DR SPIELMAN: Yes. I can't imagine a situation where a community wouldn't want to (indistinct words) but I take your point.

PROF KING: Okay. Sorry, Julie.

PROF WHITEFORD: The GP mental health care plans, obviously they cannot cause some criticism in some respects that they're not serving the purpose they were designed to serve in some mental health cases so can you give us your comments about: (1) whether we should retain the plans?; (2) if we do, how should they be different to deal with some of the issues that have been raised and also, I guess, your view about what would work for you if you had to have a way of referring, you know, patients on to other providers?

DR SPIELMAN: Again I'd like to stress that I'm speaking as an individual for this. I think that there are many people who know when they need some help and I think that for some levels of care a referral like a mental health care plan is not necessary and either maybe a small number of sessions could be accessible by people without a referral for a normal GP referral just like we'd refer to a cardiologist or a gastroenterologist to prescribe a short course of treatment or a taster. I think that mental health care plans for - in the way that they're used largely in my experience and in my experience with my colleagues who are psychologists, they can be very well done but they're often not and the way that I've conceptualised doing the eating disorders care plans, I think it's just a little - it seems to work a little bit better. I mean, that's an area that I have a bit more experience that it kind of made it flow a little bit better in terms of making a diagnosis and using some other criteria and making an assessment and writing to the therapist and asking for coordinated care, I think that works well for maybe moderate conditions and I'm aware that it's not initially set up for moderate conditions but maybe having more sessions for more complex condition, more severe depression or anxiety or complicated presentations which require longer sessions would make it a more meaningful process rather than the earlier kind of stepped care.

PROF WHITEFORD: So the draft report does recommend an increase in normal sessions.

DR SPIELMAN: Yes.

PROF WHITEFORD: (Indistinct words) try and get rid of this issue of, you know, when (indistinct words.

DR SPIELMAN: Yes.

PROF WHITEFORD: When the session count starts and finishes.

DR SPIELMAN: Yes.

PROF WHITEFORD: So to paraphrase what they're saying: for some referrals (indistinct words) letter as exists for (indistinct) specialists could apply for individuals with more complex needs, a mental health care plan might be more appropriate.

DR SPIELMAN: Yes.

PROF WHITEFORD: Is that a - - -

DR SPIELMAN: I think so.

PROF WHITEFORD: Okay.

DR SPIELMAN: And as a GP if you know your patient and their family well then one of the best gifts that you can give them, one of the best interventions you can make, is to refer to a therapist that's a match. I often talk like it's matchmaking and I don't - that's a skill and then experience knowing who's around.

PROF WHITEFORD: And I guess the information that you put in that mental health care plan for individuals with more complex needs could be in a referral letter (indistinct words) send to the, you know, psychiatrist or neurologist.

DR SPIELMAN: Yes, yes.

PROF WHITEFORD: But whether creating a mental health care plan and a structure of it would be more useful for general practitioners who may have less of an interest in mental health than you do, would be inappropriate do you think, or?

DR SPIELMAN: I don't know.

PROF WHITEFORD: You don't know.

DR SPIELMAN: I don't know. I think it would require a lot of thought and input from people in different situations, yes.

PROF WHITEFORD: One more comment or question really. Do you refer to individuals (indistinct words) to online treatments?

DR SPIELMAN: Yes.

PROF WHITEFORD: And if you do, can you just walk us through how you'd choose that over, you know, a referral to a face to face psychologist?

DR SPIELMAN: I don't often choose it over referral to face to face psychologists. I'll often offer it in an initial assessment as something that can be accessed whilst we're working things out or whilst they're waiting for treatment. I think it's very useful as a tool. It doesn't have to be just people with early disorders who - or conditions that access it. I think it can be useful as many different parts of patient's experiences. There are some that are better than others and I know that there are people who put a lot of thought into how to collate that information and how to use that in general practice. So I think it can be used as an adjunct. I don't often get a lot of feedback from my patients about whether they found it useful. Things vary from time to time, people find different things useful. I don't think there's a one size fits all. I've been involved in some trials of some online therapy for young people and I'm not aware of the outcomes yet but I found it quite difficult, so.

PROF WHITEFORD: So you don't get any feedback from the online providers of the internet based therapies?

DR SPIELMAN: Occasionally. I mean, not a lot of - I mean, there's some that do do that but I haven't found that particularly - it hasn't happened all that often.

PROF WHITEFORD: Okay.

DR SPIELMAN: I'm not sure why, whether they're not using or whether (indistinct words) feedback.

PROF WHITEFORD: Yes, look, we are told that (indistinct words) information.

DR SPIELMAN: Yes.

PROF WHITEFORD: So I guess could explain (indistinct words).

DR SPIELMAN: Yes.

MS ABRAMSON: Could I just ask you about the mental health care plans. So in lots of other areas you provide a very detailed letter to the referring - to the specialist.

DR SPIELMAN: Yes.

MS ABRAMSON: So why would you prefer to write the mental health care plan whereas if something was going for, I don't know, advanced diabetes you might say to the endocrinologist just a bit of the clinical stuff and leave it to them to manage?

DR SPIELMAN: So why would you use a mental health care plan?

MS ABRAMSON: Yes.

DR SPIELMAN: Because that's mandated, because we have to. That's what we're told to you. We're told to fill in the boxes.

MS ABRAMSON: But if you had a choice would you prefer just to write a normal referring letter?

DR SPIELMAN: Yes.

MS ABRAMSON: Thank you.

DR SPIELMAN: And I'd like to be paid properly for my time. So that does access - you know, I can understand why it's used and - but, yes, absolutely.

MS ABRAMSON: Just on the online referrals that we were just talking about. Do you think that your clinical practice might change if you were able to get like evaluations that said for a certain (indistinct words) patients it was highly successful so it's really a question about outcomes and not actually seeing the data about the programs?

DR SPIELMAN: I'm fairly informed about that so I do know that they're supposed to be successful and I have a reasonable grasp of what kind of conditions respond to what sorts of things so I don't think - - -

MS ABRAMSON: That would change. No, thank you.

DR SPIELMAN: Thank you.

PROF KING: Thank you very much.

DR SPIELMAN: Thank you.

PROF WHITEFORD: Thank you very much.

DR SPIELMAN: No worries.

PROF KING: And how did I know my colleagues were going to follow-up on the mental health care plans.

MS ABRAMSON: (Indistinct words).

PROF KING: Carmel. Sorry, Peter, you're coming up as well. Thank you. If you could state your names, organisation that you are representing and any opening comments for the transcript.

MS TEBBUTT: Thank you. So my name is Carmel Tebbutt and I'm representing the Mental Health Coordinating Council of which I am CEO.

MR GIANFRANCESCO: And I'm Peter Gianfrancesco. I'm here as a board member of the HMCC but I'm also the state manager for Neami National which is a community managed organisation.

MS TEBBUTT: Thank you. So we do have some opening comments and then happy to answer questions. So I will broadly make the opening comments but Peter may chip in as we go through. So thank you for the opportunity to speak today. The Mental Health Coordinating Council is the peak body for community managed mental health organisations in New South Wales so we provide leadership, policy leadership (indistinct words) systemic change and we also build sector capacity through research. We're a registered training organisation so we provide support for our members in that way as well.

So what I wanted to do today was talk briefly about the community managed mental health sector, address three issues that we think are a priority that are covered in the report but we would like to talk about in a little bit more detail and that is the need for more subacute residential care, the CMO workforce and also the reforms relating to proposed roles and responsibilities or governance reforms.

We do want to commend the Productivity Commission for its very comprehensive report and also the consultative approach that's been taken to preparing the report. We put in a submission as did many other organisations and individuals for those who work on mental health the challenges are well known and I think there's a lot of hope and optimism that the Productivity Commission inquiry will underpin what has been described I guess as a once in a generation reform opportunity' so I think there's a lot of hope and expectation.

There's a lot in the draft report that we agreed with particularly to focus on putting consumers at the centre recognising the social determinants of mental health and documenting the significant economic costs of mental illness. We are also pleased to see that the report acknowledges that there are significant gaps in terms of community based services and the need to provided better support and services for people in the missing middle.

We would like to see a stronger focus in the report on the role of the community managed or non-government mental health organisations in addressing this gap in support for people through the provision of psychosocial rehabilitation and support services that embody a trauma informed recovery oriented practice approach and they're essentially the services that our members provide. So they're things like accommodation support and outreach employment, education and recreation opportunities, family and carer support, self-help and peer support, counselling and clinical care in rehabilitation services and also information in advocacy.

Now, we know that the draft report refers to the role of psychosocial supports but it generally sees them as complimenting community based clinical services and while they very much do do that, they are much more than this. They are standalone services, they play a vital role in supporting recovery for people with enduring mental health conditions, they work with people over the longer term addressing more than just symptoms and they are often the key to people living well in the community.

Now, I know that you're familiar with the New South Wales program, the Housing and Accommodation Support Initiative because it is referenced in the report but we do I guess point to that as a great example of what well-funded psychosocial support services can do so HASI supports more than 1000 people a year to live independently, there's a skilled workforce that supports people with things like shopping and budgeting, joining social activities, getting to appointments, but also providing much more intense support for people with complex and coexisting needs to things like supported decision-making, managing self-care, skill building capacity, so it's much more than just a drop in service that's helping people socially engage and Peter could certainly talk in more detail about that if you wanted more information because Neami are a major HASI provider in New South Wales.

Now, I'm sure you're familiar that the program has been evaluated and the University of New South Wales evaluation demonstrated that there are significant benefits for people who participate in the program including a 24 per cent reduction in mental health-related hospital admissions following HASI supports and a 51 per cent reduction in ED presentations following two years of participation and an estimated $30m in savings each year. Now, it is our view that while there's about 1000 people supported through the HASI program in New South Wales there are many more people who would benefit from such support and in fact we had KPMG do some work for us about 12 months ago and they estimate that there's probably about another 5000 people in New South Wales who would benefit from a HASI-type support - not necessarily full blown HASI but definitely those sorts of supports. So that's just an example I guess of some of the services that our members provide.

In turning to the three areas that I wanted to provide some specific comments on. First of all workforce: we can't develop/deliver the services that people need without the workforce to be able to competently and capably deliver those services so it's critical. We support the broad thrust of the workforce recommendations in the report particularly the need for a national mental health workforce strategy but it must address the needs of the community managed mental health sector workforce strategy but it must address the needs of the community managed mental health sector workforce and we don't believe that that's adequately covered in the report and I'm sure you've heard this from other submissions as well but in New South Wales this workforce is estimated to be a quarter of the total mental health workforce so it's a significant workforce.

It's a workforce that's well trained and experienced in delivering supports to people with complex needs in the community, employing both Certificate IV and degree qualified staff with experience in working in partnership with clinical services so we are concerned that in the report there's little mention of the psychosocial support workforce outside the peer workforce and we very much support the recommendations with regards to the peer workforce but the workforce of our members is much broader than peer workers.

We have just undertaken a survey of our members in New South Wales to get a better understanding of what the New South Wales community managed mental health sector workforce looks like. Now, we're finalising that report at the moment but we'd be very happy to share it with you because - - -

MS ABRAMSON: We're very interested (indistinct words).

MS TEBBUTT: Yes, nothing's been done since 2010. This report is New South Wales specific, that's who our membership are, but nonetheless it's got some very interesting data about how many people work in the sector, what the qualifications look like, (indistinct words) between male/female workforce. Just under 50 per cent of the workforce are casual or on short term contracts so we will share that with you as part of our submission when we put it in before the end of January.

So the second area that I wanted to briefly mention is the recommendation around the need for more sub-acute residential care or step up/step down facilities so this is recommendation - I think it's 7.1 in the report. This is a particularly important recommendation for New South Wales because unlike other States we only have a handful of step up/step down facilities in New South Wales. We know there's strong evidence that this model of care provides both good outcomes for individuals but also enables better management of acute bed pressure and reduces demand for hospital admissions.

The step up/step down facilities that do exist in New South Wales are somewhat different to other States because they've largely been I guess organically driven by relationships between non-government organisations and LHDs but we believe the ones that do exist have developed some very good outcomes and Peter could talk a bit more about that because Neami run a few of those so I might hand over to Peter to talk a bit about that.

MR GIANFRANCESCO: Thanks, Carmel. Yes, Neami operates the step up/step down or sub-acute model in four states and it's fair to say that the models vary quite a lot from place to place and state to state but there are some fundamental similarities that are I think really important for the consumer journey and that is that whilst they do provide a step down function for acute hospital beds which helps relieve the bed pressure and bed blocking over time most of them can demonstrate that the people using the service more typically step up and that's actually really important because that represents a way for a person to access comfortable, familiar support and treatment in a really early stage of their acute episode and our experience has certainly been that when we do that, when we make that easy for people, we have people getting treatment for acute mental illness much earlier on, they stay in the sub-acute for a much shorter period of time and generally they stay well for longer in between episodes and so these services should be seen as something more than just a way to manage bed pressure, they should be seen as a community based facility that really delivers early intervention in sort of acute treatment.

And I suppose the other point I would make is that there's some good evidence that shows that these types of services do reduce demand for inpatient admission, they do reduce people presenting at emergency department quite significantly and more importantly they are really helpful to people and they're very acceptable to people so people want to use them and a final point would be that if we look at the various models across the country they do represent a whole lot of ways in which the CMO sector can work with the clinical sector whether it's having embedded clinicians in the team, whether it's have embedded support workers in a clinical team or whether it's the CMO directly employing the clinical staff as is the case in some of our sites and they probably represent in my view best practice in terms of that clinical psychosocial collaboration. Thank you.

MS TEBBUTT: So to finish, the third area that we wanted to briefly touch on are the recommendations around governance, federal roles and responsibilities. We strongly support the recommendation for co-defining responsibilities through a national agreement, we agree that there's need for better data and public reporting on performance of the mental health service system. We strongly support the recommendation for five year contracts, that is something that would make an enormous difference for our members in terms of being able to plan services and deliver quality over the longer term. We're still consulting our members with regards to the Commission's recommendations about the renovate versus rebuild model so we will address that in our written submission.

We certainly support what the Commission is trying to achieve with that recommendation, the need to right incentives to ensure that the most effective care and support is delivered when and where someone needs it. I guess on first glance we do have some concern that the regional commissioning authorities would be challenging to establish and that accountability for who's responsible if they don't have the funds to deliver the services that a particular region needs would be difficult to address and also some concerns that in splitting off mental health service commissioning from the delivery of physical health services, that could impact on integrated care when someone actually is in hospital so they're some initial concerns but we definitely need something that drives the right incentives in the way services are funded.

With regards to the renovate model we did just want to put on the record I guess some comments about our current experiences with the current system with Primary Health Networks which is a relatively I guess new development in Australia so our members have worked very closely with the Primary Health Networks and developed good relations, no question about that. Many of our members are funded by Primary Health Networks through their commissioning of mental health services.

There are a couple of things that we would like to say that we think would help more effective working together or more effective collaborative relationships. Many community managed organisations have decades worth of service delivery and partnership experience that we feel Primary Health Networks could more effectively utilise than what they always do. Co- commissioning models work best where community managed organisations along with people with a lived experience, families and carers are involved in discussions upfront so that they can help identify the need, shape the response, develop the model and agree upon the outcome measures and we don't see that that happens as often as it should.

We also think that obviously one of the great strengths of the Primary Health Networks is that they can adapt what they do for their local community's needs but one of the downsides to that is there's a lack of consistency in the approaches they take to commissioning services so for community managed organisations that are working on a national level, they are often dealing with multiple Primary Health Networks, different KPIs, numerous outcome measures, different lengths of contracts, gaps between when contracts start and finish, overhead budget parameters that are different, so that has a real impact on organisations that are not necessarily funded to have those sort of compliance sense contract management staff so it would be good to find a way to get the benefits of regional service delivery and regional understanding but some consistency around some of that contracting so that there isn't this sort of duplication that impacts very much on our members. So we'll leave our comments there but happy to answer any questions.

PROF KING: Thank you very much. Let me kick it off. Peter, you were talking about the Neami facilities in the different states and really very interested in that role not just as the step down from hospital, which I think we probably emphasised in our report, but actually that step up role which has been pointed out to us by a couple of parties in the hearings so I'd like to understand a bit better about how an individual who recognises that their condition's deterioration, that they're likely to have a crisis or are in crisis, who do they actually access the facility? Can they self-refer, do they need to go through the clinician, how does it work to make sure that operates as that safety net?

MR GIANFRANCESCO: Yes, there's not one single answer to that unfortunately but if I give you an example of where I think it works really well would be in Broken Hill. So Broken Hill Sub-Acute Program is operated by Neami in partnership with the local health district and I guess it's a really good example of how the clinicians and the Neami staff work together to balance out it is of access so people can self-refer but everybody is subject to a shared assessment of need and priority so we don't do that in isolation from the clinicians who have been involved in supporting that person but typically time, and this is quite a mature step up/step down, it's been operating for nearly five years, you do always see quite a focus on step down at the start and in my opinion the better step up/step downs, and often they're the ones that are operated by the CMOs', you start to see a transition to more step up over time and that can really only happen if people can directly access and refer at that point in which they believe they need something.

So if someone was self-referring and the assessment was their needs would be better met by an inpatient admission then that can happen at that time as well and likewise for people being considered for admission to the psychiatric unit, those people self-referring or, you know, presenting on a voluntary basis can be diverted straight into the step up/step down.

PROF KING: Okay, thank you for that.

MS ABRAMSON: Thank you and welcome back to the Commission. One of the things that are very well aware that we needed to more in that community mental health area, we've understood that, but we need a little bit of help to do it so the information that you're able to give us about the workforce is really important. We had the same conversation with the Australian Services yesterday because when our staff looked from the outside it was very hard, we couldn't see a system, we could see individual types of organisations so some support there would be very helpful.

So one thing I did want to ask was at the moment in our diagram we've got the clinical supports (indistinct words) the clinical being the pathway to the psychosocial, that was not actually our intention. We understand with psychosocial supports you could have someone has a low intensity in a clinical sense but very high in psychosocial so we're interested in your thoughts and happy for you to take it in notice about what type of criteria you would have for that because if you have a clinical diagnosis then, you know, you can get into certain services, certain government programs, but clearly there a range of people who just want to access the psychosocial supports and you did just speak then about self-referral so we're interested in your thoughts on that.

MR GIANFRANCESCO: Yes, so perhaps HASI is an example of that and again it does vary a little from place to place. HASI is very much geared towards the more complex end so typically people using HASI but not exclusively are going to require treatment at the same time as a focus on those psychosocial goals but it is possible that sometimes people will be receiving their treatment independently of the public health system and those people can be supported in exactly the same way just with a different set of relationships with those treating providers.

There is always a bit of a pressure in terms of ensuring that the HASI service is focused on those people who have I guess the greatest impact from their psychosocial disability and their illness and there are a whole lot of other programs that I guess are slowly disappearing or have disappeared in terms of things like Partners in Recovery and PHaMS that were probably much better geared towards easy access really targeted focused help and then people being able to move out of that system relatively quickly and I think there's a real missing piece there in our system now.

MS ABRAMSON: We'd really welcome some more thought from you on that because we know it's an area that we need to do some more work with, thank you.

PROF WHITEFORD: The question comes back to us several times about the way we describe psychosocial support service (indistinct words) way it's discussed seems to be things to different people depending on what we're talking about. So one way we try and I guess understand this to see whether the original work that was done around some sort of taxonomy of services has been progressed, I know that AIHW coordinated some work on that some time ago but it seems to have gone into abeyance. Do you have a view about a way of sort of describing those components that are essential making sure we capture their - they're not missing from some, you know, community service delivery around Australia?

MS TEBBUTT: Yes, so with regards to the taxonomy while there may be some disagreement around the edges essentially it exists and people have agreed to it so it seems to me that it's sensible to work with that and certainly we use those 18 categories in our workforce survey and we got feedback about what's being provided in New South Wales. There were a number of organisations that identified other services that they provide that they didn't feel were covered by the taxonomy so when you see the report you'll see that but essentially actually if you look at those services they probably did fit into one of the taxonomy categories, it's just people perhaps didn't see it that way.

I think it would be very helpful for the Commission to recommend that all states and territories participate in the National minimum data set for non-government mental health organisations because at the moment there's only two states that are collecting that data and it makes it difficult to tell the national story about what the CMO sector are delivering if we don't have national data. Now, there's some I guess again weaknesses in what would be collected because it would be largely output data but at least it's a start and we are working with the New South Wales Minister of Health to implement the NGOE in New South Wales and I think that we are making progress and it probably will hopefully have that implemented next year but it definitely is something that needs to be done across all states and territories.

But, you know, the taxonomy is a bit kind of - when you read it it doesn't properly convey really I guess what psychosocial support services do so Peter could probably talk more eloquently about something that resonates rather than a list of 18 fairly dry categories so I don't know if you want more on that but we wouldn't want to move away from the taxonomy.

MS ABRAMSON: As I said before we need some more assistance with this.

MR GIANFRANCESCO: Yes, and that probably is the tricky thing to understand that it goes beyond the structure of services to the values and practice that operation within and around recovery and hope and meaningfulness and, you know, you could have a psychosocial support service that was doing a whole lot of things that might be helpful but may not be leading towards a more meaningful contributing secure life so it goes beyond the definition of the service to the principles on which it operates.

PROF WHITEFORD: So have you got a view about what the resistance has been about adopting that taxonomy across the sector because is it about the fact that it's a dry list of 18 categories which - well, what's behind - what do we need to do to overcome this?

MS TEBBUTT: Yes, I can only speak for New South Wales. I don't think - we have undertaken two projects now to consult our members about their willingness to implement the National minimum data set and there's a great deal of support amongst community managed organisations to implement that in New South Wales. Yes, there's a little bit of concern about the data burden that it might impose on organisations but they're already collecting enormous amounts of data for the various contracts that they have with different organisations so I don't think there's resistance now, there may have been in the past but I don't think there's resistance now on the part of non-government organisations to participate, I think it's more just about making sure that both the Ministry and the organisations prioritise that amongst the myriad of other things that need attention, time and effort and - - -

MR ROSEN: Sorry, can I just (indistinct words).

PROF KING: Sorry, it's just impossible to do comments from the floor but if you would be interested in waiting just for a few minutes.

MS TEBBUTT: Yes, Tully Rosen did do some of the initial work - - -

PROF KING: Yes, I'll get him to join down but after a few seconds.

MS TEBBUTT: Okay. So, yes, I think that really now it's more about prioritising how that's going to happen so now in WA and Queensland they have a portal that organisations can directly use to submit their data through their health departments then on to AIHW and so we would like to see something like that in New South Wales and I think it's more just the logistic results in issue, I don't think there's any actual objection to participating in it.

PROF WHITEFORD: No, well that's good to hear.

PROF KING: All right, thank you. Just a final one and this is to take on notice, obviously very keen to get that report you're putting together on the workforce and obviously in further submissions really keen to hear any suggestions you have for recommendations relating to the psychosocial workforce that we can put to government so thank you.

PROF WHITEFORD: Thank you.

PROF KING: Thank you for that. And my apologies, would you like to - because it's on transcript you have to come down here and formally sign in as it were so if you can state your name, organisation and just your comments.

MR ROSEN: (Indistinct words).

PROF KING: Sorry, it's just to make sure we don't miss - - -

MR ROSEN: (Indistinct words) the only reason I'm trying to come in.

PROF KING: Not a problem.

MR ROSEN: My name is Tully Rosen, I'm an ex-employer for Mental Health Coordinating Council (indistinct words) this project would have been about ten years ago. I just want to give two bits of context to help you (indistinct words).

PROF KING: Please, yes.

MR ROSEN: Now, the development of the National Mental Health Data Set (indistinct words) establishments, that was developed at the same time and then parallel with the National Service Planning Framework so it aligns up nearly perfectly and was designed to do that and was also designed to be able to, once that was established, breakdown into a client level data set and outcome level data set so all of that information is there in the reports but it is, you know, it's six to ten years old some of that.

The only other thing to know about the data set and the taxonomy is that that data set was initially based on the data systems of NGOs and not much has changed so it's definitely not the NGOs that are having any issue with that. What would happen every time that it would go to a national process, we'd have all the states together, it would be built up, the states realise they had to pay for it to get rolled out, it would disappear to really a lot of it came down to federal agreement that the states could never really get the resourcing to happen.

PROF KING: Okay. Sorry, just before you finish. Harvey, have you got - - -

PROF WHITEFORD: So if you just give us a little bit more history. So the NGOs were largely supportive of it.

MR ROSEN: Yes.

PROF WHITEFORD: (Indistinct words)?

MR ROSEN: The state and the federal data strategy and information strategy bureaucrats were fully supportive.

PROF WHITEFORD: Right.

MR ROSEN: It would just end up - even when the finances were earmarked usually in budgets at the state level to implement the data set it would never make it through and so generally what would happen is they'd sort of sign up to it and then at various committees they'd have to say, 'We'll do it when we can' and that is never good.

PROF WHITEFORD: So the fact that two states picked it up and the rest didn't were about, you know, the motivation to (indistinct words).

MR ROSEN: This is just my opinion and I know that you're heavily machinated and there was so much goodwill you wouldn't believe how all of the organisations, all the government agencies, that really there was no one trying to stand in the way there, it just didn't get through.

PROF WHITEFORD: So for a recommendation from the Commission, because obviously we're supportive of (indistinct words), then there's no barrier you can identify that should stop it from happening.

MR ROSEN: The only issue is the NDIS and likely the differing nature of the data requirements for the NDIS probably doesn't line up very well but again the taxonomy is mostly covering what the sector does plus extra - plus psychosocial plus the new sector.

PROF KING: Okay, thank you.

PROF WHITEFORD: Thank you.

PROF KING: And apologies for the formalities, it's just so that we make sure everything gets on transcript so thank you, Tully. Next Alicia Boyd.

MS BOYD: Sorry, can I just sit here.

PROF KING: Yes, sorry, if you could please sit and just give me a second. Thanks. And if you could state your name, if you are representing an organisation what the organisation is and any opening comments that you'd like to make.

MS BOYD: My name is Alicia Boyd. I am representing myself and my family's lived experience of mental health challenges and also acting as carers and representatives and advocates for someone with a severe mental health issue who's currently hospitalised (indistinct words) at the moment my sister, Nicola, and I guess my initial remarks are to thank you for taking the time to have these public hearings and to engage the public and interested organisations in contributing in this way and for carrying out the review which I feel is really crucial so thank you.

PROF KING: What particular issues have you, your family, found in the roles as carers, someone who you love who obviously has mental health issues, what's worked or hasn't worked I guess from your perspective?

MS BOYD: We've had some clinical psychiatrists and nursing staff and also psychosocial supports who have been really engaged in worPROF KINGollaboratively and really working with my mother, Ann Boyd, working with my sister, Nicola Boyd and she suffers from schizophrenia and she also has quite severe autism. I also struggle with these same two disorders but I'm in a very different place in terms of personal wellness and she sometimes isn't necessarily the best advocate for her in care.

So it's been a combination of having that patient centred approached but then also bringing in the family and her boyfriend and the other supports that allow the medical team or the care team or the psychosocial support team to understand perhaps the bigger picture of what's going on and what - because sometimes she'll misrepresent things or she'll be so unwell that she'll - like all she'll focus on is that the King of Jupiter is sending her love and she had to swim in the sea with her clothes on because he was going to take her to Jupiter and, you know, like it's really profoundly difficult but when she's well she's quite lucid so it's - but where we have teams of healthcare professionals who are not willing to take us on board in that process or want to be like really prescriptive in terms of her care, has to blah or, you know, which we found we encounter or people who don't want to engage in the other supports.

So we've had quite a few psychiatrists who haven't wanted to even enter into discussion around psychosocial support and community support or assist us in anyway with that and that's been really, really very difficult and we've had a couple of psychiatrists who have really tried to actively shove my mother, Ann Boyd, out of the process and really kind of wield a bit more control around what goes on with her and it's led to some pretty disastrous results like - - -

MS ABRAMSON: Ms Boyd, can I just stop you for one moment. I'm making an assumption that you're comfortable and informed to talk on your sister's behalf.

MS BOYD: Yes, yes.

MS ABRAMSON: Thank you. And you've been very good just refraining from naming people. I'm sorry to interrupt you but it's live streamed so I just want to make sure you're comfortable.

MS BOYD: Yes, definitely, yes. And I feel - yes, there's - I think that interdisciplinary approach that also brings in the patient and the family and the other key, you know, members of her personal life into the equation because we've had the experience - like, we're not professionals, we've had the experience of witnessing her various cycles of wellness and unwellness over the last 20 years and unfortunately she's in a very bad place at the moment and it's partly been the culmination of she was given a medication she was quite allergic to and it was known to the psychiatrist, it was on her medical records but we were blocked for a short period out of being engaged in that process and so that's led to a pretty bad reaction.

She was experimentally taken off antipsychotic drugs for a while against our wishes, because she really doesn't want to take them at all and doesn't have the awareness that she needs to take them, or that she becomes really unstable and unwell without them.

So it's partly - for us it's a difficulty navigating the fact that she's very unwell and doesn't often act in her own interests, and the fact that health professionals that we're dealing with aren't always acting in a collaborative way with us, and even sort of necessarily noting the medical record and basic things like that.

PROF KING: The issues that you've raised, you found other carers and consumers raising similar issues, and they are issues that we are trying to think how best to address. So when your sister is in a good place, when she's stable, do you think there would be a possibility there that say she could make a care order, or a more legal term would be a Power of Attorney, but I'm not the lawyer, my colleague is - advanced care directive - that sort of - having access to something like that where she could say, 'Look, next time I'm in a bad place I want you guys to be involved in the conversations. I want you to have rights with regards to my treatment. I am now lucid, I can make that decision, but I know down the track I am not going to be in the situation', would that sort of thing where it then becomes a requirement on the treating teams to bring you into the conversation, would that help?

MS BOYD: I think it would help tremendously if she wanted to, if my sister wanted to go down that track and that was her consensual choice, and I think it is important that it is something that she - - -

PROF KING: Chooses.

MS BOYD: - - - she has, you know, an independent choice over, definitely.

PROF KING: Okay. Anything on this particular bit, or just - okay. Can I ask you about - your experience is with mental health that is cyclical in nature, and one of the things that we've grappled with in our draft report, and we need to do more work on as we move towards the final report, is that we seem to keep hitting government programs and services and so on, but aren't cyclical. I mean the most obvious is things like Disability Support Pensions, other income supports which you're either on or you're off. Are you able to comment at all on - have you found that there is a lack of flexibility in health services or other services just recognising the fact that mental illness isn't just a constant, it's not like an amputee is an amputee - sorry, I'm not expressing myself very well, but - - -

MS BOYD: I think you've articulated yourself well. From my own lived experience I've had a lot of difficult at times of me accessing income support. I'm a professional conference organiser and I am often really quite capable and functional and producing some of the biggest events in Australia, but when I'm not - when I'm in a place where say my mental health has been affected by the scarcity of work in Australia it's a really kind of cyclical industry events. I've had a lot of trouble being able to access any kind of assistance, and I'm only really personally capable of getting the psychological support that I need and psychiatrist support that I need when I am earning well, because I have to pay for it out of my own pocket because - and I see a really good psychologist who's a transpersonal psychologist.

He's brilliant, he's really helped me over the last five years, and I'm starting to see a psychiatrist soon to see if maybe being on a mild antipsychotic might assist me to maintain wellness with my - particularly as an autistic person I'm very vulnerable to excessive bouts of stress. I kind of can collapse into a little bit of a mild psychotic state and I'm hopeful that that will help me to maintain my personal resilience.

I don't extend into these extreme states like my sister thankfully, but I think we've got the same, I guess, or a lot of the same kind of make-up, it's just more she's been through this semi-dysfunctional system in a different capacity to me. I've been able to make my own independent choices of who - where I'm getting the care, who I'm engaging with, whereas for her because she's been in this public system and she's been quite a lot more severe she hasn't had that freedom. So for me it's difficult, because at the times when I might really need the psychological aids the most I'm very often not able to pay for them.

PROF KING: Just one final one and then I will pass over to my colleagues. Can I ask you about stigma and discrimination, and if you face that and - have you got any thoughts about what we can recommend to government to try and reduce - preferably remove, but I'm not quite sure if we could ever remove the stigma and discrimination - but to at least reduce stigma and discrimination around mental health.

MS BOYD: I think that stigma is a (indistinct) social issue. It's a community awareness related issue. I think that it's something that most people would to some extent, and I'm ashamed to say I to a good extent hold around people with mental health disorders and it's something that I'm trying to work on personally in terms of my own mindfulness and my own personal growth around that and not using disabling language or derogatory language around mental health - you know, having a wellness focus towards myself when I'm well, you know, treating it as if it's a medical issue, which it is, and treating my autism as if it's a different neuro type at first, and when I'm compromised by it it's a bit of a disability, not treating, not pathologising myself about it, not down talking myself about it.

These stigmas I think are really prevalent in the community and they're very - it's difficult to navigate in the workplace. I find I tend to go better if I don't raise my autism in the workplace. I tend to have a much better go of it. I was experimentally trying to be quite open about my disability for a while there and it hasn't really worked for me. I've tended to function a lot better and be treated with a lot more equal respect when I don't, and when I'm - you know, when I'm quite well and functional I don't really need to raise it. That's been something that I've noticed I think.

To change that attitude - I've seen a lot of really brilliant community awareness campaigns around a lot of the work that's been done by Beyond Blue has been really reducing stigma, Black Dog Institute, like just in terms of that community scale, and I think people with autism speaking up around their lived experiences and showing that we're not all always, you know, completely socially incapable, incapable of holding up regular jobs, you know, there's a broad range of people on the autism spectrum who are leading really quite functional lives. I've seen a lot of power in the self-advocacy movement, like autism self-advocacy, people speaking out about their own lived experiences and supporting one another, and that has been, I think, a really powerful way of reducing the stigma around basically empowering us to seek for ourselves.

PROF KING: Thank you.

MS ABRAMSON: First of all could I thank you for coming today and for sharing your feelings with us. I wanted to ask you a bit more about the workplace, because clearly you have been working. But it's not just the attitudes of people in the workplace, we're thinking through some really practical things that - you know, what type of things would make a difference for you in a workplace? Was it flexibility of being able to work some days and not other days, what type of things?

MS BOYD: For me the main things that have really contributed to the workplace being functional for me have been really simple things like having a healthy workplace culture around bullying and things like that. I've had a few workplaces where bullying has been really rife and it's really set me off, you know. I have a very low capacity for that. But I've had brilliant workplaces where we've had a little bit of organisational bullying, but the management has taken a really strong approach about it and we've worked on resolution of issues. You know, kind of like all of those bullying guides that you have to work when you get inducted into a workplace say that you should do very few organisations actually follow. That's been the biggest thing for me.

In terms of reasonable expectations for work flow and what my workload is expected to be, like expecting me to push myself, but not crazily unrealistic, and sometimes in my industry that is the case.

MS ABRAMSON: So it would be quite difficult in any industry because it's peaks and troughs.

MS BOYD: It can be a peak and trough related thing, but in a lot of organisations they really manage their work flow quite effectively and they're very logical about it. So they're not stretching themselves beyond their capacity, not expecting people on a routine to work beyond the usual 9 to 5 unless there's, you know, you can add on potentially two or three hours in a week quite comfortably, but I've worked in some organisations where 60, 70 hours a week was expected, you know, and I'd have like a 6 am meeting in the morning and then I'd have a 10 pm meeting in the evening, and particularly as I'm going on in my career and I want to keep producing larger scale events and working on things like that I'm finding contract-based work has been really helpful allowing me to work on project milestones, so taking a bit of space back from having to like potentially even working, you know, an eighth of the time on these kind of larger scale shows. So I'm able to earn fairly well and still perform.

Kind of unfortunately, but I've been making peace with it, a bit recently working on events that are a bit below my career level, but are still, you know, regular earners for the organisations that I'm working for has been helpful in the short term, but I'm not wanting to rest on that forever, you know what I mean. So another thing I'm looking to do in the next two to three years starting my own organisation and producing my own events on a small scale to start with and then, you know, tracking on from there. But at the moment, yes, it's just been really mindful constraints. I think the issues from my personal experience, and I can only really speak from my own personal experience and I guess like the experiences I've seen shared by other people with autism the big thing for me is just really understanding the human constraints, really understanding that the things that are - I don't personally think that people with autism are necessarily that different from most people, we're just a little bit more sensitive to the things that might be dysfunctional for other people as well.

So I mean if anyone is going to be forced on a regular basis to work for a 70 hour week or deals with things like organisational bullying you might be a bit more resilient to work, but it's going to have some kind of negative psychological impact, these kinds of things. So I don't think, and I know from my personal experience, most of the things haven't been things that - I don't believe they're unique to people with autism, these kinds of workplace stresses, it's just more creating - - -

MS ABRAMSON: (Indistinct) impact on you.

MS BOYD: Yes. So I think creating like just more health workplaces would solve a lot of the issues.

MS ABRAMSON: Thank you for that. Can I ask you also, if you present for a physical health issue do you find that people immediately concentrate on your mental health issue, because we've had some evidence from people that they go to the doctor for a physical health issue but they're classified as a mental health patient and perhaps don't get the care they should get.

MS BOYD: I've definitely witness my sister experience this on a number of occasions. She has liver issues now because she had a suicide attempt earlier this year and she took a really large amount of Panadol and it's damaged her liver and she's had huge issues in the hospital she's in getting regular medical checks because they just don't - they don't regard the mental health ward in the same way in terms of their medical needs, and so she got sepsis two weeks ago, which was really upsetting. That's been resolved now and she seems to be in a good - have good bloods now, but that concerns me. For me personally I have a really good GP I've seen for the last 20 years and I'm very cautious about health professionals I see. So I don't personally have negative experiences around that myself, but I definitely witnessed that my sister has in a big way.

MS ABRAMSON: Thank you. Just one more question. Carer support, so that (indistinct) of carer help we're very keen for them to be able if they want to to participate in more employment. So if you have any views about what would assist somebody in a care role actually participating.

MS BOYD: Giving carers opportunities to participate in the employment in - - -

MS ABRAMSON: Yes.

MS BOYD: I personally would be really interested in helping with autism related advocacy and peer support work, and for me I guess I just don't really know how to go about it. I don't know what avenues are there. In my contractor's job two weeks ago now I ran a conference on suicide prevention and we had a lot of discussion of really brilliant peer support programs going and a lot of discussion around the skill shortages out there in terms of peer workers, and so I approached a couple of them following on from that to reach out about that, but I think there's just a bit of a lack of understanding maybe how to reach appropriate people with the lived experience or carers to bring them into that kind of work.

MS ABRAMSON: Thank you very much. Thanks a lot.

PROF KING: Thank you very much. Roger Gurr, and, Professor Gurr, if you could state your name, if you're representing an organisation the organisation and any introductory comments that you would like to make.

A/PROF GURR: So my name is Roger Gurr and I'm a psychiatrist. I am an associate professor with the University of Western Sydney and I'm representing my career long interest in funding methodology and governance with mental health. So four messages I wanted to actually get across to the Commission this afternoon. First of all I want to say I think you've written an excellent draft report, but I've got a few concerns.

So I start off with saying just a bit about my history though so you actually know where I come from. I actually started the first community-based mental health service in the city of Blacktown in the 1980s and Harvey wrote about that at one stage. I've also been an area director of mental health for six and a half years in Western Sydney covering 1.2 million population until I had to leave the job because it was diverting too much of the budget. I've been involved in the development and management of seven NGOs over the years, so I'm very aware of non-government areas. I've also done consulting and in 2008 I actually initiated the round table document on funding methodology and governance with PricewaterhouseCoopers and the AHHA, which I did send in and I think a lot of your ideas are very similar to what we actually wrote in that report.

At the moment also for 38 years I've had a foot in the private practice camps, I (indistinct) for the ground there part-time, and for the last four and a half years I've been a part-time clinical director of the headspace early psychosis program in Western Sydney. I have also as part of (indistinct) funding I've made sure I have been part of the two attempts to actually introduce activity-based funding for mental health back in 2000, 1998, 1999 and whatever it was the first one, and then also I'm an independent clinician on the mental health working group over the current attempt, and I made sure I got onto it because I have great concerns about activity-based funding for mental health, because basically the methodology is about actually assessing, you know, trying to find factors in which you could differentiate costs, but also then it's about actually costing what's done now and then actually applying that as a way of saying, well should we actually be shrinking the funding, et cetera.

The trouble is that none of the services around Australia actually have quality models of care any sort of evidence-based, and so if you're going to apply that methodology you are going to be costing services that are totally underfunded and not actually doing the job effectively, and therefore you start (indistinct) from there and it's just a slippery slope to the bottom. So please don't support activity-based funding, there are much better ways through the contract in my view.

Also I am very much in favour of the rebuild model and certainly an advocate for commissions over the years and been involved in the establishment of the Western Australian Commission as well as worked for the New South Wales Commission. So I just wanted to tweak what you've put in there and to say I think a National Mental Health Commission not only needs to be a statutory body at arm's length from government, but much more than just a regulatory body. We really need a body like that to be the knowledge management organisation, the one that can actually consult with everybody, keep up with the evidence-base, make sure the proposals are prepared for government for which a lot of sector consensus around what should happen; it is evidence-based. (Indistinct) government's (indistinct) between what's proposed and what they actually then fund, but it does mean that there's more likely to be sensible ideas coming. So I'm very frustrated with the Public Service Westminster system in that you have public service at the (indistinct) level that are forever rotating, so they're always content free.

The state system has a few public servants but they keep cutting back on the number of people giving advice to the ministry, and really people make proposals to government from within the Public Service, but it's a real secret until the minister actually announces it. Once the minister has announced it you can't change it because the minister has announced it, and as a manager of services the number of times I then had programs presented to me to actually implement, which have no real basis with managerial process, et cetera, as six and a half years as an area director of mental health I was never once actually asked what did I think my area actually needed and what did I think the government should actually be funding. Basically it's all secrecy, and I really think that's why you need a National Mental Health Commission that can actually do things in public without the same political implications that a ministry actually has in protecting its minister.

The other thing is that also I just think the National Mental Health Commission needs to have considerable funding, because I think that the fund holder actually then has a lot of power over what actually happens, and particularly what's missing in Australia is commission research. So the current research bodies are not an easy way of getting the sort of research that I think needs to happen in terms of developing better services. We've got this thing where the universities have produced lots of papers in a short period of time and they don't tend to want to do long term perspective studies where you have to incorporate a lot of treatment activity. So a funding body won't pay for the treatment activity - sorry, the research bodies won't pay for that. So I think there are a lot of really big issues we need to be addressing and it really requires commission research.

Harvey has a role in this, but certainly the National Mental Health Service planning framework really shouldn't be transparent and available for criticism and improvement and be managed by the National Mental Health Commission, because I was working for the New South Wales Commission in 2013 when the Beta - first ever (indistinct) came out. I was allowed to read all the background papers, so I know exactly what's sort of in that initial proposal, but I was never allowed of course to actually play with the spreadsheet, and the fact that now millions of dollars have been spent on this and it's really taxpayers money, it's our money that's being spent and it should be - I tried to get it under freedom of information twice, and then finally got told it was going to be released the following year.

Well, it got released to a holding spot where you have to either be an employee I think of LHD or a PHM or a ministry and basically sign a secrecy agreement I would think to say you cannot reveal what you actually found there, and yet this again is a really key bit of information, because it was an attempt to provide a reasonably evidence-based reasonable set level of service provision across the country and the problem that happened in 2013 was once they ran the spreadsheet there was sticker shock when they discovered you'd have to spend at least two and a half billion dollars more to actually reach a reasonable level of service provision. So I know Harvey's used it in the report as well, but I just think it really - the Commission really should push that it's actually made public and not be a secret.

The other thing that I really want to talk about though, and I have a passion for this, and that is that I've come to realise that developmental trauma is arguably the greatest public health issue we face, causing most personal, family, social and economic pain and it needs to be explicitly addressed now we know how to treat it more effectively. So there's a load of evidence out there about the huge cost to society of trauma, and the trouble is we have services that say they provide trauma reform care, but that's not the same thing as actually treating the trauma.

What we know is that the trauma in childhood, adverse experiences in childhood actually change the brain. The brain is plastic and actually there are evolutionary protective mechanisms come into play which structurally change the brain to actually enable a child to survive in a toxic environment until they reach puberty. You can actually measure those changes in the brain through imaging. But once you get to puberty your evolutionary behavioural programming comes into play that says no longer are you a dependent child, now you have to be an adult, you have to compete with your peers in order to find the best mate, find the resources to raise the next generation.

A lot of those protective mechanisms then become problematic, and that's why primary care headspace sites, because I happen to sit across three of those as well, and I see from their intake meetings the young people walking through the door with obvious developmental trauma issues, and it's tragic because the headspace model does not actually have the means to look after them. They have not even got the means to fully properly diagnose what's going on because there are no psychiatrists attached; hard to get the GPs. You're relying on often very junior clinicians who on the job they get trained as their first job to do the triaging and assessment, and then you rely on some private practitioners to provide the treatment, and in areas like Mount Druitt you're lucky if you can get one or two private practitioners to be altruistic enough to actually come out there and actually see people, because there were high no show rates and cancellation rates, and it was just not economic for them.

So what we really need to do is to have an inactive program to pick it up, those people in that 12 to 25 age group and actually treat the trauma. Three-quarters of the people actually achieve suicide, people with severe and significant developmental trauma, and it's at least 17 per cent of the population that actually have significant trauma. So this is not - this is a huge number. What happens is my professions ignored it as psychiatrist, and most of the other professions have ignored it as well, and why; because they don't want to ask about trauma, because if you ask you'd have to know what you're going to do about it, and most of them have no idea what to do about it. So the client picks up the fact that their therapist is afraid and their body language shows they don't really want to hear about it, so they shut up and they don't actually tell you, and there's evidence in the literature that the people really want to tell you about their trauma right at the beginning if they can, if they feel safe and they can trust that there is actually a welcoming service which will do something about their trauma.

The thing is too that a lot of psychologists really only get trained in CBT. Now, that may work for certain sorts of trauma, but we're talking about a whole range of traumas from neglect, from emotional abuses and major trauma that's hardly researched, rather than just physical abuse and sexual assault and so on, and if you've been emotionally abused all your life exposure therapy is just not going to work. Is the therapist going to behave like an abusing parent in order to expose? No, I don't think so.

I have chaired the board of the Torture & Trauma Service in New South Wales called STARTTS for 30 years and we've been developing programs for treating every sort of trauma and we say 7,000 to 8,000 refugees a year with every type of trauma. What they have found working on a hierarchy of care model is that there's at least 15 per cent of that population who do not get better with any standard treatment, they only get better once they have neuro feedback, and now there are controlled studies for people with chronic PTSD with a whole range of other conditions, including chronic psychosis where neuro feedback is the technique that is really enabling people to become fully functional again. It's about changing the brain network activity, and the brain finds its own solutions for operant conditioning. There is 20 years of evidence. You can see it all in the American Centres for Disease Control, and also I think I put a paper into the Commission in general about trauma.

So I just think it always - it makes me emotional when I see these young people, and I think it would be very said if this important Commission and board ignores the massive development trauma issues and does not provide (indistinct) a comment and recommendations to rapidly progress our knowledge and delivery of effective treatments, and that will need Commission (indistinct). Thank you.

PROF KING: Thank you, Professor. Can I start off - and thank you also for the paper that you did provide to the Commission, because I can remember reading that on developmental trauma and I found it very useful. So I'd like to start on that, but I'd like to start recognising we're not clinicians, there's treatment there and we need to make sure that for that group, particularly in that 12 to 25 year age range that they can get access to the treatment, the appropriate treatment for their particular form of trauma.

But that still raises an issue that came up earlier this morning that I'd like to get your thoughts on. Often, the trauma is evidence in the behaviour of the child much earlier on and we heard some lived experience examples this morning of exactly that. Where the trauma is potentially related to the family situation, how – and sorry, I'll just finish off the question by saying – and we also heard this morning from – and it was a reaction that occurred after our draft report came out is, well, you know testing children, evaluating children at that – oh, you're just going to put them on medications and that's a bad thing, and so on.

Do you have any thoughts about how we deal with that issue of even earlier intervention so that they don't actually get to the point where they need the trauma therapy?

A/PROF GURR: Exactly. Well, I mean, to me there are four phases we should be addressing. We should be addressing – and I used to do this at Blacktown Hospital - you'd see the woman in the maternity ward and you'd use the, I think it was the Edinburgh Questionnaire and you could just tell who was actually going to have difficulties in raising their children.

And the problem was, yes we have programs to send around a nice nurse, you know, a motherly figure and so on, which helped to some extent but still not actually treating the trauma. So you've got trauma passing from generation to generation. And so we really need programs that address it. I think with a 12 to 25 year old, I'm really aiming to say we want to actually address before people get pregnant.

It's really about how do we help people to actually become more settled and make better choices about their mate and actually reduce things like self-medication of drugs.

So then you've got the early childhood period, and yes, you know, a lot of the trauma happens immediately from birth or even before birth. And so that needs to be picked up when the child needs – needs need to be addressed there and then, too.

The New Zealand Dunedin study did a study following 1037 consecutive births in Dunedin Hospital. They started with a thorough assessment of children at the age of 3. They found four factors that actually explained the 80 per cent use of resources by the age of 38 by data matching in New Zealand. And the four factors were low intelligence, evidence of childhood behavioural disturbance, low socio-economic status and evidence of maltreatment. And predict 81 per cent of gaol convictions, you know. Sixty-six per cent of insurance claims because it actually affects physical health as well.

The torture and trauma, STARTTS has actually gone working into earlier and earlier and earlier into childhood because they actually find as well that some of their TPs actually work with quite young children. And so not only you have to turnaround a child soldier, you know, who's got to sit in the classroom and concentrate and learn English and whatever, they can't do it - after neuro-feedback, they can. Well, young children can actually also participate in neuro-feedback. And this is more targeted than neuro-feedbacks also used for ADHD, but it's a bit – a bit uncertain there about how good that is, because there are five different sorts of ADHD and they don't always get picked.

So I'm saying yes, we need special services for maternity and perinatal, we need special services for early childhood and we need special services for those in adolescent years because you may have missed people with our lack of attempt to, you know, screen properly our population and the various important stages.

But you also have all those legacy people then left after the age of 25, because PTSD and these trauma effects can last until death because medication does not cure it. Okay, so anyone just giving medication for it, all they're doing is tinkering with the edges and I'm saying substantive treatments like CBT often don't help.

When your brain has to react to threat and for trauma, language parts of the brain are not necessary. So the language parts of the brain don't light up and you don't lay down language memories and so you also can't talk about it in a language sense, your language therapy very well. And as soon as you're anxious and are talking in a therapy session, that also doesn't work very well. So neuroscience is really getting to the point now where we can actually see what's going on and we can actually address it.

PROF KING: Okay. Thank you.

WHITFORD AC: Roger, how are you?

PROFESSOR GURR: I'm good. Yes.

WHITFORD AC: Roger's been around a long time now, experienced a lot of assemblies. Sorry, just to come back to your question, your point about activity-based funding. So there are obviously issues that you've raised and you know well about activity-based funding and its ability to providing – as I get it, there's two issues that you raised.

One is costing classification based on existing services being forced on existing services which, you know, are often insufficient. Secondly, the ability for the characteristics of what we collect to predict the cost and that's then a challenge with DIG's for example.

A/PROF GURR: Yes.

WHITFORD AC: However, we are concerned about the need to drive efficiency in community-based services, so do you have comments you could make as to how we could deal with that in the absence of a DIG-based - - -

A/PROF GURR: Well, we've got a real conflict here because the sufficiency to get who knows where or there's efficiency around actually having something that works and you get the outcome you really want and that's what I'm concerned about is that I really passionately believe we have to be funding things for which there's a clear evidence base. And even if it requires high levels of investment up front, it is actually producing the goods down the track. That's what's important.

And the State systems are basically in New South Wales, the money just gets diverted. So when I was the area director, $15m, I put my finger on it was actually being diverted out of community-based services. So the clinicians there cannot provide good practice. The recovery services died, et cetera.

So I think it's – with activity-based, it's a question of how do you incorporate with inter – with inter-contracted services because I think it's contracts and fidelity tools and so on that enable you to best control what actually happens. Because then at least you may be recording and acquiring good evidence of the outcome and you're actually, you know, expecting people to actually stick to the models, stick to the evidence, because as soon as you go beyond any specialised thing and you start merging or changing things around, the focus gets lost.

I can tell you from the four and a-half years I've had with the Early Psychosis Program, it has taken us several years to really get into the groove of what it is we have to do and how we have to go about it. The big problem also with adolescent services though is the reluctance and the ambivalence about being labelled and being mentally ill and so the no-show rate is about nine – I think it's about 12 per cent and the cancellation at the last minute rate is about 27 per cent and those things don't appear in your, you know, data system. And yet, it makes it look like it's obviously not very - it's not very efficient. But in fact, the staff are very actively chasing and trying to engage work with the young people.

So I think it's – you've got to know the detail. I've been through so many accreditation processes, again in the State system to know they do nothing. I've never seen the benefit come out of a standard accreditation process. So that's why I've become reconvinced that we have to get out of the State system and we have to have commissioning and it has to be a very knowledgeable commissioning so that's the problem with PHN's. They're scrambling to try and get their knowledge base together but in fact with 31, there's just not that expertise available. And that's why I think the National Commission needs to have that role.

WHITFORD AC: So just building on that, again. One of the issues that's been put to us is that rather than trying to build the system around what is now. Build a system around what we should have so that service paying framework (indistinct) and we would agree that being made transparent to the public and being able to do advised improvement is clearly what should be happening. What's your view about trying to build a classification around, say, with something like the service paying framework would recommend for an area given it's – I guess you're going to recommend increased resources in most places.

A/PROF GURR: Yes, well, I mean, I think that's an involved – it almost has to be seen as an evolution, which is why I'm saying it should be transparent and improvable so people like me should be able to come along with an idea and say, 'Look, now I've got the evidence. I've pulled this together. Here's something that I think is worth a bet.' Because again, often with emerging things there isn't enough evidence already and so I get that criticism and I talk about neuro-feedback. There will – and they'll say well, where's the evidence, where's the evidence?

Well, there is not – there is evidence but not enough evidence, but we won't get the evidence unless we actually not only commission a search, but also create a treatment environment, and I sent along a proposal of the other I think saying it needs to be a model with a hierarchy of care model just like with psychosis, just like the (indistinct) and trauma service has where you do the simplest things with people, but then you actually have the opportunity as they need more intense or more different sorts of therapy, you can provide it because for example with trauma and with psychosis, it's not just the pills and the psychotic symptoms, it's absolutely about resocialisation. It's about recovery; it's about making sure you finish your education, get your job and actually are able to compete in the (indistinct) market place for (indistinct).

PROF KING: Thank you. Ione Lewis. And, again, if you could state your name, if you're representing an organisation, your organisation, and any opening comments that you'd like to make for the transcript.

DR LEWIS: My name is Dr Ione Lewis and I represent Grief Journey which is a not for profit providing services for people freed by suicide. So the focus is, you know, at the stage that mental health services or health services have failed or weren't even sought by the person who has suicided and so that's a very complex field to provide services in.

So Grief Journey started out of lived experience or the people involved in Grief Journey have lived experience or suicide and, you know, are fairly critical of the services that they receive, so it's quite a different focus. But I have really appreciated all the presentations I've heard today and the care and effort that, you know, is going into services like headspace.

There's also other strengths-based, lived experience services that are springing up all over the country really and the gaps that there are in services for suicide grief people and our interest overlaps with your interest, but it isn't just mental health. It's like a vendiagram.

PROF KING: Yes.

DR LEWIS: Suicide and suicide bereavement are much larger than mental health and I actually think the focus on mental health and suicide doesn't really help prevent suicide because they're so complex and there are so many factors that lie outside of mental health.

So it's clear that during emotional distress that arises from suicide and that that probably lasts for the people closest to the person who died for the rest of their life but, you know, obviously varying intensities, and I think a recovery model is really important, that it is really possible to live a life that, you know, has quality and is satisfying. You know, from very early on, I don't think that's the message that we often receive. It's often a very hopeless message.

So the need for suicide, for people to receive effective help, support and information is not being appropriately met and in one Australia study by Wilson and Clark, they found half of the participants who identified a need for help actually received it and over half of those didn't find that satisfactory. So, you know, it's kind of an area that more needs to be done.

I guess I've got five concerns that I'd like to put to you on behalf of Grief Journey and that's, first of all, dedicated suicide bereavement services often exclude people who are newly bereaved by suicide from accessing ongoing support groups because they're too distressed without offering services.

But if you look at services for victims of violent crime, that is not at all the case. There is, you know, great care taken to offer support to people, you know, in their early crisis stage. So two very similar experiences, homicide bereavement, suicide bereavement, very different response and se can't help feeling that stigma and discrimination have a lot to do with that; those stigmas around suicide.

And professional practices in suicide bereavement are exclusionary and unwelcoming. For example being required to attend face to face screening interviews prior to being admitted to a support group, even when that involves travel, and also delivery of support groups inside business hours and this dominant model of groups is also discriminatory and unhelpful because people naturally need individual support.

Indeed, if somebody is very distressed, it's a very good idea to offer them individual grief therapy and I think there's quite a, you know, lack of tolerance for intense grief in, you know, our cultures as well. In Australia where it's not really acceptable to be expressing grief, so even at funerals people can told they've been very dignified; that means they didn't cry. You know, they've definitely got that focus about grief.

And I think it's really important that people with just as mental health consumer movement which is so inspiring that people with lived experience of suicide and experience in supporting people bereaved on a suicide should be consulted and there really is that need for very early support by people who are further along in their grieving than the acutely bereaved person. I think that's very useful and just in my community I've done things like had walks with people.

I'm a very experienced therapist, 35 years of experience, and I'm an experienced academic, 25 years of experience, but I simply can't go past a walk saying, 'You've already lived through your worst day. You can survive this and life can be good again, but it will be different; a different life,' and I think that's very helpful.

I think also we shouldn't just think about therapy services. I think you need to think about - you often need mediation services. There's a lot of conflict about funerals; access to ashes, wills, a lack of wills, so we need things like mediation services. People are packing up houses, they need support with that. They might not be able to live in the house and they might need support to live elsewhere because the suicide happened in the home. People need assistance to visit the place. There's a lot of sacred places for people around the country when you look at the number of suicides each year. Now, there needs to be visits to those places and (indistinct) realising and that is very helpful for people's recovery process.

There's a need for advocacy, financial support. If you think of somebody newly bereaved on Newstart, they're just going to get breached. You know, they're not going to be able to make those responsibilities and actually a grief benefit was removed from Centrelink. So, you know, we have this huge area of unmet need. There'd be impact on people's work lives, inquest years later where people need leave and support. So there's this ongoing process that is inadequately resourced, except by people bereaved by suicide doing it for each other.

And also, obviously services need to be tailored to the cultural needs of local communities. So if you look at what's happening in the Kimberleys, you know, obviously the way that is responded to is very different and I have done training in working with suicide bereavement in WA at his year in four communities, but we're very concerned about, you know, rolling kind of deaths where one triggers another.

And I also would like to comment that we've got a popular model of combining suicide prevention and suicide bereavement services in one service. For example suicide call back service, and they say that they provide services to suicide effected people. But really, there's quite a paradigm clash there between what you need for somebody who is suicidal, as you would all know, and what you need for somebody like me on the other side. It's not the same skillset, it's not the same philosophy. But you know, somebody suicide bereaved, needs to accept that the suicide happened, but with someone suicidal – somebody who is suicidal, we don't' want to accept that they're going to suicide, we want to actually give them the message their life is precious, and we want to prevent that death.

So, there's very different models, there's very different philosophies, very different professional skills needed to work with suicidal people and suicide bereaved people. And also people bereaved by suicide are often very aware of the lack of services for the person who died, and they frankly don't want to take up the time in a crisis service. Why would we want to do that? The suicide rate is not going down, you know? It's a continuing crisis, especially for 15- to 24-year-olds.

Health professionals are not adequately trained in grief. I speak as a social worker and a psychotherapist who did the training that Scarlett referred to this morning, the west – out of the Westmead program. Trauma was a big part of that, but grief was not, and if you look at the accreditation standards for the different professions, grief, you know, doesn't play a big part in those accreditation standards a lot of the time. And this, you know, this certainly is interested in training. I think people – there was really a huge attendance, recently, at the mental health professional online training. I think there was 1,600 people attending that, so there is a lot of interest, but you know, that also isn't very in depth, it didn't give you skills for how you would actually work with somebody who's suicidal, let alone the post-(indistinct) part of the presentation.

Also, I think it's really important that service models are not the dominant model in mental health delivery, which is cognitive-behavioural therapy. It should be based on attachment theory. That could be any model, narrative therapy, Michael White wrote a beautiful article about saying hello to grief. You know, lots of counselling and psychotherapy models have the understanding of normal grief. Newly bereaved people have received very inappropriate psychological treatment, that conflates normal grieving with negative cognitions, which is not a negative cognitions.

And so it made a number of recommendations for what could happen short term and medium term and long term in my submission, and just a chance for any questions that you have. Obviously, I'm very passionate about - - -

PROF KING: Thank you. So I guess, where do you see the funding for suicide bereavement services fitting, I guess, within the model? Because whilst, as you say, not everyone who suicides is mentally – has mental illness, not everyone with mental illness has suicidal ideation, and so – and now we're moving a step further. We're saying, well, people who are grieving a loss, due to suicide. So I'm sort of thinking, well, where does that fit? Does that come under, in a sense, our enquiry? Is it a mental health service, or is it - - -

DR LEWIS: Yes, I think that's a good question. Or, you mentioned suicide quite a few times in your report, so the outcome of suicide should be considered, I think, by your enquiry, by the recommendations shouldn't fit within mental health services, and I think the senate enquiry into suicide, in 2010, I was an expert witness for the senate enquiry, on behalf of my peak body, and you know, that said there should be a national strategy for people who are suicide bereaved, and that still hasn't happened. You've got this ad hoc funding, or I've got this little service here in Victoria, so let's fund that. And you end up with someone based in Wagna, who I met recently, providing crisis support to suicidal people, NDIS, advocacy and suicide bereavement for nearly the whole of New South Wales rural areas.

So, you know, we need to think about where this funding should sit; Department of Health, or, you know? We need to think about that, but there hasn't really been any discussion since the senate enquiry on a national level about suicide bereavement.

PROF KING: Okay. Perhaps, follow that up, and apologies if this comes across as slightly ignorant, because suicide bereavement is not something that I've looked at or thought, really, of strongly, before, but of course bereavement, more generally, particular – you know, so, for example, you know what people who have been in long term relationships, and one partner dies, that that quite often leads to mental ill health. Is suicide bereavement significantly different from more general mental ill health, or issues that are raised from bereavement? So, is it – I understand the different – yes?

DR LEWIS: I think the issues that are raised are different, because there are police involved. They seize things, that's the language, they've seized things in the home. There could be a coronial inquiry, there could be an inquest, there could be issues about insurance, because the person died by suicide. So I think the – the experiences that come after a suicide death are very different, but grief – there's very similar grief experiences, however the person died. Of course, there's thing in common, but you're dealing with really unique challenged, just like telling, breaking the news to people. It's actually the suicide bereaved person breaking the news to people, actually holding a committee of people, sometimes young people, going through their first loss.

So, you know, there's one of heroes, really, doing that. They do a lot of caring and holding, you know, while they're acutely bereaved. People cry, when they talk to them. They often end up just like homicide bereavement, looking after the person that they've told. Yeah, I think it – I think there's different legal implications, but, you know, there's things that are in common as well.

PROF KING: Thank you.

MS ABRAMSON: Could I just ask, and thank you for coming today, what the best gateways into such services? Because family would know immediately, be connected with mental health issues, because you might be the first time that they knew that there was a problem.

DR LEWIS: That's true, yeah. Well, GPs would be, but I think people go online. So, there's a little group in Bunbury, WA, that has an online group on Facebook that's a closed group, and they also meat, and they provide things like childcare, which often don't think about in planning a service. And there's very complex, you know, supports that they're providing. There's an online group that has over 60 members now on Facebook, a closed group called Australian Suicide Loss Supporting Each Other, so people go on Facebook or Google and find the services that are out there. I think they're very comfortable with a peer model, because it's not judgmental, it's not been provided by a health service that perhaps let them down.

MS ABRAMSON: Also, wouldn't there be – I mean, we've had this in other areas, a danger with people accessing services on the internet without (indistinct), because I'd imagine that there will be some things that people see that will not be helpful. So is it something that you see as a kind of process?

DR LEWIS: Well, no, because I'll tell you why I think that. I think people are acutely disempowered by suicide; they've lost control over their life, and I think that they need to find the service that's best for them, and I also think, like a lot of the health service pamphlets, are quite hopeless, and they, you know, talk about outdated theories like stage theories of grief. You know, there's some very poor quality to the services, and the people will be having contact with the coroner's office, but they might find that a very difficult experience and need support with that as well. So yes, the coroner's office would be a central place that everybody is having contact with, all around the country, but not necessarily a therapeutic experience.

MS ABRAMSON: I had understood, and I might have this wrong, but a number of the coroner's reports have put a lot of effort into the support that they will provide to families, but of course not every suicide is going to result in an open coroner's inquest.

DR LEWIS: That's right, yes. Well have you ever seen a valuation of a coroner service?

MS ABRAMSON: I haven't, but I have been involved with the coronial service in unfortunate circumstances.

DR LEWIS: Yes. So I think there isn't a lot of research on how families experience coroners courts and social workers in coroners courts, and I think they vary vastly across state and territory lines in what they – even what they see as their role, actually.

MS ABRAMSON: No, I've certainly seen that as a practicing lawyer, which has been my experience (indistinct).

DR LEWIS: Yes, yes, yes.

MS ABRAMSON: (Indistinct.)

PROF KING: Thank you very much. Let's break now for afternoon tea, and resume at 3.40.

SHORT ADJOURNMENT

RESUMED

PROF KING: So excuse me. Let me restart after afternoon tea, and apologies for getting called out just then. Gita, if you would be happy to say your name for the transcript, any organisation you're representing, if you're representing an organisation, and any opening comments that you'd like to make.

MS IRWIN: My name is Gita Irwin. I have been a carer for my mother, who suffers chronic depression and low functioning bipolar disorder for over two decades. I don't have an affiliation with any particular organisation, but I have done stuff with Carers NSW, et cetera.

PROF KING: Yes, and if there are any opening comments you'd like to make.

MS IRWIN: I've been looking after my mum for two decades, and over that time, I've had dealings with public hospitals, pretty much all of them in this district: eastern suburbs, inner west, hell, even Sutherland. I've had dealings with private hospitals, and I've had dealings with alternate therapies and all kinds of things. We've tried everything to conquer this. And during that time, I've noticed certain things that worked and certain things that didn't, and I had a look at your - the report, (indistinct) to be honest I had a look at the overview. The report is massively long.

PROF KING: Very long, yes, apologies.

MS IRWIN: And so I came here today to address a few things that I feel needed clarification, others I felt were missing. I wanted to have a talk about inpatient environment for those who do manage to get inside hospital beds. I wanted to talk about lack of social interaction. I wanted to talk about simplicity of access to care and affordability of access, which is a big issue for a lot of people suffering mental health.

Recently I had an experience – my mum's condition is such that there's peaks and troughs, so you'll have times where she's functional and it's all great, and other times where she just crashes. And I recently had an experience where she crashed and it was crisis time, and I couldn't get a hold of any mental health assistance. I called the acute care team, because that's what I've always been trained to do, is to go to them first. Couldn't get them on the phone, got an answering machine, and then the first appointment we could get with the psychiatrist was in three months' time, which leaves my hands kind of tied for three months.

PROF KING: Yes.

MS IRWIN: So why didn't I look around for other psychiatrists? I did, but my mum's an aged care pensioner, and all those other psychiatrists wanted to charge 400 to $500 an hour. And it's not that she's not worth that, it's just literally, we don't have the money to pay it, and even if you get your Medicare rebate, whatever it is, you're hundreds of dollars out of pocket. And it makes me wonder how it is that people get mental healthcare if they can't afford it. And also, there's the other thing of access. A lot of psychiatrists we called, they said their books were full. Like it seemed to be they have a set quota of patients and they were full, like, "We don't have any space, his books are full, her books are full." I can list a bunch of names that this happened to me recently, it's a new clinic. I don't think that's necessary though, you get the point.

PROF KING: No. I understand, yes.

MS IRWIN: But this is a nation wide problem, from what I hear, so I know my experience can't be unique.

PROF KING: So when - - -

MS IRWIN: What happens is it leaves people like us who are carers or family members – I mean one of the great crises of mental health is it doesn't just affect the mental health person, it affects their environment and the people around them, especially the people who are trying their best to look after them.

PROF KING: Yes.

MS IRWIN: So you're forced to make sacrifices of your time, money, energy, whatever because that access is not available and it's not affordable. So there's point one.

The point two, the inpatient environment care. I've had several occasions where my mum has been admitted into inpatient facilities in Prince of Wales and St Vincent's Caritas and then Sutherland and I've had some really traumatic experiences in that time. I mean, the few times that she ended up in the Kiloh Centre, sometimes it was without even my permit or approval because I would put her into private hospitals, thinking, oh, we've got private healthcare cover.

MS ABRAMSON: I'm sorry to interrupt you but because it's a public transcript, could I get you to talk in general terms about the places that and the experiences that you've had?

MS IRWIN: Well, in the private hospitals, in the public hospitals that we've had, the way the system works is for those who are fortunate enough to have health insurance, which my mum does.

MS ABRAMSON: I'm sorry, it was more about naming institutions.

MS IRWIN: Yes, not name. I will try not to name them. But the way it works is you go into a private hospital but if they think your case is too acute, they will transfer you into a public acute facility and unfortunately they do not always notify the carers or relatives when they do that. So you get a nasty shock when you turn up to visit and, oh, she's been moved to whichever institution. And then when they get inside those places, they're put with a whole assortment of people and there's no consideration to their individual state and the suitability of the environment that they're put into.

In my submission, I likened it to a gaol in that with gaols minor crooks are put with major crooks and there's been lots of studies on what a disaster it is because it gets people exposed to all kinds of undesirable elements and I'm not saying that different people shouldn't be put together but I do feel that there are different stages and levels of mental health and that should also be assessed when they're putting people into an inpatient environment, because it doesn't do either party any good to do that. So my mum came out of those episodes deeply traumatised and really upset.

PROF KING: So from the clinical environment she'd been put in it actually added to - or created trauma.

MS IRWIN: Yes, I went to a mental tribunal to get her moved, okay, and luckily I got that one that happened and she went to another facility because they're not all bad.

PROF KING: Yes.

MS IRWIN: But unfortunately a lot of them are.

PROF KING: Some of them are.

MS IRWIN: Okay. And sadly in the mental health system it is very much - it's an individual basis thing on who you get. I'm not going to name names but some people are a lot more compassionate and sensitive to than others are, and so it is luck of the draw.

PROF KING: Yes.

MS IRWIN: There's no unified system in place for dealing with people, you know, and on that occasion I got lucky and we got her into a place where it was a quieter environment, less people screaming at her, abusing her, you know, she had one case where she'd been urinated on. It was so awful. And when I got her moved, all of that disappeared and so her trauma gradually lessened after a few weeks and the place that I got her to move to had a - I don't know if I'd call it a holistic program but an integrated program where they (indistinct) physical therapy, they looked at her diet and her medication. But anyway, they looked at several elements and they also did things that promoted social interaction, they have activities with people and they took them out for walks and outings and stuff, which is fantastic.

PROF KING: Was that still a public facility?

MS IRWIN: Yes, this was a public facility. It was a rare program and as far as I know, they don't offer the same thing now.

PROF KING: All right. So they may have been trialling it, for example, and - - -

MS IRWIN: Yes, I don't know what the situation is, I just know we were very fortunate and which brings me to my fourth point which is I do feel that the programs that are given to people in mental health are not looking at their entire circumstances. A lot of these people are very lonely and there is a lack of social interaction and there are programs out there that help you with that but they are short term programs. The ones that we were accessing through public health, community healthcare facilities usually lasted for about three months to one year and they were great while they were on but then after that she crashed back down again. And I can't expect them to last forever but some sort of facility or organisation which enables and encourages people to socially interact because you're talking about people who struggle to get out of bed in the morning. To tell them, oh, you can go online and find this is not going to help anyone. The people who come to your house and take you out and take you to places and get you involved in activities and once you start lifting, that encourages it.

PROF KING: Can I just - on that, if those services were there, so as you've said, your mother has cyclical episodes, as you put it, she crashes, ends up in hospital, if the in community supports were there, if there were the services where someone came around and took her out, helped her engage, mix with other people, there might be other peer support might be provided, do you think - I don't want to ask this as a clinical question but do you think that would be effective in helping her not crash out? I mean, have you noticed anything where when her condition deteriorates it's because she's not getting that sort of interaction or - - -

MS IRWIN: Look, I would love to give you an easy answer and say that's a one all fix but in my experience, like I said, I can't speak for other mental health disorders, I can only speak for what acute depression's been like and living with it. Yes, it's a mixture of getting the medication right, the social interaction right, possible alternate therapies, diet, exercise, it's a multi-pronged program and that's what I want to see, somewhere there's a multi-pronged program. And what I would like to see is a case manager. I shouldn't have to chase five different organisations to get one whole integrated service. Because I'm having to call this, call that person, call that person, I'm playing snakes and ladders on the phone every week and I am bloody sick of it.

PROF KING: Yes. So and you may not have - I'm not sure if you noticed, but yes, we actually recommend, for example, for acute depression, severe depression, we actually recommend that there should be case managers to make sure that people can access the services, they know about the services, that they're linked in to a complete team of care, I think we call it in our - - -

MS IRWIN: There's supposed to already be that system in place but you seem to get one and then they seem to fade off and you lose them. Like the psychiatrist, I had no idea that mum had not seen the psychiatrist for a year. I was like, how did the year pass and we didn't see a psychiatrist. You know, we had one. Don't know where he went but he went. You know, now I'm having to get her on to another program and hopefully that person will help me get a case manager and I've got to jump through these hoops again.

PROF KING: Yes. Just on - sorry, I've got two thoughts that are going in the same time. Just on your role as a carer, so you said that your mum, for example, gets moved from private facility to a public one and you're not even notified. One of the things that we've been tossing around is an idea of we'll call it an advanced care directive where when an individual, when a consumer is stable, when they're having a good patch, when they're in recovery, they can then nominate, well, these are the people that I want involved in my care and when I get to a point where I've deteriorated and I really need others to make the clinical decisions or the relevant service decisions for me, these are the people I want to make them. Do you think that would help? Would that be something that your mother would be interested in being part of?

MS IRWIN: Well, see, I thought about this and I got what was called a general power of attorney, thinking this was going to fix this problem. I would leave the paperwork with people and clearly they did not look at it or consult it because decisions were made without my authorisation or at least my acknowledgment of involvement.

I mean, the other thing is that the challenge is getting into a private hospital in the first place. Beds are rare and highly in demand and you can be on a waiting list for that as well. So and they're not the be all answer. Sometimes I've had better service in the public health system. Like I said, it's very much who you're dealing with at the time.

PROF KING: Yes, but you're exactly right though. I mean, we've seen in other areas where advanced care plans, the clinicians tend to have a habit of ignoring them.

MS IRWIN: It's extremely frustrating. Also, it doesn't seem to be a system where everyone can look at the history. I would've thought there was an online system by now, maybe there is.

PROF KING: No.

MS IRWIN: There isn't?

PROF KING: No.

MS IRWIN: And you're always having to reexplain the same thing to every single doctor and I'm like, we have an online database now for everything else, why can't we just have one where all the symptoms, all the history, everything's there, they could look it up, they could be informed and not waste my time with questions they should already know.

PROF KING: Yes. No, we agree completely with that (indistinct). I've said in another forum, but I think it's amazing that we're in the 21st century and we sort of seem to be, well, maybe at the beginnings of the 20th century in terms of our getting data together and having an integrated consumer controlled data that's built around health but - - -

MS ABRAMSON: Can I ask a couple of questions, first of all, thanks very much for coming to talk to us today and I can hear how frustrating this experience has been. I want to ask two questions, the first one was you mentioned the mental health tribunal. So I'm interested what your interaction was with them and why you needed to go there?

MS IRWIN: Well, I've had two engagements with mental health tribunals. One felt terrible at the time but it ended up doing good, which is one where they demanded to keep her in there longer when I wanted to take her out there earlier. In the long term, they were right, because they were trialling a new med and actually needed to be there longer.

You know, so but the other one where I had to get her moved, I had to apply, I had to put in a submission, then they had the tribunal and I was allowed to speak and say my piece and go, look, this is not working, she's in this acute ward, this has happened, this has happened, you know, is there a better place for her? And then they gave me that other mental health team in the same hospital, they had another unit, and said, well, we can try and put her here and see how this works.

My only complaint about the whole situation was I wasn't told how long the duration would be and so just when she was improving they discharged her and I was like, oh, keep her for a bit longer and just let her get to that one step, you know.

MS ABRAMSON: So it was because she was an involuntary patient that the jurisdiction of the mental health tribunal - - -

MS IRWIN: Yes, yes, as far as I understand it, yes.

MS ABRAMSON: Yes. No, I understand. The second thing was you managed to get your mum into a good program, I'm just wondering how you found that program?

MS IRWIN: I'm looking online for stuff all the time and asking. I mean, so one of the programs was referred to me through Carers New South Wales, which is an organisation I got in touch with. They were much better a few years ago before they underwent a whole bunch of budget cuts, but I'm told there's supposed to be a new program coming in called Gateway or something and that will be wonderful. But they referred to a carer respite program that had a whole bunch of activities for my mum and was run through this hospital facility in the - can I say the name of the hospital? No. Okay, but eastern suburbs hospital that everyone knows about. It was run through them and they did this program.

MS ABRAMSON: We're not so fussed about the name of the institutions but we're just fussed about naming individuals part of them.

PROF KING: Yes.

MS IRWIN: Anyway, Prince of Wales had a Euroa unit and the Euroa I think is still there. What programs it runs, I don't know. But at the time it was run by a professor who was trialling, he was very determined to try and fix my mum and so he was trying everything, you know, he had her attached to the Black Dog Institute and trialling magnetic therapy and trialling basal nerve therapy, they - anyway, DVT or whatever it is, but he had her trialling a whole bunch of stuff. Some worked, some didn't but I appreciated his effort and the fact that he also got in a program where you got an occupational therapist and we got a physiotherapist out of that. Didn't last forever but hey, for the six months it did, it was great. She got out of the house and got her out of the bed and got her out of her evil smoPROF KINGorner and got her doing some physical exercise, which is - - -

PROF KING: Important, yes.

MS IRWIN: - - - a real achievement when it happens, you know.

MS ABRAMSON: When you looked at the online services, were there any that had consumer reviews or consumer reviews as the main (indistinct)?

MS IRWIN: Not at the time, like I said, this particular episode is going back a decade ago. I've in the interim had different experiences and taken mum overseas and trialled alternative therapies and stuff, that's also a mixed bag but this commission's not about that. But at that time, no, there was no online reviews or anything like that.

PROF KING: Thank you very much.

MS IRWIN: You're welcome.

PROF KING: Next, Arsho. And if you could state your name, if you're representing an organisation, your organisation, and any opening comments that you'd like to make.

MS KALLOGHLIAN: My name is Arsho Kalloghlian. I represent The Grassroots Approach Programs organisation. It's an organisation that creates programs for mainly about relationships and I also read the draft report and I agree that there needs to be preventative measures put in place for mental health and addressing parents and addressing it at preschool level and school level, I absolutely agree but the way I would like to approach it actually even further back than that.

The grassroots of - I believe in society are the senior high school students and by addressing it at that level before they leave school, I believe you get a lot more people empowered and knowledgeable about how to do relationships well. So with the current divorce rate being almost 50 per cent and half of those involving children, it is dysfunctional and highly conflicting family situations that have a huge impact on children and it affects their schooling, it affects their anxiety, their ability to learn. It affects at many levels.

There's quite a few research that shows the impact of conflict family situations or divorce of parents that it has on children and through teaching the senior high school students relational skills that will help them develop healthy environment, healthy marriages, healthy couple relationships, it actually does help bring up the next generation to be a lot more secure and trusting and mentally, physically, emotionally healthy.

So The Grassroots Approach Programs has two programs, one is for teachers, which has currently approved by NSWESA, the New South Wales Education Standards Authority, and that is about teaching teachers awareness as to why some students may be struggling, why they don't have the capacity to learn like the other students do and how to help those situations. And it all comes down to relationship that the teacher has with the students that promotes the students' capacity to be able to learn and retain knowledge, not just learn but actually retain knowledge and then be able to express that knowledge.

So that is the crux of what I do and I believe I'm really disappointed that along with STEM subjects, the PDHP subject that does - - -

MS ABRAMSON: Would you be kind enough to spell out for the transcript what the acronym stands for?

PROF KING: PDHP.

MS KALLOGHLIAN: PDHP, personal and physical development, education development. So it teaches very basically wellbeing skills, tolerance, respect and all those sort of things but as anyone who's been married knows, that once you're in a relationship, respect isn't enough, you really do need relational skills that are going to stop your relationship from downward spiralling.

There was a research in the US that was carried out on 509 couples who are divorcing to find out what was the most common reason that couples divorce and it was found that majority of them were due to unrealistic expectations of what marriage should look like and lack of commitment. So based on that, I think it is important to talk about and normalise what relationships look like, the difficulties that are not (indistinct) but most certainly will arise and talk about the different phases that every relationship goes through and how to navigate through the second most difficult phase which is the conflicting phase, the phase two which all conflict comes out, differences come out and it's quite often the couple don't have the skills to navigate through those conflict stage and it leads to separation and divorce or just getting stuck in that dysfunctional relationship.

So the 50 per cent that do remain married are not necessarily all happy marriages, functioning marriages where children are being brought up in a healthy environment.

So what I would like the productivity commission to do is actually address this with the educational minister about introducing a relationship model that every single high school student has to know before they leave school and has to be able to - it's not just for marriage, those relational skills can actually be applied at work. A lot of people constantly are changing work because they don't get along with the people that they work with. As soon as conflicts arise, it's no longer a pleasure to be working in the company, doing the job that they love doing. So these relational skills will actually help in the work place as well as in friendships, in family, but most importantly within marriage.

PROF KING: Thank you. Just a question on that: so you're focused on seeing your high school, and I can see why from the point of view, particularly with the perspective of marriage and relationships in adult life. I wonder though, have you thought about whether it really needs as program throughout schools? So one of the things that it meant to exist at the moment, is social and emotional wellbeing programs, right throughout the school curriculum.

MS KALLOGHLIAN: Yes.

PROF KING: And we've seen a mixed bag, and it differs between Australian states. But I was wondering if you've thought about whether the sort of program you're talking about is really – rather than being a separate, standalone program for senior high-school students - - -

MS KALLOGHLIAN: (Indistinct).

PROF KING: - - - whether it actually fit into a more integrated program.

MS KALLOGHLIAN: Absolutely. Absolutely. And that was my purpose for also doing a professional development program, because it actually – the teachers become the role model for the students of what a good behaviour is, what caring attitude is, and all those kind of behaviours. Whereas, I think, when children experience compassion and caring attitude, they know that that is the right way to behave, that that is a desirable way to behave. So it can be integrated at every level of the schooling times. And it is derived from psychological perspective, so we do talk about emotional intelligence.

We talk about what does love and happiness actually mean, we unpack it, because everybody wants to be happy, everybody wants to – they think, you know, falling in love is – that's all you need in order to have a happy marriage. So, there's – nothing could be further than the truth. So, just to expose that, those realities, before they leave school, so that whey then – we also teach about thinking about the end form the beginning, when you are getting into a relationship. If you are getting into a casual relationship, what is it going to look like if either one decides that they're not –they don't want to say, even if you never intended – so we do prepare them in so many different aspects, and get them thinking about making healthy decisions and choices, and not to be getting into it without knowing the skills. And we also integrate how to raise healthy children. The fundamental things that every parent should know in raising children, and yep.

PROF KING: So has there been any, I guess, longitudinal study, so looking at the program, seeing how that's effected the relevant students, as they've gone forward, over the next 10, 15, 20 years, to see, you know, does it – the gold standard would be, does it have an effect on divorce rates? Are the children, or the students, 15 years later, in better relationships than cohorts who haven't done that yet. Has there been any formal studies on that, so that the evidence - - -

MS KALLOGHLIAN: It hasn't been around that long, for them to study. But the first group of students that did sit through the program are now third year into their adult life, and I have actually had emails saying that it has helped them in their work situation, just knowing how to help someone who does have dysfunctional behaviour, and they have been traumatised, they haven't come from a good place; how to actually promote healing in that person, just by role modelling, caring attitude towards them. So, instead of reacting, actually being proactive, and setting the culture instead of reacting from the culture that's already there.

So I have had a letter from my first students, but the greatest impact has been from the teachers who have sat as supervisors, during those classes, who have said it has actually transformer their relationship. Just by knowing that, you know, forgiveness is not something that needs to be earned, that it's something that you do because you're a forgiving person, you respect because you're a respectful person, not because the other person deserves it or earns it.

PROF KING: Okay. Julie?

MS ABRAMSON: Just one thing I wanted to ask, we have a very crowded curriculum, and the pressure on teachers is enormous. And it was my understanding, and I may have got this wrong, that social and relationship skills are built into the way that teachers teach these days?

MS KALLOGHLIAN: It's very platonic. It's very platonic, and the students themselves - - -

MS ABRAMSON: Could you explain what you mean by that?

MS KALLOGHLIAN: Sure. I've had students say that nothing that they learn at school – this is a year 12 student who said this. Nothing that they learn at school comes anywhere close to the reality of what relationships – yes, they learn respect, and tolerance, and, you know acceptance and all those sorts of things, but none of those things actually prepare a person for real life, and the conflict – you learn conflict resolution skills, but it's like, it's actually adopting a particular attitude in order to resolve that conflict. It's not just about clear communication. There is so much emphasis on communicating. Two people can communicate very clearly how annoyed they are, or how disappointed they are, or how, you know, what the other person is saying is not acceptable, so unless the attitude is changed, clear communication alone doesn't resolve conflict.

MS ABRAMSON: You see, our opinion one way or the other is just for the purposes of what we're talking about; do you see the school, why do you see the school as the place to deliver relationship, what's the word, it's not advice?

MS KALLOGHLIAN: Skill building program. Yep.

MS ABRAMSON: Skill building, capacity building.

MS KALLOGHLIAN: Yep. Because once they leave school, it is very unlikely that they will seek to learn about relationships. There seems to be a common belief that everybody knows how to do relationships. If things go wrong, it's the other person's fault. It's not something that people look for. So I believe the best place is the senior high school, because, they are old enough – and sometimes they have even experienced being in relationships, so they can relate to it. And they're old enough to understand it, and then hopefully the – what they learn in here will stay with them through their life.

MS ABRAMSON: Thank you.

MS KALLOGHLIAN: As a preventative measure, rather than – I'm a psychotherapist, and I have my own private practise, and I do look after marriage – marital conflict, quite often, and I believe prevention is better than cure. Because once the marriage does get to that dysfunctional level, it becomes very, very difficult to change habits, to change behaviour at that stage. So for me, it's prevention is better than trying to heal it at the other end. And about the crowded curriculum, I also do EAP in schools, so I did before, and quite often on another note, teachers are overworked. They are overloaded, and a lot of them say their work doesn't finish until 7 pm on that day. They have a lot of reporting to do, preparation to do, and it is affecting their own family relationships, their own mental and health wellbeing.

So I think that's another thing that needs to be looked at, is to actually lighten the load on the teachers, because a lot of them are leaving the work that they love doing the most, because of the amount of work that they have to do, and it's affecting their health and their family relationships.

MS ABRAMSON: Thank you.

PROF KING: Thank you very much. Next, Shelly Wilkins. And again, if you can state your name and your organisation which you're representing, and any opening comments that you have.

MS WILKINS: Thank you. Good afternoon. My name is Shelly Wilkins. I'm the Executive Director of the National Office of the Citizens Commission on Human Rights. We're an international organisation, and we were co-founded in 1969 by the Church of Scientology, and Professor of Psychiatry, the late Dr Thomas Szasz. And we were established to investigate and expose psychiatric violations of human rights. That's the only area that we work in, and we assist people that have been harmed within the system to lodge complaints, work with their lawyers, and do what, you know, various types of action to assist them. We conduct education campaigns, we have an exhibition. We fill the gap of providing the knowledge about psychiatric drug warnings, and you would have heard the – you know, the consumer information is not in the packets, this morning in various types of things. So that's, in a nutshell, our organisation.

Okay. So, mental health in Australia has received record funding of $9.1 billion in 2016-17, which is an increase of 31 per cent on the previous six years. The contrary fact is that despite this, we are told we are sicker than ever, and not getting better. We can only ask ourselves, 'What is being done with these billions, and why aren't there clear, reliable outcomes?' It is time for a cold, hard look without fear or favour to dig into this, and this is what we ask of the Productivity Commission.

I want to say clearly at the outset that this is not a problem of more funding.
Having worked in this area now for more than 20 years, I know that it one of accountability and results for dollars spent, and continuing to fund - and of continuing to fund treatment with measurable harm. Where are the results for the financial investment already made into a system where patients are not truly helped?

Why isn't the government demanding results such as decreased numbers of people and children being labelled with a mental disorder and decreased psychotropic drug reliance? The use of psychiatric drugs has reached an all time high. In 2017/18, there were 4.2 million Australians taking psychiatric drugs. This is actually the equivalent of the population of Western Australia and South Australia combined.

Accompanying this rise are the 47,000 adverse drug reaction reports made to the Therapeutic Goods Administration for antidepressants, antipsychotics, and ADHD drugs, and this includes over 1,700 deaths. Of these deaths, over 700 were linked to the antipsychotic Clozapine, and each death represents the loss of an individual person with family and friends. Imagine 700 people dying after eating foods with harmful chemical additives. There would be a national outcry, and the additive would be pulled from the market and banned.

Appallingly, Australia is among the top five countries in the world taking antidepressants, and suicides are increasing as you've heard, and as your report also covers. There are now 67 Therapeutic Goods Administration warnings on psychiatric drugs, including seven that warn of the risk of suicide with antidepressants. The Australian government has not approved the use of antidepressants for children under 18 for depression. Despite this, in 2017/18, there were over 100,000 children under the age of 17 on antidepressants.

It's no wonder that since 2008/09, suicides in young people have increased 40 per cent, while at the same time antidepressant use has increased approximately 60 per cent. So this link between psychiatric and drugs really needs vital investigation, and obviously, clearly not everybody who takes an antidepressant will commit suicide. But the Australian government - and the results are out that clearly there is a link there, and it does need to be looked at.

And then when it comes to, within the draft report, the screening of zero to three-year-olds. We're quite concerned about that, and it's a shame Professor Whiteford is not here, because would have, you know, appreciated hearing his questions, you know, to me about this area. The screening of zero to three-year-olds will be based on a checklist, on a subjective checklist, and if you look into the area, you can see that it will be based on, is the infant or the toddler, are they whining, are they crying, are they missing their parents when they leave, are they not sleeping, are they eating irregularly, and then, you know, are they hyperactive, and these types of things.

And it's based on a checklist. There are no scientific tests to prove that any child or any adult actually has a psychiatric disorder; not something that I'm saying, the main psychiatric manual used in Australia actually states that. The Diagnostic and Statistical Manual of Mental Disorders, that is, and the Pharmaceutical Benefits Scheme use DSM-5 and Medicare are using DSM-4. So we're quite concerned about the increasing number of infants and toddlers that could potentially be put on psychiatric drugs, and at risk.

In 2008/09, we already had children under the age of one on psychiatric drugs, and we, as an organisation, we have to pay to obtain the statistics for by age of the numbers of children on drugs. Last time I did this, it cost of $5,000, and the public have a right to know, because this is part of accountability and part of monitoring. So now we cannot get the age breakup for under six, so I cannot tell you how many children under one are currently on a psychiatric drug because it will not - they won't - will not provide it.

So what is really long overdue for is an impartial look at what is really occurring. An honest review of the drug and brain interventions, and failing programs like headspace, where we say enough is enough. Fund and implement programs and mental health care that doesn't harm, leaving in its wake so many children put on mind-altering drugs.

I would like to draw your attention also to some other key problems. Why is it that only in the Western Australian Mental Health Act is there a criminal fine levied for failing to report sexual abuse of a patient by a staff member? Why is it that in Victoria there are no criminal fines or prison terms for ill-treatment or wilful neglect of a patient in the Victorian Mental Health Act? Yet if a person wounds, mutilates, abuses, worries, torments or terrifies an animal, they can be fined up to 40,000 or imprisoned for up to 12 months under the Prevention of Cruelty to Animals Act in Victoria? I'm sure you agree there's something very wrong with this.

And speaking further about abusive treatments. Why should a vulnerable person in desperate need of compassionate help be forcibly restrained and dragged down the corridor to the given more electroshock after they've already had so many of them? And why should their parent have to go to court to stop the electroshock? Because electroshock can cause brain damage, memory loss, cardiovascular complications, and it can cause death, and the father obviously could see in his son what had actually happened to his son. And this is not just a one instant. We take the calls at CCHR every single day.

Medicare actually funded over 36,000 electroshocks last year. Western Australia bans the use of electroshock on children under 14 years old. Why hasn't every state and territory afforded children this protection? Why is electroshock even on the market? Because there's the invented term, 'treatment resistant depression', which can ensure lifelong patients and profits. This is a massive psychiatric drug failure. It's not that the patient is resistant.

But for once, let's call a spade a spade. The drugs have failed. Treatment has failed, pouring more money into failure while concealing this with claims that patients and children are treatment resistant, and now maintenance electroshock, or some other brain intervention, is needed cannot continue. Add this to the conflicts of interest in the industry and you can see why Australia is facing the damage from the profit-driven drug industry that has more attention on filling their coffers than helping patients in need.

CCHR is actually justifiably enraged by the abusive treatments and lack of holistic care. CCHR has been documenting Australia's mental health decline since 1974, when it was first established here in Australia, and back then, we had to fight just for the right to informed consent, let alone the right to be not subject to such damaging treatments as deep sleep treatment, which is thankfully now banned. But the wake-up call has been around.

Numerous government inquiries have been held, abuse is uncovered, and recommendations made. Yet here we are again today hearing the same song, perhaps with a different tune, which of course is more funding for the same in too many cases. Now is the chance to really do something about it, and this can be a totally different inquiry to the past and really make a difference.

The Australian public needs this inquiry to name and define results needed, especially in terms of numbers of patients recovered and leading fulfilling lives, and make the funds and practices accountable for meeting those stated goals and results. To do anything other is just reinforcing what can only be labelled as consumer fraud for the last whatever - how many decades it is.

So we would like the Commission to tell patients the truth. That there's no test to confirm any psychiatric diagnosis, to eliminate the harmful treatments and the conflicts of interest that have driven - driven them, and we would like to see true mental health for everybody, and for our children specifically, for our future generation. And there are so many alternatives, and it is about finding the cause of the problem for each person, which can vary greatly.

There isn't a blanket, you know - a pill for every ill. What is happening with that person, what do they need, and please let's redirect the funding into the areas that genuinely help people and make them accountable for results.

PROF KING: Thank you for that. Can I pick up actually on your last point? Because that exactly feeds into the first question that I had.

MS WILKINS: Sure.

PROF KING: So for people who feel they need assistance - - -

MS WILKINS: Yes, and they do.

PROF KING: **- - -** and you're saying that - and do need assistance.

MS WILKINS: Yes.

PROF KING: And the medication, the clinical approach is not the right approach. Do you see the funding then going into the sort of psychosocial supports, whether that's the things we heard about earlier today, such as exercise interactions, housing support, those sort of - is that where you would see the system needs to focus?

MS WILKINS: When somebody contacts us, because people can become extremely distressed, anxiety, depression, they can act, you know, they can act psychotic. There's no dispute about that. The thing that needs to be done is finding the cause for each problem, and we reckon when the first thing that somebody does is actually go to their GP. Go to their GP and get a thorough, full physical check out, because it's very well known, and medical studies have shown, that if someone has a physical condition it can manifest as a so-called psychiatric symptom. They're actually not mentally ill; they have a physical condition.

So that's one of the key things, and as regards to funding of that, of course, GPs have - they have their 10 minute visit, they've got their long visit, they've got all sorts of those things. But if this is done and the person's helped, and they do have a physical condition, then they're not going into the system, so the funding will not be necessary. And yes, of course, at the start, as everybody goes to see a GP initially, there will be an increase in the amount of money required.

But that will obviously lessen, because we want people to be back in the community, happy and healthy and productive and, you know, kids doing well at school, and that's actually the result that - you know, that has to occur. But it doesn't occur when children are put on psychiatric drugs. You can't mask it. Find out what's happening with that child. You know, are they behind in school because they need tutoring. Are they being bullied at home? You know, are people homeless. The need somewhere to say.

You know, there's so many things where the funding can be redirected, because we do need to spend the funding. But let's make sure it's accountable.

PROF KING: Okay. So recognise that there's situations where mental health may be related to a physical condition.

MS WILKINS: Yes.

PROF KING: It may be related to things like financial stress.

MS WILKINS: Yes.

PROF KING: But as the example earlier today of one person who had suffered from significant trauma, and I'm not sure if you were here. She had suffered from sexual abuse. So that's a situation where it's clearly the sort of support needed, you know, it's not just a physical condition, as such.

MS WILKINS: No, no, absolutely not.

PROF KING: So what would you see as being the services for that sort of - for someone who has suffered from many years of sexual abuse, possibly within the (indistinct).

MS WILKINS: Yes. I'm not a clinician.

PROF KING: No, no. I understand. I understand.

MS WILKINS: And I'm not a medical doctor, so I really - you know, we actually, as a - CCHR does not recommend any specific form of treatment, because I'm not a doctor. I cannot give medical advice, and it really is - I mean, it's about informed choice. You know, if one patient may want to, I don't know, you know, see somebody and someone wants to see somebody else, and the thing is, the funding like - you know, the services that are provided, are they accountable? Are the results working?

You know, it might be that someone needs to - you know, medical doctors recommend that good sleep, good diet, and exercise. So amongst that, you know, you might need - you would need dieticians. You know, you might need - maybe someone is depressed because they've got a physical condition and they can't exercise. So, you know what I mean? You might need exercise specialists and - you know, there are a lot of facilities and a lot of things that are going to be needed.

If someone is chronically depressed because their finances are a mess, and I don't know, if mine were a mess, I wouldn't - you know what I mean?

PROF KING: Yes.

MS WILKINS: So like, help them with their finances. What is going on for each person, and then if you do that, then they return to society in better shape, without having been damaged by electroshock, and then they can no longer work and they have memory loss, and you know, the kids - parents are looking at their children going, I don't know why my son is no longer active, and, you know, he sits in the corner and, you know, I've lost my son because he's on Ritalin, for example.

And the side-effects of the drugs, you know, need to very much be looked at. You know, antipsychotics can cause massive weight gain. So then again, that puts more pressure on the medical system, and we really do want, as I know, that we want everybody to return to good health. You know, we experience that. I'm fortunately extremely lucky, and you know, to hear, you know, day in, day out of the abuse that people are experiencing in the mental health system, it drives me, because it is really not okay.

PROF KING: Okay, thank you.

MS WILKINS: Yes.

MS ABRAMSON: I just wanted to understand, Ms Wilkins, the point that you made about the Mental Health Act?

MS WILKINS: Yes.

MS ABRAMSON: You said the Western Australian Act had criminal provisions. Were you talking about when treatment is provided by people within a mental health facility? Is that what you (indistinct)?

MS WILKINS: I mentioned that it's the only Mental Health Act in the country that actually has a criminal finding in it for not reporting sexual abuse of patient. It's the only one. The laws, I'm sure you're probably aware of, because you're a lawyer, the laws vary across the country, and they do. Psychosurgery, cutting and burning the brain, completely illegal in NSW and the Northern Territory. Banned for children under 16 in Western Australia and South Australia. Queensland banned the cutting and burning of the brain for all ages, all ages. And Victoria, there are no bans at all and they're performing it.

The NSW government actually conducted an inquiry into the, you know, effectiveness and, you know, safety and effectiveness of psychosurgery when the Mental Health Act was under review here. And the end result of that was, there is no evidence to prove that it's safe and effective, and yet it's still being done. So if people are actually helped with the cause of their problem, then they will - and I mean, sometimes it's severe. Sometimes you won't find the physical condition in the first go. And, you know, it can be a myriad of problems.

But we really do, because we're talking about people's lives, and their families. And the abusive treatments are not working, because the inquiries continue and you can't have accountability in an inquiry if you don't look at what is actually being done. Just as an analogy, and this is not to make less of the desperation that people are under, because I hear it every day, and all my volunteers hear it every day.

If you're running a business and you keep throwing money at it, and it's not working, you want to look at what are the people in that industry doing? You know, what are they doing? Are the treatments effective? What is actually being given to the person, as an actual - you know, as the reason why the system keeps failing. Because we have, as you would know, had so many inquiries. I don't know if you recall the Royal Commission into Deep Sleep Therapy.

PROF KING: Yes.

MS WILKINS: That was an actual - you know, that was an inquiry. You know, and as a result, it was banned. But what was looked at was what was being done in the facility. And, you know, if you want to - if we all want happy and healthy kids and happy and healthy families, then we have to find the cause of the problem for each person. We have to get rid of the harmful abuse and the psychiatric drugs with their potentially dangerous side-effects.

Patients and consumers need to be educated. There needs to be warnings on boxes, you know, to warn that - of the - at least of the suicidal reactions, the fact that they can report side-effects. We did a survey at one point, and nobody - most people didn't know who the Therapeutic Goods Administration was, let alone to know that they could report a side-effect. And these are the areas, and then, from that account - - -

MS ABRAMSON: Excuse me, can I just - we're very mindful of time.

MS WILKINS: Sure. Not a problem. Not a problem at all. Yes.

PROF KING: Thank you very much.

MS WILKINS: You're welcome.

MS ABRAMSON: Thank you very much.

MS WILKINS: Thank you very much.

MS ABRAMSON: Sorry, we just had a time constraint.

MS WILKINS: Completely fine. Very appreciated.

PROF KING: Next, Andrew Pryor. So if you can state your name, any group that you're representing, if you're representing a group, and any introductory remarks that you like to make, for the transcript.

MR PRYOR: Great, thank you. Yes, my name is Andrew Prior. So I'm here as an individual. So I'm involved with several organisations, but I'm not speaking for them, and I don't represent them today. So just to cover them off; so I'm really here as a carer for my daughter, who's been through a journey, and giving you some of my reflections on that journey with her through the mental health - various mental health services, and also as a partner with my wife having been - also been through their own challenges. So in terms of organisations that I'm involved with that I'm not representing today, so I'm on the board of Flourish Australia, I'm on the board of Mental Health Carers New South Wales, who was represented yesterday, and I also do work part-time with headspace, two days a week, over at western Sydney in three headspace sites. So happy to take questions in relation to those, but I won't be speaking for them so - - -

PROF KING: No, understand.

MR PRYOR: So I guess in terms of my journey, I guess I was - like, my background is a corporate career, so for 25 or 30 years. I had the opportunity about 18 months ago with changes there to basically focus my life and this phase of my life on not for profit mental health, hence the organisations I'm involved in. I'm a graduate of Australian Institute of Company Directors and I'm on the boards I've mentioned. But what really got me there is through the journey with my daughter and realising what needs are out there in terms of mental health, and so really I welcome the Productivity Commission. I agree with others that have said it's a once in a lifetime generational opportunity for change.

And I - listening to as much as I could yesterday, in terms of some of the people presenting and thank you for the public hearings. So I was driving around western Sydney through all the headspace sites. So I listened to it where I could and it was a good - really great the live streaming, worked very well, and obviously I spent time listening to people today and there's been some fantastic presentations. So thank you for the opportunity of having these open forums. So with my daughter, she's had lots of challenges through her teenage years, came to a head during HSC year, as they tend to, and then she's sort of - in a period of three years following that, she was in and out of hospitals for about cumulative six months. Public systems, private hospital systems, which I'll get to in a minute.

In addition, with my wife she's just celebrated her 20 year anniversary of weekly psychologist sessions, working her through childhood trauma and I've been on that journey with her as well. So through these - with my daughter, we've seen plenty of different services. So I guess reflecting on what some people have said today and just my thoughts on some of the - I've read through the report, and also heard what a lot of people have got to say and I thought I would just throw my two cents worth in. With my daughter, she's currently on 12 different medications. She's been out of hospital for 18 months, and so that's administered to her daily. And one of those is Clozapine, which was mentioned earlier, which is obviously one of the most controlled drugs around and I know it has had side effects, that was just mentioned, but for her that's sort of probably been a life saver.

So - and that's made such a difference with her not having her psychotic symptoms, and being able to get back to some sort of life, some fulfilling life, what that means to her. So she has, with her medication, put on about 50 kilograms, on that. They say on average you put on about 12 kilograms. From what I understand, people in the know, it can be anywhere between zero and 50. She's at the higher end, and as a parent you'd be - you're concerned in relation to the physical consequences of that and from what I understand from people in the know, they're in researching, that significant side effect there's no - no solution in sight for that, from what I understand, for the next range of drugs that are coming through.

So these are the current drugs that they're doing and all - they all have these significant side effects which then has a double impact on the physical side effects as well. So in terms of - I just want to reflect on a couple of things in the draft report. Firstly, funding. Look, I think the five year funding is absolutely fundamental. You know, obviously at the moment it's one year, two year, three year funding at very best. You know, I come from a corporate background. That just means these organisations can't be strategic, short, medium term, it's always too short term thinking. So I think that's a really important one, and secondly it also, from what I can see, is a major flow on impact to attracting the right people into these services and retaining them when they have alternatives at the moment where - which isn't contract based.

So I think that's quite fundamental and I applaud that. Secondly, in terms of the MBS I note, I think, in the report that currently the proposal is to go from 10 to 20, I guess, MBS supported visits. The first thing I would say is I applaud the - the latest announcement of the eating disorders which is for 40 sessions a year. I'm not sure the clinical evidence or medical base for you recommending 20. To me people that have complex needs need to be engaged on a weekly basis. So I applaud 40 and I'm not sure where 20 came from. So I would think people with complex needs such as trauma, disassociation, and I really put my - you know, I'm really thankful for Scarlett earlier today talking about some of these complex issues.

So I really - it's fantastic that we've made progress with MBS on eating disorders, but that shouldn't stop there and I'm not sure why you're recommending 20. So I think we should be focusing on the weekly basis, so 40, when you exclude other things, you'll probably get there. So that would be my proposal and as people have said today that doesn't cover the full cost anyway, that just means you're getting more back. So in terms of scale, one reflection I have and I note the CEO of headspace, Jason, has quoted that in terms of the 110 headspace sites currently unbelievably there's 70 different organisations running those headspace sites. So from my perspective again from a corporate background, you know, I guess this is a lack of scale in terms of people being able to - you know, you don't have the scale to be able to manage these locations, which impacts all sorts of things, you know, collaboration, learning, best practice et cetera.

So to me it's fragmented and so I think - you know, I think scale brings a lot of things. It also enables things like effective youth engagement and family friends engagement which I'm involved with headspace, and these are quite critical and the more scale people can have the more they're likely to be involved with these types of things. Also they play a critical role in the (indistinct) model for headspace. So as I said I'm a big supporter, but I think these should be adopted much more broadly in terms of services and programs to ensure that there's a youth voice where it's youth related service, and likewise that there's family and care engagement where - where possible, and I'm not sure that was - came through in the report.

In terms of collaboration between CMOs, rather than competitions, I think the NDIS seems to have had an impact on people being more competitive as well as the whole tender process through the PHNs. I think in terms of collaboration PIR, which is now defunct as you know, was a good example of collaboration and people working together and I think there's advantages in doing that. So again - - -

PROF KING: Sorry, just for the transcript PIR is - - -

MR PRYOR: Yes, whatever it was called, yes.

PROF KING: Partners in Recovery. It's all right.

MR PRYOR: (Indistinct) program. Forgotten it already, because it's been defunct. So - but that's a good example. But I think part of collaboration is people also - organisations focusing on their strengthens. So for instance I think you mentioned in your report ReachOut as having a fantastic digital platform, these type of things. So - and headspace obviously having a good physical footprint and a well known brand, you know, recognition brand, and then someone like Flourish, you know, having a good reputation over many years of, you know - you know, people with complexity, giving employment and having a fantastic peer workforce. So I think there's a whole lot of collaboration that can be - which I don't think really came through in the report as well.

So NDIS, I'm not sure how that works with scope, but I think those mental health challenges have been pretty well documented, including permanency but that's a continuing challenge which I know a separate analysis is being worked on. In terms of co-design, I thank and applaud Irene from Being yesterday bringing this to your attention. Obviously this should be fully embedded in this process and fully embedded in - and I guess this is a component of that, but this isn't co-design, and I guess trying to work through what that means for a process but also rolling out co-design elements in terms of programs going forward as well and again I think that could be better put through this process. So - and in terms of funding also co-design through peak bodies, such as Being and Mental Health Carers New South Wales is also something that we need to be focused more on, just make sure we're training people with what co-design is about.

So I support everything that Jonathan said yesterday in terms of carers and the carers involvement in the journey. I won't go back over that because I think Jonathan has covered that, but I thank Jonathan and Peta for presenting yesterday, and I also support in the draft report a lot of the focus is on navigation and pathways. This is a clear problem everywhere, and I guess in terms of - yes, so some of the recommendations that makes sense to me. In terms of early intervention, obviously I have involvement with headspace with the early psychosis program, and that's been piloted for many years which I think Orygen touched on yesterday and Roger touched on earlier. So, one of the successes, and evidence based program is that it's the breadth of the program which means it's successful. So, but it's in pilot phase, too, and it needs to be rolled out. It's a tragedy we've only got three early psychosis programs within the population of Sydney. It's a tragedy there's not any in Southwestern Sydney. So there's funding for a pilot, but there's no funding for the next phase of being rolled out. So we've got a successful program, let's roll it out. And I think, also, yeah, the fact Southwestern Sydney isn't covered with this type of thing is just, in my view, unbelievable.

So, I guess from my perspective, being involved in the early psychosis program, it's what's next, and I think what's been touched on by Scarlett and with Professor Roger Gurr earlier today in terms of trauma, is a very – you know, again, the fact it wasn't a big highlight in your report, I think Scarlett said three times, she was able to count that, but to me, trauma and childhood trauma is the next phase. So what specific programs are we running that actually focusses on trauma, and so actually, from the start like we did with early psychosis program, it's a ten year program – it's a ten year timeframe to get that up and running, but what's next.

Likewise, borderline personality disorder. Some specific, you know – you know, as you know there's a high level of self-harm with people that identify with borderline personality disorder, so can we have specific programs that are being developed, evidence-based, that can actually focus on the next ones after psychosis and after trauma. So, also, I just wanted to ensure, in terms of, obviously, there's been touched on about trauma informed services, and training is an important part of that. We also just want to touch on your focuses on the 0-3, I know you've touched on that today, in terms of the 0-3s, and the screening programs.

I just want to bring to your attention, and make sure you've seen, that there was the Murdoch Children's Research Institute, had a really fantastic report, which as presented out in Blacktown, in relation to 1,000 days from inception. So if you have not had the chance to read that, that is a really rounded report. I'm happy to send it through if you haven't got that. A couple of other things, I fully support what's been recommended in terms of IPS. I know that was a core part of the report. I've seen that in place at both headspace Penrith, but also with the early psychosis program, and so the rollover of that, I agree, would be fantastic.

I also support the priority population focuses, in particular on barrier, whether it's contra-sensitive services, LGBTQI was covered earlier today, Aboriginal/Torres Strait Islanders – all of these make sense. We should be focusing, and we should be prioritising funding on these focus areas. Data capture, I totally agree with what's been said. I think headspace leads the way in capturing LGBTQI communities. Most services don't, so I support exactly what they said earlier today. Just a couple of reflections, if I can, on hospitals, emergency departments - - -

MS ABRAMSON: (Indistinct).

MR PRYOR: Okay, yes. So, that's why I told you. I'll cover off in terms of hospitals, the public and private hospital system we've been to both. The public hospital systems are a bit like holding pens. There's no programs embedded within these acute walls at all to help people to develop their skills, and there's no real psychological treatment that's happening in these acute walls, in my experience. The private system, there are some – more so, some programs that are there, but I won't spend time on that. But TMSETC, we've had experience with all those, and these need to be tried, because it might work for some people.

Emergency departments, can I just touch on this briefly, is that we've spent an hour in there, never less than four hours. These need to be – emergency departments, and I agree with some of the reports about having alternatives to that, and also have places, safe places, to be there. And that's why I agree with all of that in the report. The only thing is, the proportion of staffing at the moment, in these wards, relative to the people that are presenting with mental health challenges or illnesses, is not right. And so you're waiting for one registrar, and that's why you can be waiting eight hours. And so you'll be the first person there, the last person to leave.

PROF KING: Can we – I know we want to ask a couple of questions, and - - -

MR PRYOR: Okay, yeah, that's fine. So, I think my last comment is, we need to get an appropriate and equitable share of health funding. So I think we need increased funding, and we need to be more proportionate to physical health funding, and numbers need to be in billions, not in hundreds of millions. So, yep.

PROF KING: Can I just run on, sort of, to headspace collaboration. I just want to make sure I understand your point. So, you said there's 70 different organisations run 120 headspace sites.

MR PRYOR: 110, yes. So that's the lead agents. The lead agencies, yes.

PROF KING: Yes. But you're worried about lack of scale fragmentation. My understanding of those is that headspace is a franchise model, so – in the sense, you know, it would be like saying, any other franchise is run by a whole lot of different people, but it's guided very strongly by a central office. So I want to make sure I understand the headspace model, because we've heard the exact opposite, that it's not fragmented enough, that it isn't response to local needs, has been one of the things that was put to us. So, that's the first one. Secondly, when you're talking about collaboration, how do you see that working? And again, perhaps using your headspace experience. So they're my two.

MR PRYOR: Yes. I'd say, and referring to scale is that rather than having on lead agency looking after one side, that you may be looking after regional areas, and I've seen that work within Western Sydney, where it's got multiple places, and so therefore you find that people are learning from each other in terms of how they're engaging with the community and later.

PROF KING: Okay.

MR PRYOR: And also, you touched on it earlier today, I would also say the consortium is also different. I know we were talking about Bondi earlier today, but the consortium cases is what's also tailored towards what's appropriate for each of the headspace sites and their locations. So that's what makes it different, and so therefore you might be engaging in very different consortium partners in Western Sydney than you may be at Bondi. And so, the consortium process does work, and that's the model that's there, but the model doesn't tell you who your consortium partners are. So that's up to you to engage within that. So I think we can be – I guess my point on collaboration isn't so much within that headspace environment. My point on that is more about scale, and just making sure that we just have best practice by leveraging off having scale and having lead agencies that are not just looking after one particular site.

PROF KING: Okay, thank you. Julie?

MS ABRAMSON: No, I don't have anything.

PROF KING: Great. Thank you very much.

MR PRYOR: Thank you.

PROF KING: Now, I don't have the details of the next person.

MS ABRAMSON: Is there anybody else who'd like to give evidence whilst we're here? You need to do it from the table, and you'll need to announce who you are and where you're from.

PROF KING: We'll just say, we do have one other person to go.

MS DUCASSE: I'd like to, but I'll be really quick.

PROF KING: Yes.

MS DUCASSE: My name is Libby Ducasse, and I'm in Sydney, but I'm born and bred in Adelaide. I followed my journey with my elder sister who had a breakdown, they called it back in those days. She's ten years older than me, and I followed her psychiatric journey since I was 8 years old, which has been really heartbreaking. I could go over different stories that I could tell you about the number of psychiatrists that she's had. I've listened to the stories that have been told today, about her coming out of a psychiatric ward a lot worse than when she first entered. The level of care that she had, the different drugs that she had, the side effects, committing suicide, attempting the committing suicide.

But I wanted to take this opportunity to just say something else right now: I really appreciate that you two are here, at this time, and this place, and you have a chance to make a big difference, a mark on Australia, as of today. I really believe in that different primal effect that that lady mentioned with the dark hair, that cared for her mother, about we need a chance in Australia. If a psychiatric treatment is working, where is the results? I didn't see it on my sister. I haven't seen it.

A friend of mine recently had a break up, which was really nasty, and she went to see a psychiatrist. She told me, she's not going back, because it just made her feel worse. The tablets made her feel so weird, she couldn't feel anything. These are not the results that we want. If I had a choice for my sister, I would have had her in a very calm environment to get over this initial stress; she was only 18 at the time, and I think having that different primal effect, having been able to have proper care. If they go to a psychiatric ward, like this gentleman who just spoke, said there is only one registrar. I've experienced that with her. My whole family, we had to wait for hours, and like, that was like eight years ago. I don't know what it's like now, but you guys can make the change.

You can make a difference on the whole of Australia, like with Shelley talking about how in, I think it was Melbourne, there's no thing on someone being harmed on mental health. You can change it. Not just for your families or your own self personal integrity that you've been given this great honour, but you can do it for all Australians, all the children. Like it's very hard to have an early intervention program and have a checklist, because as a parent, I'm a mum, we all know that we've got different children. Some of them are - like I've got five sisters, my mum and dad had six girls, we are all different. I was very chatty and lively, one was a total book reader, you know, quite quiet, we are all different, but by you guys just making the right decisions, putting some laws in place that go right around for Australia, going in yourself and looking for yourself. Not just sitting behind a desk, go into that psychiatric home, just have a look - have a look and see.

PROF KING: Thank you very much.

MS ABRAMSON: Thank you very much. Could I now - we would like to close - - -

MS DUCASSE: Did you want a question?

MS ABRAMSON: No.

MS DUCASSE: Sorry, I will go back to my seat then.

MS ABRAMSON: We were actually going to close the hearing, because we want to take one witness in camera. So if we can ask people to leave the room and after that we will close the proceedings for the day. So if you would be kind enough to leave so that we can - - -

PROF KING: Take in camera. Thank you.

MS ABRAMSON: If we can also cut the live stream, please. Can I just confirm if you didn't mind saying your name for the transcript. You don't have to.

PROF KING: It's up to you.

MS BARIT: No, that's fine.

MS ABRAMSON: That's fine?

MS BARIT: Yes. My name is Deborah Barit, and I want to cover a couple of points. One is a personal experience and one is a comment from my professional experience. I will start with my personal experience. In May this year my 30 year old daughter committed suicide. This was her seventh attempt. Now, this isn't who she was. I want to put a bit of background in.

My daughter was incredibly bright. At 3 she learned to - she taught herself to read and at 5 she was reading Roald Dahl novels. Then she got into the opportunity class and in Grade 5 she developed diabetes, Type 1 diabetes. She was very good about it, she controlled her own blood sugars, et cetera. When she finished primary school she was given opportunities in terms of both winning scholarships to private schools and getting into selective schools. She finished high school with a UAI of 98.7.

Late - it probably started when she was 16, but I misunderstood it as going through her teenage rebellion years. She started self-harming only in terms of her diabetes. So she wasn't looking after her diet, et cetera, and she explained to me the diabetes had deprived her of her childhood. When she finished school she went to university and for the first time she couldn't cope, and for the first time in her whole life she failed a subject. We talked about it and she decided to take some time out and started some really dangerous behaviours, which surprised me; partying, drinking. No, she didn't take drugs except medication.

The next year we discussed the fact that she should have a year off and give herself time. We talked about getting some counselling, but her opinion was she should have her own - that she should be capable of sorting out her own life, and then went off the rails. She quit her job and she went overseas and disappeared in the sense that there was virtually no contact and the only way I could track her was by the credit card bills that came in for me to pay.

When she came back from overseas she developed a whole new personality. She became aggressive, rude, inconsiderate and there was nothing I could do. Again we discussed her getting some help, but, no, she refused. The GP was seeing her regularly talking to her, and one day I had this terrible sense that she was going to attempt suicide. I can't explain it. It was just this awful sense. I rang my GP and I actually asked her about what's it called, having her committed. My GP explained - said to me I was overreacting because my daughter could put on a really good act.

Two weeks later she made her first attempt. She ended up in hospital and we sat in the emergency department for five hours. Having taken an overdose I didn't know if she was going to get worse, if they wouldn't get to her in time. So I was fortunate I have a couple of nephews who are doctors. They're interstate. I rang one of them because that's the only way I could find out that it was okay, she was sitting there and she wanted to go home.

Anyway they did admit her and she was put in the observation ward, which was a nightmare of a place. There were no windows and the whole thing was open, it was mixed, and the staff were all locked into a glass cage I suppose. Anyway they were going to let her out the next day because it hadn't been a serious attempt. My GP convinced them to keep her for a couple of days just so we could get respite care. She came out, there was no follow up except for - what it's called - the crisis team.

PROF KING: Yes, the CAT teams or - yes.

MS BARIT: My experience with the crisis team was very similar to the lady who was talking about her mother. The crisis team came to see her, and my daughter explained to them that she was fine; there was nothing wrong with her and as a result, they decided there was no need to follow up and when I talked to them - because in those days I had no idea - they informed me that the best thing I could do was get a counsellor and cope.

A couple of years later my daughter dropped in and out of university, she did some work, she did another overdose, and each time she did it - and this time it was a different hospital. We went there, they checked her out, the psychiatrist talked to her, I wasn't spoken to because she was over 18; nothing, and we were told that as soon as her blood pressure came down and the heart beat came down, she could be released and she was, at midnight they discharged her.

These sort of experiences I found really difficult. We had counsellors, given the nature of who my daughter was, who had no idea and so she started playing games with counsellors, with psychiatrists, because she could have fun because they treated her as a half-wit. So, she was several steps ahead of each and every one of them, which wasn't very productive, but they didn't want to know who she was and that was a result of continuing, and over a period of time she upped the anti each time she made a suicide attempt.

Each time it was a bit more serious and each time it was terrifying, but there was no follow-up. I was told, 'Hey, it's not so bad, it's okay,' and I thought, 'No, it's not okay.' I begged for help and the information I was given was, 'It's too complex, it's too long-term.'

Even contacting private psychologists, they rejected it because it involved the family. It was too complex, they didn't want to take it on - social workers, and so we continued and each time she upped the anti a bit more, and in 2015, by this stage, apart from her diabetic medication, she was on a whole series of different medications including Seroquel.

Now, I'm sure there was a piece of paper that said, but the fact that it makes you hungry all the time, interacted with everything about being a Type I diabetic. Her blood sugars went out of control and she took more and more insulin which, as most people know, makes them aggressive because it's got testosterone and the more you take, the more it becomes dangerous.

Anyway, the psychiatrist at the time told her, because she was anxious, just to take an extra Seroquel, and so she did and she got more anxious and she took another one, and she took another one, and she ended up with full-blown psychosis where she tried to kill her sister and so, she had to go into hospital and she was in a - because she'd been committed, and she didn't know who I was, she didn't know who anybody was. She was totally out of control. They had to put her away because she thought she lived on another planet.

So after that, we put her in a private but the doctor hadn't told her that you might be able to take one more Seroquel, but because of the anxiety she just kept taking it and no one said you were going to get a psychosis. And during all this time, every time we saw a different psychiatrist, my daughter got a different diagnosis and therefore, different medications and different treatments which turned out to be inappropriate. And in between all this, I couldn't get her out of bed. She went to bed for about four years, I mean literally.

So after this episode we got more help and after the psychosis they gave her two new diagnoses. The others were not appropriate and, as a result, she got new medication.

PROF KING: Can I just clarify; was she being taken off the medications or were they just adding more and more medications?

MS BARIT: Some of the medications were removed and others were upped.

PROF KING: Yes.

MS BARIT: As a result of her psychotic episode, my other daughter had to leave home because it was - she had to move out because it was no longer safe to leave them together. I don't know that people understand how the family was destroyed, and I was still told it was just too complex.

Time went on and we got someone really good. This was a private service who came in and actually got my daughter out of bed; literally, and got her back into a social environment and got her to start going to TAFE to do her higher school certificate.

PROF KING: This was a psychiatrist?

MS BARIT: Pardon?

PROF KING: The person who you're talking about now, is that a psychiatrist who did this?

MS BARIT: It was a psychiatric physiotherapist; and convinced her to go back to TAFE - - -

PROF KING: Yes.

MS BARIT: Not that she needed to do her higher school certificate again, as you would understand, but to get her into a routine.

PROF KING: No; interaction, yes.

MS BARIT: So my daughter went to it, but having done all the subjects that she'd wanted to do, she took up things like advanced maths and chemistry, which she'd never done and she did really well in that too.

PROF KING: Yes.

MS BARIT: So again, she decided to do physiotherapy but she was unstable again, and so it came and went. She was finally diagnosed with body dysmorphia and bipolar too, and finally, we stopped using the services or the hospitals around us because in her many dealings with lots of psychiatrists and psychologists, she'd actually come across one she liked.

However, they didn't practice in Sydney, so she connected to that one that was in a country area, but in a city-country area, and she used to commute two hours one way because she trusted him, and we sent her to the hospital where he could look after her.

PROF KING: To practice, yes.

MS BARIT: It was the best positive thing that had happened. He didn't treat her like a moron; he didn't treat her like a medical - like, a condition, if you know what I mean; a mental case.

PROF KING: Yes.

MS BARIT: He treated her like a human being and an intelligent human being and she really started to improve; and there was hope - for the first time in 10 years there was hope. She actually moved out of home at the age of 29 and moved down there and started to develop a life. She enrolled at Sydney Uni and she'd started doing the study she'd always wanted to do, which was English literature.

And everything was going okay and then, early this year, she started to actually reconnect with her friends, see people. When it was her birthday last year, which was in December, she turned 30. She had a party. We went down for it and the first greeting she gave me was, 'Mum, we made it.' You've got no idea what that meant because for most of her life I didn't think she'd get to 25.

The beginning of this year she went to visit a friend in Canberra. She had a terrible accident. They were walking, she was carrying the friend's baby, she fell and broke her ankle severely. She was rushed to hospital to be operated on and when she got there, she explained; a) I'm a Type I diabetic; b) I've got osteopenia. For those who don't know, it's brittle bone.

PROF KING: Yes.

MS BARIT: They operated and they tried to get her out of hospital on the third day, as soon as she could put her foot down. So I rang up and said, 'Now, this is nowhere what a Type I diabetic, what it means in terms of healing.'

PROF KING: Yes.

MS BARIT: She lived on her own. She had stairs; so to get into her building to get to her place. So they gave us an extra day and from that, I'd kept private insurance for her, I got her into a rehab hospital near where she lived for seven days and then, they sent her home.

No services provided because a) you don't get seen for six weeks. She got an orthopaedic surgeon who specialised in ankles who was a sub-specialist in it and she did absolutely everything she was told, and after six weeks, maybe seven, despite having osteopenia and despite being a Type I diabetic, she was told she could put her foot down, she could start putting weight on her foot.

So she did. All the thing fell apart. She was in excruciating pain. She took herself to hospital, and when she got there, she was told to stay there. They had to remove the whole thing.

PROF KING: Yes.

MS BARIT: Right? So there she was in hospital. She explained to the doctor, the nurse, that she was a Type I diabetic blah blah blah and she had a pump - you know, an insulin pump.

PROF KING: Yes.

MS ABRAMSON: Yes, absolutely.

MS BARIT: In the middle of the night the pump stopped working. So she called over the nurse and explained that she was a Type I diabetic, that she was going to be first on the list, that her blood sugars were rising; the pump wasn't working, and the nurse said to her - and she asked to speak to someone in endocrinology - the nurse informed her that there was no need for any of this because they'll give her four units, short acting insulin, before they put her into the operating theatre.

She tried to explain that, you know, previously she'd had an infusion and saline, but she was told it wasn't necessary, and she had to take her blood sugars every hour and they keep going up and up.

PROF KING: Yes.

MS BARIT: So by the time the blood sugars hit 15 - I assume you understand what 15 means?

PROF KING: I understand that's very high, yes.

MS BARIT: Pardon?

PROF KING: I understand it's very high.

MS BARIT: Well, it's ketoacidosis territory.

PROF KING: Yes.

MS BARIT: She called the nurse again, and the nurse told her exactly the same thing. Then, she rang me, as I was leaving to get on the train to go and stay with her, and I rang them and I talked to another nurse and I explained it and all that, and I told the nurse I wanted a review and I wasn't happy with the treatment, at which stage, the nurse replied, 'I'm sorry to hear you're not satisfied. I will go and tell the other nurse.' Went off to tell the other nurse and the other nurse said, 'Don't worry, we'll give her four units,' at which stage her blood sugars were 17.

So she screamed the place down and an intern from endocrinology turned up, followed by the registrar, followed by the consultant, and by the time I got there she had a huge sign on her bed describing diabetes and what ketoacidosis is; a huge sheet so the staff - - -

PROF KING: Could understand.

MS BARIT: And i don't think diabetes is a particularly uncommon condition.

PROF KING: No; disease.

MS BARIT: So it was touch and go between, hey, they would operate later or she'd end up in ICU. That was the beginning of a whole series of disasters. So she had that op and the next one was an external fixation, which looked like something out of the dialects of the Doctor Who. Then, of course, there were complications with the diabetes. Then, there was an infection, so it had to be operated again.

PROF KING: Again.

MS BARIT: Then, the contraption shifted. So between January and April she'd had five surgeries. She'd asked for help but was told the only services, like, transport - because she couldn't get anywhere - - -

PROF KING: Yes.

MS BARIT: Were only for the aged, 'Sorry.' That's what the social worker said and said she'd just have to fend for herself and sent her home with the tube for - what's it called? Antibiotics.

PROF KING: A drip, yes.

MS BARIT: So if a nurse had to come in daily to change that and to - - -

MS ABRAMSON: IV antibiotics.

PROF KING: For IV, yes.

MS BARIT: Pardon?

MS ABRAMSON: Was it IV antibiotics?

MS BARIT: Yes. Sorry, I can't - - -

PROF KING: No, no.

MS ABRAMSON: No, that's fine.

MS BARIT: Anyway, she started really struggling. I was commuting twice a week because I still work. I was financially supporting her significantly.

PROF KING: Yes.

MS BARIT: She started talking about suicide again and I said - because she'd had a monumental suicide attempt in 2015 where she was 13 days in intensive care and after that, two days on the ward, and they sent her home. She had pneumonia, she couldn't breathe, but the psych unit said it was okay. So then she'd almost died.

So I talked to her and said how'd she'd promised and, you know, got her GP involved who was now down there. Anyway, she came up, we talked, I wanted her to stay, but I was going in to stay for work and she couldn't stay because she was totally connected to, you know, having her dressings changed - - -

PROF KING: Yes, all down at the hospital now.

MS BARIT: And we had an arrangement that when I came back - it was my other daughter's and my birthday and we were going to go down and celebrate our birthdays with her, take her out. She rang me the day before. She'd been talking about how she'd realised how some of the things she worried about were unimportant, how she understood that she'd created some of her own problems and it was the first time in 12 years she'd had insight. It was, like, seeing my daughter come back.

So I rang her and the day before she said to me, 'And tell my sister I love her,' and that was the last words, because when we got there the next day, there was no answer. I got the agent, we walked in and we found her. Those five operations and the fact that nobody - everybody listened, but nobody heard.

PROF KING: Yes.

MS BARIT: And I want to say a couple more things - - -

PROF KING: Yes; please.

MS BARIT: Because I didn't see the point of, you know, having an inquiry because there was no purpose to it. My daughter had a history of attempting suicide. It's not like they were going to go and say, 'Oh, we slipped up,' because it was the system; so I didn't.

But I do want to say one thing. In my professional life I am a trainer, I train people for job interviews and my area for expertise is training doctors for medical speciality interviews, and I've been doing that for 15 years, both, to get into specialties and consultants, and I can tell you that it isn't their fault. What it is is a total system of training hospital - the feedback and role modelling they give - that makes them incapable of hearing their patients.

PROF KING: Yes.

MS BARIT: Their whole training is memory based. It's model-based on problem, solution; based on evidence-based medicine; and the focus is solve a problem. Patient is a condition, you eliminate, you treat and you get rid of them; and in that process, they eliminate the person because the focus isn't to solve the condition, and that the way they get through medicine is through memory.

PROF KING: Yes.

MS BARIT: They have this ability for vast quantities of really complex information, but what's missing in that training is the application of it. That you can memorise it, but unless you apply it in an individual and adaptive circumstances, it has no value; you're not treating the patient, you're treating a medical condition.

PROF KING: Yes.

MS BARIT: The hospital system just exacerbates it because they're overworked, they've got no time, they've got all this stuff, and so the easiest way to do it is to follow that process. I've been training doctors for a long time; I've got enormous respect for them. But one of the things that they do admit, which I think is really important, is they're not 100 per cent present when they see patients.

By the time the patient's saying something to them, they're already writing their notes for the management plan and going to the next one, and it's not their fault in a sense that they have no time, but it can cause enormous problems for patients, and one of the things they do is they don't talk about their patients by name. They talk about them as 'the adenectomy, bed such and such'.

PROF KING: Yes, it becomes depersonalised.

MS BARIT: Pardon?

PROF KING: It becomes depersonalised.

MS BARIT: Yes, and the other thing is, the whole feedback system of how you progress becomes really destructive, because while it's intended to be balanced, it never is. It's always about, 'You've got to do better at this,' or, 'You've got to learn about that.' It is never about how much you've achieved. So as a result, they don't have any self-confidence. As a profession, they are probably the least confident of professions, and you can hear it in the language they often use. Does that surprise you?

PROF KING: Yes, it does; because I was thinking - - -

MS BARIT: No.

PROF KING: That the clinical culture, it's a very hierarchical culture.

MS BARIT: No, because if you spend your whole life only looking at what I haven't learnt, what I haven't achieved, what I'm not good enough, because that's your feedback, you have no basis on which to say, 'Look, at me, I've gotten to here', and it's something I learnt through my work.

PROF KING: Yes.

MS BARIT: I won't go into the role modelling that - it's very important , but they don't usually get trained. They don't know how to role model, supervise, so it's this continuous thing.

PROF KING: Yes.

MS ABRAMSON: We do have a little bit of a time constraint. I think we've got the room until 6.00

MS BARIT: Sorry, I will finish.

PROF KING: No, no.

MS ABRAMSON: No, I didn't want to hurry you up. It's just that we have some logistical things.

MS BARIT: No, that's fine. But one of the thing that strikes me is because they are trained in such constraints that they don't have time to listen. They listen, but they don't hear, and I think, to me, that's one of the keys.

PROF KING: Yes.

MS BARIT: Because my daughter spent all that time telling each and every one of them. Right? And they all were there and she wasn't inarticulate, she could speak English. Do you know?

PROF KING: Yes, they're not listening to what she needs.

MS BARIT: No, they listen. What they didn't do was hear.

PROF KING: Hear; correct.

MS BARIT: And because it's process-driven, it isn't adapted. Predominantly after six weeks, everybody gets up and walks.

PROF KING: Yes.

MS BARIT: So that's my comment on that. I'm sorry I've taken so long.

PROF KING: No, no.

MS ABRAMSON: No, it matters a lot and it's very difficult; the story that you've told to us and it's very important to us.

PROF KING: Yes, it's very important.

MS ABRAMSON: And can I also say that the Commission is very sorry for your loss.

MS BARIT: Thank you.

PROF KING: Can I ask? Because what you've raised in an issue we haven't really dealt with in-depth so far, but I think we need to, which is that the clinical culture that you've discussed there at the end - because we talk about a consumer-centred mental health service.

MS BARIT: Yes, but - - -

PROF KING: But you can't have it if you don't have people hearing what the consumers are saying and - - -

MS BARIT: Yes. I don't like the word 'consumer'. You see I think consumer dehumanises.

PROF KING: Okay.

MS BARIT: 'Consumer' is like, you know, 'the human resources department'. Do you know what I mean? It depersonalises and people don't feel connected to it.

PROF KING: Interestingly, patient is usually viewed as worse.

MS BARIT: Yes.

PROF KING: So I'm not sure there's a good term of the persons.

MS BARIT: I think it's like branding. You know, to me branding is a corporate thing.

PROF KING: Yes.

MS ABRAMSON: Can we ask, where there any other - we've soon got to look at (indistinct). Is there anything else that you wanted to talk to us about?

MS BARIT: I want to add one more thing.

PROF KING: Please.

MS ABRAMSON: Sure.

MS BARIT: I have a background in disability. I worked in the Commonwealth disability services for at least 15 years. I worked with long-term unemployed, I trained people who are on the Work for the Dole scheme.

MS ABRAMSON: Yes; Job Active.

MS BARIT: Pardon?

MS ABRAMSON: I'm must talking about the programs. Yes, please, continue.

MS BARIT: So I have a reasonable background and understanding of services in terms of background and I couldn't (indistinct) my way through the system.

PROF KING: Yes, all right.

MS BARIT: That's all I'd like to add and I'm sorry to have taken so long.

PROF KING: No, no.

MS ABRAMSON: No, that's a very powerful testimony and we're very grateful because you sat through two days of hearing, and what you've said to us, the lived experience of people matters enormously to this inquiry.

PROF KING: Yes.

MS ABRAMSON: So thank you very much of giving us the privilege of listening to you.

PROF KING: Yes; to your story.

MS BARIT: Thank you for listening to me.

PROF KING: Thank you.

MS BARIT: I will put in my remarks about doctor training.

MS ABRAMSON: Thank you.

PROF KING: That would be fantastic because it is an issue that we have to understand and we have to grapple with.

MS BARIT: I think that is a big issue that the way doctors are trained, but more importantly, the pressure on them.

PROF KING: Yes.

MS ABRAMSON: Thank you very much.

PROF KING: Thank you very much.

MS BARIT: Thank you for listening.

PROF KING: Thank you.

MS ABRAMSON: So, Dr King, I think you can formally close the - - -

PROF KING: Well, I'll formally close the - - -

MS ABRAMSON: Adjourn the hearing - - -

PROF KING: Adjourn is the term. Yes, that's right.

MS ABRAMSON: Until next (indistinct).

PROF KING: Adjourn the hearings for today and we will reconvene on Thursday in Broken Hill.

MS ABRAMSON: Thank you.

PROF KING: Some of us will reconvene on Thursday in Broken Hill.

MATTER ADJOURNED UNTIL
THURSDAY 28 NOVEMBER 2019