REPORT ON PROCEEDINGS BEFORE

PUBLIC ACCOUNTS COMMITTEE (PAC)

INQUIRY INTO THE MANAGEMENT OF HEALTH CARE DELIVERY IN NSW

At Preston-Stanley Room, Sydney on Tuesday 31 October 2017

The Committee met at 9:35 a.m.

PRESENT

Mr Bruch Notley-Smith (Chair)

Mr Lee Evans
Mr Greg Piper
Mr Mark Taylor

The CHAIR: I declare open day two of the Public Accounts Committee hearing on its inquiry into the management of healthcare delivery in New South Wales. Good morning and thank you for appearing at this hearing, which follows the hearing conducted yesterday where evidence was taken from the Ministry of Health and other peak health organisations in New South Wales. Today's hearing will focus more closely on mental health services and individuals with direct experience of the health system. Before the proceedings commence, I remind everyone to switch off their mobile phones as they interfere with the Hansard recording equipment. Please do not switch phones to silent mode; they should be switched off completely.

For the benefit of people in the gallery, I note that the Committee has resolved to authorise the media to broadcast sound and video excerpts of its public proceedings. Copies of the guidelines governing the coverage of proceedings are available. I welcome Ms Lourey and Dr Smyth from the Mental Health Commission of New South Wales. Good morning and thank you for appearing today before the Committee to give evidence. As part of the formalities, please take the oath or make an affirmation.

CATHERINE MARY LOUREY, Commissioner, Mental Health Commission of NSW, affirmed and examined

TIMOTHY JOHN SMYTH, Expert Consultant, Mental Health Commission of NSW. affirmed and examined

The CHAIR: Before we proceed, do either of you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Ms LOUREY: No.

The CHAIR: Would either or both of you like to make an opening statement?

Ms LOUREY: I would like to make an opening statement. I thank the Public Accounts Committee for the opportunity to address today's hearing. The Mental Health Commission of New South Wales is an independent statutory agency established in 2012 and is responsible for monitoring, reviewing and improving the mental health system and the mental health and wellbeing of people in New South Wales. In all of our work, we are guided by the lived experience of people with mental illness and their families and carers who support them. As members would be aware, in addition to our written submission we have shared our "Review of transparency and accountability of mental health funding to health services". The funding review has been tabled in Parliament and is directly relevant to this inquiry. Dr Tim Smyth was one of the authors of the review and he is with me here today.

The mental health sector has been undergoing significant changes on a number of fronts for some years. The commission's concern is to ensure that these changes lead to comprehensive, person-centred, high-quality and evidence-based models of care for people experiencing mental health problems, including improved community-based services in line with the reforms adopted by the Government in "Living Well: A Strategic Plan for Mental Health in NSW 2014-2024". Since the transition to activity-based funding and devolved decision-making, local health districts and speciality health networks are increasingly responsible for determining service mix, staffing levels and models of care. A stronger local focus on planning and delivering mental health services built on detailed knowledge of local communities and needs is welcome. However, this has left a State-level planning and needs assessment vacuum. It allows the mental health system to progress reform and service development inconsistently across the State. As solely a funding and purchasing model, activity-based funding cannot by itself ensure access to high-quality evidence-based modelling of care for people with a mental health condition or for their families and carers.

For mental health, activity-based funding cannot take account of the other service supports a person may need to ensure that their improved outcomes from hospital or community treatment are maintained. Many people with chronic and complex mental health conditions will require longer-term coordinated care packages involving multiple providers across the health and human services sectors. Co-commissioning of mental health services in conjunction with primary health networks and other funders and service providers is increasingly likely in the coming years. Indeed, it is one of the platforms of the Commonwealth's National Mental Health Performance Framework.

The Mental Health Commission of New South Wales review of mental health funding confirmed that there are significant challenges with data quality in health care, especially for non-admitted and other community-based services. A strong governance and accountability framework, appropriate and effective implementation of activity-based funding, and transparent public reporting on performance and outcomes are critically dependent on quality data. In addition, the funding review highlighted a paucity of mental health key performance indicators in the Ministry of Health's service agreements with health services; limited review of performance, apart from financial results and activity against activity-based funding; and national rated activity unit targets in local health district and senior executive and board reports. It identified the absence of public reporting of outcomes for mental health services. The funding review provides a suggested way forward in response to these issues, and I commend it to the Committee.

Finally, I note that this inquiry was extended to take account of issues connected with seclusion and restraint. I acknowledge the review of these issues being led by the chief psychiatrist and advise the Committee that one of the commission's part-time deputy commissioners, Dr Robyn Shields, is a member of the review panel. The commission commends NSW Health for the training that has already been undertaken to reduce seclusion and restraint. However, the critical challenge is changing the culture within mental health units, ensuring there are robust quality and safety mechanisms and effective complaints processes. The trauma-informed recovery practice of multidisciplinary teams, including mental health peer workers, needs to be the basis of any mental health service model. It will go a long way in changing inpatient unit culture to become more humane and compassionate and to restoring the human rights of individuals when they are clients of the public mental health system.

The CHAIR: Thank you, commissioner. I will cut to the chase. Is the delivery of mental healthcare services in New South Wales in crisis?

Ms LOUREY: I would not use that word. There are many challenges, and I think there are many good services that are moving to the models of care that we need and to integrated services and links between inpatient units in the community and more broadly integration with other service providers, whether they be community-managed organisations or local primary health networks. However, there are areas where there is improvement, and that is most definite. I was in rural New South Wales recently, and the issues there are different from those in Sydney. When we look at the picture across New South Wales, we must be mindful that it is not the same everywhere we go; each community has its own issues, and some have large challenges. However, when I look at the broad spectrum, I think there is great change, but there is still a lot more to be done.

The CHAIR: There has been some criticism of this inquiry in that it is very focused, but not exclusively focused, on data collection and its transparency, distribution and utilisation. Your submission and your opening statement speak strongly in favour of data collection and its appropriate use. Do you think it is essential in reforming mental healthcare delivery in New South Wales to have the correct data?

Ms LOUREY: Yes, I do, but it is not so much the data, I would have to say; it is also that understanding, holding people to account, and system accountability. It is not whether we count things better, more clearly, more accurately and more consistently, which is obviously important, but it is how we use that information. Therefore, it is also around the mix of data. What we are also after is having data which is not only about activity and throughput but also about health outcomes and knowing that, after a person has an interaction with a public mental health system, indeed their health has improved and that can be in a measurable way. Therefore, we know that we have got value for money but also that we are having services that are effective and therefore based on good evidence-based practice. Would you like to add anything, Dr Smyth?

Dr SMYTH: I would agree. The importance of data is turning it into information that then is used to plan for better services, ensure that the service delivery is improving health outcomes and it is a challenge across the health system in moving beyond just counting things to being able to show the positive impact, or the negative impact, it is having on people's health—particularly people living with a chronic health condition. There is very good data about what happens inside a hospital. There is still very poor data about what happens outside hospitals across Australia in the primary care system, general practice as well as in community health and ambulatory care services. If you are going to be able to better plan services and to show that this service model is more effective, you have to have that information behind it. But I would agree also with the commissioner that the accountability side of things also is important because that in turn will drive better data quality. A saying that is often quoted is that if you wait for perfect data you will die before you get it; but if you start to use the data, things start to get better.

The CHAIR: So you are saying there is a lack of data outside the formalised hospital structure and a lack of integration of all the data across the various delivery systems.

Dr SMYTH: That is correct, and that applies across the Australian healthcare system. It is something that Commonwealth, State and Territory health Ministers acknowledge and are working on. There will be various elements about getting better interoperability between clinical information systems. As the MyHealth record becomes a richer data source, it will be able to provide a better basis for that. The Australian Institute of Health and Welfare has done a lot of good work, and continues to do, about looking at the various datasets and trying to get a picture about what is happening for people as they move through the system.

As we know, particularly for people who are living with a chronic mental condition, they will have care in the community, they will have care in the hospital and they will have care from a community-managed non-government organisation [NGO]. Carers provide a hell of a lot of care for people living with a chronic mental illness. They will have interaction with social support, Centrelink, and housing issues. They particularly have multiple interactions. If you are going to get a good picture about how they are going and looking to having better and improved outcomes, you have to look across that, not just at what happened inside the inpatient unit last week.

The CHAIR: In some of the submissions it has been mentioned that whilst the data is collected, it is not interrogated and used in a manner that can bring about cultural change within the organisations.

Ms LOUREY: The Ministry of Health has a section called Inform, which is its mental health data unit. There is a lot of data. The health system generates a lot of data. The knack is about selecting which data will inform upon change and inform upon clinical variation of practice. One of the roles of that particular unit is to look at the mental health performance data of individual services and benchmark that, and then go to each of the local health districts and have discussions around how practice or other issues may impact upon that performance. In response to your statement that we have a lot of data and do we use it to its full extent, I would say no; but I would also say that we are still not counting the right type of data, so it is still quite transactional. As Dr Smyth said, we are not measuring outcomes in a consistent way. For mental health, I think that continuum of care from the inpatient unit to the community also needs to be very clearly articulated. The community mental health data is incredibly poor, as are the datasets for our community mental health community-based organisations. The Community Managed Organisation [CMO] sector data also is very poor.

Mr MARK TAYLOR: Thank you, commissioner and Dr Smyth. Commissioner, in your submission you refer to training requirements in mental health units. You used the term "peer workforce". Would you make some comments around those?

Ms LOUREY: Yes. The peer workforce comprises individuals with lived experience of mental illness who then use their expertise with lived experience to bring that to work alongside and in one sense coach and mentor others who are on their own mental health recovery journey. A peer worker is not a volunteer. They are paid people. They can undertake a certificate IV course in peer work, so they also have a training or an education program themselves. The key with a mental health peer worker—and they are in New South Wales inpatient units and services as well is in the community managed sector—is that they are internationally an emerging workforce. Their strength is that they can bring hope to the individual. They can model recovery and they can also change the dynamic within the inpatient unit or the service so that it is a more caring and person-centred environment. I think that is really key because it not only gives hope to the individual as they go through their particular treatment program but also models the potential to the other staff. They realise that there is hope and that there is, I suppose, a greater understanding of the individual and their particular plight. That, in turn, goes to one of the other issues that I know is before the Committee, which is around the impacts upon seclusion and restrictive or coercive practices, because you may find that an individual can de-escalate much more with a peer worker and then that avoids the trajectory around escalation of issues that may result in a seclusion.

Mr MARK TAYLOR: That goes to your opening statement about cultural change. Do you have any other commentary around cultural change ideas?

Ms LOUREY: It is an interesting thing in mental health units where culture can have such an impact on the recovery journey of an individual and on the way that the teams operate. I do not think we would be talking about cultural change in an orthopaedic ward or in a maternity ward, maybe. It is an interesting thing in and of itself that the attitudes and the capacity, the skills and the confidence of staff can directly influence the kind of the therapeutic milieu of the unit, of the level of calmness, or the level of frustration. I think that there has been much research done on culture in units. There is a lot of evidence around what a good therapeutic model looks like—about having trauma and recovery focused models of care. These all bring together, I suppose, a much more person-centred environment in the wards. That is around training of staff, having them adequately resourced and having an environment where, as I said, the culture is a more collaborative person-centred culture. It makes a big difference and you will find that there is a lot of evidence around that.

Mr GREG PIPER: I want to talk about activity-based funding and things like that, but since we are talking about culture, there is one area I particularly want to go to because it is an area that has frustrated me for many years. Dr Smyth, we have met before.

Dr SMYTH: The Hunter Area Health Service.

Mr GREG PIPER: Yes.

Dr SMYTH: Indeed, back in the nineties.

Mr GREG PIPER: Yes. I am well aware of your extensive experience here, Commissioner. I have googled you as well.

Ms LOUREY: Oh right; excellent.

Mr GREG PIPER: I was pleased to hear you use the term "therapeutic milieu". We do not hear that used, or people do not understand what is expected of these places, but this is what we are trying to achieve. One of the ways I have observed this is through key staff who have not just the clinical training but also the life experience to be able to bring those things together. Often that takes a bit of time. It is not something that is achieved in the short term. Has it been your experience, or is it your view that we have lost the skill set that we need there?

Yesterday we received a report from the NSW Nurses and Midwives' Association. I do not know whether you have seen this yet, but I am sure you will. It was discussed today in the media. It is a raw document with survey responses from nursing staff. They touch on many of these issues, in particular, the loss of a generation of staff who are now retiring who have probably been in the system for a long time, and the loss of good mentors in the system. Do you have any view about the need for a good mix of skill sets and life experience within that frontline service, in particular in the institutional setting where some of these more invasive practices of seclusion and restraint are used, or with the example at Lismore that we are also discussing?

Ms LOUREY: I think you are correct in that the staff and the nursing workforce are under a lot of pressure. The ageing of the workforce is one of those pressures but we have a lot of good, new nurses coming up. Recruitment is an issue. Attracting people to work in mental health is an issue. I think we really need to look seriously at how we can have a sustainable workforce. I know the Ministry of |Health was here yesterday but currently the ministry is undertaking the development of a mental health workforce strategy. The culture and the issues of retaining and recruiting nurses is a key part of that. It is definitely something that goes to training; it goes to resourcing and it also goes to leadership. There are so many changes in mental health—in the expectations of the community and in the expectations of patients and of their families and carers—that there is a new dynamic. I think nursing, as well as allied health professionals and others in the multidisciplinary team, have to find a new way of working. That is part of the issue. We are developing a new model and we need to pause, reflect and look at our education and training. Are we equipping nurses and supporting them in the right way through this change period?

The CHAIR: Dr Smyth, do you have any further comment on that area?

Dr SMYTH: The only additional comment I make is by way of context based on my experience and work in public sector health services. In some ways I feel that mental health strategically made a mistake by seceding from the health system a couple of decades ago because they thought that would protect them. We ended up with separate mental capital works, mental health budgets and mental health training. Everything was separate. It was not intended but in my view that enabled the rest of the health system to say, "Mental health is your problem not our problem." What has been happening now, particularly over the past decade, is trying to reintegrate mental health so that mental health is everybody's responsibility. Emergency department staff know full well that they need to have skills about managing people with a mental health condition.

Increasingly, we know that people living with other chronic illnesses will get depression and will have other mental health problems. A comprehensive cancer service needs to have mental health skills. We know that within a workforce, whether it is in health or elsewhere, we need to have a mentally healthy workforce. Industry and other businesses are realising that mental health is their business. I think strategically mental health made the mistake of seceding and now we need to bring it back in. In that way I think it will improve the skill mix and also the capabilities of staff, whether they are nursing, medical or allied health. The separation of the mental health system also I think made it harder to recruit and retain staff because the mental health system decided that it would only treat people when they got severely mentally ill. Almost bizarrely you had to go downhill before you could get into the mental health service and then come back up again. We now know through stepped models of care that that is not the right approach to take.

There has been a variety of factors as well as the background factors of the age of the health workforce. Increasingly, and quite understandably, people want to work part time; there is a difference in family and carer responsibilities and rural workforce issues, and mental health is not immune from those. Philosophically, as you can tell, I think one of the problems was that mental health seceded. There are all sorts of examples. A hospital campus would be rebuilt but the mental health unit would not because that is in mental health capital works. Fortunately, that is starting to change.

Mr GREG PIPER: You have identified a large systemic failure that is not seen in the short term.

Dr SMYTH: Yes, and I think it happened by accident rather than by design. Mental health thought that would protect them but in effect I think strategically it was the wrong decision for mental health as a system to take.

Mr GREG PIPER: I come back to comments about resourcing mental health. Your submission and your opening comments referred to activity-based funding, which seems to me to be quite good for a lot of areas—it is certainly good for accounting and auditing—but perhaps it is not so good in every circumstance. In particular, you identified that this is a system that fails to address the community-based provision of services to the benefit of bricks and mortar, institutional-type settings. Have you approached the Government about this? Has this been flagged before? I understand that it is part of an upcoming submission.

Ms LOUREY: Yes. We tabled our report in Parliament in July. I suppose the fundamental issue around activity-based funding is that it does focus on the inpatient episode of care without understanding, as Dr

Smyth just said, that if you have more funding in the community you can divert an admission, or avoid an admission, and that the efficacy of that inpatient episode is dependant upon what happens after discharge. Your costs around that episode will vary from local health district to local health district. The issue regarding the model is that because the inpatient episode does not give any recognition to what happens after discharge, you could in effect be purchasing failure, which means you could be purchasing a seven-day admission. But you know that if there is no community follow up and no active community-based services are available to that person you will end up with a readmission. When you do that costing, if you want that investment in the inpatient unit to be the best value for money for the hospital and the best outcomes for the individual, you need to have a costing that goes across those services so you know you are purchasing a package for the individual.

Mr LEE EVANS: I would like to broach a subject that was brought up during the public consultation at Lismore. It was difficult as it was a government-led campaign against smoking. It was about psychiatric patients who go in and part of the whole process is that they have to give up cigarettes and that causes them to be aggravated and obviously upset, although they are on patches and other things. De-escalation of violent outbursts can be achieved by these patients sitting down and having a cigarette. Another part of the government-led campaign to get people off cigarettes is to ask: Is it the right time to put somebody who is having a psychotic episode on a no smoking program or should the primary aim be to get them off the psychotic episode and worry about their smoking as a follow-up? I understand that the facilities are set up for non-smoking but for someone to give up smoking while they are having a serious psychotic episode is probably secondary to getting them through that psychotic episode. Do you have any comments on that?

Ms LOUREY: I would offer a comment that it comes down to the decision of the treating team but it should be made with the person at the time and you would hope also that that person would be able to engage with their service in a way where they could also have an advanced care directive. When you are well you are working with your team and you can say, "Okay, if I come inunwell and I get admitted, these are the kinds of things how I would like to be treated ", so you can do some planning around that. The only other observation I would make, which is really general, is that smoking is a major health issue for people with severe mental illness.

You probably are aware that people with severe mental illness on average die 25 years younger than the rest of us and that really is outrageous from my perspective. It goes a bit to what Dr Smyth was saying earlier around siloing—the physical healthcare needs of people with serious mental illness are as important as their mental illness. It has to be seen as a whole-of-person treatment model and support for them. Yes, I believe that smoking reduction and cessation is really part of the whole strategy of enabling people to live healthy and longer lives. In regard to how we engage with individuals, each person should be able to make those decisions and they should be able to be supported by their treating team or their case manager ahead of an admission.

Mr LEE EVANS: Another comment that came through—it is a personal story—was that the person with mental illness, Tourette's, did not want to try to seek help, knowing full well that they needed it but because that regime was there they avoided getting help.

Ms LOUREY: Yes, it is not very person-centred care, is it?

Mr LEE EVANS: No, it is not.

Dr SMYTH: It seems to me that it is more an issue about how it is done and how the policy is implemented. The science behind the policy is sound. As the Commissioner said, there is clear evidence about a significantly shorter life expectancy for people living with a chronic mental illness than a comparative group of people who do not have chronic mental illness. It is not because of suicide; it is because of heart disease, it is because of obesity and it is because of smoking-related disorders. It is because unfortunately sometimes mental health services do a very good mental health assessment but no-one took the blood pressure and the client has not been connected to a good general practitioner [GP]. I am not saying that we do not have good GPs but everybody living with a chronic mental illness needs to be connected with a GP who understands them, is competent in managing the mental illness in the primary care setting but also is making sure that they are looking after their physical health. That is a significant gap that we have in Australia.

The Royal College of Psychiatrists in the United Kingdom, I think to its credit, raised this issue and got that College energised about it before the College in Australia did. The College in Australia is now energised about it. That is another gap that we need to close—the gap between physical health and mental health. So it is how it is done. If that person is not willing to come back to the inpatient unit there may be other care settings where they can have their assessment and care managed, and they do not have to come into the inpatient setting. There are also the occupational health and safety issues about staff in the unit. There are also other patients in that unit who may not wish to be exposed to cigarette smoke. Then of course they might be smoking something else other than tobacco.

Mr GREG PIPER: You correctly identify that this cohort of people who have a particularly long-term mental illness do have reduced life expectancy. One of the things you did not mention was the long-term use of psychotropic drugs, which is a significant factor in that. The question that Mr Evans referred to about smoking has some relevance in that any of us would clearly understand that somebody in an acute—and it is the minority—very reactive, aggressive psychotic episode, who is a long-term smoker, is probably going to have their situation exacerbated when presenting voluntarily, or maybe more likely involuntarily, and told, "You are now giving up smoking". The survey referred to earlier from the Nurses Association stated, "Smoking or rather no smoking has been the biggest cause of physical aggression in acute mental health units. Before the punitive law was enacted nurses had far less issues with aggression in acute units."

I do not wish to go in to bat for smoking per se because I agree that it has a huge impact on each person, but also it has side-stream smoke and third parties are affected. However, I asked NSW Health representatives yesterday their views on perhaps allowing the use of e-cigarettes in those situations to try to deal at least with the initial problems. Therefore, we do set aside pretty well for most purposes side-stream smoke or third party impacts. There is certainly enough debate to suggest that perhaps e-cigarettes are not as bad as smoking, regardless of the fact that they provide nicotine. Do you see any way in which something like this could be explored as an alternative or some compromise, given that people are exposed to not smoke but aggression that could cause harm to those persons or to those trying to provide care?

Ms LOUREY: I think we do have to be real around people's expectations. Smoking is an addiction; it is not a choice. But I would have to say again it is how that individual is engaged with their mental health team and it is how they come together when that person is well. If a person has complex needs and chronic care needs that person will be a known client to the service. It is really around not waiting until they get to the inpatient episode to have those discussions ahead of time. I acknowledge that where there are incidents on units or wards we need to be mindful of all the people who are on the ward, whether they be other patients or staff. I think that the local health service therefore needs to be much more focused on how they manage that and to engage with their staff. If the nurses are feeling that this is an issue that needs better management, indeed it needs better management.

Mr MARK TAYLOR: Commissioner, you made recommendations on legislating the Chief Psychiatrist. What are the reasons around that recommendation.

Ms LOUREY: And strengthening the roles?

Mr MARK TAYLOR: Yes I want some commentary around that.

Ms LOUREY: The role of the Chief Psychiatrist is a particular and important one. We are seeing evidence of this through his independent leadership of the current review. There are other jurisdictions where the Chief Psychiatrist has more authority and we think that this would lend strength to the New South Wales position. I would also say that it is how Chief Psychiatrists exercise their current roles and responsibilities and engage with others in undertaking their work. In some aspects I think it would be worth pursuing other models such as in Victoria. In New South Wales we have a Clinical Excellence Commission, the Agency for Clinical Innovation, the Bureau of Health Information and other organisations that go some way towards meeting those public reporting and other functions that other jurisdictions do. We could look at how the NSW Chief Psychiatrist's position operates, but I think it has to be seen within the broader accountability and public reporting that we have within New South Wales.

The CHAIR: The Mental Health Commission of NSW and the Bureau of Health Information [BHI] were developing a public report about mental health services in New South Wales. That project was discontinued due to the unavailability of data in the Ministry of Health. What were the reasons given by the Ministry of Health for the unavailability of this data?

Ms LOUREY: The reasons that were given were primarily around problems with the robustness of the data, the timeliness and the comprehensiveness. I understand since that time the Ministry of Health is now actively working with BHI to reignite that project. I look forward to the Ministry of Health and BHI commencing that work.

Mr GREG PIPER: This Committee has to look at important issues relating to seclusion and restraint. The commission has been involved in producing policy that hopefully is applied that talks about alternatives to seclusion and restraint. Realistically could you talk to what they might be in a practical sense? What alternatives could best be applied rather than seclusion and restraint?

Ms LOUREY: I can take this on notice but there is a lot of evidence and we have a lot of sites across New South Wales and Australia where seclusion and restraint have been reduced. At the national level the Beacon project looked at trialling evidence-based interventions to reduce seclusion and restraint and there was great success. We need to start from a base where we know it can be done and we know it can be successfully done in a safe way. Having said that, those interventions are around improved training, de-escalation, greater informal interactions between staff and clinicians, peer workers and having an environment that is not so contained. At the heart of all that is also listening to people's lived experience, people who have experienced seclusion and people who have been on wards where there is a heightened level of concern or aggression. We need to understand that it is also about having designs for our inpatient units so people have safe spaces to go to de-escalate and to get away from other people who may be irritating them. They are all human at the end of the day but they may just need some time out. It is also about having a facility that is designed to allow people that space.

When we look at how our patient cohort is changing in our inpatient units—and by that I mean having people with more acute illnesses—we could say that is a good thing. That would mean that people who can be treated and supported in the community are not going to an inpatient unit unnecessarily. We just have to be mindful that if that is what is changing in our inpatient units we also have to step up to that and think about what it means for our staffing and what it means in designing our inpatient units so we can manage the recovery of those individuals in a safe way and they can de-escalate and we do not have aggression. Also we have to be able to allow our staff to operate in the best way possible. They are professionals and they are educated. People do not want to become mental health nurses, psychiatrists or allied health workers without a commitment to working with people to improve their outcomes. We also need an environment where they can work to the top of their professional level.

Mr GREG PIPER: We come back largely to what you were talking about earlier—the culture, and having staff with the skill sets, experience and confidence to use alternatives.

Ms LOUREY: Yes.

The CHAIR: Dr Smyth you mentioned earlier that it was critical for people with a chronic mental health illness to have a competent general practitioner. What is your experience of the level of competency within the general practice cohort?

Dr SMYTH: It has improved significantly over the past 10 to 15 years. That has been a combination of general practitioners and their practice nurses and their other staff recognising that they need to get more competent as well as confident about managing patients who have a mental health condition. The College of General Practitioners and the training program for GP registrars now has a much stronger element in relation to mental health. Then groups in New South Wales such as the Black Dog Institute—and I am a director—does a lot of programs about training. I think we have still have problems when a person who is living with a chronic mental health condition may not necessarily have good carers support in social isolation and they will not have a regular general practitioner. They may use an emergency department or drop in to a medical centre.

There is a need to connect people so they are connected to a GP who will continually be part of their treating team. That allows the mental health services to link in with that GP as well and it becomes a mutually reinforcing system. But I am much more optimistic than I would have been in the 1980s. We have come a long way. The ability now of a general practitioner to pick up that there may be a mental health issue, even in the proverbial 10 minute consultation, is much better than it was 10 or 15 years ago. It is going to be a never ending story. We need to continue to work on that.

The CHAIR: Within the general practitioner cohort is the acceptance of the role of psychologists improving in your opinion in dealing with mental health problems rather than a psychiatric approach to it?

Dr SMYTH: Yes, very much so. Also programs are now available through the primary health networks for general practice to refer patients into counselling and psychology services at no cost to those patients. There is coverage under the Medicare benefits scheme for that now. So there is the opportunity to do that.

I do not think people say that the answer to every mental health condition is a tablet; it is very much a multidisciplinary approach. That would include practice nurses as well as psychologists and counsellors, and even reception staff. You can see that in practices that have a reasonable cohort of patients with a chronic mental illness. Their reception staff are different. They are better able to manage appointments and when people arrive they make sure things are happening. Those practices tend also to have a practice nurse. There are also specialist mental health nurses who are funded. However, there are not enough specialist mental health nurses who want to work in the community in a general practice. The funding for that program is again provided through the primary health networks. There are many practices that now have a funded specialist mental health nurse as well.

The CHAIR: Thank you for appearing before the Committee today. Members have asked a number of questions on notice. Would you be willing to provide answers within 14 days?

Ms LOUREY: Yes.

(The witnesses withdrew)

ELYSE SUEWAH CAIN, Policy Lead, NSW Council of Social Services, affirmed and examined

The CHAIR: Welcome to today's hearing. Do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Ms CAIN: No.

The CHAIR: Would you like to make an opening statement?

Ms CAIN: Thank you for the opportunity to appear at this hearing. I am sure members are aware of the work that the NSW Council of Social Service [NCOSS] does, but for the benefit of the people present I will make some comments. NCOSS works with and for people experiencing poverty and disadvantage to see positive change in our communities. We represent the health and community sector and support it in delivering services that develop and grow as needs and circumstances evolve. We generally operate under the principle that when poverty and inequality rates are low, everyone in New South Wales benefits. In this context, we approach key issues such as health and healthcare delivery through an equity lens to shine a light on the unique and significant impact that these issues have on people who are experiencing or who are at risk of poverty and disadvantage in New South Wales.

As I am sure members are aware, our submission to this inquiry focused on oral health as an area that is too often overlooked and treated as secondary to general health. We know that the impact of poor oral health can be far-reaching on people's lives. For people experiencing poverty and disadvantage, it can compound and entrench that disadvantage further. Results of our cost-of-living surveys from the past two years—the reports of which I have with me and which I am happy to submit as additional evidence—have shown that access to affordable dental health care is one of the top priorities for people living under the poverty line in New South Wales. We are failing to provide an adequate level of care to those people who need it most in this area.

We see part of the problem as a lack of extensive and routinely collected population-based data. This lack of data makes it difficult to track trends accurately and to change overall oral health, and also the oral health of particular vulnerable groups over time. This makes it very difficult to develop targeted and effective policy responses to address these gaps and to support delivery of these services. Our priority is to ensure that there is enough investment by the New South Wales Government to improve access to timely dental care for those who need it most, and that there is robust and integrated data to support this service delivery. That is the focus of our submission and I am happy to take questions.

The CHAIR: Thank you very much. As you said, your submission focuses on oral health and states that data is collected only on the quality of dental services provided, which results in a lack of comprehensive, routinely collected population-based data in this area. Do you think that is indicative of a lack of population data in all areas of health care?

Ms CAIN: I think there is always more that can be done in collecting data about health outcomes in population-based groups. One of the reasons we focused our submission on oral health is that in our view it seems to be an area that has significant information and data gaps. We know that the Centre for Oral Health Strategy in the Ministry of Health is doing work in this space and recognises that it is an issue. However, it needs more support and resources from the Government to be able to approach this from a coordinated perspective and to ensure population-based data is collected across all primary health networks and local health districts across the State. That is particularly important in regional and remote New South Wales, where we know access to dental health services and dental health outcomes is particularly bad. The needs of these areas should be mapped, and we need data to be able to support that.

The CHAIR: Rather than data being collected for the sake of collecting it, obviously patient outcomes and data on them are critically important. How are we doing that in New South Wales?

Ms CAIN: In general?

The CHAIR: Yes.

Ms CAIN: I am not an expert in a number of areas around data. However, a lot of good work is being done, particularly in looking at health outcomes in Aboriginal communities and how service delivery in regional and remote New South Wales is interacting with the health outcomes for groups in those areas. More work could be done in not only oral health but also mental health outcomes, particularly for vulnerable young families with small children and babies. There is a data gap in that area as well. We are definitely on the right track in the information we have available and what we know about vulnerable groups in New South Wales. However, more certainly needs to be done to link specific health outcomes with specific vulnerable groups, and particularly location-based data, and to understand how we can improve service delivery in the areas that need it most.

The CHAIR: In your submission you state that the information published by NSW Health relating to wait times is not accessible in a way that enables consumers to understand how long they can expect to wait for a particular procedure. Can you expand on that? What information would you like to see made available?

Ms CAIN: The way NSW Health and other health groups in New South Wales provide statistics means that consumers must trawl through a lot of information on websites to access what they need. If you are someone for whom accessibility might be an issue—you may have vision impairment or an intellectual disability, for example—that kind of information is not available in a format that will make it easy for you to understand how much time you will need to wait in order to access dental treatment.

What we would want to be seeing are things like: Is it a very accessible, clearly formatted, plain English portal for health consumers to, at the click of a button, see what is the likely amount of time you will be waiting if you were to put your name down for dental assessment and treatment today, and how long it would take for you to be able to access that treatment? It needs to be something that is very patient-centred and person-centred. It needs to be co-designed with health consumers and above all it absolutely needs to be accessible.

The CHAIR: At the moment, are the wait times triaged?

Ms CAIN: I am not aware whether or not they are triaged. My understanding, and from what I am aware is available, is that they are split at the moment into wait times for adults awaiting dental assessment and then those waiting dental treatment: I am not sure if those are triaged. But, as far as I am aware, that triaged information, if it is triaged, is not available to the public.

Mr MARK TAYLOR: As a matter of interest, obviously Aboriginal communities in western New South Wales are suffering from a disadvantage as far as oral care is concerned. What other groups in the community did your research detail as suffering from a lack of the availability of dental care?

Ms CAIN: When we talk about vulnerable groups, we are talking about, obviously as you have mentioned, Indigenous communities but we are also talking about people from culturally and linguistically diverse [CALD] communities—culturally and linguistically diverse backgrounds—and people who are living below the poverty line in New South Wales and also those who are living in regional and rural New South Wales. Generally, right across the board, health outcomes in most areas, not just in oral health, are always poorer for people who are from these vulnerable groups.

Mr MARK TAYLOR: Does your research indicate that it is more prevalent in rural communities than in remote communities?

Ms CAIN: The extent of our research is really confined to our cost-of-living surveys, which is of around 400 households in New South Wales living under the poverty line. What we do know from those results is that regional respondents are more likely to see that lack of services in their area as a barrier to accessing affordable health care. Twenty-five per cent of respondents from regional New South Wales would agree with that statement, as opposed to 12 per cent of respondents in Sydney. Certainly, for people in regional and remote areas there is a perception that there are a number of barriers to accessing health care, whether it is due to the fact that those services simply are not available in their area or and perhaps relatedly that they do not have the transport options available to be able to leave the local area and access those services where they are available elsewhere. Certainly from consultations that we have had in communities over the last couple of years and from what we see in our cost-of-living surveys, that is certainly a much bigger concern for communities in regional New South Wales than in metropolitan New South Wales.

Mr GREG PIPER: Ms Cain, in the NSW Council of Social Service [NCOSS] submission, it refers to a bottom line being the cost or the funds that might be needed to address the shortfall. You have suggested an additional $25 million be allocated to oral health services in New South Wales. How has that value been derived? Who has NCOSS worked with to identify this? Is it a proportion of the overall Commonwealth ask? A lot of this is often debated in that Federal arena, not just at the State level. What the States typically have argued is that they need more support there. Can you elaborate on how that $25 million was identified and how it would then be applied under the scenario?

Ms CAIN: I have to take that question on notice because we do have our costings process that was around that pre-budget submission from last year, which predates my time at NCOSS. I will have to check that for you and get back to you on that. But certainly that is something that came out of our pre-budget submission to the New South Wales Government, so it is funding that we sought at the time from the New South Wales Government. Since that time in the 2017-18 budget $10 million was dedicated towards expanding oral health services, which was fantastic and absolutely a step in the right direction, but generally our position is that there still needs to be more funding in this space.

Mr GREG PIPER: Ms Cain, rather than using the term "the additional cost" to service, it is more like an investment in good health in that poor oral health affects so much of a person's activity—their ability to find work, access to other health services and things like that.

Ms CAIN: Yes.

Mr GREG PIPER: Has there been any work from NCOSS or an attempt to identify the savings across the State or the benefits that would accrue from that additional investment?

Ms CAIN: No. That is not work that NCOSS has done previously, but we do work very closely with bodies like the Australian Dental Association, who I am sure have that type of information available to them.

Mr GREG PIPER: Okay. Thank you.

The CHAIR: Is there an area in health care that you believe, or NCOSS believes, sets the benchmark for population-based data collection and for service delivery?

Ms CAIN: Without saying that I do not think there is a shining beacon for data collection and information, certainly what we have seen in the data around health outcomes in Aboriginal communities I think is absolutely where we sort of need to be and it is a step in the right direction. But across the board, there really needs to be a lot of improvement in population data collection across a range of health areas and not just specifically in those areas but also how they interact with each other. Obviously, within health there are a lot of intersecting issues and interactions between different health systems and things like that. In some ways, while there has been great work done in the Indigenous health space, how that communicates and interacts with the data that is being collected, or the lack of data being collected, in other areas also is a concern.

The CHAIR: There are no other questions. Thank you for appearing before the Committee today, Ms Cain. The Committee will have further questions that we will send to you in writing. Are you happy to receive those and reply to them within 14 days of their receipt?

Ms CAIN: Absolutely.

The CHAIR: Thank you again for appearing before the Committee. Your evidence has been very helpful.

Ms CAIN: Thank you.

(The witness withdrew)

(Short adjournment)

ROBERT GEORGE ILAHI RAMJAN, Chief Executive Officer, Schizophrenia Fellowship of NSW , affirmed and examined

ANTHONY WALTER FORSTER HARRIS, Chair, One Door Mental Health, affirmed and examined

The CHAIR: Before we proceed, do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Mr RAMJAN: No.

The CHAIR: Would either or both of you like to make an opening statement?

Mr RAMJAN: We will make a very brief opening statement. One Door Mental Health, formerly Schizophrenia Fellowship of NSW, commenced in 1985. It is a unique coalition of people with a mental illness, their carers, workers in the mental health field and supporters. We have approximately 350 staff, around 500 volunteers, offices in more than 40 locations across New South Wales and the Australian Capital Territory, and close to 70 support groups. It is no surprise that people with a mental illness are still the subject of inadequate services. There has been at least one inquiry or royal commission report completed every year since Federation in this county. What is happening here today is not new. In 2002 the upper House Pezzutti inquiry into mental health services is a recent memory. The New South Wales Mental Health Sentinel Events Review Committee in 2005 is more recent. The fourth report into the Tracking Tragedy process in 2008, of which I was chair of the working party, is even more recent.

There is clear evidence that the day of highest risk of completed suicide for a person with a mental illness is on the day of discharge. The next day of highest risk is the second day after discharge. Various studies in Australia and internationally identify that the first 28 days after an admission are a very high risk for a person completing suicide. It needs to be accepted that the major mental illnesses are life-threatening for people who have them and services should be built around that risk. We are not asking for anything special for people with a mental illness. All we are asking for is parity—parity with other illnesses and parity with the treatment available for those illnesses. It should be recognised at the outset that mental illness is a burden on health in this State of around 14 per cent. The funding for mental health services should be around 14 per cent, not around the 7 per cent that it currently is. We also have some information for each member of the Committee.

The CHAIR: Excellent, thank you. You mentioned that the highest probability of suicide is on the day after discharge.

Mr RAMJAN: On the day of discharge.

The CHAIR: On the day of discharge. Does that suggest that people are being discharged too early and/or that primary and community care is not there for them?

Mr RAMJAN: I think it suggests a range of things. Maybe some people are being discharged too early. Maybe some people are not getting the follow-up as required. One of the things in the pack that we have for the Committee is a piece of independent research on a hospital-to-home program that we ran in three locations in New South Wales, two metropolitan and one regional. It was run over a period and the independent research was done by the University of Sydney. Our team was a peer team, so people with a mental illness linking with the person in hospital and accompanying them at the point of discharge, with a six-month follow-up. In that period there was not one suicide attempt and only one readmission to hospital for the group of people involved. There was no cherrypicking; whoever was referred got into the program. It could be that people are being discharged too early. It could be that they are not getting the support that they require in the transition to return to home.

The CHAIR: Do you suggest that this program may be the model that should be adopted?

Mr RAMJAN: I do not think there is a one-size-fits-all, but this is a model that we have demonstrated that works. We have taken it to the Federal Department of Health to try to get funding. As proof of concept, they looked at it. Minister Hunt's policy adviser looked at it and said, "We no longer need proof of concept. You have proved it." So we have a proved model.

The CHAIR: Will you describe to the Committee the characteristics of the program?

Mr RAMJAN: Because it is peer-to-peer we will have somebody who has tertiary qualifications sitting at the top of the team, but all of the workers are peer workers. One of the most important things in the area of mental illness is a trusted relationship, which can be a trusted therapeutic relationship. The peers are able to trust each other much more readily than they trust a community mental health worker or a hospital worker.

There is a degree of empathy, a degree of knowledge and a degree of shared experience, having been through the same process. People are being discharged from hospital back to their accommodation, wherever that might be, with no food available, no money available. Our team is able to assist with those things, to make sure that the person is going back, that there is food there and they can help them go shopping. They can look after the basics of life, not necessarily in a clinical way but in a naturalistic, humane way, to make sure that they are set up for their return to the community.

They also create a link point. There is massive evidence around this. In the United States people being discharged from hospital were sent a postcard at one week, two weeks, four weeks and three months. It dramatically reduced the readmission rate for those people, just sending a postcard that basically said, "We care. What is happening? What is going on with you?" A lot of the solutions to problems in the mental illness field are not high tech and they are not super intensive. They are just: Let us care. People need hope. We operate in the field of hopelessness. A professor of psychiatric nursing at a mid-western university in the United States did research. The control group just got standard treatment. The test group got standard treatment and three to five messages of hope each day. This is something everybody can do. It worked. It was highly significant in the difference between the two cohorts.

The CHAIR: Professor Harris, please add to the discussion whenever you would like.

Associate Professor HARRIS: The problem of completed suicide is a very difficult one. There is no single solution to what is a multifactorial problem. The international research suggests that you need to approach it from multiple different points of view. That goes to things such as reducing access to means. That goes to having good education of general practitioners. Part of what we are saying is that excellence in follow-up is a part of that matrix of care which needs to be there to try to fill in the gaps.

International literature would suggest that that sort of intensive after-hospital care is an important component. By itself, it is not the whole solution. Obviously you need to have that backup by expert community mental health teams and by general practitioners who can provide appropriate care for the severe exacerbation of the mental illness that caused the person coming into hospital. But the continuity of care—care by people who have been in the shoes of the person who is coming out of hospital—from that peer worker is an important part of that matrix and can help to reduce completed suicide rates.

The CHAIR: And that is sadly lacking at the moment?

Mr RAMJAN: The policy in New South Wales is follow-up within seven days when we know that the risk is on day one and we are not getting 100 per cent follow-up within seven days. I think it is somewhere around the 70 per cent mark. If we take the evidence that exists, one of the things in your pack is a document from—

Associate Professor HARRIS: It is 1995 or 1996.

Mr RAMJAN: Some considerable time ago, which notes exactly that—that this is a point of risk. It is a public health bulletin from 20 or 30 years ago so we have known about it for a while. The policy is follow-up within seven days and we are not getting beyond 70 per cent with our follow-up. Our program, the hospital to home—whether it is our program or something else—the follow-up has to be on day one. It has to be in the transition from the hospital to home.

The CHAIR: Why is that follow-up only reaching 70 per cent? What do you put that down to?

Associate Professor HARRIS: There are a number of reasons. Partly it may be things such as the number of people who may be needed to be followed up, partly it may be the perception of whether they do need to be followed up. Not everyone needs to be followed up and the need to do that may be still a little unclear. The important thing is that there is a differentiation between the expert care of the community mental health teams and the type of caring that a peer or a hospital-to-home type program can provide. It is a more intensive level of care. It is less on the timetable of mental health teams that have a wide range of other things to do and are understaffed at the best of times. It is care that is able to be there, recognising the needs of the individual who has been discharged from hospital and to help them pick up. People have come into hospital from an environment which has not been sympathetic, which has not been supportive enough for them. Sending them straight back into that same environment is asking often for a repeat unfortunately, so trying to change something about that is very important.

Mr MARK TAYLOR: The submission makes reference to the disparity between the treatment of public and private mental health patients. Do you have any commentary about that?

Mr RAMJAN: One of the difficulties that has existed for a long time is the lack of integration between public and private. People can see a private psychiatrist and private psychologist and that has created barriers between public mental health services and the private system in not necessarily sharing information and not collaborating. The thing that some people with a mental illness really need is a single consistent plan that everybody is working towards. That interface between public and private has waxed and waned. There have been Ministers for Health of both Labor and Coalition persuasion who have talked about the need to integrate public and private mental health services and who have issued memos saying there should be no barrier between someone seeing a private psychiatrist and still accessing the public mental health system but we still do not have that in place. The lack of equity in the process for somebody going into a private psychiatric hospital can be there for a period until they are settled in a public hospital. The risk is always there that on Friday their manager is looking for the least unwell people to discharge so that there are beds available for weekend admissions and that is a risk point for the person who is discharged without immediate follow-up in that discharge process.

Mr GREG PIPER: I want to touch on an issue that has been topical of late for obvious reasons and that is around seclusion and restraint. You have addressed that specifically. You have said there can be better ways of dealing with it. I would like your views generally about seclusion and restraint. I note the concerns you raised in your submission about the lack of data around that area; I think it is the first time I have seen it written down that there is not necessarily any way for the official visitors to be able to audit the number of times seclusion is used. I would like your view about the application of seclusion and restraint typically within our public institution type settings?

Mr RAMJAN: Let us look at it from a variety of different perspectives. I used to work at Cumberland Hospital, a government psychiatric hospital, back in the 1970s. We did not have seclusion. Why?

Mr GREG PIPER: Chemical restraint?

Mr RAMJAN: No. We had observation wards with open doors and had nurses sitting within those observation wards. So there was a male observation ward. I worked in psychogeriatrics but prior to that I worked for NSW Health, Health Services Research, doing research on the comparison between schedule 1, 2 and 5 psychiatric hospitals, and Cumberland Hospital was one of the ones we looked at. The nursing staff would be on observations and in 1920 two admission wards, there was a male observation ward and a female observation ward and at both ends nursing staff sat there. There were no seclusion rooms being used. It was a nursing management issue how to deal with those people. Yes, occasionally if somebody was disturbed medication may well be given to calm them down. Is that preferable to locking somebody in seclusion in a room with bare walls, a mattress on the floor, a tin in the corner? I think it probably is. I think it is probably less traumatising for the person to have their symptoms dealt with in a medical way rather than to have the symptoms dealt with in a brutal, harsh prison way.

To go a step further than that, how is seclusion used in other places? I have been lucky to see a number of admission units in various places around the world. The hospital that reportedly had the best recovery rate in the world was in India just outside of Agra. They had no seclusion rooms there at all. I have seen forensic hospitals in Japan where they do have a seclusion room and the patients book time in the seclusion room. It is not a punishment; it is a place of calmness and respect. They book time in there. This seclusion room is one that has a queen-size bed in it, is properly made up and has a television on the wall. The back wall is plate-glass and outside that is a waterfall and the sound of the water coming out of the waterfall comes into the room, so they book time in it.

The comparison between what we do and what is done internationally is massive. The other thing that I would throw into it is the NSW Police Force. The NSW Police Force mental health intervention team in its four-day training gets de-escalation training. De-escalation has to be the first choice and not, "Let's bang somebody up in a room and leave them there so that they can learn their lesson." These people are unwell, and are not necessarily in control of what is happening. What they need is caring de-escalation and not isolation.

Associate Professor HARRIS: I add that this is where the funding difference between the general medical care that I might see in Westmead Hospital where I work and the psychiatric units comes into play. So additional care, additional hands, specialling—or double specialling as it used to be called—is an important way of doing that. But if you do not have the funds to bring on those extra hands, the intensive care version, I suppose, of psychiatric care gets cuts down to its bone and that unfortunately may be a seclusion room. The other part of this which I think is important is that as part of the seclusion process people are often given medication. They are given an injection quite forcibly. Considering the large numbers of people who come into mental health facilities with backgrounds of abuse or trauma, that is really quite a markedly re-traumatising event for those individuals as they are in the place that is trying to give them treatment. When I teach my junior doctors how to do that safely you are talking about at least five people assisting to hold that person. That is a traumatising experience for everybody, I would have to say. Increasing that level of care so you do not have to go to that extreme is very important.

Mr RAMJAN: The hospital that I should just quickly mention, which I forgot about, was the admission unit in Canberra in the Australian Capital Territory. I understand that they have a seclusion room but they do not use it. When you go into that admission unit—Peter Norrie was the Chief Psychiatrist I visited and he has shown me through—the staff are meant to be on the floor. It is very rare that staff will not be on the floor. The main area of the admission unit is like a Qantas club. There are lounges, there is a barista and it is a lovely environment to be in. At the time that I visited it had been open for about 18 months and they had had no assaults on the ward, no use of the seclusion room, one patient had gone over the wall, which was a fairly low wall, and within a day had brought themselves back. So there are models within the country that are worth having a look at.

The CHAIR: You were working at Cumberland Hospital in the 1970s and you did not use seclusion?

Mr RAMJAN: No.

The CHAIR: In this day and age how did we arrive at a situation where patients in the mental health system are treated in this traumatic and almost brutal way. How can that be an accepted form of practice within the mental health system?

Mr RAMJAN: To be honest, I do not know. I think one of the difficulties that exists, which I guess should be considered by this Committee, is the workforce itself. It is becoming harder and harder to recruit psychiatric nurses. Prior to that, when I worked at Callan Park back in the late 1960s and early 1970s the nursing staff was a mix of males and females. In the late 1960s and early 1970s a lot of the male nurses who were still working at Callan Park were ex-servicemen, so you had some big blokes on the ward. They were not big blokes who were involved in what I think was called a take-down. The big blokes would go up to somebody in distress and put their arm around their shoulder and quietly talk into their ears. I think a hell of a lot more work needs to be done on recruiting, developing and valuing our mental health workforce. I think the average age of a psychiatric nurse in Australia is somewhere in the mid-fifties now. We need to be attracting younger people who will learn how to do the job and stay within mental health services. We bleed good staff to other areas on a regular basis.

Mr GREG PIPER: Earlier I raised with the mental health commissioner the skill set and experience of frontline clinicians. By the way I was a former mental health psychiatric nurse at Morisset. It was a similar period—not in the 1960s but I had similar experiences. I asked whether there was a loss of an important group of people within those frontline services who were particularly good at mentoring. I imagine that in that role you would have had people who would have mentored you as a young healthcare professional and perhaps you mentored others. It seems that we are losing a lot of those people and I do not understand why. Do you agree that that is a problem? We are not upskilling people or we do not have people with life experiences who could do exactly what you describe—that is, go up to a person in distress and, rather than do a take-down, put their arm around them and gently de-escalate the situation?

Mr RAMJAN: I think it is an essential part of the mental health service. We need to value our staff. It is not just the nurses; we lose psychiatrists to private practice and we lose occupational therapists to the insurance industry.

Mr GREG PIPER: Domestic staff—everybody who interacts with a client can be beneficial but can also be an aggravator. That is more of a comment.

Mr RAMJAN: I think we need to value the staff. We need to keep them and we need to find the means to continue the training of staff. Mentoring I think is critically important. Systems can change when experience is lost. Somehow we need to rebuild it because I think we have lost a lot. The recovery concept, looking at mental illness, is not a hopeless course to deterioration, disability and death. But looking at it as a model where people can regain skills, have a meaningful life and have a contributing life, as the National Mental Health Commission says, puts the positives into it. It should be an attractive area for younger people coming through the professions and joining them. I think all of us—Government, the Department of Health and the non-government sector—need to do a lot more to ensure that we attract those people and we keep them. In the non-government sector we are forced to employ people under the National Disability Insurance Scheme at Social, Community, Home Care and Disability Services [SCHCADS] levels one, two, three and four. This is a pretty poor rate of pay and we are not going to keep staff at that rate of pay.

Associate Professor HARRIS: The only thing I would add is that this country went through a period in the 1970s and in early 2000 in which there was very little investment in mental health services and that meant that those services ran down. I am sure in some of your site visits you may have visited some mental health facilities that are quite antique—

Mr GREG PIPER: We call them heritage now—

Associate Professor HARRIS: That are heritage. That run down in physical circumstances was linked to a run down of support for clinicians on the ground. That made it harder to stay within mental health services and made private practice, when those opportunities arose, much more attractive. So there was a steady drain of staff out of the public service. That is a reflection of past neglect.

Mr LEE EVANS: I read your report which states that more than 10,000 people accessed your services and that 6,000 outreach calls were made. I refer to your point about suicide prevention and follow up. Do you have any data that backs you up and that shows those outreach phone calls made a difference?

Mr RAMJAN: No academic data. One of the great difficulties being non-government is that we do not get funding to do research. Anecdotally, we have very strong evidence. My mum has been one of our outreach volunteers for 17 years so she has been calling a bunch of people on a monthly basis for more than 17 years. She delights in telling me about the progress those people have made. These are people who have a diagnosis of chronic paranoid schizophrenia with co-morbid drug and alcohol problems who over that period have avoided readmission to hospital, have had some training and got a job, and got married. Anecdotally there have been many. For us to do the research requires money we do not have. There is evidence internationally. The postcard thing I talked about before has been done. There is also evidence out of the University of Stockholm, but I forget the guy's name. They have done controlled research around these kinds of interactions and what the outcomes will be. We do not have evidence, but internationally there is evidence that says these things will make a difference.

Mr LEE EVANS: I am not expecting you to provide anything other than anecdotal evidence. Over the 31 years, do you think you have avoided people taking their own lives as a result of the follow-up calls?

Mr RAMJAN: Without a doubt. We also have an outreach service or crisis line, but it is used less and less now. We have had calls from people who were contemplating suicide and we have been able to talk them down. Where we have not been able to, we have called emergency services to assist them. Yes, I have absolutely no doubt we have had an impact. Beyond that, have we had an impact on quality of life? There are so many stories, and I will relate just one. We have a clubhouse at Balgowlah that provides psychosocial intervention for people with a mental illness. It is a model that has been around for a long time. Some people view it as being out of date or archaic, but it is a model that works. It started in the United States in 1948. Within that model there is a program called "Transition Employment".

We learn the job and then we train someone with a mental illness to do it. We finally found a job in the staff canteen at the Novotel Sydney Manly Pacific—the five-star hotel on Manly Beach. The person who was going to do the job was someone who in the old scheme had hebephrenic schizophrenia—I think it is now called chronic undifferentiated schizophrenia. She was child-like in her behaviour and was quite unwell. She was in her mid-thirties and had never worked. We spent nine months getting that job, but as chief executive officer I said, "No, she can't do it. Someone else must do it. We spent nine months getting the job and someone who can do it should do it." The members came back to me two days later and said, "We've looked at the standards. It's her turn and she has to do it. If we lose the job, tough luck. We'll find another one."

That woman exploded in that job. She has moved from being in a NSW Health group home to a Housing NSW home to private rental. She has never stopped working, and she is able to buy makeup and clothes that suit her body shape. She has not had an admission since, and that happened in 1998. There are many stories like that, not only about suicide but also about people recovering. In some ways the recovery is much greater than simply improved quality of life and coping with the illness; the illness has actually moved into the background.

Mr LEE EVANS: That sounds like a success to me.

Mr RAMJAN: You can do the calculations on hospital bed days saved. Our clubhouse at Balgowlah did a review and was able to identify a 95 per cent reduction in hospital bed days for its clients. We established another clubhouse in Tamworth called Billabong. In collaboration with the Government mental health service, it was able to identify a 93 per cent reduction in hospital bed days. You would think therefore that there would be fewer patients in the beds, but in Tamworth the beds were still full. It is not an immediate saving. However, the staff said there was not the pressure there had been to move people out quickly. People were able to be treated until they were well enough to be discharged.

The CHAIR: Thank you very much for appearing before the Committee today. Your evidence has been very enlightening. Are you happy to provide written replies to any further questions the Committee may have within 14 days of receipt?

Mr RAMJAN: I am happy to.

Associate Professor HARRIS: Yes.

(The witnesses withdrew)

BRETT ANTHONY COLLINS, Justice Action Coordinator, affirmed and examined

YOLANDE LUCIRE, Private Practice Psychiatrist and Forensic Pharmacogeneticist, Justice Action, affirmed and examined

NICHOLAS SUMMERHAYS, Justice Action Assistant Coordinator, affirmed and examined

DOUGLAS JOHN HOLMES, Justice Action Mental Health Consultant, Justice Action, sworn and examined

KERRY ANNE O'MALLEY, volunteer, Justice Action, sworn and examined

The CHAIR: Before we proceed, do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Mr COLLINS: No. We are quite comfortable, thank you.

The CHAIR: Excellent. You may have realised that we are having public address challenges, so I need you to speak into the microphones; otherwise, we cannot hear you. The Committee members might also do so. Would any or all of you like to make an opening statement?

Mr COLLINS: I have asked each member of the team to speak for two minutes. Each person has a separate and particular point of interest and focus. First of all, I will address the Committee. The Justice Action position is unique. When I say "unique", I speak in terms of our standing alone and taking positions working directly with mental health consumers. As a person who is more involved in the prison area—and Justice Action is best known for the criminal justice area—we are so surprised that we have to take the position we take on mental health. We stand by ourselves continuously. We are doing what we have to do at this moment. We actually would like to stand aside and have a mental health consumer organisation in the same form we have to take our place. In the interim, we take that position.

I have some more materials to hand to the Committee. I know we have given you a fair amount of material already. We would like to give you another two items: One is the newspaper that goes to all the mental health consumers nationally. It is for people who are held in detention and, I say particularly carefully, people who are both in the criminal justice system and the mental health system in locked hospitals. One is a newspaper. It is the only national paper to go into those areas. We also would like to give to the Committee a copy of the "Our Pick" report. It is not referred to in the documents that we have given to you already. The "Mad in Australia" document is referred to and that is part of the documentation, but the "Our Pick" report is also an essential part of what we are offering. I will draw on the opening paragraph in the "Our Pick" report, which was published in 2010. It was published internationally in Ireland as well as in the Forensic Hospital in New South Wales:

> The OUR PICK Report accuses the Australian health industry of corruption and proposes the empowerment of mental health patients and prisoners to achieve effective delivery of services.

It comes up with a proposal, which is an enabling proposal that would allow an organisation, such as Justice Action, to exist and to be self-sufficient. Our position is unique and we say that very carefully. Our position is unique insomuch as we support ourselves. We do not ask for any money from anyone. We have our own social enterprise, which allows us to stand by ourselves, and we have support from the general community who give us work for a social enterprise that is a printing and design company called BreakOut Media Communications. It has been running for 33 years. It runs on the back of organisations like unions and also community groups, including mental health organisations, giving printing and design work to our social enterprise, which goes straight into Justice Action and keeps us independent of any government support. In the past, we had government support.

At one stage I was chair of a company that ran a halfway house. When the Government disagreed with our submission, which was totally correct, it then withdrew our funding. From that point on we decided that we could not perform the function we had, which was representing people inside prisons. We withdrew from the funded organisation and set up our social enterprise. What do we propose if that happens again? Our position in relation to mental health is really clear. The National Mental Health Commission said that our publication, which is called "Mad in Australia" and which is part of a submission, is pretty much "a necessary voice of the people who are in the system who cost upwards of a million dollars a year a person". That is a statement from the National Mental Health Commission about this publication, which is part of our submission. Our role in talking for mental health consumers is longstanding. I was asked to speak for Justice Action at the National Mental Health Commission as one of the six experts in Australia on the issues of forensic mental health patients. That was a position we took and we were asked to present on their behalf.

I do not wish to go any further with that, but there are a couple of things I would like to say. One is that we would like support for an organisation such as Justice Action to be set up in the mental health area. We are happy to be part of that support. We would like that to be the position in Callan Park in relation to Rose Cottage, which is currently not being used. It used to be held by the Mental Health Coordinating Council. For a period of three days we sat in the ambulance station saying, "This is an area that should be set up for a social enterprise space for mental health consumers." For a long time we put a proposal to the Sydney Harbour Foreshore Authority and we had the support of mental health organisations across the board. We have to really gauge it a little bit but we are looking for Rose Cottage as a base for a consumer organisation to be set up to properly represent mental health consumers. Justice Action would be very happy to support the base for that.

The essential part of our statement is that what happened to Miriam Merten is standard behaviour. We disagree entirely with what the Coroner said. There is a structural problem involving mental health. We are shocked and disgusted about the way the health department has treated people who are vulnerable and who are disabled. We see it as par for the course. Unless they are significant changes we will see it again and again. We will maintain our standard and we will continue to criticise in the way we have. In 2010 we issued a statement accusing the mental health industry of corruption. The Miriam Merten case is what you would expect when you get vulnerable people who are not able to speak for themselves. We look for the Committee's support and ask for support. We have some proposals that we would like to develop a bit later in our presentation.

Dr LUCIRE: I have brought in a document published yesterday on a website called Mad in America after Robert Whitaker's first book. There are six copies there. I have also brought in a brief email from a woman in Hungary who, by my assessment, has chronic post-traumatic akathisia. She is going to die. She is going to commit suicide. I get three of these a week from Australia and everywhere else. My colleagues do not recognise the late post-withdrawal or post-withdrawal akathisia. There is a major problem in the education of psychiatrists in Australia who do not know the difference between mental illnesses, which cannot be diagnosed until every other cause of their symptoms has been eliminated, and medication-induced states. It is a systemic error of Australian psychiatry that has grown and grown since the nineties. I have been a psychiatrist for 52 years. I have a six-page curriculum vitae [CV], a multidiscipline PhD in public health, and half a dozen or more papers on the discipline of pharmacogenetics.

At the moment there is a petition being circulated for a royal commission into psychiatric practices because psychiatric practices in Australia are inconsistent with our human rights obligations. My submission was a commentary on the recent study of mortality and morbidity in people taking psychiatric drugs. Has any of you read part of it? Okay. The point about mortality is that it is underpinned by morbidity, which means that for everybody who dies from psychiatric drugs and from various forms of organ failure there are probably 30 or 40 admissions, and they cost money. For everybody who commits suicide, there are 100 people who have suicidal ideation and 20 who are admitted for suicide attempts. I was under the impression that this Committee is an accounts committee and I focused on those things that generate costs. The human elements of it are obvious; a second is corruption, but the corruption comes from the pharmaceutical industry. Five minutes on the internet will tell you that we have approved drugs in Australia that have paid massive fines under the False Claims Act in the United States.

We have no way of dealing with these pharmaceutical problems. The drug companies are foreign donors and they give to both sides of politics. They are capable of destroying people. They have damn near destroyed me by putting in the paper that I was ordered into treatment by the medical board and the registrar of the medical board just laughed and said the journalist got it wrong. That is the sort of thing they do. They have damn near destroyed my practice. But it gave me what they call gardening leave. That is when I retrained myself in the discipline of pharmacogenetics and now I am one of the major authors in this discipline, specialising in antidepressant and antipsychotic-induced suicides and homicides and their relationship to metabolising genes. That is how I used my time when they destroyed me.

The regulators are captured. The Australian Prudential Regulation Authority [APRA] and Medical Council are captured by the Royal Australian and New Zealand College of Psychiatrists, which takes the position that it does not believe the contents of presciber information or the warnings of suicide and homicide put out by the United States Food and Drug Administration, which has the data. Australia—I think it was a little earlier; it was in the time of John Howard and Tony Abbott—signed a free trade agreement with the United States and we adopted the procedures used by the Food and Drug Administration for licensing drugs, and they are vanishing low. A drug needs to surpass sugar pills in two clinical trials on any criterion they like in order to be approved, and there has to be approval. Thank you for your time.

Mr SUMMERHAYS: I wanted to talk briefly about the importance of computers in prison cells and how that can improve the outcomes for prisoners generally and for mental health. First of all, if prisoners are locked in their cells for up to 18 hours a day, that is 18 hours when they are not achieving anything. If there is a computer in the prison cell—obviously with a reduced capacity to access the internet so it is secure—it provides opportunities for the prisoners to receive online counselling—probably face-to-face video counselling. It provides an opportunity for them to educate themselves, either through TAFE, university or an informal education. It also allows them to reduce the social isolation of being locked in prison. They would be able to email approved email addresses to communicate with their friends and family.

What we have seen is that education in prison can reduce recidivism by about 36 per cent and improve the outcome of you getting a job after you leave prison by 13 per cent. I think that having computers in cells allows for prisoners to improve themselves in such a way that is going to reduce the costs to society and also improve their mental health outcomes.

Mr COLLINS: Can I just intervene at this stage. Mr Summerhays is talking about is what has already been agreed by the Government—to give New South Wales prisoners access to computers in cells. That applies equally to people who are in mental health facilities. We are really talking about mental health facilities as well. This has already been agreed to by the New South Wales Government for prisoners but mental health patients have not received that benefit.

Mr HOLMES: I have been involved in mental health reform in New South Wales since 1992 when I was diagnosed with bipolar effective disorder. I have been working in both a voluntary and paid capacity. I was executive officer for the NSW Consumer Advisory Group, which is now called BEING, for six years. For the past 11 years I have been working at St Vincent's Hospital as a consumer participation officer. I am now 67 and I am lucky enough to have access to a pension and I am semi-retired. I will give you my reason for supporting the work that Justice Action does. When I was with the NSW Consumer Advisory Group I was often warned to steer away from particular topics. In 2003 I approached Mr Collins to try to raise the profile of people being treated in the forensic system. I approached him to try to highlight some of the treatment of people in the forensic system and also in some of the hospitals.

There is enough evidence of that with some of the cases we have taken to the Supreme Court. The one thing I think will help is if this Committee could give some thought to the Mental Health Act that drives how people are meant to be treated. They slipped in a section called section 195 which simply says, "This section overrides section 3, section 68 and section 105." Those three sections relate to the objects of the Act. So the objects are gone. The rights are dealt with in section 68, and section 105 deals with the amount of force that people can use to administer medication, which leads to coercive practice. I am happy to talk more about some of the work that we have developed with consumers being employed in the system and some of the benefits it has created.

Mrs O'MALLEY: This is just a little of my experiences with mental health. Forty-seven years ago I became a single mother and had the baby adopted out. There was a lot of grief for me at that time. I had no real support after the birth. I became sleepless and had no appetite so I was placed in Prince Henry psychiatric hospital where I was given Stelazine every day and injected every two weeks with Modecate, the most horrible drug. I was told it was just like a vitamin injection, but it was not. This went on for seven months and I became severely depressed and apathetic. After the seven months I was discharged and found it nearly impossible to put my life back together again. That was the beginning of my introduction to mental health.

Three years later I entered into a very difficult marriage with a man who loved alcohol and gambling more than me. We have four children, three of whom were born under general anaesthetic. Three times I came out of the anaesthetic in a psychotic state and was immediately placed in the psychiatric ward and medicated heavily for many weeks. It was very difficult then to bond with the babies and look after the babies. On the birth of my last child I asked for an epidural and there was no psychiatric intervention that time. Over the years I did not handle stress well and I had many hospital admissions, one of which came close to ending my life. This time the treating psychiatrist overdosed me and I ended up in a coma. It took me months to recover from this dreadful occurrence and there was never any apology.

After discharge from each hospital it was expected that I would stay on medication but I could not because it always made me feel worse; that is, it caused me to be depressed, apathetic and feel abnormal. Mental health began to enforce community treatment orders. Those times when I breached them they sent ambulance officers and police to my home who removed me in handcuffs. During the past seven months I have had to endure mental health interference again with forced injections of Paliperidone and Epilim tablets. Dr Lucire believes both are unnecessary for me. I am still experiencing side effects of anxiety and depression.

In early 2015 Dr Lucire ordered genetic testing for me, which proved that I cannot properly metabolise many of the drugs that have been forced upon me. Since then other treating psychiatrists continued to ignore the results of the genetic testing. They also ordered this testing 11 years ago but failed to do so. It has been most distressing to find myself disrespected and controlled by this unhelpful system of the health department, which has had a detrimental effect on my health and risked my life. Thank you for listening.

The CHAIR: Thank you for sharing.

Mr COLLINS: Could I just make a comment, please?

The CHAIR: Yes.

Mr COLLINS: Kerry O'Malley is the focus of our presentation. On 17 October, two weeks ago, we represented Kerry O'Malley before the Mental Health Review Tribunal, arguing that she should not be forcibly medicated. She had undergone that degradation over a period of years. We won her case back in May 2015—Yolande Lucire and the Justice Action team that you see here behind you and her sister beside her, yet the health department still forcibly medicated her back in March this year. Two weeks ago we had to stand beside her again, only us—Justice Action only—an unfunded organisation, no lawyers, and we defended her and won because we had a compelling case but the health department fought tooth and nail against us to continue her forced medication.

Now that is the sort of behaviour we are talking about. That is why we look for support from the Committee to ensure that there is a group such as Justice Action to do the job. The Mental Health Advocacy Service, as established, is a part of the Legal Aid Commission and has a number of lawyers who have continually let down mental health consumers. We went to them and asked them again and again for support. They have stopped us; they have blocked us from access to case histories. When we prepared this mental health information sheet, which is a negotiated document with the Mental Health Review Tribunal, right after we went to the Supreme Court three times with people such as Kerry O'Malley to stop the forcible medication and finally had an agreed document with the Mental Health Review Tribunal and the Mental Health Advocacy Service, which is supposed to be the legal aid organisation supporting people like Kerry O'Malley, it would not even engage with us with that document.

We saw an email between the two leading people who said, "Should I answer this? I am not going to put names to it." This is one of the Mental Health Advocacy Service lawyers talking to the head of the service. That is disgraceful and that is the standard situation. That is why it is not good enough for the client to say, "This is just one senior nurse who is responsible for what happened to me"; this is a structural problem for which we need an answer. We should not have to do the work behind Kerry O'Malley. We are all volunteers. I am an old age pensioner too. It is not my job; we do not want to do it but we are doing it because we have to do it. We are looking for support from you people to make sure we can set up a structure of some sort that will make a difference. If we do not do that, it is a disgrace.

Dr LUCIRE: I would like to say a few words about the Mental Health Review Tribunal. I was working in the prisons around 1992 when it was established and it was established because the belief then was that psychiatrists were keeping their patients for too long and if they no longer had an hallucination or a delusion they had to be released. The Mental Health Advocacy Centre was funded for $2 million, which would be the equivalent of $10 million today. I am not quite sure what has happened but now the thing has turned into the exact opposite of what was intended, that is, they argue that if a patient has once had an hallucination or a delusion they should be maintained on medication.

The literature on maintaining people on medication shows that they have one-third more admissions because of neurotoxic states. They have admissions for neurotoxic states and not for mental illnesses, which is completely wrong and I do not know who told them. It is a sham. If you have a tribunal that routinely believes a junior nurse who has never met the patient, who appears for the health department over my report, including pharmacogenetics, having signed the expert code of conduct, giving them the epidemiology, the risks and the micro stuff about why this patient cannot tolerate that drug and if she must have a drug she has to be metabolised for a different pathway or a lower dose, the onus of proof should be on the health department to prove why they want to maintain a patient.

The situation now is that the patient says, "This drug makes me want to kill myself; it makes me want to kill other people." So what do they do? They enforce it. Instead of a 1per cent mortality rate, which they had in clinical trials for these drugs because they removed anybody who said they were suicidal or violent, we now have a much higher rate of suicide and death because these patients, who would have been removed from the clinical trial, are now on enforced medication. There is something completely upside down there. There are, I believe, 16,000 people in New South Wales on forced treatment. I was a psychiatrist for a good 20 years before forced treatment was introduced. We negotiated with the patient. We found the right drug and the right dose for the right amount of time, took them off it slowly and some of them never had another breakdown. Thank you.

Mr GREG PIPER: You come at this from such a radical, different position.

Dr LUCIRE: That is correct.

Mr GREG PIPER: I accept that. I am fascinated by the pharmacogenetic side being brought into the mental health environment. While I am aware of it being used, particularly for targeted things such as cancer treatment and the like, it is an obvious one that should be developed. Thank you for those insights. Mrs O'Malley, you gave a very moving but brief overview of what you went through and I thank you for that. I have a question around the issue of restraint and seclusion, which is a big part of what you talk about. If we set aside chemical restraint at this stage—I understand what you say there—I would like your comments on alternatives to physical restraint and seclusion. I know you have already addressed this but I would appreciate further insight.

Mr COLLINS: I would like to deal with it, if you do not mind. We have addressed two national forums that have been set up on reduction of seclusion and restraint, so we have dealt with all the key psychiatrists from all the States and Territories and produced documents. I think one of the documents is part of our submission. We have spent a long time on this. A lot of data has been done on seclusion and every State and Territory, after deciding that some people have done it badly—with youth in Western Australia being six times the rate of other places—it was decided, "Oh, let's normalise it". Then it came to the issue of restraint. The issue of physical restraint is not problematic. If people are going to hurt other people, punch other people and that sort of thing, there are many ways of dealing with that; we have a proposal for that.

The issue of chemical restraint is something that has been snuck in underneath that because that is of much more significant concern to everyone here and to people like Kerry O'Malley. The consumers all say, "This is a big issue for us because we can't get out of bed really." A whole range of things come out of that. It is very easy management and a big temptation. What we said to the 9th National Forum of Seclusion and Restraint was, "You're doing really well because you are now doing data acceptance of seclusion. That is great. How do you know you are not just moving the people who were previously held in physical seclusion into being chemically medicated instead? You are doing really well in reducing that but are you just transferring that group into chemical restraint and medicating them in a way you didn't do before?" There was a hushed silence there.

The question was asked again and again and they all dodged it. So we then very carefully looked into how is the medication given to people and what is the documentation of that medication given? We then put a proposal to each chief psychiatrist right across Australia and everybody who is an expert in the area—all the academics who were engaged. We went to them all and we said, "What about supporting a proposal that at least you document whether or not the consumer wants the medication that you are giving them. Just say yes or no." A leading expert at the University of Melbourne who had been allocated by the National Mental Health Commission said, "You are right. This is an issue. We should examine it." We said, "Okay, what about having support for it?" We tried to engage them all and they all dodged.

Let us not ignore the issue about chemical restraint. That is a very live issue. It affected people like Kerry O'Malley and there might be about 16,000 people in New South Wales who are on community treatment orders who are required to take the medication that they are given. We have a key proposal. We do not want people suddenly to go mad and to run around like idiots. We want people to survive. They are our people; they are our families. We came up with quite a few different proposals but the strongest one of all is having people who have experienced mental health issues themselves as consumer workers, as peer workers working beside the person, or as mentors.

Someone who has had a problem and who has had a mental health issue themselves is the best person to be a mentor for others. You have them sitting beside them trained and employed. The very people who had a witness, you use the strength of their experience, you train them and then they have a function and they may even get a bit of money—it does not need to be much money. They have a function, they get training and they are working beside the person who has the mental health issue. It means they then have a friend and someone who they can deal with. It is a win for everyone. Then you do not have the psychiatric nurses saying how difficult it is for them because you have people who know what it is like to be on the receiving end of mental health assisting them. You have the patient, the consumer, taking responsibility for their own lives. Instead of having people forcing things on them you have them engaging and taking responsibility, which is an essential part of it.

Mr GREG PIPER: Mr Collins, I was not trying to diminish the issue of chemical restraint; I understand how significant it is. I was saying that chemical restraint is a blanket-type approach that will suppress somebody over a long period. I want to know what alternatives there are to the immediate issue of restraint or seclusion in acute episodes?

Mr COLLINS: We accept the crisis situation. In fact, that is exactly what we did with the situation with Kerry. Kerry had an experience which was a crisis situation for her. She was under a lot of stress. She had just come back from Ireland. She had been six months with no medication at all and she came back and did not have a home to go to. She came back really stressed and then she could not get to sleep. She identified the problem and then she needed some support to deal with it. At that stage she agrees that she needed some sort of intervention but it needed to be crisis intervention. That is what was being offered by Dr Lucire who said that there was no problem. We have a personal management plan which is an advanced directive—

Mr GREG PIPER: Can Dr Lucire make a contribution?

Dr LUCIRE: The increased need for restraint, and the increased rate of suicide and homicide under mental health care started with the ADHD drugs but really shut up with the new generation antipsychotics and antidepressants, all of which have akathisia, which is my area of expertise, as a side effect. Akathisia is associated with suicidality and violence. The people that they have to put on restraints have akathisia. They have been given the wrong drug at the wrong dose. Older drugs like core Chromocene were marketed as major tranquilisers. These new drugs are not tranquilisers. The more they give them, the worse they get.

Mr Collins talked a person who had died. That would be an akathisia case. I can prove it to you on a one-to-one basis. Kerry was an akathisia case. It all boils down to the education of psychiatrists, the fraudulent promotion of psychiatric drugs in Australia compared with the United States, and the role played by peer opinion leaders who are hugely funded by the pharmaceutical industry in creating government policy. I can only imagine the big fight they must have had with the National Mental Health Commission in order to get this study done. There are people who say "This does not happen. These drugs are good. This is somebody with a mental illness." I have watched psychiatry for 52 years now and I am no fool. I saw it going up and up and it is the drugs.

Mr HOLMES: Just to give a short answer to the question, in about 2005 NSW Health brought over some people from America who talked about six principles that needed to be put in place to allow seclusion and restraint to be reduced. They were able to demonstrate it through data. The stumbling block in New South Wales is the nurses union. They have been very rigid in the way that they have worked. One of the strategies was around how they got consumers and carers involved in developing what we call advanced directives or care plans and some de-briefing that went on. If you went to NSW Health you could get data to show where the units are using these six strategies and where there is a large reduction in the amount of seclusion. As I said, the nurses union is causing a lot of the problems at the moment.

The CHAIR: The Committee may request you to appear at subsequent hearings when it delves into matters much more specifically.

Dr LUCIRE: Thank you.

The CHAIR: In the meantime are you happy to answer any questions in writing that the Committee may send you?

Dr LUCIRE: Yes.

Mr COLLINS: Can I ask one thing? I note that one of the functions of the Committee is to examine the Government's use of resources and associated financial costs. I draw attention to the resource of Callan Park which is currently not being used. The Rose Cottage there is vacant. We are caring for it. We are maintaining it and making sure it is in reasonable sort of order. We would like some support for that to be the base for setting up an organisation such as our own. We would just support it. We do not ask for any funding to do so. There is enough support outside of the mental health industry for that to happen. If we could even just get some sort of supporting statement for the development of Rose Cottage as a consumer-based organisation to support mental health in New South Wales we would give support to that and not ask for any money to do so. That would be a very useful thing for this Committee to support.

The CHAIR: The Committee is not in a position to be able to give you any support at this point in time until it finalises its report.

Dr LUCIRE: I heard why nurses are not going into psychiatric care. I footnoted the questions asked in this Parliament—until New South Wales stopped releasing the figures—which showed that eight people were killed by mental health patients—patients being treated by NSW Health annually. Most of them are nurses and healthcare workers. The union is useless. They should be up in arms about it.

(The witnesses withdrew)

JENNIFER MARY ALLEN, private citizen, sworn and examined

The CHAIR: Thank you for appearing before the Committee and giving evidence. Do you have questions about any procedural matters?

Ms ALLEN: No.

The CHAIR: Do you wish to make an opening statement?

Ms ALLEN: Thank you for this opportunity to share my experience. I am here to represent the memory of my brother and to honour the unwavering care my parents gave him throughout his struggle with paranoid schizophrenia. I am also here to represent the malcontent of the carers and consumers who access services provided by Hunter New England Mental Health. My submission outlines the failure of mental health services to provide psychiatric care for my brother two days before he took his life. My submission does not outline the 17 years during which we struggled to get him help. Nor does it outline the failure of the mental health system to engage services within the community to provide ongoing care after his discharge from the Mater Mental Health inpatient unit in 2014.

First, I will provide some background to the primary reason I decided to make a submission to this inquiry. My brother lived in his unit for approximately 10 years. It was on one of the busiest main roads linking the Hunter Valley to the Newcastle city. His door was approximately two metres from the road. He sat in his doorway on a blue milk crate and watched the world go by every day for 10 years. He was a constant landmark on people's journey to and from the city every day for 10 years. He had become an icon, although we were not aware of his notoriety until after he passed away.

When my brother passed away, I put a post on my Facebook page informing our family and friends of our loss. I added that there was an off-chance that they may know my brother. I stated his location and his daily spot in his doorway. I also informed them that he had paranoid schizophrenia. When I changed the privacy settings of that post to "public", within only a few hours my post had more than 5,000 shares. The people of Newcastle were all talking about the man in the doorway. For the first time, his constant yet silent presence in their everyday life had a name—Bernie Sessions. The tributes began to flow immediately. Those who drove past or took their daily exercise past his door began to create a shrine of remembrance. Hundreds of bunches of flowers, teddy bears from schoolchildren, cards, notes and prayers were left by his doorway. A local street artist also made a large mural, although he did not know my brother or my family.

Giving the man in the doorway a name and telling his story personalised mental illness. I was receiving hundreds of messages from people in the community telling me about the man who lived in their doorway—be it their husband, son, brother or friend. It was my decision to go public with the news that Hunter New England Mental Health had refused Bernie care two days before he took his life that caused the social movement in Newcastle. When my brother died, he was born again through the groundswell of community support to mobilise change. The death of my brother and the community engagement soon drew the attention of the media and our politicians. ABC Radio Newcastle notified me that its Facebook story had reached more than 500,000 people.

I will now return to my submission. I did my best to use the terms of reference for my submission, but I found they were not central to the main issues that are festering in our mental health system. When the horrific footage of Ms Merton wandering the corridors of Lismore Base Hospital mental health facility were leaked, it was not only the people of New South Wales who were left speechless. Our leaders were also deeply affected by the abhorrent treatment of Ms Merton. The New South Wales Minister for Health and the Minister for Mental Health announced there would be an inquiry into her tragic death to investigate whether it was part of a much wider systemic problem. The concern that Minister Hazzard and Minister Davies publicly flaunted over the treatment of Ms Merton led one to believe that their motivation to investigate the failing mental health system was legitimate.

However, once the impact of the incident wore off, so did the Ministers' vigour in investigating the system that allowed it. The parliamentary inquiry they promised did not eventuate. Instead, it has been tacked onto this existing inquiry. I call for an independent inquiry into the New South Wales mental health system. One of the things I want to achieve through my mental health awareness campaign is to bolster conversation about people's experiences with mental illness. I believe that together the people and the professionals can produce a world-class mental health system that empowers, supports and rehabilitates. We have your expertise and the frontline knowledge of the people. I hope that we can all work together to meet the needs of the marginalised and the mentally unwell people of New South Wales.

The CHAIR: Your submission points to a lack of consumer data sharing between the health services, specifically general practitioners and mental health services. How do you think data sharing in the area of mental health care can be improved?

Ms ALLEN: It let my brother down because there was no communication or collaboration between his general practitioner and the service that ejected him from its referrals. When he was released from the mental health unit in 2014, they did not put him on a community treatment order. Perhaps they should have. However, that information did not seem to get passed on to the treating team in the community. If it had, they might then have imposed a community treatment order themselves when they saw that Bernie was no longer coming to his appointments. He stopped going to his appointments because he was too anxious. He was severely paranoid, but there was no follow-up. He just slipped through. If the general practitioner who was administering his medication had been working in collaboration with the mental health service or the treating team, he might have been able to notify them that Bernie had not been to renew his medication. He had stopped taking it for months or years, but the service dropped him.

The CHAIR: And he had not seen his general practitioner in those years?

Ms ALLEN: No. But there was no conversation between the treating team and his general practitioner to verify that. They assumed he was taking his medication because he said he was.

Mr MARK TAYLOR: How did you find your involvement as a carer? Did you have access to information about your brother's treatment?

Ms ALLEN: My mother was my brother's main carer; I was in the background a lot. There was not a lot of conversation about Bernie's mental health. We did not really know we were carers.

Mr MARK TAYLOR: Do you know if your mother tried to obtain information about your brother's treatment and was unable to get that?

Ms ALLEN: Do you mind if I ask her?

Mr MARK TAYLOR: I am sorry. No.

Ms ALLEN: Is that okay?

Mr MARK TAYLOR: Yes.

Ms ALLEN: I do remember going to the doctor with mum because we were concerned that he was so unwell, so paranoid and so erratic. We could not get a team to go and visit him. But, no, the doctor did not provide any information.

Mr MARK TAYLOR: One of the other things raised was having like a helpline boosted up to more like a 000 line. Do you want to make some comments about that?

Ms ALLEN: Absolutely. The mental health helpline is a good idea, but it acts as a wall. It is just another barrier to try to get through to get help. On the day I rang, two days before my brother passed away, I explained the situation but I did not ever get to speak to the treating teams in Newcastle. I only spoke to the telephone operator, who passed on the information. I think there is a lot to be said about the tone of voice when someone calls as to whether you can hear if they are in crisis. She misunderstood and she thought I was calling about housing because my brother was trying to move in with my parents, who are elderly. She has obviously passed on this information to the treating team, who said that he is not acute enough.

Two days later he took his life. I wonder about if I had been able to speak to the team. If we can get immediate help—even if the consumer does not want to help—the carers are in crisis also. It is a terrible moment. You cannot think straight. You cannot go to work. It is hard to get on with your life because you are worrying and trying to get help. I remember that day I rang the helpline I was on the phone from 8.00 a.m. all the way to 3.00 a.m., going around in circles, and the mental helpline did not ever call me back until I rang them and they said, "Oh yes, look there is an email, and your brother is just not acute enough, I'm sorry."

Mr GREG PIPER: Ms Allen, can I first of all pass on my condolences to you and your family for your loss.

Ms ALLEN: Mum has a hearing impairment.

Mr GREG PIPER: I offer my condolences to your family for the loss of your brother, your son and brother-in-law. Is that your husband and son?

Ms ALLEN: Yes.

Mr GREG PIPER: Thank you for taking the step to come along here, speak to us about this and to represent Bernie in this way. You are quite right: I will confirm to the panel that the death and loss of Bernie Sessions made a huge impact in the local area around the Lower Hunter. You obviously want to make something come from that, so thank you for doing that.

Ms ALLEN: Can I just add that I think the reason it made such an impact is that Newcastle is in crisis with mental health. It affects so many people. Finally, people felt that there was hope that somebody was speaking out—that something may change.

Mr GREG PIPER: That may well be the case. I do not want to say what my views are on that at this point, but what I do want to ask about is the history of your experience. Your brother had been diagnosed as a paranoid schizophrenic some 10 years ago.

Ms ALLEN: No, longer than that. He went for treatment when he was 18, I think.

Mr GREG PIPER: Okay. It was for a considerable time. Therefore you have been exposed to the mental health system, or at least your observation of it is quite considerable. Did you see over that time a deterioration in the system and in the assistance that your brother was able to access, or did he purposely withdraw from access to the mental health system, or from the mental health system?

Ms ALLEN: No. Which part of the question would you like me to answer? You asked if I had noticed a deterioration over the many years.

Mr GREG PIPER: I am wondering whether or not the level of service that your brother was offered over the years diminished for whatever reason—whether it was changes in the system or staff that maybe tended to become more dismissive of his case.

Ms ALLEN: I think the problem was they have not been able to sustain their employees, so there were a lot of caseworker changes that he slipped through. He did have one good caseworker back in 2014. That was the first time he was admitted to a psychiatric unit in 14 years and that took a lot of hard work to get him there. It was ringing three times a day for a week until I could get somebody to go there. But there were still barriers in speaking with them. Bernard did not have a phone because he was a paranoid schizophrenic. He had no electronic equipment because he felt he was being surveyed through that.

Mr GREG PIPER: Yes.

Ms ALLEN: There was a barrier there. They said, "Oh, we could ring him."

Mr GREG PIPER: If I smiled, let me just say that I know and understand that circumstance. That is a complicating issue. I appreciate that and I am certainly not diminishing what you have said.

Ms ALLEN: I know. I understand. If you do not laugh, you will cry.

Mr GREG PIPER: No. I can almost picture the situation that you had there. I did not want to go to that. You mentioned of course that he had one caseworker that he got to know quite well. You are saying there was a failure. You are saying there was not a consistency in this?

Ms ALLEN: No, there was not.

Mr GREG PIPER: I assume that that caseworker developed a particular understanding of Bernie.

Ms ALLEN: I think they got sick of me ringing.

Mr GREG PIPER: But there would have been a bit more of a personal relationship between that caseworker and Bernie.

Ms ALLEN: Yes, that is right, and then he moved positions. But even then he was a great caseworker. Just to get them to see Bernie, I did manage to get them to come to the house—to Bernard's house—and physically see him. That is when they removed him and took him into psychiatric care. That was 2014. But following that, caseworkers came and went. Some did not ever come and visit Bernie, but the last one did. He did come and just said they would offer Bernard a National Disability Insurance Scheme [NDIS] package. Bernie said, "No", and so they said, "Well, there's nothing more we can do for you", and they ejected him from the service.

Mr GREG PIPER: Ms Allen, I think you were here for some of the earlier testimony. You would have heard that there is concern about how a system sometimes mandates and enforces certain treatments to which the client or patient, however you want to describe it, is not agreeable. How do you feel about that? Do you believe that in that circumstance your brother should have been involuntarily treated within the confines, say, of the Mater mental health unit? Is that what you would have liked to have seen, or would that have been the next logical step?

Ms ALLEN: I believe that if Bernie was here today and he did not have a mental illness he would not want to have taken his life. He had hopes and dreams. He liked to volunteer and he wanted a relationship with a woman. I believe that we had Bernie's best interests at heart and we knew that he was unwell. I understand that being involuntary does remove someone's civil liberties, but he would still be alive today.

Mr GREG PIPER: Based on your personal knowledge of him, your closeness and familial knowledge, you believe that when he was rational he would write an advanced care directive, I think the term is, that said, "Yes, put me in."

Ms ALLEN: Absolutely.

Mr LEE EVANS: Thank you very much for giving us some insight into a personal story. Were you here for the Privacy Commissioner's evidence yesterday?

Ms ALLEN: I was here for some of it. My son's school rang in the middle of it.

Mr LEE EVANS: The impact of your story was getting information. This is what we are trying to tease out because privacy in the health system is a stalwart in New South Wales. In situations where somebody is ill the next of kin have a great deal of trouble trying to get basic information. Was that an issue for you in the situation you were in?

Ms ALLEN: Did we have difficulties accessing information?

Mr LEE EVANS: Did you hit a wall trying to get basic information of where you could go and about Bernie's situation?

Ms ALLEN: Information on how we can get help; is that what you mean?

Mr LEE EVANS: Just his personal information—you as a relative?

Ms ALLEN: No, we did not have any access to that at all. Are you talking about MyHealth? Is it the MyHealth that they are looking at?

Mr LEE EVANS: I am talking about eHealth.

Ms ALLEN: What is eHealth?

Mr LEE EVANS: Just that basic information about where he is up to and what drugs he is on. You could not get any of that information?

Ms ALLEN: I see that that would be a positive thing in that it would have helped the general practitioner [GP], his treating team and his family stay in the loop, I guess.

Mr LEE EVANS: Did he visit his GP?

Ms ALLEN: Not for a long time. He was doing so in the beginning when we finally got him help in 2014. Prior to that he had not left his front door in more than two years because he had agoraphobia and he thought he was under house arrest by the police. So he did not step out the door. No, he was not going to his GP then. We did get help in 2014. Following that, yes, he was going to his GP to get the scripts for his medication, but once he was too anxious to leave the house he stopped going. We did not know that. He had one bottle of pills. I did ask for them to put them in the Webster packaging so we could see, because he would just shake the bottle and say, "No. See, I've got them. I've been taking them." But if we were able to see then we would not have had to ask him; we could just have looked. But they did not follow that directive.

The CHAIR: What has the community health team told you subsequently?

Ms ALLEN: The community mental health team?

The CHAIR: Yes.

Ms ALLEN: What have they told me after he passed away? I was involved in their root cause analysis, which I can provide if you need it. I have been able to work with them and we have been able to come to the conclusion that the checklist that they stick to when you ring the mental health helpline is a barrier as it really only looks at the psycho side of things whereas they need to move to a more psycho-social assessment model because that is what they have missed. Bernie's house being sold was a psycho-social stressor, and they missed that. Yes, that is the change they are looking at implementing but I think that is a change we need to implement statewide.

The CHAIR: Did they raise any issues or did you raise any issues with them about the resourcing of the service?

Ms ALLEN: Yes, absolutely. We did discuss that the community treatment order should have happened when he stopped seeing his GP because they were informed that they needed to put on a community treatment order if they felt it necessary. But people were not coming around. He just fell through the cracks basically, between people leaving. Sorry, what was the first part of the question?

The CHAIR: You have answered it. Thank you for appearing today. My condolences to your family. It must have been very difficult for you and your mother to come here. We certainly have other questions for you but would you be willing to appear at a subsequent hearing when we are dealing with more detailed matters?

Ms ALLEN: Absolutely.

The CHAIR: Any questions we have right now we will send to you in writing and we would be happy for you to get the answers back to us.

Ms ALLEN: Within 14 days?

The CHAIR: We say 14 days, but this inquiry is quite large so you can get them back to us when it is appropriate. Once again, thank you.

Ms ALLEN: You could perhaps thank Mr Hazzard for that, for making it extra large, because it was meant to be just the health. It is his fault.

The CHAIR: Mental health is part of the health system and we are looking into it.

Ms ALLEN: And we are grateful. Thank you.

(The witness withdrew)

The Committee adjourned at 12.47 p.m.