

**REPORT OF PROCEEDINGS BEFORE**

**SELECT COMMITTEE ON MENTAL HEALTH**

**INQUIRY INTO MENTAL HEALTH ISSUES  
IN NEW SOUTH WALES**

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**At Sydney on Tuesday 28 May 2002**

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**The Committee met at 9.30 a.m.**

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**PRESENT**

The Hon. Dr Brian Pezzutti (Chair)

The Hon Dr Arthur Chesterfield-Evans

The Hon. Amanda Fazio

The Hon. John Hatzistergos

**DIANA XUEXUN QIAN**, Acting Deputy Chairperson, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, and

**DONALD KEVIN BYRNE**, Executive Officer, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, sworn and examined:

**LEONIE MANNS**, Former Chairperson, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, and

**MARIKA KONTELLIS**, Counsellor, Disability Council of New South Wales, xx xxxx xxxxx, xxxxxxxxx, affirmed and examined:

**CHAIR:** I welcome representatives of the Disability Council of New South Wales. This morning the Committee is inquiring particularly into those issues to do with the dual diagnosis of disability and mental illness. This afternoon we will deal with the other dual diagnosis of mental illness and ageing. Are you each conversant with the terms of reference of the inquiry?

**Ms QIAN:** Yes.

**Mr BYRNE:** Yes.

**Ms MANNS:** Yes.

**Ms KONTELLIS:** Yes.

**CHAIR:** Would you like to include your submission as part of your evidence?

**Mr BYRNE:** Yes.

**CHAIR:** I advise all witnesses that if you consider as any stage during your evidence that in the public interest certain evidence or documents that you may wish to present should be heard or seen only by the Committee, the Committee will be willing to accede to your request. However, I must make you aware that the Legislative Council may overturn the Committee's decision and make this evidence public. Would one or all of you like to make an opening statement?

**Ms QIAN:** Yes. I will give a brief overview of the role of the Disability Council of New South Wales. Marika will then give an overview of the submission.

**CHAIR:** Thank you.

**Ms QIAN:** The Disability Council of New South Wales is the official adviser to the New South Wales Government. It also functions as the advisory body to the Commonwealth. It was established in 1984 under section 16 of the New South Wales Community Welfare Act. The role and functions defined by the Act are to monitor the development and implementation of the Government's policy in relation to people with disabilities, produce advice to the Government, to promote the integration of people with disabilities in the general community, and to promote innovative services in relation to people with disabilities. The council consists of 18 members appointed by the Governor and it is supported by secretariat staff.

**Ms KONTELLIS:** We would like to take this opportunity to say that the council continues to support the intent of the Richmond report—that is an important message—and acknowledges that there have been some positive developments for people with mental health problems in New South Wales over the years. A key message—we will certainly talk about this; we understand that you are particularly interested in the issues surrounding dual diagnoses—is that we continue to support people with many complex, high-level needs often in a very resource-restricted environment or in an environment where resources are inflexible. We will start with that statement and go forward from there.

**CHAIR:** I have now read almost all of the submissions and one of the issues raised is that, when the disability sector was Richmonded—in other words, people were moved from institutions into more community-based accommodation and support—it appeared from a previous inquiry by the Social Issues Committee that the

then Minister, the Hon. Ron Dyer, entered into a contract to ensure that there was lifelong care for people with disabilities under the circumstances of deinstitutionalisation. Is that correct?

**Ms MANNS:** Yes, so I understand.

**CHAIR:** Does that also work for people with a mental illness who are disabled?

**Ms MANNS:** Not usually. These people are within the intellectual disability system for the most part. Their mental illnesses are not often addressed appropriately: many of the issues around mental health problems are simply put down to challenging behaviour and, as such, are treated differently. They are often inappropriately and incorrectly medicated and very often over-medicated. So medication becomes a quite serious issue. These people are often supported alone in a house by the Department of Community Services. That is very costly and it is often still not the appropriate interface with mental health services. There is a really big problem in Australia with psychiatry for people with an intellectual disability and mental illness. For the population of disabled persons with mental illness, we should probably have about 30 psychiatrists working within this specialty group. We have six within the whole country. That is a major issue to begin with.

**The Hon. AMANDA FAZIO:** Is that 30 nationally?

**Ms MANNS:** Yes. That is those with a special interest.

**CHAIR:** How many do we have in New South Wales?

**Ms MANNS:** I am not exactly sure but I think two or three. That makes things quite difficult from the beginning because psychiatrists are not au fait with the problems. Psychiatrists and other mental health staff find it difficult to treat these patients because they do not understand the complexities.

**CHAIR:** One of the submissions—I do not know whether or not it was yours—raised the issue of deinstitutionalisation and pointed out that experienced nursing staff which were associated with people with a disability and dual diagnosis in institutions really did not find a place or have the expertise of dealing with these matters in the community.

**Ms MANNS:** I would say that that is quite true. This probably has not continued so much into the psychiatric area but it is very common in areas around nutrition and all sorts of other things. But one of the main things that happened in the Department of Community Services was that it became quite de-professionalised. That was because of a lot of things; there were social issues at the time as well. The professions within intellectual disability were not as well developed and they continued to just diminish.

**CHAIR:** This was really a loss of professional skill—specialised skills?

**Ms MANNS:** Yes. But I think for example with nurses, that has continued across the field. Mental health and disability nursing runs across everything, really because within nursing training at universities, there is very little scope for specialist disability nursing or mental health nursing. There is often very little inclination for undergraduates to take this up.

**CHAIR:** With the generalist training at universities, there is a certain amount in the curriculum—we have received this evidence on a number of occasions through submissions—but to attract people to go into these specialised fields in the first place is difficult, but, in the second place, what are the training positions available for somebody who does want to go into this field, or who is in this field and wants to extend themselves?

**Ms MANNS:** There is no training currently available in disability nursing, on my understanding. This quite a lot of opportunity for people to do the training but it is not taken up. There are always vacancies. I think it is probably not technical enough and I think quite often on placements there is very little effort made to enthuse students, and sometimes incidents happen that frighten them. I think we also have to note that the average age of mental health nurses in this State is approximately 49, so not only is there a generational gap but there is also an educational gap between many of the undergraduates and the current staff.

**Ms KONTELLIS:** The context of that is that there is a huge demand for nursing per se across the State. Nurses basically have the pick of the area they want to choose to work in. We are importing nurses from overseas. They come into the country and if they have nursing qualifications, they are almost guaranteed a job. It is difficult to attract nurses to work in the sector. I will take two steps back and respond to your initial question about lifelong disability care and support. While it is true that many people who have mental health problems and another

disability may live alone, the reality is that many people with mental health problems are being cared for what we term the informal sector, that is, their mums, their dads, their husbands and their wives. They often do not seek support unless there is a crisis. The crisis will come and a crisis usually is an acute episode. They will enter the hospital system. But the reality is that the informal sector is providing the lifelong care until a crisis occurs. Our system is not ready—preventive ready—to support families to do some planning.

**CHAIR:** This is the issue of assertive care which is what we are getting to with general mental health issues. Is that what you are talking about?

**Ms KONTELLIS:** Yes.

**CHAIR:** Although there is a guarantee of care for people with an intellectual disability and for dual diagnosis people in whom we are particularly interested, they are looked after by their mums or their relatives, or, if they have financial resources, they live by themselves. The backstop for that is meant to be the community mental health nurses in this regard and the community mental health service. What you are saying is that, like all the other areas, their assertive care is the problem—visiting regularly, and so on.

**Ms KONTELLIS:** Yes. It is stretched.

**CHAIR:** On page three of your submission you have made a point about when people actually have to access public hospital care. That might happen because of a physical or a mental illness. What is the situation?

**Ms KONTELLIS:** Access to public hospital care?

**CHAIR:** Yes, for either physical or mental illness. Say they de-compensate physically—because many of them are disabled—or mentally, what is the situation?

**Ms MANNS:** That depends on where you go. My experience has been that there are quite a number of mental health units that are not physically accessible. It is a major problem because quite often a person with mental illness becomes physically disabled through unsuccessful suicide attempts. That is a very big issue and the other issue is that there is very little access if you are deaf. Currently in the public health system in New South Wales I do not think we have any psychiatrists who treat the deaf. We did have one for many years but he has now gone into private practice. I may be wrong, but that is the state of affairs to my knowledge. The issue of people who have an intellectual disability is very difficult because nobody wants them.

There is still the argument that goes on, "You belong to DOCS", "No, you belong to mental health." I would say that things are beginning to improve in that area and those departments are starting to talk to each other quite a bit, but sometimes it does not get down to the local areas and I think that is a problem. I do not think it is wilful or done with malicious intent; it may be an issue of resources, not necessarily even financial resources, but the training, education and ability to care for this group.

**Ms KONTELLIS:** There are inequities. Where we live will often dictate how we fare.

**CHAIR:** I was wondering about the geographic solution. Where are the best places?

**Ms MANNS:** Certainly the Sydney metropolitan area.

**CHAIR:** The inner city?

**Ms KONTELLIS:** Yes.

**Ms MANNS:** I do not think so, if you have a disability, no.

**Ms KONTELLIS:** If you compare that to the rural and remote areas that if you have across the State, clearly if you live in country New South Wales—

**CHAIR:** Or western Sydney?

**Ms KONTELLIS:** There are some good facilities in western Sydney.

**Ms MANNS:** In western Sydney, I think you might do a bit better because they are more used to it. The larger intellectual disability institutions are out there, so they may do a little bit better.

**CHAIR:** Are they still in the institutions though?

**Ms MANNS:** Yes.

**CHAIR:** How many?

**Ms MANNS:** There are 1,200 people to my knowledge.

**Ms KONTELLIS:** Or 2,500, including children. You have got the Lachlan centre, you have got Marsden, and you have got Peat Island.

**CHAIR:** Just for intellectual incapacity?

**Ms MANNS:** Yes.

**CHAIR:** We are not really inquiring into intellectual disability.

**Ms MANNS:** As far as institutions in mental health are concerned, we have Rozelle, which is still open, we have Morisset, and Bloomfield has both.

**Ms KONTELLIS:** Lachlan, of course, has people who have a mental illness.

**CHAIR:** At the time of Richmond in 1983, the majority of the disability and mentally ill people—of course, Richmond went to both issues—were housed outside. What is the sort of percentage drop now?

**Ms MANNS:** Most of the people who were moved outside were those people from the intellectual disability service. They closed one big institution, the one at Gladesville, and took smaller groups out of others. But really at that time, none of the big psychiatric institutions closed.

**The Hon. AMANDA FAZIO:** What about Kenmore?

**Ms MANNS:** Kenmore closed recently.

**CHAIR:** What about Peat Island?

**Ms MANNS:** Peat Island is still there and it is excluded from the current deinstitutionalisation.

**CHAIR:** How has New South Wales gone compared with other States with the deinstitutionalisation for disability and also mental illness? Are you in a position to know that?

**Ms MANNS:** I am in a reasonable position to know. We have done better than many States. I would say that Victoria has probably done the best. However, some of the models they have adopted are questionable. They have opened a lot of what I would say basically are institutions in the community.

**CHAIR:** Mini-institutions?

**Ms MANNS:** Yes, 20 beds. They are everywhere. It is just the same as a hospital but it is small. South Australia still has very large institutions. South Australia has the largest institution currently, although if we put 400 beds at Rozelle we will have the largest.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Evidence has been given that 36 per cent of disabled people have a mental illness. Does that mean all disabilities or is that just people with intellectual disabilities? Presumably, 36 per cent of people with physical disabilities do not have that incidence?

**Ms MANNS:** Why would they not? People with a physical disability would probably have the same ratio as the rest of the community, which is about 20 per cent.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** So it is not that much up?

**Ms MANNS:** No. I would think not but my understanding of those figures from Professor Stuart Einfeld is that he is referring to intellectual disability at about 36 per cent. I think I said the other day about a third.

**CHAIR:** That must be difficult to work out given the diagnostic criteria. There is a note by a professor of nursing in one of our latest submissions, from the College of Psychiatric Nursing New South Wales Branch, that refers to the difficulties of making a diagnosis and the various models that are used. But generally about a third have dual diagnosis?

**Ms MANNS:** That is a third of people with intellectual disability, yes.

**CHAIR:** What sort of numbers are we talking here?

**Ms KONTELLIS:** That is very hard to determine. We know that about 15 to 17 per cent of the New South Wales population has a disability.

**Mr BYRNE:** It is 19.3 per cent.

**CHAIR:** But I am talking about intellectual disability.

**Mr BYRNE:** I could get you those figures. I have them back in the office.

**CHAIR:** It would be worth while. Some people are IQ lowish but function quite well and have quite a successful outgoing life. Some children with Down's syndrome may or may not be intellectually disabled but do not have a great deal of problem in getting through their life with the support of family. But there are those with a severe intellectual incapacity. How many of those would there be in the State where there is an absolute reliance on—

**Ms MANNS:** I am not sure but Kevin could supply the Committee with those figures.

**Mr BYRNE:** I do not have them broken down with a really clear delineation between severe, moderate and mild. That is quite subjective.

**CHAIR:** I am more interested in the level of support needed rather than the actual IQ levels.

**Ms MANNS:** I would think that that information should be available from DADHC.

**CHAIR:** Would a higher percentage of the people who are severely mentally incapacitated and who need support from DOCS have a mental illness as well or a lower percentage?

**Ms MANNS:** That would be hard to estimate, Dr Pezzutti. I think it would be across the board. It is very hard to estimate because whether the incidence would be higher because of, say, a depressive illness because of the disability, which is hard to diagnose, I do not know. But I know that it is high and it is worrying.

**CHAIR:** If these people are either in an institution or in the community what is the level of support that DOCS receives from the mental health service to care for these people?

**Ms MANNS:** Again I would say that that would be fairly patchy and it would depend on a local relationship mostly. It is interesting. There are good relationships at the highest levels and those linkages have been made. Then at the coal face it is mixed. So it would depend on the local relationship. In a rural area in that situation you might get a better deal because they know each other—or you might not because they might not like each other. It is a really tricky situation and it becomes often a war on turf.

**Ms KONTELLIS:** And it is within the context of resources. If an agency is responsible for caring for a person with an intellectual disability who also happens to have a mental illness it is usually DOCS but a lot of the time it is an NGO, for example, the Spastic Centre of New South Wales, the Northcott Society, the Down Syndrome Association et cetera. Chances are the kind of support they will get from the Department of Health is a one-off visit for some information in support of how to deal with or to support the person. There would be limited ongoing support.

**CHAIR:** This would be the most challenging thing to deal with in a family situation or even in a group home.

**Ms MANNS:** Quite often people in the group home or the family may not even know that mental health problems are involved. It is just all written off as part of the disability. They are often given antipsychotic

medication. Most of the studies find that the doses are too high and the types of medication are still quite old-fashioned. This is simply because there is not the expertise in that area. Psychiatrists who will be treating the rest of the population with mental health problems with modern, up-to-date medication where possible may not have access to these groups of people and so the medication becomes historical. Their doses are historical.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** You mean they are phenothiazines rather than the SSRIs are they?

**Ms MANNS:** Absolutely, and they would be on big doses of Modecate, Haldol or Largactil.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Still?

**Ms MANNS:** Yes.

**CHAIR:** You say that admission to an emergency department is particularly challenging. What is that all about?

**Ms MANNS:** I think it is challenging for anybody. We were basically talking in general about people with mental health problems, that it is a challenge to get past the emergency doctor.

**CHAIR:** They also break their arms and they also have the problems that everybody else has.

**Ms MANNS:** Once you have a file from the psychiatric department quite often the staff sees that and thinks that it is one of theirs.

**CHAIR:** But they are faced with the reality that the person also has a broken arm.

**Ms MANNS:** It may or may not get dealt with. People have come to hospital complaining of a sore arm and been told they are psychotic and delusional. They go up to the psych unit, who discover that they have a broken arm. Hopefully this sort of thing is being reduced by the placement of mental health nurses within emergency departments but it happens constantly. The physical health of people with mental illness and with other disabilities is often neglected.

**CHAIR:** You have partly dealt with the bit about drugs. Is that a matter of cost to the State system?

**Ms MANNS:** I do not think so, no. I see no hesitation in those drugs being prescribed throughout the rest of the public system.

**CHAIR:** It is simply a matter of diagnosis and care?

**Ms MANNS:** Yes, and expertise. I do not think it is deliberate.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** In the social issues committee inquiry into disability services there were difficulties in establishing how many disabled people there were, and more importantly—if that is the word—what level of resource deficit there is in terms of unmet need. There seemed to be a lot of definition problems in this. There had not been a record of people who had the problem so it was a question of how many had presented. The figures were either totally patchy in the sense of who had presented. Many had presented and then gone back to their informal carers, as Marika talked about. In fact the number visible were just the tip of the iceberg in a sense. There was a lot of doubt about that. I gather that in the new disability access system, SAS, there is still no capture mechanism to get an idea of the numbers. Do we then go back to something like the incidence at a population level from the AIHW?

**Ms MANNS:** To my knowledge we have not done any broad national work on the epidemiology of disability. But we have done good epidemiology work in mental health.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** So the figures are better?

**Ms MANNS:** The figures are very good because the 1997 survey under the national mental health strategy is one of the largest international surveys. It is well recognised. The figure is one in four, and higher if you are taking in young people because under 24 they took in substance abuse as well, so it becomes about 28 per cent at that level. That is believed to be fairly accurate. But that report also stated that 40 per cent of those people never sought service from mental health services. I would expect that those figures may extrapolate throughout the nation.

**CHAIR:** So having a virtual disability almost cuts you out of a fair share of access to care?

**Ms MANNS:** Yes, I would think so. Some work is being done to address it.

**CHAIR:** Apart from getting them all in to have a psychiatric X-ray like checking for TB, how could these people who already have enormous difficulties be helped first to find out whether they do have a mental illness and, secondly, be treated for it?

**Ms MANNS:** I think it is probably time for another audit of medication levels in group homes and institutions?

**CHAIR:** But that still does not get to the 40 per cent who are not even accessing care. They might be better off without it, of course.

**Ms KONTELLIS:** The big issue is around advocacy and information, support to carers, the informal system. I know many carers who do not know that services and information exist.

**CHAIR:** Surely that is a matter for DOCS. All these people would be known to DOCS, would they not?

**Ms KONTELLIS:** No.

**CHAIR:** If they are on a disability pension, for example, they would be known to DOCS because you have to get certain reports and so on to get a disability pension. It is not something that the GP just writes out.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I think they are.

**Ms QIAN:** No, they are diagnosed by a specialist but it may not be related to DOCS.

**CHAIR:** In doing the assessment perhaps the specialist should be doing something about asking to be in contact for a care plan, for example. One of the responsibilities of DOCS is to produce care plans to assist carers.

**Ms MANNS:** Everybody with a disability does not go before DOCS. So everybody with a disability does not end up with a care plan.

**CHAIR:** No, but for intellectual disability where you are getting a pension for it and you are getting an assessment, that assessment is meant to be lifestyle assessment, is it not?

**Ms KONTELLIS:** Care assessment sometimes.

**CHAIR:** Is there good communication with relatives and carers about needs and access to those services available?

**Ms KONTELLIS:** Not always. This is a very important point. Not everyone is known to DOCS. A significant proportion of people with disabilities, particularly those people with very high complex needs, have come into the system. The people who have moderate needs are more likely to have high complex needs five or ten years down the track because of their life changes.

**CHAIR:** Or their relative dies.

**Ms KONTELLIS:** Exactly. They will come into the system in a crisis. Is there good information to carers and relatives? Sometimes there is; sometimes there is not. It depends on who you are. It depends whether you speak English, whether you live in a city, whether you have a good informal support structure around you. It depends on whether you have money. It depends on a whole range of things. If you have not got those things chances are you do not know. Your central point of contact usually is your GP. There are some very good GPs out there who are providing some excellent services but there are some GPs who are just providing that very clinical service, "There is your fee. Go home"; no access to information. That is the front door for many people. Usually the GP speaks their own language or they are down the road; they have known the family for years. That is it. People often do not have a front door for information and that is certainly a major issue. We are seeing it again and again.

**CHAIR:** How many GPs would say "Yes, this person really needs care" and they contact DOCS or ask the person to be in touch with DOCS about getting a carer?



**Ms MANNS:** Most would but not all.

**CHAIR:** But if they did, most GPs might say it is a bit of a waste of time because there are not any services here anyway so why raise their expectations.

**Ms MANNS:** I think it is also an issue in smaller communities because they are isolated by geography or language or culture, the GP may just be providing the medical care and not know and just support the family at home.

**CHAIR:** What about the issue here where you have got funding issues? Does anybody want to talk about the availability or a mix of services?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I do not have a handle on this and having worked through the disability sector where there was a lot of controversy about whether the care plans existed in any real form for most people, they have an obligation to have one and they say that they do but there seems some doubt about the real use of that. In terms of the resources per diagnosed person, there was a new move to introduce two tools, one of which the acronym was SNAP which I think was a tick box system where you looked at what they could do and therefore how much resources they needed to. In that analogy the number of people was not clear, the number of people who had SNAPs was not clear and the validity of the SNAP was not clear; then the resources were not there and the plans were of dubious value. So getting a handle on what needs there were and how they were being met was very vague.

Now to what extent does that analogy hold in mental health? My understanding is that people commit suicide without being treated. There are people sleeping under the eaves of Parliament House and down in Tom Uren Place. Even this good survey from, presumably, the Department of Health, the AIHW, to what extent is this quantified as to how many people are there and is some estimate made of their needs and the type of needs compared to the amount of resources there are available? How much of this has been systematised? Can you give me figures?

**Ms MANNS:** Within New South Wales?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Yes.

**Ms MANNS:** Again I think it is very patchy but I do think that New South Wales are starting to get probably some of the best information collection available in the country.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** This is population based, is it?

**Ms MANNS:** Yes, population health and moving to a population based care.

**CHAIR:** Having got the information, having got the person in front of you, how is that matched up when you do a plan? How does that match up with the resources available to support the plan?

**Ms KONTELLIS:** Again — I'm sorry to keep saying this — it depends where you live etc. Some people are going to get a good service; they are going to get a good package of support; some people are going to get a not so good package of support. Some people are even going to go in front of that person to develop a care program. I think that is a key issue.

**CHAIR:** But surely this is something the government should know about because you are really talking only about needs. If somebody does a plan and they say "It is no good putting on a plan to produce some speech therapy for us because (a) there are no speech therapists available or (b) we have not got the money to pay for it." So to what extent are those plans complete when they say "Well, we can't do this, this and this"?

**Ms KONTELLIS:** We do need to get better at counting and measuring and finding out what the need is. There is no doubt about that. We do need to get better at it.

**Ms MANNS:** I think there is a big feel within all at government to do that counting and if I was there I would be fearful too.

**CHAIR:** The Disability Council of New South Wales, one of your responsibilities is to do that, is it not?

**Ms MANNS:** It certainly is something that we do advise is done but we cannot do it. We cannot count the numbers.

**CHAIR:** No, but you can get an idea of the numbers of people who are not getting what you think they should be getting.

**Ms MANNS:** And we do and there are. I would say all the advocacy groups have a good idea of what the numbers are out there of each individual disability type but I would think that the dual diagnosis particularly would be difficult to count. Going back to the Hon. Chesterfield Evans' question, I do not think they are capturing the people under the eaves.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** No, but they are pretty bad, cases in a sense, not being captured. That is why if they are not being captured it seems to me there must be a lot of morbidity.

**Ms MANNS:** There is a lot of morbidity in that area and I would also say that there is very strong evidence that not all of this group would have classic mental illness, that a lot of it would be brain injury and those sorts of things. I am not saying that is a reason to leave them under the eaves.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** When Marika says it is variable from area to area are you saying that this is quantified and you could give me figures on this or are you saying these are anecdotes of what happens in practice and that to go from a general statement of anecdotal experience to a quantification is still a leap that is not possible?

**Ms KONTELLIS:** There is hard evidence to support the fact that you if you live in rural remote areas you are not going to access services. So yes, we have got some of those figures. A lot of the information is anecdotal; a lot of the information has been collected from peak groups and organisations working with people on the ground, people with disabilities, and in hearing what they have said. One of the other hats I have is the Guardianship Tribunal of New South Wales. They have some very good facts and figures of the amounts of people that are coming in every year for a new application for guardianship. They are the people who have reached a crisis in their life; they have no one; someone needs to make an urgent decision in their life. There are about six and a half thousand new applications to the tribunal every year. Something like 55 percent of those are all people with dementia; the rest are mix of younger people with disabilities. You can certainly get some sort of feel of who is coming through and who is not coming through. From some numbers you need to be able to collate some of that information and get a bigger snapshot. Clearly DADACH is in the process of doing that.

**CHAIR:** So obviously we do not know the numbers?

**Ms MANNS:** If anybody should have the numbers I believe DADACH should have the numbers but I do not know whether they do.

**Ms KONTELLIS:** Health should have some numbers as well.

**CHAIR:** Every one of these people at some stage go through the health system and even if it is a fairly well managing person who has Down syndrome with mum and dad now 80 and they are 40—of course they used not to live quite so long but they now do—and the 80-year-old mums and dads are now worried about what happens if one of them dies. Once they get more infirm themselves what is going to happen to their daughter or son who has been living with them very happily, going out to a job or whatever, but when they die and there is nobody there to look after the nitty-gritty, get them there on time and so on. This is what goes to the guardianship board eventually?

**Ms KONTELLIS:** That is a very good example.

**CHAIR:** Or they get some other guardian appointed. There is a whole care package that has got to go with that.

**Ms MANNS:** I am sure these questions were dealt with at the disability inquiry in great depth as well.

**CHAIR:** The other issue you have is about funding issues at the bottom of the page. There is an issue about staffing.

**The Hon. JOHN HATZISTERGOS:** Could I ask a question under the last dot point about availability and mix of services, about the lack of cultural and linguistic services? Are you able to elaborate on that, whether these services exist and exactly where are the shortages?

**Ms QIAN:** There is a huge issue in terms of access to information. People from culturally and linguistically diverse communities do not know where to access services; they could not find the door and one thing that was pointed out was, they can go to their GP and use that as the way to access services but it really depends on who you are seeing and whether the GP is aware of these existing services and once you find out about the services, the information provided to you by the service is not in your language so it is not accessible to you. There is a huge problem in terms of providing interpreting services and having material translated in your language and there is also a cultural issue in that the mainstream mental health services staff are not aware of the cultural differences or religious differences.

There is some hard evidence in terms of the service access. About 15 or 16 per cent of the disability population are people from a non-English speaking background and the services access rate is about 3 per cent. So it is only a very few of them who actually access the services. The majority of them are hidden in the community not knowing that they have a right to access services and not fully aware of what is happening to them because there is a huge gap in terms of promoting community awareness about mental health issues in different communities. Usually you will have information in English about educational and mental health issues but they are not available, they are not penetrating the ethnic communities.

**The Hon. JOHN HATZISTERGOS:** Can you tell me a little bit about the Transcultural Mental Health Centre?

**Ms MANNS:** I was going to add something to Ms Qian's evidence. The problem again is a little bit patchy too. I would think that there are some, areas particularly in Sydney, where the mental health team's cultural experience and knowledge is good, and I would support that it is, but if there is a dominant culture in that area they have taken it on quite well in a number of cases I would have to say. On the other hand, there are other places which do not know of the existence of the Transcultural Mental Health Centre. This is a State wide-body. They provide referrals. For example, if I was a Cambodian speaking woman who needed some counselling or some psychiatric care, if I was able to find out how to do it, somebody could contact the Transcultural Mental Health Centre for me on my behalf—a doctor or a community worker—and they would quite possibly be able to get a counsellor or some sort of a therapist who could speak the language. The service they provide is very good but again it is not widespread. Also I think some of the mental health services do not know about it.

I was recently sitting on the Mental Health Review Tribunal at Cumberland hospital which is on the same campus as the Transcultural Mental Health Centre and there was a person before us with some major issues of language and culture but they had not been referred on. The big issue that I find within the system is that the mental health professionals will say to you a person is mute; once you find an interpreter they are not mute. Or they are thought disordered and I say, "How do we know that they are thought disordered?", "Well, no-one could understand them." It might be perfectly logical. For all we know they might have no disorder.

**CHAIR:** We will hear evidence from the transcultural people as they are reasonably well-funded and they are often the key to the door.

**Ms MANN:** I would have nothing but support for what they do.

**CHAIR:** Often they are the pathway to success.

**Ms MANN:** I know that they have done some very good work, but it is still patchy.

**CHAIR:** It is often difficult for some cultures to accept that a child is mentally disabled and that fact is often hidden.

**Ms QIAN:** That is right. There is heaps to do.

**CHAIR:** When I was a junior doctor in Wagga Wagga in 1970 an orthopaedic surgeon went to Wagga Wagga and set up a practice. He got as patients all these kids with club feet—kids who had been hidden from the community. Nobody in the community knew that these children were alive. One child, who is now aged 19, is out in the community after a simple operation. People would hide children with disabilities. Even relatives would not know about children who were disabled.

**Ms QIAN:** Some ethnic communities have a very negative view about people with disabilities. People with disabilities and, in particular, people with mental illness, are regarded as bringing shame on a family. Of all the disabilities, mental illness is seen as a huge embarrassment to the family. So a lot of those people would have been hidden away, although they would have been well cared for by their families. However, there is a barrier in relation to accessing services. That is why I mentioned earlier that it is critical to promote community awareness of mental health issues.

**CHAIR:** We will hear evidence from that group. What are you able to do to assist somebody? Let us say that a general practitioner [GP] has as a patient somebody who is disabled and who also has a mental illness, for example, a kid with Down syndrome. I keep referring to Down syndrome because it is easily recognisable. Let us say that that child is mildly intellectually disabled and very depressed. What if the GP wants to help? Could he ring the Disability Council of New South Wales and ask, "Where in my area can I get this sort of support?"

**Mr BYRNE:** Sadly, we do not have that information.

**Ms KONTELLIS:** They could ring the New South Wales Council of Intellectual Disability.

**Ms MANN:** They could also ring the Association for Mental Health. The Disability Council of New South Wales would point them in the right direction. We have a very large list of all the advocacy services.

**CHAIR:** So you would be a point of contact for people and you would advertise that fact? You would find the right buttons to push?

**Ms MANN:** Yes.

**Ms KONTELLIS:** One of the things that peak groups are doing—not only councillors as advisers but also other peak groups to whom, no doubt, you will speak or to whom you have spoken—is infiltrating the GP networks across the State. We see GPs as being crucial.

**CHAIR:** There is the following statement on page 5 of your submission:

It is not clear how effectively the savings achieved from devolution of specialist psychiatric hospitals have been applied to the development of community services.

What steps have you taken to find out how transparent that has been? What has been your experience?

**Ms MANN:** The Disability Council's involvement in mental health issues has not always been as strong as it is now. Probably in the past not very much work has been done to look at that, which was why the Disability Council saw this inquiry as an opportunity to do some of that work. I think we would be as well placed as anybody else to see the transparency. I would probably repeat the evidence that I gave before this Committee last week: I think that we must again look at the transparency of the area health services and the way in which the funding operates.

**CHAIR:** You have no knowledge of it?

**Ms MANN:** If you can find out where the health money goes after it leaves Treasury, it would be pretty good.

**Ms KONTELLIS:** We know that the non-government sector is providing services to people with mental health problems. That area is one of the most underresourced programs in New South Wales.

**CHAIR:** It is the lowest funded. In summary, your last recommendation is:

The Council sees little commitment to the Disability Services Act by most health facilities, including the non-government services.

Is that just in regard to mental health, or does it relate to the intellectually disabled and disabled persons?

**Ms MANN:** It is about the principles of the application of the Disability Services Act. Most people would tell you—and you would probably know—that with the introduction of that Act New South Wales Health was exempted. However, non-government services under mental health were included. None of them conformed to the Disability Services Act. They spent many months developing transition plans that would allow them to conform. They worked with conciliators but there was no money in the end. Consequently, that would be the reason for that.

It is not that the non-government sector does not have a commitment to the principles of the Disability Services Act. It does, but it is unable to conform. I do not know for certain, but it is my belief that New South Wales Health has allowed the non-government sector to come within its exemption.

**CHAIR:** We could simply change the Act to include health as a conforming part of the community in relation to the Disability Services Act. I am particularly interested in mental health in this inquiry, but that would be a step.

**Ms KONTELLIS:** We would welcome that recommendation.

**Ms MANN:** We would welcome that recommendation, but I think you realise why it wanted that exemption.

**CHAIR:** It relates to resources, capital works and so on. At the end of the day the private sector and the non-government sector are obliged to conform.

**Ms MANN:** I think that is unfortunate because many of those non-government organisations put an incredible amount of work into transition plans and they get nowhere.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I noticed that representatives from the New South Wales Aged Care Alliance referred to confused and disturbed elderly [CADE] units. There seemed to be some controversy about whether that was the way to go. What is your opinion about those units? Should there be more of those units, or should there be alternative models?

**Ms KONTELLIS:** There was some talk about de-funding those units. The Alzheimer's Association, in particular, had a loud voice and said that those units, which are legitimate, provide a very good service. If we take them away we will have nothing left. One of the messages is that we clearly have a mix of needs in our community; therefore, we need a mix of services. The CADE unit model is a good, valid model for people who are appropriately assessed as requiring that short-term support before they enter another level of care. Usually, that may be either stabilising their dementia or the mental health issue that is associated with ageing and supporting the carer to support them when they go back home or, more likely, they move into an aged care facility. So if you are asking whether that is a model that should exist, yes, it is one model that should exist.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is it a group home for confused and disabled elderly?

**Ms MANN:** There is not universal support for that model.

**CHAIR:** This afternoon we will be having discussions with aged people.

**Ms KONTELLIS:** It is a bit more than a group home.

**CHAIR:** If I have a child who is intellectually disabled, who has challenging behaviour, and who is a risk to himself and to me, and I call the community health team, do I have any guarantee that it will come in a timely fashion?

**Ms KONTELLIS:** Yes, they will come.

**Ms MANN:** I think they will come.

**CHAIR:** In a timely fashion?

**Ms MANN:** Yes. I do not know what would happen after that. I would not like to guarantee what would happen. They will come. However, it would depend on who they are, what their attitude is, how well resourced they are, and what their response is. They may well say, "Sorry, this is not our problem. This is the problem of the Department of Community Services", or they may actually assist you in getting the Department of Community Services involved.

**Ms KONTELLIS:** The chances are that, if you have done it once, you will not do it again. You will not call a second time.

**CHAIR:** Why?

**Ms MANN:** Because your experience will be bad.

**The Hon. AMANDA FAZIO:** What makes you automatically say that the response will be bad?

**Ms KONTELLIS:** If you reach a point where you decide to call the mental health team you would probably be in a position where you would need to call the police. If you are at a stage where your son or daughter is having an acute episode, clearly, it is quite traumatic for everybody involved. What will happen is that the person will be placed, medicated and then discharged, often without follow-up support. That experience is often a negative experience for families. So they will think twice, three times or four times before they have to use that avenue again. Often they have very limited choices about what other avenues they can use. But, yes, people do use that avenue when push comes to shove. And push does come to shove.

**Ms MANN:** The clientele about whom Dr Pezzutti was talking are fairly severely intellectually disabled—people with what we would call challenging behaviour. The outcome for that family is that again the police would come because the mental health team would not be able to handle them. They would probably end up getting some sort of service. I doubt whether they would be discharged. But they could end up in gaol or they could end up, long term, in a very inappropriate placement—in a psychiatric hospital, which would not be right for them or, as I said before, in a group home on their own.

**CHAIR:** If there is anything else that you would like to add later, please free to do so. We may need to get back to you with further questions. Would you be happy with that?

**Mr BYRNE:** Yes. There were a couple of areas that we wanted to cover—areas that we would like to cover later.

**CHAIR:** I would be delighted if you deal later with some of the issues that we were not able to deal with today.

**(The witnesses withdrew)**

**HELENA BRIGID O'CONNELL**, Executive Officer, New South Wales Council for Intellectual Disability, Level 3/22-36 Mountain Street, Broadway, affirmed and examined:

**CHAIR:** Would you like the submission that was made on behalf of the council by Ms Lee Wilson to be included as part of your sworn evidence?

**Ms O'CONNELL:** Yes.

**CHAIR:** If you should consider at any stage during your evidence that in the public interest certain evidence or documents you may wish to present should be heard or seen only by the Committee, the Committee would be willing to accede to your request. However, you should be aware that the Legislative Council may overturn the Committee's decision and make the evidence public. Would you like to make an opening statement?

**Ms O'CONNELL:** Yes, I would. Firstly I will outline the issue and then describe some of the problems, and also describe some areas where there are better practices and movement towards some changes. The issue of what we call dual diagnosis, which is where people with intellectual disability also have a mental illness, has only recently been acknowledged in the sector and at this stage there needs to be a lot more research into it. Because of that, there are a lot of concerns about lack of service and lack of co-ordination of service. For people with intellectual disability, severe problems with social interaction and extreme difficulty with adapting to change may constitute a psychiatric disorder.

At the moment it is very difficult to estimate the percentage or numbers of people with intellectual disability who also have a mental illness. The estimates are somewhere between 10 and 40 per cent of people. There is a European study that puts it as high as 70 per cent, but that might be a bit of an aberration. I think the main issue in relation to this is assessment. It is very difficult to assess people with intellectual disability, but if that is compounded by a mental illness that is also very difficult due to communication problems. Often people are not able to identify or articulate their symptoms to a psychiatrist if they are being assessed.

A psychiatric disability often includes anxiety disorders or post-traumatic stress. Some people coming out of institutions experience this along with other associated grief, loss and other areas. A lot of these things are very difficult for someone to diagnose if the person is having difficulty communicating. If the person is stressed or anxious, they are often overwhelmed by a hospital setting. That is one of the main issues. Therefore, when someone is being assessed there is a need for a third person to be involved. That person can only really describe what they observe; it is not easy for them to interpret what they are seeing. So there are lots of areas that compound diagnosing a person with intellectual disability with a mental illness.

One of the main problems is that this area has only recently been recognised. In the past there was an assumption that a person was acting out, or had what was called a challenging behaviour. This was often considered to be part of their intellectual disability. But more recently there is an understanding about the extremes of challenging behaviour or extreme difficulties in social interaction. This is now described as a psychiatric disability or mental illness. Because of that, there is quite clear lack of expertise in both fields, across disability and the health field. In terms of training and information within the council and psychology curricula, very little attention is paid to people with intellectual disability. For example, a psychologist in DADHC may have some understanding of intellectual disability, which could be limited also, but they have even less understanding of the combination of psychiatric disability and intellectual disability. So there is a real lack of expertise.

Even amongst psychiatrists there is a lack of interest in developmental disability, so that crossover is quite difficult. But there are some areas in which there have been some improvements more recently. There is a group called psychiatrists in development disability, which is now meeting regularly. So there is a crossover at that level, which is very important, and that is a welcome shift in the area. The lack of expertise is really across the board, at the level of support workers within disability services, and counsellors within mental health teams and community health settings.

**CHAIR:** Are you speaking about intellectual disability arising from problems encountered at birth?

**Ms O'CONNELL:** What is referred to within our jurisdiction as intellectual disability is an acquired cognitive disability before the age of 18. And yes, it could be through a birth defect.

**CHAIR:** If the person becomes intellectually disabled as a result of a head injury at age 25—

**Ms O'CONNELL:** That person has what is called an acquired brain injury, referred to as ABI.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** For a person under the age of 18, it is a congenital condition?

**Ms O'CONNELL:** Yes, that is right.

**CHAIR:** It would appear that the number of head injuries as a result of car accidents is lessening, the number of children born with disabilities is lessening, but the big growth would have to be amongst people who are at the other end of the scale?

**Ms O'CONNELL:** People who are ageing?

**CHAIR:** Yes.

**Ms O'CONNELL:** Yes, that is true. It is not so much that it is growing but that it is being clearly diagnosed. When I spoke about a prevalence of 10 to 40 per cent, that does not relate to the ageing population but to diagnosis. Thirty or 40 years ago people would have simply lived in institutions with their schizophrenia and their intellectual disability.

**CHAIR:** And they would have been treated as people who had all sorts of problems?

**Ms O'CONNELL:** Yes. The thinking then was that these people are "feeble-minded", that they are probably not even capable of having emotions, so they could not have an "emotional disorder". So there was no real thinking around that. But as people have moved into the community, these people have been observed. Some people are able to cope better in the community; others have had major problems, particularly with anxiety disorders.

**CHAIR:** Intellectual disability is considered to be congenital if a person gets it before the age of 18, but for a person who has a head injury when he is 19 it is considered to be an acquired brain injury?

**Ms O'CONNELL:** That is right, and therefore that person will go through a different service pathway.

**CHAIR:** So people who suffer a head injury at age 15 and those who suffer a head injury at age 19 are treated in a slightly different way. As a peak, funded body that is an important distinction, is it not?

**Ms O'CONNELL:** Yes. And there is another peak body for people with acquired brain injury, called the Brain Injury Association. I was referring to treatment. Obviously, some people need to be treated with medication. But often people are better treated around something very specific. Often they have difficulty accessing employment or a particular life task, so often treatment focuses on something very specific. This would not necessarily happen for a person without intellectual disability, but what seems to have worked best is the focus on a particular area of a person's life where sometimes their psychiatric disability or mental illness is more observable or obvious and sometimes that comes out in social settings.

But if they are sitting at home on their own, that is not always the case. The treatments are quite varied. Some people are simply put into psychiatric hospitals, and there are major difficulties there because of communication. Others are treated within community settings, and there are difficulties there because of the access to services through the area health service.

**CHAIR:** How many of the people who come under your ambit are still in institutions?

**Ms O'CONNELL:** Currently in New South Wales there are still about 2,500 people living in institutions, and the current Government has a commitment to have those people living in the community by 2010.

**CHAIR:** How many were there originally?

**Ms O'CONNELL:** I could not answer that. But I would say that during the 1960s and 1970s most people went from home, often very soon after they were born, into a large institution.

**CHAIR:** The evidence before the Committee is that of those, about 30 per cent would have a mental illness as well as an intellectual disability.



**Ms O'CONNELL:** Okay. So going back, of the total population, the estimates of people with an intellectual disability would be 1 per cent to 3 per cent of the population, depending on how they are diagnosed. Currently in New South Wales, that is about 180,000 people. Not all of those people would have been living in institutions; they would have stayed at home. Some people stayed at home right through their lives and then had a crisis. What was considered the most appropriate thinking at the time was to take people away from their families if they were born with intellectual disability and put them into a care facility.

**CHAIR:** We are talking about 2,500, and there are 180,000 in the community. So less than 1 per cent of those people who are intellectually disabled are in institutions, is that the bottom line?

**Ms O'CONNELL:** Yes. But not all of those people in institutions will have psychiatric disability.

**CHAIR:** The evidence before the Committee is that about 30 per cent of the 180,000 people in the broader community would have a mental illness.

**Ms O'CONNELL:** The figures I have are between 10 and 40 per cent. It varies because of the difficulties in assessment and diagnosis, and the lack of expertise. I think one of the main issues is lack of co-ordination between health and disability services, and I am sure you have heard that before. That co-ordination is started at a very high level, in terms of the human services CEO level, right down to the local area health services and local disability regions. There are some instances where there have been some positive changes, and I think we need to acknowledge that. The former DOCS and now the Department of Disability, Ageing and Home Care Disability Services Directorate [DADHC DSD] had a protocol with Health some years ago. Obviously people came from Health into DOCS in the late 1980s, and a protocol was developed somewhere down the line from there. But, as I understand it, that was never particularly effective.

What has been more effective has been some local project-based initiatives. For example, in Bankstown there is a service agreement between DADHC disability services and the mental health team. So there have been some areas where there have been some good agreements. DADHC head office has implemented a pilot project called local support co-ordination. In eight regions in New South Wales, a person called a local support co-ordinator is established in the area, and the role of that person is to co-ordinate services for people with intellectual disability to link them into disability services but also generic services. That often includes mental health services, possibly drug and alcohol services, employment services, and all those other areas. That is an excellent initiative. It has been very successful in Western Australia and in other States as well. There are some areas where things are moving slowly and if those things continue to be implemented their will be some changes.

There are a couple of areas I did not mention. One is deinstitutionalisation. At the moment it focuses on finding accommodation for people to live in. While there is a recognition, I am concerned there is not enough work and resources going into community services for these people. Many people coming out of institutions will have a psychiatric disability and others will have, even if it is short term, some kind of post-traumatic stress disorder. They are used to living with 30 people, and we might not think that is a good thing, but change it to something else and people experience some loss. There needs to be a lot of support in place for people in those circumstances.

**CHAIR:** Of course, we are getting down to the most challenging 2,500 now, are we not?

**Ms O'CONNELL:** We are, yes. The other area that people have heard me talk about before is the prevalence of people with intellectual disability who are caught up in the criminal justice system. Many of those people also have a psychiatric disability and currently the service provision for those people is just not there to a degree. In mental health and disability we are talking about two sets of agencies needing to work together. If we bring in another co-factor of criminal justice issues, we have to have Corrective Services, Juvenile Justice, Probation and Parole, the prison system, the courts and police, but at the moment if somebody presents at a police station and is arrested—and I think somebody mentioned that in evidence earlier—the police find it very difficult. They do not know what to do. I have had a person from the police say to me that they have rung a mental health service and have been asked, "Do they have an intellectual disability or mental health?"

The police are not in a position to make any decision about that but they have this person taking up their time and probably a patrol car that could be used for something else. They do not know what to do with this person and they are driving around trying to find somewhere to put them. At this stage there are not many places for them. So, they may end up in gaol, they may end up in a large institution and find it very difficult to get out of those places—places like Rydalmere, where they may stay for a long time because at the moment no processes are in place to find appropriate accommodation for them. The issues for those people with intellectual disabilities are very serious, we would argue.

**CHAIR:** Just on that issue, you can be not guilty of a crime by reason of mental illness and therefore be diverted to the mental health service. If you do not have a mental disability but you are intellectually incapacitated, is there a defence that you are not able to plead, or whatever? In other words, is there a diversion process for that in the same way as there is for mental illness?

**Ms O'CONNELL:** No, there is not. People might not be fit for trial. There is nowhere for anyone to go. People may end up in places like Rydalmere, and Kanangra is a forensic unit once they had been convicted.

**CHAIR:** But they cannot be caught up in the forensic process. If they do not have a mental illness but are simply people with intellectual disabilities which are severe—

**Ms O'CONNELL:** Often these people do not have severe intellectual disabilities. They have what used to be called mild or moderate intellectual disability, but they have an associated offending behaviour.

**The Hon. JOHN HATZISTERGOS:** What are we talking about, a low IQ or something?

**Ms O'CONNELL:** Basically.

**The Hon. AMANDA FAZIO:** Around 50 or something?

**Ms O'CONNELL:** Yes.

**CHAIR:** Say somebody who is IQ 50 but with no evidence of a mental illness and they are out there throwing bricks through walls—

**Ms O'CONNELL:** That is the type of thing they might be doing, or lighting fires or something.

**CHAIR:** If they are mentally ill they can be diverted to mental health treatment under the Magistrates Act and so on. If they are just intellectually disabled, what is the diversion for them?

**Ms O'CONNELL:** They get diverted to the same system (under the jurisdiction of the Mental Health (Criminal Procedures) Act 1990. Whether people with intellectual disability also have a mental illness or not, they still come under the jurisdiction of this Act.

**CHAIR:** But they are not mentally ill?

**Ms O'CONNELL:** That is right.

**CHAIR:** To get on to that process you have to be declared to be mentally ill.

**Ms O'CONNELL:** That is true, but these people sometimes go through that same system.

**CHAIR:** They can be dual diagnosis, yes, but if they are simply intellectually incapacitated or intellectually disabled, I do not know what the situation there is.

**Ms O'CONNELL:** The situation is that if they are able to be tried they will be convicted and possibly go to gaol. There is a unit, for example, in Long Bay Gaol specifically for people with intellectual disabilities. That may be the path that they take. They may not be tried and they may end up going into another facility like Rydalmere.

**CHAIR:** How can they be imprisoned?

**Ms O'CONNELL:** They may be under guardianship.

**CHAIR:** At Long Bay?

**Ms O'CONNELL:** No, I am talking about if they come before a court.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Did the work of Jonathan Carne in this make any difference? He was doing an assessment of the Local Courts of intellectual disability and of people coming before the courts. Did that make any difference to what happened? Has his report come out?

**Ms O'CONNELL:** No, I do not think it has.

**CHAIR:** He is coming before the Committee later in the week. We will make sure we ask him.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** The fact that a person working in the field does not know is in a sense significant at the delivery of service level, is it not? Somebody who does research may say it is great and they have presented it but it does not mean it has filtered down.

**Ms O'CONNELL:** Some significant research has been done. CID commissioned a report recently called The Framework Report. Prior to that there was another very significant report for people with intellectual disability caught up in the criminal justice system. At the moment there is a very high awareness of the issue and some research has been done but we need some resources for services basically and we need better co-ordination of the current services. It is not always about money. In this case there is a need for more resources but there also needs to be better training and support for people working in the system.

**CHAIR:** The issue you raise is a lack of collaboration. I think you mean imperfect rather than absolute lack. It is not just between the two sectors, it is between the two sectors and the other people concerned—the carers and the non-government organisations [NGOs] or something.

**Ms O'CONNELL:** When I say the sectors, I mean the service providers. I think the issue of NGOs is worth discussing. The non-government services are not that well funded, so often people from the non-government services are not able to address the needs of people with intellectual disability or who have mental illness. So, those people tend to stay in the DADHC or DOCS.

**CHAIR:** The non-government sector is better supported in the disability sector than it seems to be in the mental health sector.

**Ms O'CONNELL:** I think it is better resourced. I would say that is true. I am not sure about mental health, but I would say that is the case. But in dealing with people with complex needs, there is very little access to clinical services within the non-government sector.

**CHAIR:** That is true. Certainly not even in the private sector. You raise the issue about access to regular care and treatment for people with mental illness in New South Wales, particularly in rural areas. If we can just concentrate on your area of expertise, particularly dual diagnosis; do many people have to take the geographic option and move to ensure their son or daughter or whatever gets appropriate services?

**Ms O'CONNELL:** I think the families may not move but the person may have to move, and that creates another associated difficulty in that they may have to move into an accommodation service nearer the clinical services.

**CHAIR:** So if you were out at Wee Waa you might have to move into Tamworth or Moree?

**Ms O'CONNELL:** Possibly, for sure. And I suppose all these issues are exacerbated for people of non-English speaking background and Aboriginal people, particularly those who are caught up in the criminal justice system as well, and people in institutions.

**CHAIR:** John raised the question earlier about the transcultural mental health service and you raise it certainly on the second-last page of your submission. How easy is it to distinguish between somebody who is culturally different and somebody who is intellectually not up to it? You know, these dumb savages approach.

**Ms O'CONNELL:** I think it probably is. I think it is changing now. I think there is more awareness but that has been an issue, for sure.

**CHAIR:** It is an issue still in Australia where we have just about every culture represented in our health system. Of the workers and the non-government organisations, just about every culture is in there doing the work. Health employs hundreds of thousands of people from different cultures. If we cannot get that sort of thing right in New South Wales we are not likely to get it right anywhere in the world, are we?

**Ms O'CONNELL:** I cannot comment on that but I think there is a lack of awareness of the person as a whole person and where awareness appears to focus on the disability or the person's cultural background. I think our disability services are still to a degree very Anglo-Celtic in their approach in how we see numbers of people in group homes as being totally appropriate and people being totally autonomous from their families by the time they

are 18 or 20 or whatever. That may or may not be appropriate in some cultures. I think that is changing and we have a very long way to go around that.

**CHAIR:** How many of the people that you deal with who are intellectually disabled and have mental illness have a full-time guardian appointed under the Guardianship Act?

**Ms O'CONNELL:** Many do, and I could not give you numbers.

**CHAIR:** This is the majority?

**Ms O'CONNELL:** I would say that is the case, yes.

**CHAIR:** It is not necessarily the case with everybody who has a mental illness? If you have a son who is a schizophrenic, you cannot get that order.

**Ms O'CONNELL:** But because of the system people are identified maybe through the criminal justice system and the disability system. They may be getting moved on from one accommodation facility to another because of the difficulty to settle and live comfortably in the home. So they can be identified. It depends of course how involved the family members are. Many people with a mental illness and intellectual disability have few family members involved. They are often people who have lower support needs for their intellectual disability. Their adaptive behaviours are not too bad, they can often live on the streets or in a hostel or something, so they are often quite independent of their families. Because of that there are issues with them not having any regular support people in their lives, so they often do not turn up to appointments or they make one appointment but do not get to the next appointment because they could have problems telling the time of getting money for a bus fare.

**CHAIR:** What comes first, the chicken or the egg? Are they homeless and without family support because they are both intellectually challenged and also have a mental illness, and if you fix those two up would they be much more palatable in the family? It is a matter of tolerance levels, is it not?

**Ms O'CONNELL:** Yes, it might be, and I think many people we are talking about who are homeless or living in hostels or whatever have been people who have come out of some of our larger institutions anyway so their families have possibly not been involved in their lives for a very long time.

**CHAIR:** What percentage of people who have come as a result of Richmond ended up in hostels, on the street or in prison?

**Ms O'CONNELL:** I do not have that percentage of people with intellectual disability.

**CHAIR:** The dual diagnostics I am talking about.

**Ms O'CONNELL:** So am I. I could not answer that at this stage. I mean, 30 per cent of people who live in boarding houses have intellectual disability and many of those people will also have a psychiatric disability.

**CHAIR:** But you have no handle on the numbers of those people?

**Ms O'CONNELL:** A lot of those people are not diagnosed the way they present to services and present to Centrelink for their disability support pension and that other support area, but they might not have had a real diagnosis or they may have had a diagnosis at some stage in their lives but they have not gone for continued treatment. They are not having their medication checked regularly. So, it is pretty hard to track those people. That is why I said at the outset there needs to be more research. It is only very recently accepted that people who have intellectual disability also have psychiatric problems.

**CHAIR:** That has been recognised for a while. Currently to receive a disability support pension a person has to go before a specialist who will make that judgment—and that is to be extended to social workers and the Commonwealth is looking at disability pensions in regard to "functioning" rather than what the doctor says. That may increase the number of people on pensions, of course.

**Ms O'CONNELL:** It may.

**CHAIR:** Do they automatically end up with a care planner? If they have been approved to receive a pension for financial support, do they also get advice about the support services to which they are entitled and which are available to them?

**Ms O'CONNELL:** Within Centrelink there are disability support officers. People who are on a disability support pension are certainly referred to someone within Centrelink who refers them to those services.

**CHAIR:** The caseworker is responsible for saying that a person is entitled to a pension but does the caseworker advise the person of other services which the person can access and offer to assist in accessing?

**Ms O'CONNELL:** The caseworker may not necessarily assist in accessing, but may give the information. There are not enough resources available to assist persons. That is what I said before.

**CHAIR:** If the person has an intellectual incapacity it is very difficult for him to ring up to make an appointment?

**Ms O'CONNELL:** That is correct. There would be support for people who need to make appointments. The caseworker may, depending on the time of day, their workload, or whatever, go with the person to the appointment. That certainly happens, but not in all cases and not everyone has access to that. A term used within the services is "acceptance of service". Often it is written on someone's file that he or she did not accept the service. But as I mentioned before, often they do not know that time of the appointment, they cannot read the card, they cannot find their way around hospital, they do not have the money for the bus fare, and so on.

**CHAIR:** The Commonwealth identifies it and decides that a person is entitled to a service and makes the appointments. But the providers of the services are at a State level for people with an intellectual disability, except for employment and training.

**Ms O'CONNELL:** Employment and training is through the Commonwealth. Day programs and accommodation services are through the State.

**CHAIR:** A lot of people who are intellectually disabled and others do not want to live where the department wants them to live. Some prefer to live on the streets. How can you best support them so that they can leave an itinerant life if they want to and still provide their housing needs, if you like?

**Ms O'CONNELL:** That role belongs to the Supported Accommodation Assistance Program, which often steps in for homeless people; they run refuges, et cetera. Often people from the service are not comfortable in dealing with people with intellectual disabilities. Sometimes they have a bit of an understanding of mental illness, but in some of the areas in which people need more assistance they would need to be referred to the Department of Ageing, Disability and Home Care [DADHC].

**CHAIR:** There was a constant theme through the carers, in particular, who say that it would be good if there were a file and an individual person named to look after person X, and that that person should keep the file up to date. Therefore, when someone is called during a crisis that person would know a bit about the mental and physical history and would be able to assist with urgent care. What is your view on that?

**Ms O'CONNELL:** If a person is within a system there would be a file, within DADHC or a non-government service.

**CHAIR:** But the mental health file will not be there?

**Ms O'CONNELL:** There would be something on their file if they have been diagnosed with some kind of psychiatric disability. Either they have been to a general practitioner and being prescribed some medication or they had been assessed by a psychiatrist.

**CHAIR:** How would that get onto their file?

**Ms O'CONNELL:** If there is a file on the person there would be some file notes put in by the key worker or whoever took the person for assessment.

**CHAIR:** But these people move around; Sydney today, Melbourne tomorrow.

**Ms O'CONNELL:** Yes, that is right. I am talking about someone who is in the system. At the moment I cannot see how that would work. Is very difficult to keep in touch with itinerant people.

**CHAIR:** The group that is particularly concerning is the dual diagnosis and intellectual capacity. They either do not remember or are not capable of necessarily understanding directions, because of the intellectual capacity. Therefore their need for appropriate assessment and advice and options for treatment would depend upon someone who may treat them in Moree today and Orange tomorrow. All the steps have to be gone through again unless there is some sort of floating file, if you know what I mean.

**Ms O'CONNELL:** I do. But the area you identified before, Centrelink, is the most consistent service that most people will access so that they can get their disability support pension. They go through the process only once a year. There are not many services that people are in contact with regularly, except perhaps the police in some cases.

**CHAIR:** That pension is put into a person's bank account?

**Ms O'CONNELL:** Yes. And once a year or once in two years people are assessed.

**CHAIR:** But even if they are assessed, they still have a bank account into which the money is put. How, otherwise, can they be found? How can there be a record of them without total invasion of privacy?

**Ms O'CONNELL:** Obviously privacy issues are involved. It is very difficult. From an advocacy perspective we would have to be careful about how we infringe on people's rights to live their lives the way they choose.

**CHAIR:** To what extent does privacy get in the way of care?

**Ms O'CONNELL:** It is very subjective, a difficult question to answer.

**CHAIR:** Is that a problem for the people you deal with?

**Ms O'CONNELL:** I would say that it is for some, but not a lot. Most people are aware that they need some support and they are very good at creating their own network.

**CHAIR:** Of course, they have a guardian?

**Ms O'CONNELL:** Some do, a lot do.

**CHAIR:** If I were a doctor seeing someone who came to me with a broken arm I could find a guardian who would tell me a bit about their background and would probably have a record of that.

**Ms O'CONNELL:** Some records would be kept by the Public Guardian, yes.

**CHAIR:** Or by the person appointed as a guardian?

**Ms O'CONNELL:** Yes. In most of these cases they would be under the Public Guardian. Private guardians are usually a family member.

**CHAIR:** When people are deinstitutionalised, what sort of training and support is necessary? What dollars are we talking about for every person within the institution? They are trained, a care plan is worked out, the service is ready to receive them, the house has been bought, and so on. What time and dollars are involved?

**Ms O'CONNELL:** At the moment seems to be taking quite a long time.

**CHAIR:** We are getting down to more difficult people, of course,

**Ms O'CONNELL:** Yes. It is taking a long time for a lot of people to move. There are lots of areas that need to be looked at. There needs to be community support and some of that is paid for out of various areas, not necessarily the disability budget. A lot of people coming out of institutions could cost up to \$100,000 a year for their support, some certainly cost less. We are reluctant to see the department purchase a house and put that person in that house for life; nobody lives in the same house for their whole life.

We would like to see an individual support plan. Care plans can get confused with the care plans under the Children and Young Persons (Care and Protection) Act. We are talking about individual support plans, which we call ISP. We would like to see plans that are developed around the life changes of a person so that as they age they

have different desires. They may not want to live in the city. They may not want to live with certain people anymore. Those opportunities need to be in place.

**CHAIR:** How much input does the community mental health team have with the support plan? This inquiry is focusing on mental illness. For someone with dual diagnosis who goes out into the community, what sort of communication and commitment is there from the community mental health team?

**Ms O'CONNELL:** People in the disability sector might argue that at this stage there is very little. In our research, in the *Framework Report*, the clinicians whom we consulted with felt that the mental health teams trying to keep people out of their sector to a degree. That has changed, and is still changing to a degree, but it comes back to the pressure that mental health teams are under to deal with everyone. Often there is a focus on primary disability. If the primary disability of a person is an intellectual disability, his psychiatric disability is secondary and so we need him to be dealt with in the disability sector. But that kind of siloing of disability or diagnosis is not helpful to the person, obviously. I think that that is changing, but a whole lot more work needs to be done.

Another important area is general practitioners [GP], and that has probably been mentioned already. Under recent changes to Medicare GPs can be paid to participate in casework. That has been a significant change. But in terms of input from the mental health teams there is still quite a long way to go. To a degree there is so much pressure on the mental health teams. The thinking has not shifted that this is a person, whether they have an intellectual disability or not, but that person has a mental illness and they are our responsibility. That thinking has not changed, but I believe that it will over time.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** The Committee has received a submission stating that if a client had a primary disability and another person tried to say that something else was a primary disability, there would be an obligation on the person who said that that primary disability was not in their field to make sure that the client was treated in the appropriate field. Is it universally accepted that that happens?

**Ms O'CONNELL:** The issue is treating the disability and not the person.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Perhaps we should not use the word "treated". If the client is sent to another agency you have to make sure that they do not get lost.

**Ms O'CONNELL:** If you send them to a disability agency at this stage they will not necessarily get the treatment they need for their mental health needs. There is no good outcome for the person in those circumstances. Within DADAHC there are some services, but they are very stretched.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Can you suggest what areas the Committee should investigate to obtain a protocol for co-operation between the departments for dual-diagnosis people, from the top to bottom?

**Ms O'CONNELL:** It needs to start at the top.

**CHAIR:** Are there any models, that you are aware of?

**Ms O'CONNELL:** Bankstown mental health, and you have probably been told about that.

**CHAIR:** Yes. That is part of South West Sydney Area Health Service.

**Ms O'CONNELL:** Yes. The local support co-ordination pilot, as it is at the moment, within DADAHC, although not specifically focusing on mental health, does work at the grass roots, with the families if necessary, with the community mental health teams, drug and alcohol services, police, or whoever. The role of those people is to co-ordinate the services and the life of the person with an intellectual disability. If that model was increased things could change quite significantly poor people.

**CHAIR:** Does this person act as more than an advocate?

**Ms O'CONNELL:** This person is not an advocate. The person's role is to identify supports and find services in the area and do some networking.

**CHAIR:** Is that different from individual advocacy?

**Ms O'CONNELL:** Yes. The outcome might be the same but it would be considered a different process. It is a service provision modelled within the department. That is a reasonable way to describe it and it has worked very well in other States. It has been in place here for only 18 months. I think it is working well.

**CHAIR:** In which States is it working well?

**Ms O'CONNELL:** Western Australia, where it is called the local area co-ordination, here is called the local support co-ordinator.

**CHAIR:** When you get your copy of *Hansard* would you mind correcting it as quickly as you can so that it can be put onto the web site. If you wish to add anything to what you said today would you communicate that to the Committee.

**(The witness withdrew)**



**JOYCE MARIE SAID**, Executive Director, After Care, Chair, Mental Health Co-ordinating Council, Rozelle Hospital, and

**PHIL JOHN NADIN**, Deputy Chair, Mental Health Co-ordinating Council, Rozelle Hospital sworn and examined:

**JENNA BATEMAN**, Executive Officer, Mental Health Co-ordinating Council, Rozelle Hospital affirmed and examined:

**CHAIR:** In what capacity are you appearing before the Committee?

**Ms SAID:** As Chair of the Mental Health Co-ordinating Panel.

**CHAIR:** Are you conversant with the terms of reference?

**Ms SAID:** Yes, I am.

**CHAIR:** Is the submission that has been presented to us under the authorship of Ms Jenna Bateman to be part of your sworn evidence?

**Ms SAID:** Yes, it is.

**CHAIR:** In what capacity are you appearing before the Committee?

**Ms BATEMAN:** As Executive Officer of the Mental Health Co-ordinating Council.

**CHAIR:** Are you conversant with the terms of reference?

**Ms BATEMAN:** Yes, I am.

**CHAIR:** You are appearing as the Deputy Chair?

**Mr NADIN:** Yes, I am.

**CHAIR:** You are conversant with the terms of reference?

**Mr NADIN:** Yes.

**CHAIR:** Should any of you consider at any stage during your evidence that in the public interest certain evidence or documents that you may wish to present should be heard or seen only by the Committee, the Committee would be willing to accede to your request. Please be aware that the Legislative Council may overturn the Committee's decision and make his evidence public. Would one or all of you like to make a statement in regard to either submission you have made or any other statement?

**Ms SAID:** We have agreed that Mr Nadin will do that.

**Mr NADIN:** The primary thing that the Mental Health Co-ordinating Council is concerned about, and we have certainly addressed the terms of reference in a submission, is that the terms of reference of the council may not lead the inquiry into the area which is of greatest concern to the Mental Health Co-ordinating Council. Put simply, it is the issue of funding for the mental health non-government sector. You would probably be aware of the facts as they stand at present. Of all the State and Territories in Australia, New South Wales devotes the smallest percentage of its mental health budget to the non-government sector. The overall national average, by looking at the performance of all the States and Territories, 5 per cent of the mental health budget is directed to non-government organisations [NGO]. In New South Wales the figure is 1.7 per cent, which is far below the national average. It is the worst performance of all the States and Territories.

When the national mental health strategy commenced in 1996, New South Wales was in the position of providing the lowest level of funding for the NGO sector. Since then we have regressed. We are still providing the lowest level of funding for the NGO sector, but in fact the share is getting smaller and not larger. The funding is

simply indicative of a major problem, which is the lack of rehabilitation services, psychosocial rehabilitation services and other services in the community that are necessary to support people with mental illness in the community. As we have had this shift, and as there should have been, away from institutional care to maintaining people in the community—and our submission shows that there is research and evidence to support the fact that people with mental illness prefer to live in the community and they do better when they are living in the community—the evidence is that is where they should be by and large.

There will always be a small percentage, but by and large that should be the thrust of mental health policy, to maintain people living in the community. There can really be no argument with that. But if we take the next step, funding to make that policy a reality just does not occur. There simply are not sufficient resources put into community care to be able to provide for people the way they seek that sort of support in the community. The end result of that is that people get sick, and when they get sick there is nowhere else for them to go other than back to hospital. The effect of that is devastating for the person, but also it is costing the State a small fortune. It is a lot more expensive to maintain beds in hospitals and to provide acute care facilities than it is to provide support facilities in the community, a lot more expensive. There is a wealth of research from America that shows that people can be maintained adequately in the community and that there are paybacks to the overall system.

**The Hon. JOHN HATZISTERGOS:** This is all prefaced on the basis of the State's percentage of time spent towards NGOs as a proportion of the mental health budget, is that right?

**Mr NADIN:** That is correct.

**The Hon. JOHN HATZISTERGOS:** Would you not need to take us, firstly, to what the mental health budget is in various State before you start dissecting percentages?

**CHAIR:** I would not go there.

**The Hon. JOHN HATZISTERGOS:** It is all based on a premise that New South Wales is low and getting lower. But that depends upon what amounts are spent on a State basis. I do not know, but the amounts may be relatively higher if the budget for New South Wales relative to other States is higher than other States. Do you follow what I am saying?

**Mr NADIN:** Yes. If I could answer that—

**The Hon. JOHN HATZISTERGOS:** You do not have to do it now.

**Mr NADIN:** It is fairly complicated, and I appreciate your raising the point.

**The Hon. JOHN HATZISTERGOS:** It is complicated, and we need that background before we can really understand the extent of the crisis.

**CHAIR:** Page 5 of the submission shows that the amount of money spent per capita is \$1.16 in New South Wales and for the other States it is vastly higher.

**The Hon. JOHN HATZISTERGOS:** Yes, I see that.

**CHAIR:** The trouble with this is, and you are right to point it out, that the best figures we have for almost the entirety of this report are for 1997-98. They finish in 1998. It does not take account of the Minister's new budget funding. I do not know how much of that has trickled down to the community—almost none.

**Ms BATEMAN:** Almost none.

**CHAIR:** I think \$450,000 was one of the figures that was used.

**Ms SAID:** That is right.

**CHAIR:** But that still does not mean that these figures have not been updated for the other States either. It is appalling.

**The Hon. JOHN HATZISTERGOS:** We need this information.

**CHAIR:** We do. I have tried to get it from the Commonwealth because they are the ones who have the best numbers because they can require the States to do it. We are in close negotiation with the Commonwealth department to try to get the report that every State has to do for the Commonwealth every year. But the trouble is that the latest information on the last review of the 2000 report ended in June 1998.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** The people in Wollongong might be able to give us that.

**CHAIR:** I take the point made by the Hon. John Hatzistergos

**The Hon. JOHN HATZISTERGOS:** I accept what you say about these figures, but the point I really want to make is that even accepting them as they are, they are still based on proportions of mental health budgets.

**CHAIR:** No, they are actual dollars if you look at the last column.

**The Hon. JOHN HATZISTERGOS:** Are they dollars? There are percentages everywhere.

**CHAIR:** Yes, they are dollars. Per capita expenditure on mental health NGOs, that is the dollar figure for State. It is very low. But, again, they are only 1998 figures that is why I am being cautious about them. If you get the 1998 figures, New South Wales is about the third-worst funded, mental healthwise.

**The Hon. JOHN HATZISTERGOS:** It has actually gone up slightly, 1.3 to 1.7. Still, that is not very illuminating. It does not tell me anything.

**CHAIR:** But in terms of the mental health budgets for each State, some of them are not quite comparable as I understand it. There are some States that include drug and alcohol and some do not.

**Ms SAID:** That is right.

**Ms BATEMAN:** That is right.

**CHAIR:** But New South Wales is not in the top league of funding for mental health services.

**The Hon. JOHN HATZISTERGOS:** That might be the general proposition ultimately, but we need to have this sorted out. However, accepting the premise upon which you are arguing, which is basically that not enough money is being spent in New South Wales—

**Mr NADIN:** We are not so much talking about the actual dollar sum as the share of the budget. The point I am also making is that there is a saving, long term, to the system in keeping people out of hospital. If we just look at input then, to some extent, there is a risk that we will always be chasing our tails.

**The Hon. JOHN HATZISTERGOS:** But the point I am making is that there is also a lot of variance and I think the Chairman was making this point. There are various problems as to what is involved, what is in and what is out, between various States. We need to sort that out. We also need to work out what services have been provided by various States and what services have been provided in the public sector as opposed to the private sector, the NGO sector for want of a better term. We need all that sorted out. What I understand you to say is that you do not complain about the overall mental health level of funding, you are complain about your share of it. Is that correct or not?

**Mr NADIN:** I guess our bottom line is that the amount of resources that have been put into community psychosocial support and rehabilitation is not sufficient for what is needed in this State.

**The Hon. JOHN HATZISTERGOS:** That is a better way of putting.

**Mr NADIN:** Whether it is a matter of rearranging existing budgets or making the budget larger and thereby 1.7 per cent ends up being more in dollar terms—

**CHAIR:** You referred to it as "miserable".

**Mr NADIN:** That was my feeling when I said that, yes.

**CHAIR:** We will have to get more up-to-date figures because I think they will be better than that, but not a lot.

**Ms SAID:** Not a great deal.

**CHAIR:** Not a great deal?

**Ms SAID:** No, there has been very little to us.

**CHAIR:** The new \$130 million the Minister put up, the evidence is that very little of that trickled down and \$455,000 is all that is identifiable in that \$170 million over the three-year period, which will not increase it. In fact, it will drop it.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** We have asked the Minister to come up with that, and I gather that they are coming with that today.

**The Hon. JOHN HATZISTERGOS:** I do not know what the figures are. I know that we are now getting recurrent funding for schizophrenia, which is a new thing we have started.

**CHAIR:** Dr Refshauge started that some three years ago.

**The Hon. JOHN HATZISTERGOS:** Recurrent value was kicked off last year, was it not?

**Mr NADIN:** I would not know.

**Ms SAID:** There was some pick up for a program for schizophrenia.

**CHAIR:** They are coming this afternoon.

**The Hon. JOHN HATZISTERGOS:** I do not know what the figures are, but I am prepared to run on the assumption that you are making, but I would be more interested to know what the impact is.

**Ms BATEMAN:** The perspective that is useful to look at it from is readmission rates into hospital. They are figures that we do not have either. Certainly, I know that they are collected for 28 days after discharge, but we do not have figures on how many people readmit after three months, six months or 12 months. If we had a clearer picture there we would see that it is the same client group or the same people revolving through the system time and time again.

**CHAIR:** You have tried freedom of information, as we have, and you get no success.

**Ms BATEMAN:** That is right. We have tried. I have worked in inpatient units so I am very aware that people bounce back through that system. It is the same people. Part of my personal decision in moving from health into this sector was because I could see that we were discharging people, but what was happening to them once they left the hospital doors, there was not support there, obviously. They were not coming back with jobs. They were still not housed. It seemed that the work we did while they were patients was not going to make them people who were better off. They are figures I thought the Inquiry would like to have a look at, and I think that would tell us that if we increase funding into the NGO sector we would see a reduction in readmission into hospital.

**CHAIR:** That is certainly the case in Victoria, is it not?

**Ms BATEMAN:** Yes.

**CHAIR:** Would you like to continue, Mr Nadin?

**Mr NADIN:** I guess the problem we have is that when you look at growth in mental health funding in New South Wales, to the extent that there has been growth in mental health funding in this State, the direction of that growth appears overwhelmingly to be in terms of increasing the number of beds in the system. We are saying that that is the cause of the costs rising and that need is arising because the facilities and the support are not clear in the community to keep people living where they want to live and where they should live. At the end of the day you get the need for more beds. You get a bed management crisis because there simply cannot be enough beds because the demand keeps growing and because the rehabilitation services are not in the community.

From our perspective, we believe we are seeing the expression of where the State's policies are leading us. We will just end up providing more and more beds with the necessary growth in community-based rehabilitation services not occurring. It might occur to some small extent here and there but in terms of an overall plan with proper step down arrangements, out of hospitals into community care, into rehabilitation services, it just does not exist as a plan or as a reality at the moment, and we cannot see any indication that it is coming. In fact, if anything, we are probably concerned that it might be going well the other way. People are now starting to talk in government about rehabilitation in terms of clinical maintenance. We do not believe that rehabilitation is clinical maintenance.

We believe that rehabilitation is people being maintained in the community, certainly with the medication issues being dealt with but also the other range of supports, be they vocational training, supported accommodation, living skills centres or home care, whatever is required. But all those things are not being provided to the level that they are needed at the moment. The end result will be that people with initially very minor problems will tend to get sicker and sicker and they will end up back in hospital, and that cost to the community is enormous.

**CHAIR:** I think this is one of the outstanding submissions, without any doubt, in my view, in attacking the terms of reference. You make the point that in 1985 there were 55 people residing in psychiatric hospitals. Does that mean psychiatric institutions as well?

**Ms BATEMAN:** Yes.

**CHAIR:** Did that include the disability people as well?

**Ms SAID:** Yes.

**CHAIR:** That is a bit confusing. Between October 1984 and October 1987, 208 long-term patients were discharged from hospitals and placed in group homes. Were most of them disabled?

**Ms SAID:** They were people who were termed to have a mental illness and they were transferred directly under the Richmond program.

**CHAIR:** The point made in other submissions is that the money that was saved by closing beds was not put into investment in the community; in fact, it went back to Treasury. Is that your view as well?

**Ms SAID:** Yes, it is. When we were on the central Richmond Implementation Committee a lot of that was due to the fact that the transfer of a ward was never achieved, so they were never able, due to union interventions and various things, to transfer 20 people into the community at any one time. Those 208 people were little clusters of people, not a ward closure.

**CHAIR:** The submission of the Commonwealth, in comparison with other States, states that Victoria closed 40 per cent of its beds and made 40 per cent of its in-patient costs as a result of that. New South Wales closed 17 per cent of its beds but reached the benefit of only 2.5 per cent, for the reasons you say. So the money was never there to reinvest in the community.

**Ms SAID:** No.

**CHAIR:** Whereas Victoria did use its money to invest in the community.

**Ms SAID:** One reason for that was that a bed in terms of what was identified in the Richmond report may well have been eight occupied beds in a ward of 20 people. When you start to bring down the numbers of people who were being supported it was far less so they did not ever transfer those vacant beds into the community because there was no need for the use of those vacant beds. Does that make sense?

**CHAIR:** Yes, it does. The Richmond report also identified savings that could be made whereas the evidence from Europe was in fact that it was more costly, if better, in the first place for people. But as you identify, it reduces the need for crisis teams and early intervention if you do that bit right.

**Ms SAID:** That is right.

**CHAIR:** If I read your whole submission, is that what you are saying?

**Ms SAID:** Yes.

**CHAIR:** I did not want to verbal you in any way. You then go to the issue of deinstitutionalisation, if you like. You say it is a good thing and it is the right action to take but the resources simply were not there to achieve it.

**Ms SAID:** That is right, because of that non-transfer of funds across to the community.

**CHAIR:** The Mental Health Co-ordination Council is concerned that the apparent change in direction has resulted in the neglect or downgrading of services for people with continuing severe mental illness. What are you saying there?

**Ms BATEMAN:** The thing we are trying to get there is that there has been an awful lot of attention and money and funding put behind programs for depression, for promotion and prevention and early intervention. There is a whole new direction now and it is away from the rehabilitation of people with serious mental illness, and that has been occurring over the past five years or so.

**CHAIR:** And that therefore is within a relatively fixed budget; that means taking money away from the care of the people who were usually cared for in the past.

**Ms BATEMAN:** Yes.

**CHAIR:** One dot point on page three of your submission is this enormous transfer of cost and support needs to families and friends both in terms of case management and access to psychosocial rehabilitation services. What sort of transfer are we talking about?

**Ms BATEMAN:** I think the point there is that when you have decreased access of people to rehabilitation programs, outreach support and vocational programs, the consumers have less focus with their day. The outcome of that is that carers and friends have picked up a lot of the issues for that consumer. It is about shifting.

**Mr NADIN:** I think it would be incorrect to assume that there are always carers, family and friends who are able or willing to support. Psychiatric illness, by its nature, is very alienating and basically a lot of people with mental illness lose contact with their families or vice versa. It would be wrong to assume that there is always someone there to provide support. That is probably more the exception than the rule.

**CHAIR:** The next paragraph states that the number of in-patients census in psychiatric hospitals fell from 256 per 100,000 in 1950 to some 55 per 100,000 in 1995. What is the number of in-patients as per 100,000 now?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** It is in the Government's submission.

**Ms SAID:** Yes, but we do not have access to that information.

**CHAIR:** No. I could not find it either. In other words, this is even before Richmond, because Richmond was 1983, was it not?

**Ms SAID:** That is right. That relates to the 1960s.

**CHAIR:** That change happened with the new drugs and new treatments and so on so that the Richmond thing was happening and had substantially happened before Richmond?

**Ms SAID:** That is right.

**CHAIR:** They go from 55 beds down to what we have now. Do you know what it is now?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I thought there were some figures in the national—

**CHAIR:** No, there is not. We need to know how many people are in psychiatric hospitals now because that figure of 256 would have included some of the disabled as well, and some of the 55 per 100,000 would have been disabled as well. But at the time, in 1985, that was thought to be very low by international standards so in fact we had done probably a better job of deinstitutionalisation or lack of caring.

**Ms SAID:** That community follow-up not being there, it certainly created its own problems.

**CHAIR:** Then the mental health strategy came along which you clearly identified as a co-operative arrangement with all the States moving towards a single unified approach of deinstitutionalisation and appropriately moving their money. In your submission you recommend that New South Wales, in partnership with you, review the adequacy of service provision, that the data on re-admission rates be published to help with planning, and that carers be assessed for their capacity to support consumers and be included in the care packages. Are they still your recommendations?

**Ms SAID:** Yes.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Here it is—total public sector psychiatric beds per 100,000 population in 1998, New South Wales has 33.8.

**CHAIR:** It has gone down.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** That is in June 1988.

**CHAIR:** Despite the fact that the number of people who are mentally ill in the community has risen, but since 1985 there have been major changes in drug therapy. For example, the new antipsychotic drugs are vastly better than they were in 1985. We now come to the level and methods of funding of mental health services. You make the point in 2.21 of the your submission that New South Wales has no plan to identify the volume and types of mental health NGO services required on a population basis. This is particularly in regard to NGOs.

**Ms BATEMAN:** That is right.

**CHAIR:** So there is no NGO plan and therefore the dot points below that follow, do they not?

**Ms SAID:** That is right.

**CHAIR:** The issues that John went into before are the issues that we need to clarify, to have them up to date. Are these figures weighted for age and sex and prevalence?

**Ms SAID:** No.

**CHAIR:** They are weighted just for the population of New South Wales versus Queensland or whatever. Is there any evidence that there is any difference between the States in that regard?

**Ms BATEMAN:** No, not that I am aware of.

**CHAIR:** And we are talking big populations. Tasmania might be different because it has a small population, not for any other reason, I hasten to add rapidly.

**The Hon. AMANDA FAZIO:** I go back to the lack of a mental health plan for the non-government sector. As the umbrella body for community organisations involved in the provision of mental health services, how has it come about that there is no plan? Have you been waiting for some impetus from the State Government to assist you to develop that plan?

**Ms SAID:** It is due to the area health board administration and the whole area management of the services that are provided. There is no direction from the centre of mental health to the areas, telling them how to fit the NGO sector, in a partnership way, into the services that are being provided. It would have been useful from day one of this new direction of area management to see the NGOs as true partners in the service provision and have us made part of a system of management for people so that there is a seamless system for them to use. As it is at the moment, that does not exist.

**The Hon. AMANDA FAZIO:** Are there any regional plans? Does the regional co-operation between the government sector and the non-government sector vary across the State, or is it in a similar situation everywhere?

**Ms SAID:** I think the lack of NGO inclusion in the planning is the same across the State. It is starting to happen in a small way in some of the metropolitan areas. There is a little bit of it happening but in the main there are insufficient numbers of NGOs. Northern New South Wales is quite good at working with the NGOs but it is very patchy.

**The Hon. AMANDA FAZIO:** Would you prefer to see a consistent approach?

**Ms SAID:** Absolutely.

**The Hon. AMANDA FAZIO:** Would you prefer to see some sort of framework of service delivery by both the government and the non-government that builds in—

**Ms SAID:** That is right.

**Ms BATEMAN:** So, it is seen as a complete system rather than, as is currently the case, the NGO sector as an afterthought.

**CHAIR:** On page 6 of your submission you make the point that I think John was coming to about the \$107 million that the Minister increased the budget by but he could only identify \$455,000 as going to the NGO sector in that announcement. There may have been further announcements, but I notice that the Premier announced major increases that he is proposing to make for the future, which again are hospital-based.

**Ms SAID:** Yes, they are.

**CHAIR:** What sort of recommendations have you made to the Government about funding levels to allow the NGO sector to provide what services? In other words, it is no good the Government just giving you the money. What sort of plan do you have?

**Mr NADIN:** The first point we make is that we have not been consulted. It is very difficult to make recommendations to government because we have not found a way into government to talk to them about this issue. The first problem is not just the \$107 million enhancement program. Mental health funding for as far back as I can remember has not included the NGO sector in terms of looking at our capacity to provide services or any input from us about how the funds should be delivered or the quantity of funds. That is the first point. If we were asked, we would start from the point of looking at people who leave hospital. What are we going to do for people when they are discharged, with the primary aim of keeping them out of hospital? Then let us take it from there.

**CHAIR:** Do you mean that some of the NGOs should be fund holders to achieve those support services as part of a discharge plan?

**Mr NADIN:** I think we would be looking more at building the capacity of the NGO sector to have services available that people could enter into. You are implying more of an individualised approach. That would be ideal but I could never see the resources being available for that. If there was sufficient supported accommodation, such as group homes or even community-based asylums in the old sense of the word, that would be somewhere safe and supportive for people before they move on to the next stage. That would be our first point to government.

Let us talk about what we are going to do for those people who step out of the hospital. Let us look at the rehabilitation services at the hospital, for that matter. As I say, I am not talking about clinical maintenance. Then let us take it from there. We would very soon be talking about adequate levels of supported accommodation and other support services, such as entry into employment, living skills centres, drop-in centres, support centres, a whole range of psycho-social interventions, and there are dozens of them. It is a reasonably new field that is still developing.

No-one is saying that it has the full suite of services anyway. There is plenty that we could get our teeth into and get started with. We would continue to make the point that these things can be made at relatively little cost. In terms of the savings and efficiencies, it really pays off for itself over time. If you have a centre that people can drop into once a week, so long as there is maintenance of the medication, that may well be all that they need in terms of contact with others and some place to go where they feel safe and comfortable and warm on a day like this. Also, there is somebody there who is trained who can see when people need help. It might just be that they have trouble getting up in time to catch the 10 o'clock bus to come in.

**CHAIR:** A case of "John did not arrive today. I wonder what has happened to him?"

**Mr NADIN:** Yes, all those things, which, as you know, can develop into major traumas for individuals, and we know where they end up. If those sorts of things can be stopped, nipped in the bud for relatively no cost, why would we not try that?

**The Hon. AMANDA FAZIO:** We had evidence last week about care in the community for people after they have been discharged from hospital. You have mentioned group homes or supported accommodation of some form. We were told it was far preferable in terms of stabilising people in the community that they be provided with



accommodation or housing and that the support levels they need be varied at that one location. In other words, rather than people leaving an institution or a hospital and going to some form of hostel care, then moving on to living in a flat with some community support, they would be placed in the accommodation first and a package of care tailored around them. Do you agree with that?

**Ms BATEMAN:** That would be the best model.

**Ms SAID:** It is the lack of available housing that causes group homes to emerge. It is not the preferred model, I do not think, for many people who are providing support at the moment.

**CHAIR:** The other point raised about this whole issue is the lack of a funding formula. When the provision of services is contracted, such as with the Richmond fellowship, there is no funding formula for the workers.

**Mr NADIN:** It has never been on the agenda, so it is not something that we have put a lot of work into. It is something we would like looked at.

**Ms BATEMAN:** It does happen in Victoria. A lot of work is being done around that in Victoria. We would support that.

**CHAIR:** Another issue you raise is funding of NGOs. You make the point that sometimes when a new service is to begin, which could be provided by the non-government sector—for example, a project—New South Wales Health is both a purchaser and a bidder. The Centre for Mental Health may decide that this year it will spend \$5 million on a particular service. Do you say that the area health services bid to get the money when the service could be provided by non-government organisations?

**Ms SAID:** The centre would distribute the money to the areas on a ratio of some description. The area then sits at a meeting with a group of people and says, "We have decided we will allocate this much to the NGO. How much can we buy for \$100,000?" The rest of it is never discussed in terms of how that money is going to be spent. That sort of approach is exactly what happened with the \$107 million. In fact, I know the \$107 million was taken up in one area by meeting the shortfall in salaries and things like that.

**CHAIR:** That is certainly true. They were not funded for the increase in salaries. That is a separate issue. We will come to that later.

**Ms SAID:** That is what it is about: "We have some small dollars. The NGOs can have that little bit of it."

**CHAIR:** Are there any other questions from the Committee about the way in which NGOs are funded?

**The Hon. JOHN HATZISTERGOS:** At some point I would like you to address the proposition you put forward that increasing funding to the NGOs would in the long term result in a saving to the health budget. Can you point to any empirical evidence, particularly in terms of your group of affiliates, that would demonstrate that?

**Ms SAID:** If you look at it in terms of that money being used for relapse prevention, that is the outcome from using the NGO sector. The work that we do, backed up by community mental health teams, prevents relapse and hospitalisation.

**The Hon. JOHN HATZISTERGOS:** Has that been evaluated?

**Mr NADIN:** It has not been evaluated in New South Wales. We would be drawing from overseas studies. The point about looking at Victoria and at readmission rates would, I think, in time bring us to that same conclusion.

**CHAIR:** The Commonwealth-funded program in New South Wales for suicide prevention was a major funding allocation by the Commonwealth to the States. How much of that money went to NGOs?

**Ms SAID:** None of the NGOs that we represent received suicide prevention money.

**CHAIR:** We have identified that some of the \$107 million went to the NGOs. What happened to the rest of it? The Minister and Treasury made a reasonable allocation of an extra amount of money over a period of years to increase the budget. What happened to that money?

**Ms SAID:** I can only speak of two areas that I am aware of. One I know of, because it was announced to us, went to salary shortfalls. A small amount of money went to the NGOs. The balance of the money went to staff positions for the area who were told that they would have to liaise with the NGO sector as a part of their tasks. It might have been a child and adolescent worker who would also be working with the NGO sector. It was rationalised in that way.

**CHAIR:** How much of the \$107 million was new money and how much of it came from the Commonwealth?

**Ms SAID:** I am sorry, I do not know that.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Was the money provided to the adolescent liaison staff in the mental health area?

**Ms SAID:** Yes, that is how it was identified. What actually happened to it after the announcement was made to us I do not know.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** To what area did that money go?

**Ms SAID:** Western Sydney.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** To what area did the money go to cover salary shortfalls?

**Ms SAID:** Central Sydney.

**Mr NADIN:** We did ascertain at the time of the announcement that 30 per cent was to be set aside to maintain the spending power of the full mental health budget. In other words, it was to cover the consumer price index (CPI) for existing services. Then 26 per cent went into an announcement to support 150 new beds. That left 44 per cent, or \$47 million over three years for general growth. Up until October last year, of the \$47 million for general growth, which would have included new services, the NGO sector had seen \$450,000, or basically 1 per cent.

**CHAIR:** You still have two years to run, to be fair.

**Mr NADIN:** One year.

**CHAIR:** Has there been an announcement about funding for the next three years?

**Mr NADIN:** No.

**CHAIR:** Are you expecting that announcement in this year's budget?

**Mr NADIN:** We do not know.

**Ms SAID:** We are wondering what Mr Carr's announcement made on Saturday is going to do to any new money.

**CHAIR:** That is the announcement of funding for either 220 beds or 108 beds, depending on how you read it?

**Ms SAID:** Yes.

**CHAIR:** That is obviously an area we will have to explore with the department. Would you like to speak to community participation integration of mental health services?

**Ms BATEMAN:** Perhaps the main point we would like to get across is that there seems to be a move where consumers are asked to sit on committees, which have a big status and hope to achieve a lot. The Health Minister's consumer participation group is an example of this. But the consumers are not on those committees representing a constituency; they are on those committees as individuals. We would argue that is really not a useful way to structure the committees.

**CHAIR:** Is it not better for the Minister to seek advice from people who are recognised within the community as being of wisdom and knowledge, rather than seeking advice from people who are representing an agenda?

**Mr NADIN:** Our problem is that this is the only form of consultation that exists for us at the moment. We happen to have one of our members on the committee as an individual.

**CHAIR:** Do you say there is no formal mechanism of consultation?

**Mr NADIN:** No.

**CHAIR:** You have a huge number of affiliates under your umbrella of co-ordinating council. You have the Association of Relatives and Friends of the Mentally Ill [ARAFMI] and a whole range of others. Do intellectual disability people come under your umbrella?

**Ms BATEMAN:** They do not come under us, no.

**Ms SAID:** Many of the groups who are members of MHCC do support people who also have an intellectual disability.

**CHAIR:** Therefore, you have a finger in just about every pie that relates to mental health?

**Ms SAID:** Yes. Part of the boarding house reform project has been managed by our organisations as well.

**CHAIR:** Is there a practice of the Health Minister consulting with the Mental Health Co-ordinating Council on a regular basis?

**Ms SAID:** No.

**CHAIR:** When I was parliamentary secretary for health I used to spend a couple of hours with the Mental Health Co-ordinating Council every three months. I was not terribly successful in getting a great deal of things that you wanted but it was a policy process. Does that not happen now?

**Ms SAID:** No.

**CHAIR:** I thought that Dr Refshauge was good at that.

**Ms SAID:** He was quite good. The present Minister is less so.

**Ms BATEMAN:** We do sit on the Mental Health Implementation Group.

**CHAIR:** Do you have a position there as a representative of the Mental Health Co-ordinating Council?

**Ms BATEMAN:** No, I am there as an individual. When people were asked onto that committee it was as individuals.

**CHAIR:** The Minister can, through the implementation group, reach into your entire organisation using you as the head..

**Ms BATEMAN:** That is not how it was presented.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Does the implementation group work very well? I gather the group made wide changes in the implementation of the Menadue report in a number of areas. Were wide changes made in the implementation compared to what had been suggested in the Menadue report?

**Ms BATEMAN:** Mental health was not a big component of the Menadue report. Mental health got forgotten and, unfortunately, almost as an afterthought the Implementation Committee for Mental Health was set up to feed into that process. It was not initially part of the basis of that report.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** The Menadue report took a more preventive thrust to mental health in general, did it not?

**Ms BATEMAN:** Yes.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** And that was somewhat watered down in the implementation, dare I say?

**Ms BATEMAN:** Sure.

**Ms SAID:** Are you talking about the structure of the health council?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I am talking about what happened in terms of the outcomes of the report.

**Ms BATEMAN:** In terms of mental health, what happened was that the \$107 million was announced, the implementation group was set up, supposedly to decide the best way that funding should be distributed throughout the mental health system. That failed to happen and what turned out in the end was that we created policies in a number of areas. There have been policies written for rehabilitation services, non-government organisation [NGO] services, children and adolescents, eating disorders and a whole range of papers have been written which are supposed to guide area health services.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** You set up policy groups but your job, you thought, was to implement the spending of the \$107 million, but you sort of lost track of that?

**Ms BATEMAN:** And then it turned into a broad policy development.

**CHAIR:** Even if the Menadue achieved that, in other words, a lot of people working in a co-operative way with the department and the Minister to work out proper policy, the issue then becomes, for its success or failure, whether it is properly resourced to achieve the ends of the policy that is approved?

**Ms BATEMAN:** Yes.

**Ms SAID:** Perhaps there is a stage before that: it needs to get published and circulated and implemented.

**CHAIR:** We have not seen those yet, have we?

**Ms BATEMAN:** No.

**CHAIR:** Everybody else wants a whole-of-government approach but your concern on page 9 is whether it will allow buck passing. Surely with the centre for mental health and the requirements of the national health plan there should be an individual person responsible for every health service for mental health service delivery, that is the mental health plan. In other submissions we have noticed that the chief health officer in each area does not even know what the budget is?

**Ms SAID:** That is right.

**CHAIR:** Is that why you have those concerns?

**Ms SAID:** Yes, and also some discussion has occurred about the way the NGO sector, working with people who might be seen to have disabilities, is going to see it. It is that question that is always up for debate within MHCC member groups because we have learned from experience that people with multiple disabilities are shifted from department to department and we now had difficulty is to access mental health services if there is another disability concerned. For our sector to be transferred out under the banner of a disability sector is really worrying in terms of trying to access mental health services when they needed.

**CHAIR:** The Disability Act does not bind the State Department of Health?

**Ms SAID:** Originally it did. It said any services which are funded to support people with disabilities, but I do not think that necessarily has been followed.

**CHAIR:** It has an exemption.

**Ms SAID:** That is right.

**CHAIR:** Your recommendations require general consultation and that NGOs be recognised and properly resourced and consulted about whole-of-government type decisions. That does not go to individual participation, does it?

**Ms BATEMAN:** No.

**CHAIR:** I turn now to quality control.

**Mr NADIN:** I do not think we have anything to add. As service providers we support the principle.

**CHAIR:** A number of people have gone into accreditation. How many mental health services have actually been accredited?

**Ms SAID:** We were accredited in the first round when the Disability Services Act came in and it was funded by what is now DADAHC with a review committee. About 50 per cent of the services were accredited in the first round then the transition plan failed to be completed. Health did not ever pick up the funding to allow that to be achieved and so that died on the vines. Those services that were accredited stood that way for three years and then died. Then quality management services [QMS] came into being and I understand there is now a discussion at health level about changing from QMS to another form. I think the bigger challenge for us is the occupational health and safety issue. Before we get accredited we really need to comply with the new legislation and that is enormously challenging for the NGO sector.

**CHAIR:** That has been raised on page 11?

**Ms SAID:** Yes.

**CHAIR:** But there is no funding for occupational health and safety issues?

**Ms SAID:** No, or accreditation, so it effectively means for those who are under the traditional grant system, that it is a cut in services to achieve the requirements.

**CHAIR:** But you are still bound by occupation health and safety issues?

**Ms SAID:** That is why it is a cut in services in real terms.

**CHAIR:** Providing safety in the workplace and safety for people coming into care is a basic service, is it not?

**Ms SAID:** While it sounds like it is basic, it is major in terms of how the NGO sector moves forward in the future because it places a question over all outreach staff going into people's homes and that area has not been clarified under the occupational health and safety legislation. They are still working on it. A lot of NGOs do a lot of outreach services with one worker, which is an extremely dangerous situation. Health and Housing do not do it any more and a range of departments are not doing that but the NGO sector is doing it and if we are moving forward and broadening NGO services to be provided in the future—if that is on the agenda—it is a major area that we have to think about.

**CHAIR:** What about staffing levels?

**Ms SAID:** That has been spelt out clearly, I think. In the past we have not looked at our staffing needs very well as a collective. We should have been into the TAFE schools much earlier and identified some of the issues so that people could be trained to work in the NGO sector. Anything like the boarding house reform project is challenging to the NGO sector when it comes to find staff ie to work in those sorts of settings with people who sometimes are quite difficult to support and who have multiple needs.

**Ms BATEMAN:** There is some devaluing of staff who work in the NGO sector because they are not seen to have particular qualifications when in fact they have a whole range. A number of clinicians actually work in the NGO sector and have university degrees but there is specific training required for rehabilitation, for example and it is not that easy to get a hold of. TAFE runs a couple of courses but geographically not everyone can get to those courses. We have liaison with TAFE in working out what needs to be incorporated into their community support certificates and specialist mental health certificates.

**CHAIR:** If you take out the words "non-government sector" from the nine dot points on page 12 of your submission they are exactly the same?

**Ms SAID:** They are.

**CHAIR:** Training, pay levels, support and supervision, shortage of nurses across New South Wales, and not just mental health nurses, lack of adequate funds for Q and A?

**Ms SAID:** And there is a hidden one that needs to be raised, and that is the transfer of available staff to agency staff. For the first time the NGO sector is using agency staff.

**CHAIR:** You are using it?

**Ms SAID:** Yes, we have to in 24-hour supported situations, yes, so there is a higher cost when you start looking at that.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** They are a lot more expensive. Are they not double?

**Ms SAID:** They can be, but if you cannot find staff or they do not turn up—and the NGO sector only has a small pool to call on—it becomes a necessity.

**The Hon. AMANDA FAZIO:** Do the agency staff you are forced to call on have the appropriate skills and experience in dealing with people with mental health problems?

**Ms SAID:** We are led to believe they have. We have to rely on the agencies to tell us that they have the qualifications. Many are nurses, but we have discovered a couple of times that perhaps staff are not as well trained as perhaps the agencies have indicated.

**CHAIR:** The availability and mix of services is where you have concerns about the concentration on the acute in hospital to the exclusion of the assertive care, which has been a constant feature of many other submissions as well. Do you think this is where we can actually make our biggest cost saving and improve quality?

**Mr NADIN:** Certainly improving quality of service and improving the level of service provision, the gaps are obvious and the impact on the people living in the community will be enormous and beneficial.

**CHAIR:** When we were in Port Macquarie last week looking at another inquiry the mental health services there are provided by Mayne, not as a profit centre but to a fixed budget. They have had to withdraw more and more from the community-based services to support the ongoing cost of the inpatient services. Is that generally what is happening? That is the only budget we have been able to see.

**Mr NADIN:** I guess that is what we are saying is the trend we are seeing everywhere.

**CHAIR:** We are producing more institutional care?

**Ms SAID:** That is right. I think it is the northern, and it is only storytelling rather than factual that I can present to you, that some of the community services have actually now had to move on to the hospital base so that they are available for hospital as well as community.

**CHAIR:** That is an area that is relatively well funded on a statewide basis?

**Ms SAID:** Yes.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is that a bad thing?

**Ms SAID:** Well, it takes away the whole concept of community care and people being able to access a community-based service rather than a hospital-based service.

**Mr NADIN:** In terms of some sorts of needs, we would argue very strongly against institutional care, for example, it is pretty well accepted that if we can provide support and care for children and adolescents care outside of hospitals, then it will be to their long-term benefit, so I think there would be specific groups within the overall

needs group that you could target as people who should not be admitted to hospital or those institutional settings if you can at all avoid it.

**CHAIR:** The issue I raised before is in your submission on page 14, which came from the "Long Road to Recovery". We heard that evidence in Port Macquarie. At the bottom of page 14 you refer to the "recent proposed policy of episodic care in public mental health services means that clients with continuing mental health conditions no longer receive ongoing case management services. The public services now provide only episodic care and then refer the patient to his or her GP once they consider the patient has stabilised."

**Ms BATEMAN:** Yes, that is something that is increasingly evident in the way that case management services just stop after a certain amount of time and people are left without that support in the community. We would want to see those people, after that intensive case management, then refer to NGO outreach services, for example, so that there is someone keeping an eye on them so that when their household gets a bit hectic or they are beginning to isolate, there is someone who is aware of it and who can link them back or connect them with the community.

**CHAIR:** You also ask for major improvement in the activity of general practitioners and their training so that they are more involved in the general caring process. Is that happening?

**Ms SAID:** A large amount of money has been allocated by the Commonwealth for a five-year program of training of general practitioners and to extend some of that into counselling services within the general practitioners setting as well.

**CHAIR:** Changing the item numbers as well.

**Ms SAID:** That is right.

**CHAIRMAN:** A publication that I get a lot, and probably the best published, is the Hunter Urban Division of *General Practice*, by Arn Sproggis. There is a lot more activity in that. I presume that is happening in other divisions of *General Practice*. But is it enough? This is where people look for their primary care.

**Ms SAID:** I think there are a group of people who would prefer to go to a general practitioner. It is less stigmatising. But a large group of people like ongoing case management and feel better supported by that system.

**CHAIRMAN:** There is a definitional problem. At the bottom of page 15 and the top of page 16 you talk about impairment and disability. The definitional problem there is of some significance, is it not? The impairment relates directly to the symptoms of mental disorder or illness, but the disabilities are the consequences of that illness affecting the person's ability to perform the activities and tasks of everyday living, and developing and maintaining fulfilling and social relationships.

**Ms SAID:** That is the WHO description.

**CHAIRMAN:** Is that distinction between impairment and disability something that your organisation is stuck on, or not?

**Mr NADIN:** We do not think so. We have had this discussion many times, so maybe we are stuck on it, but there are a large number of people in the community who need services, and their problem is related to their mental illness, which is episodic. At different times they will move from one level of support need to another, whether it is defined as being under one heading or another.

**CHAIRMAN:** But an impairment is not necessarily a disability, is it?

**Mr NADIN:** No.

**CHAIRMAN:** The fact you have an impairment is the disconnect; there is not a correlation between one and the other.

**Mr NADIN:** No. The common factor is the mental illness and the progression in and out of that over a long time.

**CHAIRMAN:** You refer to the issue of the different models of supported residential services, which the Committee will deal with tomorrow in fuller detail. I suppose all of the different models are good for different people. But you support a range of models for adaption.

**Mr NADIN:** Precisely.

**CHAIRMAN:** We will go into those with SHELTER and others tomorrow, but there are a number of problems with that.

**Ms BATEMAN:** As we said earlier, the model that we would promote most is the model whereby support can be given or withdrawn depending on the needs of the consumer. We think that is an important model to fund. Some of the existing models exist because of the abilities that organisations have to make a little bit of money, say from rental, and therefore they can provide a program for the people using their houses.

**Ms SAID:** Not all organisations though.

**Ms BATEMAN:** Not all organisations, but some of them. That may happen to suit a particular non-government organisation. So you will find different models in use all over the place. I guess that is something negotiated at the local level.

**CHAIRMAN:** It seems to me, after looking at all of the submissions that the Committee has received to date, that the biggest issue is not just providing asylum and getting people well, even getting them mentally well, or no longer mentally ill -- which is not necessarily the same thing -- but the whole issue of psychosocial rehabilitation, giving people the ability to live a life, then socialise and then have employment. Those are the three areas about which most of the concerns arise.

**Ms SAID:** I guess the most graphic description I can give it is of someone that the organisation I work with has been asked to support. This person was living at Merrylands in a public housing place. When my staff went there at the behest of the Public Guardian they found all the doors boarded up. The man had got rid of all his furniture, and the refrigerator and all electricity had been disconnected because he was afraid of the power coming into his place. He was living on the floor of the kitchen, with cockroaches everywhere. The whole place was absolutely filthy. This man had not received any meals and was half starving.

Our staff could not get entry. All they could do was talk to the person through the door. After a period of time they got an agreement to arrange for Meals on Wheels for this person. So that opened the door, and he started to eat. The mental health team had not been to see him. He had gone off the books of the mental health team. That person eventually was relinked to the mental health system and started receiving assistance. But if another non-government organisation or another type of organisation had maintained contact with that person, he would not have got to that state. The pain that person was feeling was enormous. But trying to assist the person who has reached that psychotic level and is living in such conditions is extremely difficult.

**CHAIRMAN:** They are not taking their pills and so on?

**Ms SAID:** No.

**CHAIRMAN:** You have made certain recommendations under that heading. The last issue is data collection and outcome measure. This is a difficult area, isn't it?

**Ms BATEMAN:** We are aware of the mental health outcomes assessment tools [MHOAT] that New South Wales Health has introduced. The non-government sector has not been involved in that process and sort of sits outside it. The staff of many of our member organisations have asked for training in MHOAT, to assess whether or not it is useful for our sector. I think now there is an understanding that it is not particularly useful, that it is not sensitive enough to measure the incremental changes that happen to people once they are out of acute care services. We need to be able to demonstrate the value of non-government organisations and what are the outcomes of intervention by non-government organisations, but we need to develop tools that can measure them, and they do not currently exist. The recommendation is that we look into that. As we touched on earlier, the NGO sector is not valued in the same way that acute care services are valued. If there is one good thing that would come from this inquiry it would be to look at the issue of why community services are not valued in the same way that acute care services are.

**CHAIRMAN:** It is a bit like the chicken and the egg. For example, if the Minister decided tomorrow to double, triple or quadruple NGO funding, he would expect some fairly decent outcomes from that funding -- not so



much contracts, but something to justify to Treasury that if he spends these dollars he will get certain beneficial outcomes. Every new spending initiative is meant to produce either equality improvement or a cost saving, or both.

**Ms BATEMAN:** Yes, that is a right.

**CHAIRMAN:** So, if you do not have any outcome measures—

**Ms BATEMAN:** We certainly have them.

**CHAIRMAN:** I accept that.

**Ms BATEMAN:** Our organisations use them all the time, but they are not agreed and respected. That is what we need if the sector is to be able to increase its worth and value in the eyes of government.

**CHAIRMAN:** You would need appropriate consultation to work out the aims and outcomes, so that you could say, "We can do this or that if you give us these dollars."

**Ms BATEMAN:** That is right.

**The Hon. JOHN HATZISTERGOS:** Have you tried to benchmark with other States?

**Ms BATEMAN:** No. We did commence on a road towards benchmarking about three years ago. We did a project called the mapping, analysis and performance project, the idea of which was to benchmark services against each other as well as against other States. But we found we needed to do the groundwork first to get an understanding of exactly what existed in the sector and how we could represent what was happening in the sector. That project finished at that point. We recommended that it continue and that more substantial benchmarking be done. That has not happened.

**The Hon. JOHN HATZISTERGOS:** Is there any reason for that?

**Ms SAID:** Most organisations negotiate with the area under a contract or tender system, and the outcome of the grant or assistance is negotiated service by service, and it varies enormously within each area. For instance, you could not say that Central Sydney has outcomes that it would expect from the NGO sector, because that is not correct; they are not the same. At times there have been attempts to make them all the same, but that has not yet been achieved.

**CHAIRMAN:** When you get the transcript of this session would you correct it as best you can and return it to the secretariat as quickly as possible so that we can put it onto the web so that others who have made submissions can look at what has gone on to date if they wish. Also, if you think the Committee has missed a point, or you have missed a point and you think that something needs to be changed or added, please let us know. We may need to come back to you at a later stage in the inquiry, or dash off a few further questions to you during the inquiry. Would you be happy if we did that so that you could reply as necessary?

**Ms SAID:** Certainly.

**(The witnesses withdrew)**

**(Luncheon adjournment)**

**HENRY BRODATY**, Professor of Psychogeriatrics, Academic Department for Old Age Psychiatry, Prince of Wales Hospital, Randwick, 2031, affirmed and examined:

**CHAIR:** In what capacity do you appear before the Committee?

**Professor BRODATY:** As a private individual.

**CHAIR:** Would you like to include your submission to the Committee as part of your sworn evidence?

**Professor BRODATY:** I would.

**CHAIR:** If you should consider at any stage during your evidence that in the public interest certain evidence or documents you may wish to present should be heard or seen only by the Committee, the Committee would be willing to accede to your request. Please be aware that the Legislative Council may overturn the Committee's decision and make the evidence public. That has not happened, but it can.

**Professor BRODATY:** Yes.

**CHAIR:** You have made a very brief but highly condensed submission. Would you walk us through your submission and flesh it out before we ask questions?

**Professor BRODATY:** I make a number of points. The first point is that older people are receiving less in the way of outpatient and private psychiatric care than their counterparts.

**CHAIR:** Is that in terms of the prevalence or just the number?

**Professor BRODATY:** In term of services. I have brought before the Committee a review of Medicare items reviewing the data using 1998 figures from the Health Insurance Commission showing that older people per capita received 2.7 times fewer psychiatric services per capita Medicare items than their counterparts aged 15 to 64, and Medicare expenditure was 4.1 times less than for adults over 64 years of age.

**CHAIR:** Does that take into account the difference in the prevalence of mental illness in those two groups that you are comparing?

**Professor BRODATY:** No, it is a straight per capita comparison.

**CHAIR:** If you did that comparison what would it be?

**Professor BRODATY:** There are arguments about the comparative prevalence of various disorders by age group. Some disorders appear less common with aging, although those of us working in that field are not convinced by those figures, and other disorders such as dementia are far more common. Overall I think we can assume that there are equivalent rates of psychiatric illness.

**CHAIR:** Mental illnesses are different in different age groups?

**Professor BRODATY:** Yes, they may be or they may be more common in the elderly even.

**CHAIR:** That comment would stand up in terms of unmet need which is what you are talking about?

**Professor BRODATY:** Yes. When we come to talk about State health services we cannot assume that they are being "picked up" by the private sector. If anything, they are being three to four times less picked up by the private sector. When you look at the actual consultations of older people in private practice the Medicare data allow you to examine the item numbers, and item numbers relate to the duration of the consultations. So the consultations are shorter as well as being fewer. The implication is that when older people are being seen in private psychiatric practice they are receiving few psychological therapies, less talking treatment and perhaps more pharmacotherapy. That is the first issue.

I point out that depression is common in older people, and older men in particular have the second highest rate of suicide. If you look at the very elderly, those over 85 years of age, they have the very highest rate even though most of the publicity is being given, understandably, to those young men who are suiciding.

**CHAIR:** That is because they talk about quality adjusted life years [QALYs]?

**Professor BRODATY:** That is right and one of the difficulties which discriminates against older people—if you base health care decisions purely on quality adjusted life years—if you are 85 you are always going to be behind the eight ball compared with somebody who is 16 years of age. There are also, amongst the elderly, people who are particularly at risk for depression and for suicide and they are those with malignancy, pain and severe medical illnesses. There are strategies for detecting those and for suicide prevention. If you go to page two, looking at the recommendations that flow from that point, general practitioners have been shown to be moderately good, at best, at detecting depression in older people and suicide risk.

There certainly could be improvement amongst all health professionals in detection of suicide risk in the elderly. Priority should be given to research for psychological interventions in older people. One of the things I will be coming back to is people in residential care who are being discriminated against compared to elderly people in the community. There are high rates of psychiatric illness amongst them and yet if you look at the staff in nursing homes they are poorly trained—or untrained generally—and rates of behavioural and psychological symptoms are high.

**CHAIR:** Would that criticism equally hold for people who are living in nursing homes or other community areas such as hostels?

**Professor BRODATY:** The rates are much higher in nursing homes than in hostels, but they are certainly higher in hostels than in the community. With increasing dementia, or dependency, the rates are higher.

I will move on to my second point which is about the behavioural and psychological symptoms complicating dementia. At some time during the course of the disease, whatever the type of dementia—and Alzheimers and vascular dementia or strokes are the major causes of dementia—90 per cent of people will get some behavioural and psychiatric disturbance. For example, serious depression will occur in 20 per cent, delusions in 30 per cent, hallucinations in another 30 per cent and so on.

The majority of cases are not severe and can be dealt with by education, by talking to the families or to the staff and by teaching them strategies. A significant proportion of cases require consultation by specialist services, such as psychogeriatric services and the remaining proportion require special accommodation. They cannot be looked after in their own home and they cannot be looked after in mainstream residential care facilities. The issue of dementia is by and large a Commonwealth issue.

**CHAIR:** Why?

**Professor BRODATY:** Because nursing homes are funded by the Commonwealth, home and community care services, I think, are 60 per cent funded by the Commonwealth and Medicare consultations and pharmaceuticals are funded by the Commonwealth.

**CHAIR:** Is it not partly because dementia is seen to be a developmental disability rather than a disease state as such?

**Professor BRODATY:** No. I think it is historical. I do not think there is any conceptual reason why that has occurred.

**CHAIR:** Okay.

**Professor BRODATY:** Mental health is largely a State issue but if you have dementia and mental health problems, it can be no-one's issue, and that is one of the difficulties. Up until 1982 when (I think) Justice Powell brought down his decision saying that dementia is not a mental illness, people who were demented and who had difficult behaviour were admitted to the large psychiatric hospitals. If you went to Rozelle or Gladesville or any of those places, you would see wards full of those people. That decision came down either in late 1981 or 1982 and it really changed the face of dementia care. Indirectly it led to the guardianship legislation which was introduced in 1987 and the Board being set up in 1989. He said that dementia is not mental illness but mental impairment and that is a valid distinction. But that legalistic definition has had a flow-on that was unintended and some mental health providers within our system do not see dementia as a mental health problem. Clearly it often is, as I have just pointed out.

The difficulty is that there is no co-ordinated strategy for people with dementia and behavioural problems. We did a survey of half the nursing homes in eastern suburbs of Sydney. There were 25 nursing homes and three of those refused so that left 22, and half of those were the ones we surveyed. There were 11 nursing homes and 647 residents. We published this data over the past couple of years and we found these rates: 90 per cent of the residents in nursing homes have behavioural disturbances and 60 per cent of those were serious. Fifty per cent were rated by nurses as having psychosis—delusions or hallucinations. People in nursing homes are not well treated by health professionals. General practitioners are increasingly resisting or are reluctant to attend patients in nursing homes. The rebates are fairly poor, particularly for people who are admitted to a nursing home outside the close geographic area of the general practitioner. There is a lack of specialist services available to go to them. In some places, mental health services have said that people in nursing homes are not their responsibility and they have not gone and seen them. That is changing, I think.

Geriatric services have provided a lot of mental health care for older people in the community and in nursing homes, yet we would not expect paediatricians to be looking after mental health problems of children, or physicians to be looking after the psychiatric problems of a 40 year old. But it has been good enough, so to speak, for older people. As dementia progresses, these problems become more and more prevalent until the very end stages when people are in a vegetative state, are bed bound or are no longer able to speak. Then they are no longer able to be aggressive or express or even show emotions. At the very end stages, those behaviours disappear. On the average, such behaviour, such as aggression, screaming or depression, last for about a year. For some people it is less, and for some people it is longer. These behaviours are not forever. People who have dementia generally live about 10 years or a bit longer from onset to death. We are getting better at looking after people, particularly at the end stage, which is somewhat unfortunate; I would like to be better at the beginning stage. But that means that there are more and more people with behavioural problems as well.

What is missing? What are our recommendations? We need psychogeriatric community teams to service older people in the community and in nursing homes. They would be involved in educational programs and they would be involved in consultation and in providing advice to general practitioners and to nursing home staff. They would be involved in actually treating those patients on a case management basis or by admitting them.

**CHAIR:** How many people are you talking about in the State of New South Wales?

**Professor BRODATY:** For each area of 25,000 older people, there would need to be one team available.

**CHAIR:** How many people are there over the age of 65? I think it is approximately 30 per cent of the population, is it not?

**Professor BRODATY:** It is approximately one in eight of the population, so we have about 800,000 people. I think there are about 5.5 million people in New South Wales.

**CHAIR:** There are seven million people and there are 5.5 million voters.

**Professor BRODATY:** So it would be a little under a million—approximately 900,000 people who are at the age of 65. There are statistics. The Faculty of Psychiatry of Old Age was funded by the Centre for Mental Health to do a survey of available services. I do not recall figures but they can be obtained. What constitutes a service varies. If you look in some sectors there might be .3 of a psychiatrist and a registrar, and that would be the service. In other services, there will be a consultant, a registrar, a clinical nurse consultant, a social worker and so forth—in other words, a comprehensive team.

**CHAIR:** How long did it take you to go through 22 nursing homes for your research project to undertake basically an assessment?

**Professor BRODATY:** I went through half of them, 11 nursing homes.

**CHAIR:** It was a research project.

**Professor BRODATY:** It was funded by the Commonwealth, yes.

**CHAIR:** How long did that take? How many hours did it take for the team?

**Professor BRODATY:** It took the best part of a year.

**CHAIR:** A team could look after eleven nursing homes. This is what we are talking about, is it not?

**Professor BRODATY:** No. We would be looking after 22 nursing homes.

**CHAIR:** Plus people in the community.

**Professor BRODATY:** Plus people in the community, plus inpatients.

**CHAIR:** So you would need about 40 of these teams across the State.

**Professor BRODATY:** There are 17 area health services. I know that in our area, four teams would be required.

**CHAIR:** But for some others such as the Mid North Coast Area Health Service where there is five per cent of the State's population, you would get five per cent of that number, which is two teams.

**Professor BRODATY:** Yes, and there are different strategies for rural areas where you need to be much more flexible in the way that services are provided.

**CHAIR:** Exactly. But there are Aged Care Assessment Teams [ACAT] teams all over the place, are there not?

**Professor BRODATY:** Exactly. Geriatric services are well co-ordinated. There is a comprehensive plan for the whole of Australia. For psychogeriatric services, we have no such plan. In 1997 I co-chaired with Beverley Raphael the New South Wales Task Force On Mental Health for Older People. We submitted a draft plan in 1998 to the Centre for Mental Health. That plan was never released. A small policy was released in January 1999 by the Department of Health and in the last year or year and a half there has been a resurrection of the committee, which Beverley is chairing and on which I sit, to try to plan psychogeriatric services for the State. It is a glaring gap that we do not have any comprehensive plan for psychogeriatric services in this State. We know that 12 per cent of our population are over 65—or 13 per cent even, in New South Wales—and that will be 20 per cent by the time you and I reach 65 and 10 years beyond that. By about 2020 it will be a real problem. Even in ten years time, it will be a real problem.

If you look at populations and hospitals, in Randwick there is the Prince of Wales Hospital and the Prince of Wales Children's Hospital. If you look at the Prince of Wales Hospital, some two-thirds of the people there are over 65 years or are over 70. We do not talk about the Prince of Wales geriatric hospital, but we do talk about the Sydney Children's Hospital, as the Prince of Wales Children's Hospital now is. Older people make up the majority of people who are in general hospitals. The average age in nursing homes is 81. I am not sure of the figure, but people being provided with Home and Community Care [HACC] services—it could be 25 per cent or 50 per cent—have dementia. It is a problem that is huge, and it is growing.

**CHAIR:** But other evidence indicates that even among people in the general hospital at the Prince of Wales, 30 per cent have some sort of mental illness as well, even though they have gone in for their heart attack or their broken leg.

**Professor BRODATY:** Yes.

**CHAIR:** Is it 30 per cent? Is that the correct figure?

**Professor BRODATY:** I do not know the figure for that.

**CHAIR:** There is a figure that somebody has quoted indicating that 30 per cent of people who go into public hospitals also have a mental illness. You have ACAT services. Would it be hard to meld a psychiatric service into those ACAT services?

**Professor BRODATY:** How it is structured is open for debate. You would certainly want to have psychogeriatric assessment services—or psychogeriatric assessment teams—working alongside ACATs, whether they are integrated within ACATs or whether they are part of the mental health service. We put forward the view that they should be part of mental health rather than part of aged care, but functionally integrated with aged care. I think that either model can work. It is just a matter of having a model and having community psychogeriatric services that can service people in the community, in residential care facilities and also in in-patient facilities.

**CHAIR:** Not just nursing homes but in-patient services?

**Professor BRODATY:** Yes. The psychogeriatric service working out of Prince of Wales Hospital, with which I am familiar, sees people in their own homes and in nursing homes. It runs outpatients and it has beds within the Prince of Wales Hospital dedicated to older people.

**CHAIR:** What about the 30 per cent of patients with a mental illness who are in hospital?

**Professor BRODATY:** There is also a consultation-liaison service for patients in there. There are separate consultation-liaison services within most mental health services. The way it works in many facilities is that they can refer to psychogeriatrics as a secondary referral or geriatrics can refer directly to psychogeriatrics. But if psychogeriatrics were to take over consultation-liaison for the whole hospital we could abolish two-thirds of the consultation-liaison departments that are available.

**CHAIR:** Part of the problem for mental health is that the prevalence of mental illness in the community is very high. It does not seem to reach that threshold of vision for planning, not just for psychogeriatrics but also for psychiatric illnesses or mental illnesses generally.

**Professor BRODATY:** I would agree with you completely. It is even more pronounced amongst the elderly. If you are psychotic and 20 it is likely that you will take other drugs; that you will act out; that you will be aggressive; and that you will be noticed. If you are 80 and psychotic, you will be crazy by yourself in your apartment or your unit, believing that the neighbours are trying to poison you. A woman that I know believed that the neighbours were trying to kill her; they wanted to get her house; they were putting gas in through her apartment; they had removed shingles from her roof; and they were trying to harass her. As her neighbours on one side are Greek and her neighbours on the other side are Irish she is convinced that there are Greek and Irish conspiracies afoot to try to remove her from her house.

**CHAIR:** It is highly likely.

**Professor BRODATY:** I will not comment on that. The point is that these people are not visible; they do not create a furore, as might a younger person. Depression in an older person is more likely to be unrecognised or to be attributed just to old age. However, if you stopped functioning as well as you normally do and you saw your doctor, your doctor is much more likely to be concerned about you than he would be about someone of your father's age.

**CHAIR:** It is a big issue. Forty teams does not sound like a lot of people, but it would certainly go some way towards identifying a lot of problems. Therefore, there is a downstream need for further support—whether it be by visiting mental health teams and so on—to help relatives look after these people. Have you thought about the increased cost associated with the provision of such care, or would it be cost neutral? Have you done any research in relation to that issue?

**Professor BRODATY:** It certainly cannot be cost neutral because there is unmet need. If you want to provide services for that, it cannot be cost neutral. That is the big problem. The resource implications are large. As the demography of our population changes, surely there can be some shifting of current services to account for that. But that would occur only if current services were adequately funded. It is not my province to discuss those issues, but I understand that there are concerns about the level of funding for those services, so it would be unfair to think about moving those resources.

**CHAIR:** We come then to the whole issue that you raised about the neuropsychiatric institute, which I remember.

**Professor BRODATY:** I do not talk about the neuropsychiatric institute; I talk about neurobehavioural units. The neuropsychiatric institute is a level six referral service.

**CHAIR:** What happened to that?

**Professor BRODATY:** It is still functioning in a fairly rudimentary way.

**CHAIR:** It used to be a pretty big set up.

**Professor BRODATY:** It did. As I understand it, that has been reduced from what used to be 22 beds in its heyday—when it was at Rozelle Hospital there were perhaps even more—to two beds now. It is mainly an outpatient service.

**CHAIR:** What about the neuropsychiatric units?

**Professor BRODATY:** What I was getting at by calling them neurobehavioural units was that people with dementia and severe behavioural problems have changes in their brains. It is not as though they are difficult people just acting out; this is an illness and I sought to medicalise it. When we talk about CADE units, or special care units, it does not really recognise the organic or the physiological basis to these problems. People with these behaviours can be dealt with in a better way with good behavioural management techniques, psychologists organising programs, better use of medication and a better environment. We have certainly had people who were aggressive, hitting out and dangerous. If we move them to an environment where they have room to move, where their privacy is not being impinged upon and where there are people of a similar gender and age, their behaviour settles down remarkably.

**CHAIR:** Those units would not just be restricted to older people?

**Professor BRODATY:** They probably would be. There would be enough people to go into them. The other group with whom I am not involved are people with head injuries and behavioural disturbances.

**CHAIR:** Some people have strokes at the age of 30 or 40.

**Professor BRODATY:** Yes, that is true.

**CHAIR:** But at least this would be a place for training, would it not?

**Professor BRODATY:** The neurobehavioural units would take the severely disturbed patients who cannot be looked after within their own setting—be it in a nursing home or in their own home—and they would be there for a period of time. This was the original intention of the CADE units when they were set up in the late 1980s, as I recall.

**CHAIR:** Are they not still like that?

**Professor BRODATY:** My understanding—and there are no CADE units that I visit so I cannot be certain—is that they have silted up. The people who were transferred there are still there. As I understood it there were two aims. One was to close down some of the psychogeriatric wards in the large psychiatric hospitals and to facilitate the closure of those hospitals. Then as those people moved on they would become units for behaviourally disturbed people with dementia and they would stay there for a maximum of six or 12 months before they moved on into mainstream facilities. People with schizophrenia or alcohol-related brain damage are fairly stable. They have not deteriorated and they stay there for long periods of time. So they are not being moved on. In addition, we do not have a comprehensive plan. There were nine CADE units.

**CHAIR:** That means that, instead of having them in a big place like Callan Park, there are a whole lot of little places?

**Professor BRODATY:** There are other models for these neurobehavioural units. It could be that we, as a State, fund what are sometimes called psychogeriatric nursing homes. Victoria, which is the model, gets Commonwealth funding for the nursing home component and top-up funding from the State to look after the special problems. Western Australia also has psychogeriatric extended care units.

**CHAIR:** Did they not have some of those somewhere in Sutherland shire? Was there not a big State Government nursing home complex at Garrawarra?

**Professor BRODATY:** Garrawarra is at Sutherland. It has been renovated. I was out there a couple of months ago.

**CHAIR:** Some of them have been sold to the private sector. Did they have those units in them?

**Professor BRODATY:** They have newly constructed units there. In the last few months they have decided to take on patients with behavioural problems. The problem with Garrawarra is that it is very difficult for most families to access. It is very hard to get even general practitioners to attend patients there. There is certainly no hope of getting specialist services there. So Garrawarra certainly does exist. The whole issue of State nursing homes I think has not been properly resolved.

**CHAIR:** There has been a concerted effort to move patients out of State nursing homes and to close them down.

**Professor BRODATY:** To transfer them to the Commonwealth.

**CHAIR:** That is appropriate. There has also been an attempt to go to the contract process which is being used by the Commonwealth. However, as you have pointed out, there are some people with high needs who need protection. You would not schedule that sort of person to a private hospital. You are not allowed to do so because none of them is authorised, yet somebody who is severely mentally ill effectively can be locked up in a nursing home because it is called a nursing home.

**Professor BRODATY:** Yes. Let me give you an example. We had a very strong man, in whose care I was involved, who was an ex-football player and a boxer. When he was angry he would hit at other residents or at staff. He broke the arms and ribs of staff and residents. He was transferred from three nursing homes and eventually into a hospital in Sydney where his care took several months. It then took another several months to find a facility that was willing to take him. It was very difficult to find anyone who could look after that sort of person.

**CHAIR:** It presents a huge occupational health and safety risk for staff and patients.

**Professor BRODATY:** Exactly. I think the major impediment—if I could come to it—to adequate mental health services for older people is a lack of a co-ordinated and comprehensive plan for services. We would not accept that for children and we should not accept that for older people.

**CHAIR:** We have exactly the same problem for children. There are two children's places. Kids who are aged 14 seem to end up in St George and Prince of Wales hospitals. So there is no difference really. The services that are provided for children are not terribly different. Only two specialist places take children.

**Professor BRODATY:** I will not use that analogy.

**CHAIR:** I do not think that it is a good one. By the same token, it does not take anything away from the need.

**Professor BRODATY:** The College of Psychiatrists in Australia, New South Wales branch, has developed several plans for psychogeriatric services for the State. The Royal College of Psychiatrists in the United Kingdom has issued benchmarks for what is required. The planning document from the Centre for Mental Health, the MHCCP, has calculated on a per capita basis what is required for each age group in the way of beds and community services. So there is plenty of documentation about what is required. If you look at what is available and what is recommended or required, you will see that we are way below that.

**CHAIR:** That is short-term, medium-term, long-term and community based services?

**Professor BRODATY:** Yes, all aspects.

**CHAIR:** Obviously the Commonwealth has put a fair bit of money into supporting some older people—even people who have dementia—in their homes. There is some support from the Commonwealth for carers, pensioners and the like. There is also support from the Department of Community Services and there are HACC services for people living at home. But when you come to community mental health services there is no provision for visiting NGOs. A lot of the evidence that we have heard is to the effect that that sort of service is not being provided. Is that your experience?

**Professor BRODATY:** Yes, definitely.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** I would like to clear up the issue relating to CADE models. You said earlier that we have the teams.

**Professor BRODATY:** I can give you a model. For each area of, say, 25,000 older people, there must be a psychogeriatric team which would look after people in the community, visit people in residential care, run outpatients and look after a number of beds for in-patients. That number of beds has variously been defined as five or probably 10 beds for 25,000 people. So there is a psychogeriatric team, there is an in-patient unit and there would need to be some neurobehavioural beds, CADE-unit type beds, psychogeriatric nursing home-type beds, or whatever. For about 50,000 people, there would need to be about 12 beds.



**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is that not a CADE model with ancillary services?

**Professor BRODATY:** Yes.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** You are not saying that the CADE model is wrong; you are simply saying it is not enough?

**Professor BRODATY:** I am saying there is no CADE model in most areas of New South Wales.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** That is why I think it is dangerous to take away the CADE model.

**Professor BRODATY:** Firstly, the CADE model is not working as a CADE model; secondly, there is no CADE model for most areas of New South Wales; and thirdly, yes, we do need specialised residential facilities, which we can call CADEs or, as I try to medicalise it, neurobehavioural units or whatever. The basis for it can be a bit larger than 25,000-person pockets of older people; it could be 50,000.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Certainly in the city areas?

**Professor BRODATY:** Yes.

**CHAIR:** That would be what you would call a medium length of stay facility?

**Professor BRODATY:** Yes. I imagine most people would say, on the average, three to six months.

**CHAIR:** Given that most of them are elderly, would it not be more appropriately funded by the Commonwealth?

**Professor BRODATY:** I think it has to be a mixture.

**CHAIR:** We have multipurpose centres in country areas, which are jointly funded. This is happening in Victoria, is it not?

**Professor BRODATY:** That is exactly what is happening in Victoria.

**CHAIR:** Why can we not do the same here in New South Wales?

**Professor BRODATY:** I do not know. I think we should. If we compare New South Wales and Victorian funding for mental health services, we fall behind. If we look at older people, we are way behind. If look at psychogeriatric services, psychogeriatric nursing homes, we are way behind. Whatever parameters we use, if we do a direct comparison with Victoria, we are inferior in what we are providing.

**CHAIR:** It could be provided by either a public administration or a private administration?

**Professor BRODATY:** There is no reason why a nursing home could not dedicate one of its wings to looking after disturbed elderly people.

**CHAIR:** As long as they were guaranteed to get this PCAT team or the assistance of community mental health people.

**Professor BRODATY:** Though it would probably need extra money because they need more nursing care, and they would need support from specialist services. A number of models are possible. But, you are right, it does need a combination of Commonwealth and State funding to address that. That was my very first point.

**CHAIR:** The Commonwealth has already put up the money for the high-level care, but not for the mental health service part of it?

**Professor BRODATY:** Exactly.

**CHAIR:** I do not argue about the fairness of it all, but there could be significant costs to the State in terms of the provision of that care, to top up Commonwealth funding. The Commonwealth may have to come to the party with more capital funding, certainly for the provision of security and so on.

**Professor BRODATY:** Yes. I think they have grants for capital funding for nursing homes.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** You said that you wanted to rename the CADE units neurobehavioural units and medicalise them. The Committee heard evidence this morning that the main problem with this is that mental health services would have to be medicalised. Would you care to comment on that?

**Professor BRODATY:** The difficulty with people with dementia and behavioural problems is that they are not being understood. The cause of their problems is multifactorial, so there are biological or organic factors going on in the brain. If you compare people with aggression and dementia, and people with dementia and no aggression, there are differences that can be shown chemically and radiologically. And similarly for depression and psychosis, and so forth. So it is simply dismissed as part of the dementia. Yet, if somebody was psychotic and did not have dementia, they would not be denied the services that are available to them.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** In other words, there is a lack of expertise involved?

**Professor BRODATY:** The point about the medicalisation is saying that health needs to take some responsibility for these people.

**CHAIR:** Have you changed your views about any of the recommendations you have made in your submission?

**Professor BRODATY:** No, I have not. Also, I would like to table the paper that provides the Medicare data.

**(The witness withdrew)**



**CHRISTINE ANN REGAN**, Senior Policy Officer, New South Wales Aged Care Alliance, and 66 Albion Street, Surry Hills, and

**JEFFERY THOMAS JOHN ROWLAND**, President, Australian Society for Geriatric Medicine, New South Wales Branch, 84 Middle Street, Randwick, affirmed and examined:

**ANTHONY JAMES BROWN**, Project Officer, Men's Health Information Resource Centre, University of Western Sydney, sworn and examined:

**CHAIR:** Are you conversant with the terms of reference for the inquiry?

**Ms REGAN:** I am.

**Dr ROWLAND:** Yes, I am.

**Mr BROWN:** I am.

**CHAIR:** Would you like the submission you have sent to the Committee included as part of your sworn evidence?

**Ms REGAN:** Yes.

**CHAIR:** Mr Brown, your organisation has made a submission. The submission does not refer to this particular issue, but would you like it to form part of your sworn evidence? Or will it be dealt with at another time?

**Mr BROWN:** I believe it will be dealt with at another time.

**CHAIR:** If any of you should consider at any stage during your evidence that in the public interest certain evidence or documents you may wish to present should be heard or seen only by the Committee, the Committee would be willing to accede to your request. However, you should be aware that the Legislative Council may overturn the Committee's decision and make the evidence public. Ms Regan, would you like to elaborate on your submission to the inquiry?

**Ms REGAN:** As you would be aware, the Aged Care Alliance is the New South Wales Aged Care Alliance—not to be confused with the national Aged Care Alliance. The Aged Care Alliance is an alliance of 50 or more organisations concerned with aged care in New South Wales and we meet bi-monthly. In order to prepare our submission, we convened a working party of interested members of the alliance to gather together the points that we most wanted to put before the inquiry.

**CHAIR:** It is a very large alliance.

**Ms REGAN:** It is a very large alliance. It is also important to note that because of the diversity of members we often have a range of diverse opinions on any one issue. But the value of the alliance is that it brings all the opinions to the table and it can progress on most issues. You will see that we have put in a fairly summarised submission, some of which is enlarged in the Council of Social Service of New South Wales [NCOSS] submission, which has already been sent to the inquiry. However, the major points of our submission involve several issues. First, while we have not seen the report of the New South Wales task force into mental health services for older people, members of the working party and the alliance absolutely supported its release into the public domain, which we feel would actually improve the information to the inquiry.

**CHAIR:** But it has not been released?

**Ms REGAN:** It has not been released, to our knowledge. We spend a significant amount of time discussing the issue of older people with dementia and challenging behaviours. The alliance is particularly supporting the appropriate amount of resourcing and service provision. There is a range of opinion regarding the success of the CADE units. However, there is general support for the resourcing of specific psychogeriatric units in the community and attached in various ways. Jeff Rowland will speak more about that in moment. The alliance also talked about improved skills for service providers. We particularly mentioned general practitioners, particularly as they were often the first line of diagnosis of a mental illness in older people. There are varying degrees of understanding of the importance of mental illness as people age, and there are also varying opinions amongst

general practitioners—certainly our discussion reflected this—about the importance of mental illness from the general practitioner's viewpoint.

Similarly, related services, particularly home and community care, play a vital role in supporting families and carers of older people who are experiencing mental health issues. It has been found that very often general practitioners will treat the presenting symptoms rather than the underlying cause. The Aged Care Alliance spoke about the difficulties in dealing with the underlying mental health issues where they occurred, and the issue of home and community care being properly resourced to provide support to families and carers. As you know, the home and community care program is a joint Commonwealth-State issue, and there would then be Commonwealth-State relations in how to go about funding.

**CHAIR:** The Commonwealth looks after one portion and the State looks after another portion, is that right?

**Ms REGAN:** No. Under home and community care, it is a joint Commonwealth-State funding arrangement where 60 per cent of the Commonwealth money and 40 per cent of the State money goes into the whole for an agreed range of service provision.

**CHAIR:** And the State provides those services?

**Ms REGAN:** The State generally provides or contracts those services, yes. Although, there are some Commonwealth-specific services. Our next point relates to better recognition and integration into mainstream services. We recognise the increase in the incidence of mental health issues in older people, rather than writing them off as just an expected symptom of the ageing process. Again, we will be pushing for increased and enhanced psycho-geriatric services available within the community. It was found at the working party that older people account for a disproportionately low number of psychiatric consultations, as well as the intensity, length and degree of those consultations. We would hope the inquiry will look into that with more vigour.

We will be looking at the equity and diversity of services to older people with mental health issues. There are regional issues. We would be looking at access to generic services. We are looking at demographic populations and differences in gender. As you heard from previous witnesses, the working party found that New South Wales fell behind other jurisdictions but other experts will be able to give you more information on that issue. Finally, we would like to recognise the importance of the role of carers and families in supporting older people.

**CHAIR:** Before you get to that, you might as well deal with the issue of the mental health and wellbeing survey so we can discount that once and for all. What is your particular problem with it?

**Ms REGAN:** The working party found flaws in the methodology and a bias towards younger people, which skewed the outcome for older people. I am not an expert on that, but I would hope the inquiry would go into that.

**CHAIR:** It excluded everybody in a nursing home, for example?

**Ms REGAN:** Yes.

**CHAIR:** In other words, that has to be discounted to some extent?

**Ms REGAN:** The working party also found that there were some sweeping statements that gave impressions that we felt were not fully representative or reflective of some of the findings. Finally is the importance of carers and families as described there. I suspect that the role of the Aged Care Alliance in presenting to the inquiry would be to give you an overall overview, an overarching type of opinion.

**CHAIR:** It is very good that you can bring so many people and so many groups into what is pretty well a consensus view of the challenges, and they are not inconsiderable. We heard from Professor Brodaty who basically said much the same sort of stuff, but it is interesting that that is the view that is held by people in the community—carers, the Superannuants Association and so on. The Nurses Association is part of your organisation?

**Ms REGAN:** They are.

**CHAIR:** Is that in particular in regard to the aged care nurses that they represent?

**Ms REGAN:** Mostly, yes. The Aged Care Alliance generally looks at issues to do with aged care and was formed as part of political action around the 1997 aged care reforms as they were predicted and proposed. The Nurses Association is particularly concerned with aged care nursing and wage differentials, et cetera, and is also supportive of the number and skill of the labour force within residential aged care and increasingly in community care well.

**CHAIR:** Are there any people that you really pick out? I read this list and I am amazed—the Ethnic Communities Council, the Retirement Villages Association, Catholic Health Care.

**Ms REGAN:** It is important to recognise that not every member of the Alliance attends every meeting.

**CHAIR:** I accept that, but you are able to reach for consultation such a large number of people about an issue.

**Ms REGAN:** Absolutely. There were a couple of points that Dr Jeff Rowland would like to raise.

**CHAIR:** Certainly, yes.

**Dr ROWLAND:** First of all, I concur with most of what Professor Brodaty said previously, and clearly with what Christine has been talking about. I would like to bring up the concept of mental health boundaries and problems with graduates. Those people who reach the age of 65 suddenly graduate out of mental health and become aged care problems. This causes a number of problems with buck passing and so on.

**CHAIR:** Is 65 the cut off, is it?

**Dr ROWLAND:** In some areas, yes.

**The Hon. JOHN HATZISTERGOS:** But it is not just in mental health, is it?

**Dr ROWLAND:** No, but it is specifically a problem in mental health.

**The Hon. JOHN HATZISTERGOS:** It is a problem everywhere. You get people with all sorts of different conditions. Cardiac conditions is one that is referred to, and they hit the magic age and suddenly they are carted off to the geriatrician instead of the cardiologist.

**Dr ROWLAND:** The problem is worse in mental health, particularly as geriatricians are mostly trained as physicians and not as psychiatrists.

**The Hon. JOHN HATZISTERGOS:** I am not a doctor. You might tell me a little bit about geriatrics and what its specialty and emphasis is, and why we have these cut offs.

**Dr ROWLAND:** Geriatricians are physician trained. They are trained to be specialists in the field of medicine rather than surgery, psychiatry or those sorts of things. In a sense they are the olden-day general physician, but they have special interests. So they are general physicians who specialise in the care of the elderly. The idea is not to deal with all elderly, so there is disagreement amongst geriatricians as to what the exact group is, but most geriatricians would agree that if you are 95 and well and have a myocardial infarct, a heart attack, that that would come under a cardiologist if there was no other problem.

Geriatricians tend to deal with people who have multiple different illnesses concurrent so that it makes it difficult for a single-system specialist to deal with; that have problems with functions or difficulty actually performing the tasks of daily living; they have social difficulties so that carers are under stress or they have no carers or they require services and they tend more often than not to have cognitive difficulties, mental health type problems—dementia, delirium and quite often depression as well. That is the sort of population that is dealt with by geriatricians. They are a sick group of people, particularly the ones in hospital. They tend to be even sicker than the rest of the population in the hospital because they have multiple different illnesses and functional deficits as well.

De facto, geriatricians have taken up a lot of dementia and delirium because psycho-geriatric services have been not as diffuse as they might be and also because, as far as I am aware, the last Mental Health Act excluded dementia as being part of mental health. This made it difficult for psychiatrists to get into the area of dementia, although there are clearly a whole group of psychiatrists who call themselves psycho-geriatricians or psychiatrists of old age who deal in this area. They find it very difficult to get funding and so on because of problems with the Mental Health Act. There is not just a problem with dementia and delirium, there are also the problems of what do

you do with someone who has schizophrenia and who is now 66, or someone who has schizophrenia and who now develops dementia on top of that. Who deals with this problem? There is this constant shifting and movement to try to work out the boundaries, and this is always a problem.

**CHAIR:** Whereas, if you have heart failure you are looked after by the cardiologist but if you have schizophrenia you are looked after by the geriatrician?

**Dr ROWLAND:** You may end up being looked after by the geriatrician, because you have turned 66, and that is not the best place for you to be looked after.

**The Hon. JOHN HATZISTERGOS:** Even though you may not have any other illness?

**Dr ROWLAND:** Potentially. Hopefully there is a psycho-geriatrician or a psycho-geriatric unit in the area. In other words, it is a psychiatrist who is dealing with problems of old age, although a psychiatrist dealing with the problems of old age tends not to deal too much with schizophrenia but more with dementia.

**The Hon. JOHN HATZISTERGOS:** Are geriatricians skilled and trained to be able to deal with these sorts of illnesses or impairments?

**Dr ROWLAND:** Dementia, delirium and depression, yes; schizophrenia not so much. Everyone has a little bit of training in it but it is not our specific area. So, I would say we are not trained to deal with schizophrenia. Our aged care assessment teams [ACATs] who are associated with geriatricians are not there to deal with schizophrenia, and so on. They just cannot deal with those sorts of problems. A lot of times we find it difficult to get the mental health teams involved if the person is over 65.

**CHAIR:** Are most geriatricians in public, as in population health, practices?

**Dr ROWLAND:** Most geriatricians are level one staff specialists working for public hospitals. There are a few private geriatricians but due to relative value problems and so on, which we will not go into here, it is not economical.

**CHAIR:** So you are generally part of the ACAT teams, you are part of the process of assessment and recommendation?

**Dr ROWLAND:** Yes. To a certain extent, yes. Each area works slightly differently. This is one of the problems in aged care, it is a very geographically based speciality. In other words, you might work differently in the Liverpool area to the way you would work in, say, Westmead or Newcastle or Gosford because of the way things have been set up over time. Some geriatricians work more closely with their aged care assessment teams and some actually have difficult relations with their aged care assessment teams. But, in general, geriatricians work very closely with their aged care assessment teams.

**The Hon. JOHN HATZISTERGOS:** I want to go back to what I said to you before. This seems to me to be a general problem. I had a constituent whose family approached me in circumstances where the father was about 72. He had stroke. He was taken to one of the large public hospitals in this State. Instead of being referred to the appropriate specialist, a neurologist or whatever, he was referred to a geriatrician because of the age. He had no other problem. I am wondering to what extent the matters that you are raising are just symptomatic of some general policy or trend within the medical profession and within our hospital system, and we tend to assume that our older people should be dealt with by geriatricians rather than by people who should treat particular illnesses.

**Dr ROWLAND:** It is hard for me to talk for all geriatricians because they have different views. But I think most geriatricians would suggest to you that geriatricians are better at treating stroke than neurologists, because stroke tends to lead to functional deficits, if not cognitive, and requires social input and rehabilitation. Most of the randomised controlled studies of things like stroke units, where they are run by geriatricians, do very well; where they are run by neurologists they tend to deal more with the acute problem and then the patient gets left.

**The Hon. JOHN HATZISTERGOS:** Say a 40 year old had a stroke. You would not refer him to a geriatrician?

**Dr ROWLAND:** What you would want is a rehabilitationist to be involved very quickly and early on. The reason they would need to be seen by a neurologist is that a 40 year old should not have a stroke. You wonder what is going on. They probably have some other underlying illness that needs to be sorted out so there is a whole slew of investigations that get done on a 40 year old because it is an unexpected age for a stroke.

**The Hon. JOHN HATZISTERGOS:** Perhaps that was not a great example. Take the example you have at the top of page 3 of your submission—the person with a cardiac condition. He visits a cardiologist but an older person goes to a geriatrician. Is that a similar situation?

**Dr ROWLAND:** That might happen. An older person with a cardiac complaint may be seen by a geriatrician or by a cardiologist. If they have functional deficits and other problems, they are probably best dealt with by a geriatrician. If their only problem is cardiac, they are probably best dealt with by a cardiologist. The cardiologist will probably have more pull with the cardio-thoracic surgeon. He is going to be able to do the investigations a lot quicker because they own the cath lab and they own the echo and they can get things done more quickly and they can do the pacemaker.

The geriatrician, however, will look at the person's social aspects and deal with the family better and also deal with their functional deficits. So, if their heart failure is leading to them finding it difficult to get up and down the stairs within their house or have their own shower, the geriatrician will deal with that in a better manner than the cardiologist. So, it really depends on where they fall. If it is much more of a medical problem, the cardiologist will deal with that probably better and quicker; if the problem moves more into an area of social and functional deficits then the geriatrician will probably deal with it better.

**CHAIR:** For people who have heart problems, there is often the rehabilitation that is run by the geriatrician—getting people motivated and moving again after they have had the heart attack or heart failure.

**Dr ROWLAND:** That is right.

**CHAIR:** Of people in hospital Professor Brodaty said the vast block of people in our public hospitals for medical and surgical conditions are over 65.

**Dr ROWLAND:** Something like 30 per cent to 40 per cent of people in hospital at the moment would be over 65.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** It is that all?

**CHAIR:** It is more than that, is it not?

**Dr ROWLAND:** No. I am chairing a group called Working Group on Aged Care for the Health Council and it presented the figures to me yesterday.

**CHAIR:** Only 30 per cent?

**Dr ROWLAND:** 30 per cent to 40 per cent.

**The Hon. JOHN HATZISTERGOS:** Let us just take mental illnesses like dementia or Alzheimers. To me as a layperson my perception is that they typically coincide with the older age group. I never hear of 40 year olds getting dementia and Alzheimers and, if I do, I would imagine they would be a very small proportion?

**Dr ROWLAND:** It is a very small proportion, but they do do it.

**The Hon. JOHN HATZISTERGOS:** That seems to be the sort of illness that geriatricians would be particularly skilled at being able to treat.

**Dr ROWLAND:** Yes.

**The Hon. JOHN HATZISTERGOS:** What skills would psychiatrists have to be able to deal with those sorts of people? I am not sure that I am reading your submission correctly, but if you are suggesting that these people should be put into extreme services and taken away from geriatrics—

**Dr ROWLAND:** No. Do not take them away from geriatrics.

**The Hon. JOHN HATZISTERGOS:** —or better integrated I think is the word you used.

**Dr ROWLAND:** I think integration is very important. One of the problems is getting the support where you need it. If somebody is 75 and has had a stroke and is depressed, getting them to be seen by a psychiatrist or a



psychogeriatrician may be a difficult task, particularly if there are no psychogeriatricians. If somebody has dementia and there is no psychogeriatrician or geriatrician around you may not be able to get a psychiatry input. You need to integrate the services better. Particularly with older schizophrenics, how we deal with that should be mainly managed by psychiatrists and not by geriatricians although clearly as you age, even as a schizophrenic, you are more likely to get other problems. Therefore, you fall within the realm—

**CHAIR:** Even as a person with schizophrenia.

**Dr ROWLAND:** Even as a person with schizophrenia, sorry. You may end up with other problems and be required to be seen by a geriatrician. The problem is that the relationships need to be better set up. The difficulty is that when the aged care assessment team asks the mental health team to assist, more often than not there is friction, and that needs to be sorted out.

**CHAIR:** Probably the best advantage of the geriatricians is that they are better trained at recognising some of these mental illnesses than perhaps general practitioners and that is where, as a gateway to entry, the geriatricians have been enormously valuable.

**Dr ROWLAND:** We also need to improve screening at the general practitioner level for cognitive deficits, for dementia and for depression so that we catch the things earlier and do not wait until it becomes a problem where presentation occurs at the time of carer stress and burden. At that point if you wait until the time when the carers are about to fall apart it is very hard to support them through it to the point where they can continue to care. The idea is that if you can catch the illness at an earlier stage and provide education and carer support where the illness is at its earlier points then you can deal with it in a much better fashion and keep people at home functioning better for longer periods of time, rather than getting to the point where people require sedation or nursing home, which is not what we want.

**The Hon. JOHN HATZISTERGOS:** Many families, particularly in the non-English speaking community, go through processes of denial.

**Dr ROWLAND:** That is right, and part of that is because dementia, particularly in the non-English speaking community, is seen as a mental illness and that is a problem. One problem is that dementia falls in this gap and to a certain extent, as Henry was talking about the medicalisation of it, we need it to be seen as an illness within the mental illness kind of capacity. Also at the same time it also falls within this physician illness kind of problem, something that can be dealt with with care and with medications. There are now medications that are supposedly helping the behaviour and care of stress to a certain extent, and we expect there will be more medications down the track. It is important that we get our non-English speaking communities using the services earlier. All the information so far shows that they present a lot later when there is a lot of carer stress and burden and therefore they go to nursing home and residential care earlier because they present later and that is a problem.

**CHAIR:** Anthony, would you like to add anything before we ask questions?

**Mr BROWN:** Yes, I would like to add to the issues around equity and diversity that Christine raised. We know that mental illness affects different groups in our population differently. Particularly with older people and diversity of older people, I feel we need a better understanding of how mental illness is affecting different groups, not just groups around culture and language but also around gender. The particular example I would like to give is suicide in older people. We know that in older men the rate of suicide is something like 30 times greater for men than for women and it is an incredible number. We do not have a full understanding of why that is the case, and when we look at the data we have at the moment it is just more confusing. I am thinking of what has come out of the New South Wales Older Peoples's Health Survey 1999. The survey found that women were more likely to self-report feeling some distress or anxiety in the last four weeks before the survey, which is not what we would expect when we have men committing suicide at this greater number.

**CHAIR:** Men are not expressing any concerns but then they just top themselves for no apparent reason.

**Mr BROWN:** Exactly. So we need to have a better understanding of what is happening for men and for women, as well as for other older people.

**CHAIR:** There must be some theories about fear of dependency or anything like that.

**Mr BROWN:** There are theories and particularly I think the fear of dependency—

**CHAIR:** You must have some theories to try a strategy. There must be some strategies out there.

**Mr BROWN:** The main theories seem to be around fear of isolation and the danger of becoming isolated. For a lot of older men, their social networks are very tied into their wives' social networks so as their wife becomes ill or their wife dies perhaps that is a factor. But all these things are still theories. We still have not gathered enough data around what is happening.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is it true that women are generally younger and women live longer so the time that women are widows is much longer than the time that men are widowers. Men are actually topping themselves while their wives are still alive, and the wives are not topping themselves after their husbands have gone, which is kind of paradoxical if you are talking about isolation. It seems all wrong in commonsense terms.

**Mr BROWN:** That is part of what I am saying. It does seem all wrong in commonsense terms because we are still finding out what is happening. Those contradictions in the data that we do have is the point I am trying to raise. This is just looking at gender. When we look at issues of culture there are whole other overlays there and different things happening.

**Ms REGAN:** A relatively new group called Older Men New Ideas [OMNI] is a group for older men coming together to work on strategies to assist and advance issues of older men. I had the privilege to attend their first or second conference, at which the suicide rate was being discussed in some detail, largely by older men. It was the social isolation that was seen to be amongst that group of 80 or 90 older men who were saying that was the issue that was most likely contributing. They canvassed the theories, as Anthony said. They did have some academic work. They did say they still do not know but amongst the older men at that conference, and there was a particular demographic, they were saying that social isolation was the issue that they thought most contributed to ill health and suicide in older men.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** This was despite the fact that most of them were still married?

**Ms REGAN:** Supposedly. They did not identify whether or not they were married.

**Dr ROWLAND:** I think the other point is that men's self-esteem tends to be wrapped up a lot in their job and what they have been doing during their life. When they get to retirement age and they find that they are at home, they do not have the same support networks and so on but their wives have been basically to a certain extent—the older age group we are talking about—may have been at home for many years, already has her own social networks that she has set up over a long period and has supports. Women tend to be more forthcoming when it comes to when they have problems and discuss them amongst themselves.

Men tend to hold those problems in and do not discuss them. So they get to a point where they find that they are not getting the support or the interest in their life that they used to have. They do not talk to anyone about it. The other thing that has been shown in a number of studies is that men are much more successful at committing suicide than women. They tend to plan it more and are more aggressive in their take on it so that they are more successful when they attempt it, whereas for women it tends to be more of a cry for help and they tend not to succeed necessarily in taking their own life. That adds to the figures.

**Mr BROWN:** That leads into the second point I wanted to make around the groups like OMNI, which do seem to convey some protective factor on their members against mental illness. They are relatively inexpensive and relatively low resource groups to set up. We spoke in the submission about the importance of integration of services like HACC services. Groups like senior citizens' centres and other organisations that offer older people that opportunity for social contact and social inclusion are relatively easy to set up and resource, compared to resourcing services for people once they develop mental illnesses.

**CHAIR:** It seems that as people get older, men in particular, they leave their jobs, they tend to retire from life generally and then wonder why life is passing them by. There is no sort of work after, whereas women are often involved in some community group, meals on wheels and so on. Unless men get involved in something like that, they do have to wonder what they will do. Their wives does not want them around the house and so on.

**Dr ROWLAND:** They do not plan for their retirement; they think that it will just be a long weekend, a long holiday, and then as it drags on they find that the whole thing palls.

**Mr BROWN:** There also appear to be certain times when it is most opportune to try to engage, in this case, older men. If men have been retired for a long time and have established a pattern of isolation and social

exclusion, then it is very difficult to engage them in any social network. But at the point where they realise that retirement is not a long weekend and they cannot spend it all on the golf course or fishing or whatever they envisaged retirement to be, that is a point where they are very susceptible to joining groups like OMNI or getting involved in the community. The older men we have spoken to in our research, that appears to be the time that they join community organisations, volunteer, help out in unpaid community work. So there are opportune times when we can get people involved in these sorts of groups.

**Dr ROWLAND:** Then they provide a resource back to the community.

**CHAIR:** I accept that. That is exactly what has come out of your organisation, did it not, OMNI?

**Mr BROWN:** We have been working closely with OMNI but it is not auspiced by us; it is auspiced through the Council on the Ageing.

**Dr ROWLAND:** One more point is the problems with regards to the younger brain injured group and that is from trauma or from ethanol, which is the sort of middle aged brain injured group. They tend also to fall between the gaps and are picked up a lot by geriatricians because no-one else is dealing with their problems in the community. Residential aged care is used as a de facto placement for some of these people when in fact it is inappropriate both for them and for residential aged care. It ends up being a big problem for the community because the resources are not there to provide assistance for these people.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** This is acquired brain injuries as well as alcoholism?

**Dr ROWLAND:** Yes, acquired through trauma and alcohol, and occasionally young strokes and so on.

**CHAIRMAN:** Some time ago I visited some of the high-treatment nursing homes in Victoria and was astonished to find that a third of the people in, I think, one of the Italian homes were under 30 years of age and were basically funded by that State's equivalent of our Motor Accidents Authority. These high-care, long-care beds were in what looked like a nursing home, the only available facility that enabled these people to be close to where their families are.

**Dr ROWLAND:** The problem is that nursing homes are geared to having an environment suitable for the people in them, which tend to be the elderly, so the people in the nursing home tend to do things like play bingo and play "Roll out the Barrel" and those sorts of songs. A 25-year-old who has had a head injury will not be keen to participate in those activities, and so we end up with people being placed in a community that is totally inappropriate for them. Then you can get the opposite problem: young people, sometimes fit, who have cognitive impairment from acquired brain injury. They are dangerous to other people in the nursing home because they are spontaneous and might push over somebody or become aggressive at times. Because they are dangerous to the people in the nursing home, they require sedation and therefore become a danger to themselves. This becomes a big problem.

**CHAIRMAN:** How do we get access to this New South Wales task force report on mental health services for older people?

**Dr ROWLAND:** Beverley Raphael is running the Older Persons Mental Health Group.

**CHAIRMAN:** Did everybody sign off on that report?

**Dr ROWLAND:** I was not involved in the production of that report.

**CHAIRMAN:** Christine, to your knowledge, did everybody sign off on that report?

**Ms REGAN:** There are two versions on whether or not they have signed off on it. Several members of our working party reported to us that they had signed off on the final draft, which was then not released. It was summarised, refined and released as a different document. Members of the original working party who contributed to the New South Wales task force on mental health services for older people feel that the original report that they signed off on needs to be released, rather than the sanitised version, which we heard of at our working party meeting.

**CHAIRMAN:** What is the sanitised version called?

**Ms REGAN:** I am not sure.

**CHAIRMAN:** Has it been released?

**Ms REGAN:** We believe it has. It is merely a four-page or five-page summary, not the complete report, and not the report that members of the original working party reported to the Aged Care Alliance.

**CHAIRMAN:** The issue that you and John have gone to is the appropriate treatment of young people who have dementia, for various reasons, plus a mental illness. This morning the Disability Council raised the issue of impairment versus handicap; in other words, someone who has dementia may have certain symptoms—

**Ms REGAN:** Referred to colloquially in our circles as dual diagnosis.

**CHAIRMAN:** Today they were talking about the same thing: dual diagnosis of intellectual incapacity or various other forms of handicap, such as hearing and so on. Here, you are dealing with a very specific impairment, namely intellectual impairment due to say dementia, plus mental illness. Does the ageing process itself bring on forms of disease that could be thought of as mental illness but which really are not and are therefore not amenable to treatment?

**Dr ROWLAND:** Dementia is not caused by ageing. There is a concept called benign senescent forgetfulness. So, to a certain extent, you can have some slowing of your cognition as you age. But that is not dementia. Dementia actually requires the cognitive deficits to be actually affecting your functioning. So you have to be functionally disabled by your cognitive deficits for it to fulfil the DSM IV diagnosis of dementia.

**CHAIRMAN:** When you say dementia, you therefore mean you have a major functional incapacity?

**Dr ROWLAND:** That is right. It is only at that point that you call it dementia. Before that you would call it cognitive impairment, not otherwise specified, or benign senescent forgetfulness, which is even more benign than cognitive impairment.

**CHAIRMAN:** Tell us a bit about Alzheimer's disease, because we are going to hear a bit about that.

**Dr ROWLAND:** Alzheimer's is one of the forms of dementia, and the most common, though some of it is now being sheared off into other groups. It is a disease process first noted many years ago by Alois Alzheimer, who noted its presence in a fairly young Austrian woman. Essentially, the diagnosis of Alzheimer's is made on clinical grounds at the moment. It is a non-specific diagnosis in that you cannot do a diagnostic test such as a blood test or even a CT scan, although that will help. There are some MRI-type scans, which are fiddly, but may be more specific in their diagnostic capacities than are other tests. However, the only true way to make a definitive diagnosis of Alzheimer's disease is to do a brain biopsy. Currently, we do not do that; we wait until post-mortem if we are going to do that sort of thing. But you can pretty well form a general idea of whether someone has Alzheimer's disease or not.

**CHAIRMAN:** That would go with what Henry was talking about earlier, that there is a pathological change to the brain, not that these people are acting out. It is not someone with a normal brain who is attention seeking or being naughty; this is a demonstrable change of brain function.

**Dr ROWLAND:** Yes. On biopsy, you can show changes. Those are basically amyloid plaques and neurofibrillary tangles. People argue as to what is the chicken and what is the egg. So there are what are called the Baptists, the people who believe in beta-amyloid proteins, and the Taoists, the people who believe in the tangles being the important thing.

**CHAIRMAN:** There is new hope with the amyloid-gobbling enzymes and such processes, aren't there?

**Dr ROWLAND:** That is right. They are talking about immunisation against the amyloid. There are some fears that the amyloid is due in part to a leakage of the membranes of the blood vessels, and that this is somehow related to cholesterol handling. There are genetic tests that look at the apoE gene. Those people who are apoE4 homogeneous—in other words, they have two apoE4s, because you have two each of your apoE's—are more likely to develop Alzheimer's than the group of patients who have less apoE4s.

**CHAIRMAN:** So we should all go and get our genetic imprint done!

**Dr ROWLAND:** That is the point. It is not worth testing because, one, we do not really have a cure, and all you are going to do is worry yourself; and, two, it only doubles or triples your chances, but that does not mean

you will necessarily get Alzheimer's. Everybody who lives to about 120 will almost certainly get Alzheimer's. So the longer you live, the more likely you are to get it. If you have a number of relatives who have had it—say your mother or father developed Alzheimer's before the age of 65—that really increases your chances because that tends to indicate you may have a hereditary form of the disease.

But something like 20 to 25 per cent of the population will have Alzheimer's by the age of 80. One of our problems at the moment is that our population is ageing at a rapid rate, and particularly ageing in our old old. The people over 80 are the most rapidly increasing group in our population at the moment. So if we say 25 per cent of them will be suffering Alzheimer's disease, then we will have a very large population of demented people, to be managed by the rest of the population.

**CHAIRMAN:** There are some other conditions that produce dementia, such as the disease prevalent in Tasmania.

**Dr ROWLAND:** Huntington's chorea.

**CHAIRMAN:** Yes. As part of the disease process, sufferers become demented.

**Dr ROWLAND:** Huntington's is now something that we can screen for quite easily. There is a genetic test done by basically taking some blood, by which you can tell whether someone has or does not have Huntington's.

**CHAIRMAN:** That can be a very early dementia.

**Dr ROWLAND:** It presents early.

**CHAIRMAN:** Do those people end up in the care of the geriatric team, or what happens?

**Dr ROWLAND:** There are not that many of them, luckily.

**CHAIRMAN:** Not in New South Wales anyway.

**Dr ROWLAND:** No. In Tasmania there are many more, but there are not as many geriatricians in Tasmania. So, paradoxically, where the Huntington's sufferers are, the geriatricians are not. The other thing is that they tend to present first with abnormal movement disorders, so that they present first to the neurologist, and they present young. So they tend to get managed initially by the neurologist, who would then ask for the advice of a geriatrician when it came to the point of requiring residential care. A geneticist normally gets involved very quickly too, to try to talk to the family. One of the problems is that by the time the diagnosis is made—

**CHAIRMAN:** They have already had three kids.

**Dr ROWLAND:** They have already had three kids. So the idea is to at least talk to those kids before they have children, so that they have children in the knowledge that they may be at risk of passing on the disease because it is autosomal dominant.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is Alzheimer's a pathological process or a clinical syndrome?

**Dr ROWLAND:** It is a pathological process.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** When I was a doctor cerebrovascular disease was thought of as the underlying process. It seemed consistent with: If your arteries go to your skin you look older, and if they go to your brain you get silly. Alzheimer's seemed to be a way of tarting up a boring disease, to put it bluntly. Is Alzheimer's qualitatively different from other senile dementia states?

**Dr ROWLAND:** We do not believe in senile dementia anymore. That tends to be an ageist term used to explain why mum was forgetting to do things, delaying the making of an adequate diagnosis. Alzheimer's explains a lot of what used to be called senile dementia but, as you say, vascular dementia is the second-most common cause of dementia in our community.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Are they different on pathological grounds, or on clinical grounds?

**Dr ROWLAND:** Both. But, more and more, there are links between the two.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Then they are not different.

**Dr ROWLAND:** As I was saying before, with Alzheimer's there is now a thought about that it is cholesterol handling and so on. So it seems to be related to your vasculature, but maybe to your smaller vessels rather than multi-infarctional dementia, which tends to be large-vessel strokes, and also lacuna infarcts, or small infarcts due to high blood pressure.

**CHAIRMAN:** They are quite different disabilities.

**Dr ROWLAND:** They tend to affect different parts of the brain and present in a different fashion. Multi-infarct dementia, or vascular dementia, presents in a step-wise fashion. The sufferer tends to be okay for awhile, then gets a little bit worse when he or she has another stroke, and so on, whereas Alzheimer's has a definitive pattern of gradual decline over say 10 years, ending up with difficulty in swallowing and aspiration, and finally death. They follow a different pattern, and pathologically, when you look at them under the microscope, they are different, but there is a slurring between the two. Clearly, the older you get—particularly in our community—the more likely you are to suffer from vascular disease as well. Therefore there are a number of people who have a combination of Alzheimer's and vascular dementia. But Alzheimer's is a different process to vascular dementia.

There is also very small vessel disease, or white matter changes, or Binswanger's disease, which tends to give a subcortical-type dementia, which is another form of dementia and causes behavioural problems. There are the frontal dementias, more associated with things like alcohol and so on, which cause more behavioural problems. The other one that is very common now—probably the third-most common form of dementia, not because it is any more common but because we are diagnosing it more—is Lewy body dementia. Lewy bodies were first noticed with regard to Parkinson's disease, around the *substantia nigra*, and are related to Parkinson's disease. But we now find that the same bodies that were in that area can form in other areas of the brain and cause a Lewy body type dementia, which tends to be a little bit more frontal as well.

**CHAIRMAN:** They are much more difficult to manage.

**Dr ROWLAND:** They are much more difficult to manage. They have behavioural problems, they fall a lot, and occasionally they present initially to the psychiatrist because they look a little bit like they are psychotic, because they can present initially with hallucinations and so on. One of the things they do very differently to Alzheimer's is they fluctuate quite markedly. They can be very good one minute and very confused the next and so it looks like they are suffering from a delirium or a psychotic episode when in actual fact they are suffering from Lewy body dementia.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** There is not much treatment for cerebrovascular and Alzheimer's and they are not hugely different clinically, but the Lewy body one is?

**CHAIR:** It is behavioural?

**Dr ROWLAND:** Except that with Alzheimer's through the PBS you can provide cholinesterase inhibitors whereas for multi-infarctional dementia you cannot.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** How good is that evidence?

**Dr ROWLAND:** That it works?

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Yes.

**Dr ROWLAND:** It is not spectacular. The improvement is not great. It works in some people very well and in other people it does not work at all. There is no way to tell in whom it will or will not work. It probably works best in improving carer stress and behaviour, and yet the PBS criteria are not related to carer stress and behaviour; they are related to an artificial test with a mini-mental state examination. The mini-mental state examination is not fair to ethnic minorities because it is an artificial test that is designed in middle America and asks questions such as, "Repeat after me, no ifs, ands or buts" which is not something you can ask in Italian. The tests for it are unfair for our ethnic groups. It does seem to work in some people: it does not work in a lot. It is very expensive and some groups would fight tooth and nail to keep it available, and some groups would suggest that you could adequately use that funding elsewhere to provide services for people, rather than a great deal of people getting a medication that may not be very helpful, but there is an argument there.

**CHAIR:** Are there any further questions?

**Dr ROWLAND:** I want to stress that we need to educate health, allied health and the community with regards to dementia and delirium about: what are the illnesses? How do we find them? That there is not necessarily medical treatment but at least care that can be given to people and if they get that care early then we can deal with the problems a lot better. If we can get those sorts of messages out to the community, and also to the medical community where a lot of it is being ignored, I think we could deal with the problem a lot better than we currently are.

**CHAIR:** Is early recognition that stops them from doing something quite stupid the big issue?

**Dr ROWLAND:** Sedation for delirium is not the way to go.

**(The witnesses withdrew)**

**(The Committee adjourned at 4.03 p.m.)**