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REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

At Sydney on Monday 28 September 2009

The Committee met at 9.30 a.m.

PRESENT

The Hon. I. W. West (Chair)

The Hon. G. J. Donnelly
The Hon. M. A. Ficarra
Dr J. Kaye
The Hon. T. J. Khan
The Hon. M. S. Veitch

CHAIR: I declare the hearing open. Welcome to the first public hearing of the Standing Committee on Social Issues inquiry into substitute decision-making for people lacking capacity. Today we will be hearing from the New South Wales Trustee and Guardian, the Public Guardian, the Guardianship Tribunal, and the Disability Council of New South Wales. In addition, we will hear from witnesses with expertise in the field of substitute decision-making and the law and disability studies.

Before we commence I will make some comments about aspects of the hearing. In accordance with the terms of reference, this inquiry will focus on systemic issues in relation to provisions for substitute decision-making and, in particular, consider whether any legislative amendments are required to improve those provisions. It will not focus on individual cases and I therefore request that witnesses avoid mentioning individuals or details that may identify individuals or families unless it is absolutely essential to address the terms of reference.

The Committee has previously resolved to authorise the media to broadcast sound and video excerpts. Copies of guidelines governing broadcast of proceedings are available on the table by the door. In accordance with Legislative Council guidelines for the broadcast of proceedings, a member of the Committee and witnesses may be filmed or recorded. People in the public gallery should not be the primary focus of any filming or photographs. In reporting the proceedings of this Committee the media must take responsibility for what they publish or what interpretation is placed on anything that is said before the Committee.

Witnesses, members and their staff are advised that any messages should be delivered through the attendants or Committee Clerks. I also advise that under the standing orders of the Legislative Council any documents presented to the Committee that have not yet been tabled in Parliament may not, except with the permission of the Committee, be disclosed or published by any member of such Committee or by any person. The Committee prefers to conduct its hearings in public; however, the Committee may decide to hear certain evidence in private if there is a need to do so. If such is the case, I will ask the public and the media to leave the room. Finally, I ask everyone to turn off their mobile phones for the duration of the hearing and not to leave them on silent, as this will interfere with recording of the proceedings. I welcome our first witnesses.

IMELDA MARGARET DODDS, Acting Chief Executive Officer, New South Wales Trustee and Guardian, 160 Marsden Street, Parramatta, 2150, affirmed and examined; and

PAUL MARSHALL, Manager, Quality Service and Community Relations, New South Wales Trustee and Guardian, 160 Marsden Street, Parramatta, 2150, sworn and examined.

CHAIR: Would you like to make any opening comments?

Ms DODDS: I will keep my comments relatively brief. I appreciate the opportunity to appear before the upper House Standing Committee. This opportunity is an important one for the purposes of reviewing legislation as it pertains to adults who lack the capacity, either permanently or temporarily, to manage their affairs. I am appearing today as the Acting CEO of the New South Wales Trustee and Guardian. As the Committee knows, I am also formerly the Protective Commissioner and Public Guardian in New South Wales. The passage of the legislation establishing the New South Wales Trustee and Guardian set in place some very important changes in the way in which people's financial management affairs are conducted if they are under a financial management order. It also brought into place some important changes in relation to guardianship.

I no longer am the Public Guardian. I make that point because the Public Guardian appears later this morning to address issues that are specifically pertinent to his role as Public Guardian. I obviously have experience in that role historically, in this State and in Western Australia, but the focus of my comments this morning will be mainly in the area of financial management per se. I can, of course, make broader comments about guardianship legislation and the now New South Wales Trustee and Guardian Act, and I will do so.

CHAIR: Would you like to make any opening comments, Mr Marshall?

Mr MARSHALL: I do not think I need to add anything, thank you.

The Hon. MARIE FICARRA: I will get the ball rolling in relation to the amalgamation issues. Concerns have been expressed that the amalgamation in New South Wales of the offices of the Protective Commissioner, the Public Trustee and the Public Guardian has potential to reduce accountability and provide some conflicts of interest in the management of those areas. Could you comment on those concerns? To what extent does the New South Wales Public Guardian remain an independent entity after this amalgamation arising from the New South Wales Trustee and Guardian Act?

Ms DODDS: It is a little unclear to me what people were meaning by a conflict of interest. I assumed in the first instance that they were meaning conflict of interest between the Public Guardian and the New South Wales Trustee and Guardian. I will address that part of it first, which is the second leg of your question. In fact the passing of that legislation has strengthened the independence of the Public Guardian. Hence the comments I made earlier in about myself no longer holding the two statutory offices, which has been historically problematic, and this being the only State in Australia where it occurred. That certainly could have practically given rise to difficulties in the sense of the one officer holding decision-making authority for potentially all parts of a person's life. But that relationship has now been, for want of a better term, broken and is a welcome departure.

So the Public Guardian is only administratively responsible to the Acting Chief Executive Officer of the New South Wales Trustee and Guardian. I have absolutely no authority whatsoever to interfere with or try to direct his statutory role as a decision-maker. The office of the Public Guardian is also an on-budget agency, whereas the financial management side, or the will making side, of the New South Wales Trustee and Guardian is not; it is largely self-funding—so it is independently funded. For those reasons I think the actual separation of the two has made it more independent, not less, and has reduced the potential for a conflict of interest.

On the trustee financial management side of the equation, I could see where people might think from time to time there may be conflicts of interest that could arise in a particular matter. I suppose the classic one would be where a person under financial management is the beneficiary of a will or, perhaps, was excluded from a will where it was felt that they had a just entitlement, so a Family Provisions Act case could be commenced, and where the New South Wales Trustee and Guardian in its role as the executor of the will is also involved. This is not an uncommon set of circumstances. It is not that frequent either but it does occur, and it has occurred around Australia in equivalent organisations. There is provision in the Act, under section 21, to allow the organisation to sue itself, or take action against itself, which then allows that activity to occur, quite rightly and properly. There are precedents in other States and Territories for this to occur in equivalent bodies.

Dr JOHN KAYE: Have you ever taken action against yourself?

Ms DODDS: We are only three-months old. I can, however, say that as the former Protective Commissioner we took action in matters where the Public Trustee was the executor of the will. So yes, that has occurred.

Dr JOHN KAYE: But that is across two different bodies.

Ms DODDS: It was across two different departments.

Dr JOHN KAYE: This is within one body.

Ms DODDS: Yes, and that occurs in every other State in Australia. The Public Trustee or State Trustee, as they are variously known around the country, does both things, as does the New South Wales Trustee and Guardian.

Dr JOHN KAYE: Is there a history there of taking action?

Ms DODDS: Yes, absolutely, and the precedents and all of the protocols to assist with that.

The Hon. MARIE FICARRA: I want to ask you about client service teams. It has been suggested to the Committee that it was the practice of the Office of the Protective Commissioner and the Office of the Public Guardian to assign client service teams, and that they would have the responsibility of looking after clients individually consistent with their needs in service delivery. What is the practice within the New South Wales Trustee and Guardian in relation to client service teams? Are they still operating with the same parameters? Do they still structure the care individually? To what extent do the clients of the New South Wales Trustee and Guardian have face-to-face contact with staff? What is the responsibility of the staff towards them?

Ms DODDS: If I can start by separating out the Office of the Public Guardian, as it was, because their client service teams are structurally quite different and have been. They have three regional teams now and their service delivery is quite differently organised—I am sure the Public Guardian will explain that later. I think this question really focuses more on the former Office of the Protective Commissioner's client service teams, so I will obviously focus on that. Historically one of the reasons that the Office of the Protective Commissioner moved away from one- to-one client service delivery was a concern about the extent of control that one officer could have over an individual's entire estate. In any organisation you have a mix of staff; staff who are exceptionally good at what they do and, regrettably, there are staff who are less good at what they do. If a client had a staff member with whom they had a difficulty, or there were difficulties, then there were obviously problems—that goes without saying. When people were on leave it was, I understand, the experience that often decisions were not made in their absence. Based on recommendations of a review commissioned by New South Wales Treasury, and conducted by RSM Bird Cameron, the office restructured the way in which it delivered services in 2006. Issues arose with that restructure and when I was appointed in August of 2007 I conducted a review of that restructure with the staff and we modified the approach, which has brought into place the client service teams that operate today.

One of the things that the staff and I clearly recognised was that there will always be a group of people who will require one-to-one support, either for part of the time that their affairs are under management or possibly all of the time. Some of those eight teams are structured to deliver that. The first team is the "intake" team. When a client's affairs first come under the control of our office the intake team works on a one-to-one basis for a period of approximately three months whilst they look into the individual circumstances; it works with them, works with their family and care providers, to find out what their essential needs are; sets up a preliminary budget for them; and takes all of the necessary preliminary actions—and some of those may be very urgent actions that are required in order to make them safe from abuse or neglect, others may include the taking of legal action on their behalf. All of this is initiated before that person's circumstances are evaluated to determine which of the remaining six teams they should be allocated to.

I mentioned eight teams. The seventh team is called "finalisation"—that is a footnote for you—where the order ends or the person dies. Once the person is leaving our intake team a decision may be made that this is an individual who has very high support needs. They maybe experiencing quite challenging behaviours in their life at this point in history, and they may require the support of either our intensive team, which is a small team that can cover the State, or our office at Clarence Street if they are living in the greater Sydney metropolitan area. Alternatively, it might be the set of circumstances that the person concerned cannot communicate with us themselves and may be in or about to go in to long-term residential care, often as a result of advancing age and conditions such as dementia.

They may have regular needs in the sense of the payment of their regular rent and funds to pay for chemists' bills, haircuts, and so on. However, they will not be communicating regularly with our office. They may be assigned to the long-term residential team whose role and responsibility it is to monitor their needs on an ongoing basis. Because the person cannot communicate with us we need, at least on an annual basis if not more frequently as the need arises, to communicate with that care provider to see that their needs are being met. Currently, about 3,500 people under financial management are in that team and have their affairs managed by that team. The other alternatives are to be allocated to one of the current regional teams which are: greater Sydney metropolitan region, the northern region and the south-west region.

At the moment the three teams to which I referred are based in Sydney and at our Parramatta office. As part of the merger with the former Public Trustee, the opportunity now exists to be able to move service delivery to the branch and regional offices that are operated by our organisation and now by the New South Wales Trustee and Guardian, but formerly by the Public Trustee branch offices. That will begin to occur over the next 12 to 18 months. Early next year a new office is to be established in Bathurst and we will then begin the roll out to other regional offices, for example, Lismore, Wollongong, Newcastle and Gosford—large offices would be the early places where this would occur. Obviously that will be a complex administrative thing to do. Unless you wish me to do so, I do not think I need to go into those details today.

The effect it will have on client service delivery is the import issue. It means that smaller groups of staff will go out to those offices. Currently we are working on determining how many staff will be required in each office. That will provide a more local and more personalised service delivery than we have been able to provide with our three regional teams. Our three regional teams were a significant improvement on what was occurring before. We also know, just by tracking the work over the past 12 months, that improvements could be made and need to be made there. Currently that whole service delivery is being evaluated and its outcomes will be used to inform how we roll out our services. I am sorry that that was rather long-winded.

The Hon. MARIE FICARRA: It was very interesting and necessary.

Dr JOHN KAYE: Ms Dodds, I refer to the Common Fund and to the global financial crisis. How has the Common Fund fared through the global financial crisis? Has its value been affected? What will be the impacts on its ability to provide funds for clients?

Ms DODDS: Like everyone else in this room, we would have preferred that it never happened, but it has. The Common Fund of the former Office of the Protective Commissioner [OPC] is benchmarked and unitised. It is benchmarked to market and to the top 200 listed companies in the Australian Stock Exchange. Clients' funds perform in accordance with the market on a unit-by-unit basis. To that extent it has been affected, as everyone else in the market has been affected. However, our funds are conservatively geared. By that I mean that, broadly speaking, at any one time 70 per cent of the funds are held in cash or fixed interest, and only about 30 per cent are in equities and in listed property.

There are a variety of reasons for that. A small number of clients have over $1 million in assets and they represent about 4 per cent of our client population. Clients with assets over $250,000 all have a fully developed financial plan. Like any other financial plan, their portfolio is invested according to their individual and future needs, and it is weighted where their dollars go into fixed interest, cash and equities. All those financial plans are weighted in such a way as to keep enough money in cash and fixed interest to meet their budget needs over the forthcoming four-year to five-year period. That enables clients to weather the storm, such as we have seen recently, and not need to redeem it—if indeed they have money in equities and listed property—when it will be unfavourable to them, unless it is absolutely not avoidable.

The "not avoidable" circumstances obviously are when the order comes to an end, as we must then give the moneys back. If moneys were in listed property and equities they would then have to be redeemed. At the moment we are not redeeming from those areas for some fairly obvious reasons. Let me give you an example. It is well known that listed property fell by 35 per cent in 2007-08. The loss in our funds was less than the loss in many other similar funds. No client would have more than a maximum of around 10 per cent of their overall investment if they had money in listed properties. It does not follow automatically that every client does.

The Hon. TREVOR KHAN: When you say less, what does "less" mean? You said not less than 30 per cent or 35 per cent. Does that mean it was 30 per cent or 25 per cent?

Ms DODDS: I cannot give you those sorts of figures off the top of my head. The listed properties fell 35 per cent. That was the benchmark that occurred in 2007-08.

The Hon. TREVOR KHAN: Will you take that question on notice and give us those figures?

Ms DODDS: Yes.

Dr JOHN KAYE: In 2006 the New South Wales Legislative Assembly Public Bodies Review Committee conducted an inquiry into the Public Trustee in New South Wales. It recommended that the New South Wales Public Trustee benchmark its service delivery against the achievements of public trustees in other jurisdictions. It also recommended that the Public Trustee develop key performance indicators for all areas of its operations. Have these recommendations been implemented and, if so, how have you done against those recommendations?

Ms DODDS: Bear in mind that I have only just taken over the Public Trustee side in the past few months. However, I can tell you that there are no national benchmarks for Public Trustees.

Dr JOHN KAYE: But there are in other States.

Ms DODDS: Yes. Public Trustees exist in other States, but the Public Trustees as a body has not agreed to a process of national benchmarking. I know that for a fact because as a former Protective Commissioner I also met with them on regular occasions. With regard to the key performance indicators [KPIs], the former Public Trustee developed extensive KPIs. Also, as part of that review, there was a requirement to bring forth a revised audit process. That was implemented with a new audit committee and independent chair.

At the time, prior to the merging, I was the independent chair of the former Public Trustees Audit Committee. I may have to come back to you with details about how well they have performed against those KPIs. I can certainly tell you that they are extensive because I received my first briefing about two months ago. But if you would like the precise figures I will deliver them to you.

Dr JOHN KAYE: If you could, thank you. Could you also give us some indication of the service delivery against the benchmarks? Did you establish benchmarks as well as KPIs [key performance indicators] or did you see those as one?

Ms DODDS: I think they would be seen as the one in the lack of national benchmarks, or international benchmarks for that matter.

Dr JOHN KAYE: Were they set against other States?

Ms DODDS: That I will have to take notice because I was not a part of it.

Dr JOHN KAYE: Thank you. The same body issued a report titled, "The personal effects review of the Office of the Public Guardian and Protective Commissioner in 2001." It recommended that a panel of external financial planners be established to provide expert advice on the more complex financial planning issues. Was such a panel established?

Ms DODDS: I think what was intended there was our investment advisory committee. Yes, it was established. It met quarterly and continues in the new organisation.

Dr JOHN KAYE: Does it oversight what you do or does it give you strategic directions for financial planning?

Ms DODDS: It gives strategic oversight of the investment, the common fund, and the activities of investment. The organisation does have qualified financial planners.

Dr JOHN KAYE: Of course, I was not questioning that. I wanted a better understanding of how this outside body interacted with your financial planners.

CHAIR: Can I clarify, there is or there is not an external body?

Ms DODDS: There is.

CHAIR: What is it?

Ms DODDS: The independent Investment Advisory Committee. Its membership includes people with experience in former trustee organisations, in investment and in financial planning. There is a representative from Treasury nominated by Treasury, also the Attorney General, as CEO and the senior finance staff are ex officio on that committee. As I said, it meets quarterly. It receives reports from State Street, who manage the common fund. It quite extensively quizzes State Street about their performance and then turns its attention to the performance of the organisation.

Dr JOHN KAYE: Does that panel report back to you or does it report publicly?

Ms DODDS: It does not report publicly, interestingly. It reports into the organisation but through the annual report.

The Hon. MICHAEL VEITCH: To clarify, are you saying the information is available in your annual report?

Ms DODDS: Yes.

The Hon. MICHAEL VEITCH: My questions go toward private managers. At the outset, could you tell us how someone would come under the gambit of the Trustee? How does that happen?

Ms DODDS: It can happen either through a court or tribunal order. The Supreme Court can appoint the New South Wales Trustee and Guardian or a private financial manager. Those are largely contained to personal injury matters. The Guardianship Tribunal of New South Wales is probably, not probably, it is the largest of the bodies in terms of the number of people from whom we get orders. There is also the Mental Health Review Tribunal and currently, strictly speaking, magistrates, although that will shortly revert to the Mental Health Review Tribunal. Those three bodies can make orders appointing a financial manager. Two of them—that is, the Supreme Court and the Guardianship Tribunal—can make orders appointing either the statutory financial manager of last resort, myself, or a private financial manager. At the moment the Mental Health Review Tribunal cannot.

The Hon. MICHAEL VEITCH: What would be the basis of those orders?

Ms DODDS: The basis of the orders is, first of all, that the person before the relevant court or tribunal has a disability in the meaning of the relevant piece of legislation, which means that they are not able to manage their affairs, their financial and estate affairs, in all or part. Secondly, and I am really talking more here about the Guardianship Tribunal but the principles broadly apply, importantly, the existence of disability alone is not sufficient reason for a financial management order. If there are less formal ways in which the issues can be resolved, those are sought in the first instance. But very often there are not. So a legal impediment is found, so that there is then a need for an order to be made. Why else would you take away something so fundamentally important unless there is a clear need?

Then, finally, the issue of who should be appointed needs to be considered. Whilst it is not currently in the Guardianship Act per se, my office is considered the financial manager of last resort. It is considered that for a number of reasons and some of it is case law. But it is also commonsense and good practice that if there is someone in the person's life who is willing and able to be responsible for that they should be appointed as a private financial manager.

The Hon. MICHAEL VEITCH: Should the appointment of last resort be articulated in the Act?

Ms DODDS: I do not think it would do any harm at all and it would bring it into consistency with the guardianship issue where the Public Guardian is expressly described as the guardian of last resort.

Mr MARSHALL: Your question might be geared towards how the order actually takes place. It requires an application. Someone has to make an application for it, and that is not the New South Wales Trustee and Guardian. That is someone involved in the person's life. It can be a social worker, or it could be a doctor or a family member who recognises that there is a problem and perhaps a need for an order. They then make the application to the relevant authority. In the case of orders made through the Mental Health Review Tribunal the person is already a patient in a facility. Orders will not be made there if the person is not a patient. Therefore it comes about as a result usually of someone working in the health system who recognises the person as having a problem—perhaps bills are not being paid, et cetera. That then goes up before the Mental Health Review Tribunal.

The Hon. MICHAEL VEITCH: Can the orders be challenged?

Mr MARSHALL: The orders can be challenged. At the time the order is made any parties who attend the hearing, if it is at the Guardianship Tribunal or the Supreme Court, are permitted to put their views about why they think an order is or is not required. If it is before the Mental Health Review Tribunal the hearing is not usually attended by other parties. However, those orders are different in terms of the fact that the CEO of the New South Wales Trustee and Guardian has an obligation to consider the need for continuation of management once the person is discharged from hospital. Once the order is made there is provision for a person to seek a review of that order by the authority that made it. If they are unhappy with the outcome of the review by the authority, they can go to the Administrative Decisions Tribunal.

Ms DODDS: That is also a matter that may be better put to the president of the tribunal, whom I see is appearing this afternoon. The issue of who is a party to an application is an important point.

The Hon. MICHAEL VEITCH: In your submission you support a proposal to amend the Act to allow the Mental Health Review Tribunal to appoint a private manager. I want to ask a couple of questions in relation to that. In the submission you state, "The Trustee and Guardian is to authorise and direct the performance of private managers appointed by the Supreme Court or the Guardianship Tribunal." How do you direct the performance of a private manager?

Ms DODDS: When a private manager is appointed they must provide a plan to our office about how they propose to manage this person's estate. That may have some very particular requirements in it. For example, and this is a very common example, most people under private management at the moment are elderly and quite often they are in or about to go into aged care and their family member usually is appointed. It is often the case that the family home may need to be sold to provide the funds for that to occur. That sort of plan is put up; basically, "This is what needs to happen for my mother/father." We review that plan and we agree with it or talk to the private manager about where their needs to be refinement.

Those refinements are not around us being unreasonable; it is just that the private manager is bound by legislation as well. They may be proposing something that they cannot do. It could be an investment that is outside the provisions of the Trustee Act, for example. So we would provide advice on that. But then on the basis of that plan we would prepare the directions and authorities, which give them the power to do what they need to do to manage their family member's affairs. Using property as an example, it might be that there is a multiple property portfolio but the directions and authorities only provide for the sale of a particular piece of property in order to give effect to part of the plan. That is not to say that in the future another piece of property may need to be sold. They would simply come back and get a reissuing of directions.

The Hon. MICHAEL VEITCH: If you have an issue with the performance of a private manager, what processes are available to you to intervene or provide corrective guidance?

Ms DODDS: One of the first things we do is check that they have complied with the directions and authorities. We also require private managers to submit accounts on an annual basis for auditing. That is another opportunity to see if there are problems emerging. If we think it is redeemable—some people find the task of being a private manager much more onerous than they imagined—then we can provide them with information and some level of guidance to assist with that. However, if we have severe concerns about the nature of the activities they are undertaking, we can apply to the relevant court or tribunal to have the order reviewed and to have the financial manager replaced with another financial manager, if we think that is warranted.

The Hon. MICHAEL VEITCH: Can financial managers levy an administration fee for their services?

Ms DODDS: They cannot levy a fee per se. They can be reimbursed for costs that they incur. They can also employ an accountant to assist them. That is all part of the directions and authorities discussion that goes on. But they cannot say, "And my fee for being a private manager is." That is not permissible.

The Hon. MICHAEL VEITCH: If an individual were to pass away, for how long after the date of death is a private manager involved in the management of the financial affairs?

Ms DODDS: For exactly the same time frame that we are. The order ceases upon death. There is some small provision in the legislation to allow for moneys that are necessary or activities in train, but it is really very tightly governed. It has to go over to the executor then to deal with.

Mr MARSHALL: A private manager would have the authority, for example, to pay for a funeral bill. They would also have the authority to honour any commitments that were made prior to the person passing away. But other than that, they would have to leave that in the hands of the executor.

The Hon. GREG DONNELLY: Thank you for coming today to provide evidence for our inquiry. I have some questions on notice but I am not sure you have seen them particularly. One of our general questions picks up some issues the Hon. Michael Veitch raised. It is number 11 on my general set of questions. I will read it out in case you do not have it in front of you. It says:

> The Guardianship Tribunal when deciding on a guardianship order is required under section 14 of the Guardianship Act to consider the views of the person, the person's spouse—

if the relationship is supposedly continuing—

> and the person's carer, if any. However, the tribunal, the courts and the Mental Health Review Tribunal are not required to take into account the views of these people when making a financial management order.

I would like you to express your views on two questions that flow from that. First, is there a reason the views of these people are not required to be considered when making a financial management order?

Ms DODDS: Again I think it is a question better put to the president of the tribunal, but despite the lack of legislative reference, in practice it does occur whenever a person is able to give a view to the Guardianship Tribunal and also when the financial management order is in place. That actually does occur in practice and has been occurring for a good many years. I stress, when the person is able to give that view. When they are not able to give that view at all, then in the financial management and as with the tribunal, we turn to people who may be able to provide some insight into what were the person's views and values et cetera. However, specific legislative provision would remove any doubt about that.

The Hon. GREG DONNELLY: Should we reflect on some specific legislative provision?

Ms DODDS: I think whenever there is an apparent inconsistency where the Act says one thing in one area but not in another, even when the practice is occurring, it is no doubt better to put it into the legislation. Then it brings it into equilibrium because the making of a guardianship order or a financial management order is an incredibly serious thing. No-one denies that it is taking away the most fundamental of human rights. So I think putting these things beyond doubt is worthwhile. Yes, I do.

Mr MARSHALL: I might add that in situations where an order is made and there has not been involvement in the hearing process by all family members or all interested family members, it does make our role as the financial manager more difficult because we then tend to be the recipient of concerns people have about the process by which the order was made, which of course is not our role. Our role is to concentrate on making substitute decisions. Really, it is a matter for the authority that made the order to deal with the process by which they engage with other parties and take into account their views. We cannot answer for them in relation to that. It can make management quite difficult. I suppose it is better if those things are canvassed at the time the order is being made so that everyone feels they have had the opportunity to say their piece in relation to the need for the order and who should be appointed if a decision is made for a financial management order to be made.

The Hon. GREG DONNELLY: Through your answers you have, in effect, answer the second part of the question. So I shall not pursue that. You raised a point about the participation and involvement of family members. These days with the formal structure of family being somewhat different to what it may have been, say, certainly three generations ago, and use of the phrase "alleged families" when there are—I will choose my words carefully—many potentially interested parties or family members, is that leading to added complexity in working through a range of views that may be put forward in considering these sensitive issues?

Ms DODDS: Inevitably it does. It gives rise to the complexities that we see in other venues. Put simply: Yes, it does. But it does not mean that it is always impossible. The essence of the issue will be how well the family unit is communicating amongst themselves and if there are fractures—and they can occur in families that are not blended equally as they can in blended families—then these will emerge and they become, sometimes, extremely difficult conflicts, very painful conflicts for everyone concerned. But the financial manager, be it the NSW Trustee and Guardian or the private financial manager, must deal with that.

The Hon. GREG DONNELLY: Do you find yourself having to, in essence, in a number of circumstances, mediate over what are conflicting positions that are coming forward?

Ms DODDS: Our primary role is driven by the principles that are in section 39 of the Act, and they mirror the principles of the Guardianship Act. The absolute focus of our endeavours has to be the person themselves and their best interests. Any decision we make must be driven by that. Very often the interests of the family may conflict with what is in the person's best interests, so mediating that is difficult. Were we to even use formal mediation—which, by the way, we do not regularly, but if it is needed—straightaway there is an issue of a power imbalance, and the power imbalance is for the person themselves, and how you represent their needs and who is representing that. In fact, we are representing that. So it is complex.

Do we try to resolve these issues and explain to the family members why we are making a decision, that these are the factors we are taking into consideration? Yes, we do. For major decisions, and, broadly speaking, they are obviously the ones like disposal of large assets, et cetera, those decisions are put in writing and made available to people, and are appealable.

Mr MARSHALL: I suppose as a corollary to that there is often an expectation that our office's role is to mediate between different interested parties, and, as Ms Dodds just said, we certainly attempt to resolve, where we can, impasses that may arise where you cannot get agreement about what is in the best interests of the person. But ultimately we are there to make decisions in the best interests of the person, and really to take on the role of mediating situations between family members would become a full-time job in itself. What we will try to do—and that is often a role that falls to me—is to try to encourage people to seek their own mediation and try to take, I suppose, some responsibility for working out their own dynamic in such a way that we can all become focused on what is in the best interests of the person.

CHAIR: However, the difficulty you have under section 39, besides the resources issue, which you allude to, in trying to come to grips with the conflicts between management and advocacy and the third-party—obviously, with section 39 you are acting in the interests of the person that you either have the funds management responsibilities for and/or the advocacy responsibilities for—the family members or the interested parties for the person you are managing and advocating for are fundamental to that person you are representing. I am still coming to grips with the fact that the reviews are internal and the speed of review and taking into account the difficulties of training and guidance of people who are related or interested in the person. I hear what you say about regions but I sense that there are some real resources problems in coming to grips with how you continuously advocate on behalf of the person you are representing under section 39 who is fundamentally linked to family members and others that you are saying really you do not represent.

Ms DODDS: We certainly legally do not represent the family and others; we represent the client—the person under the financial management order. But also in those principles, as you rightly point out, we have to take into account their relationships, their cultural and linguistic background and goals, of course, to try to keep people involved in the community as far as possible. They are all complex principles that have to be weighed up in any given decision at any one time, and sometimes they will work out well and other times they will not. We may not be able to meet all of the family desires because they conflict with what is in the best interests of our client.

CHAIR: But who makes the decision that they conflict?

Ms DODDS: Ultimately a client service officer will make that decision. Let us take, for example, the sale of the family home, which is often one of the most contentious, and we can all understand that—the place we grew up in; we might have very strong attachments to it and it has to be sold because mum or dad have to go into care. There may be very many competing views around that. When the decision is made the reasons are given to all of the relevant people and they can seek a review of that decision internally. It is reviewed by an officer senior to the one who made the original decision and who had no role in making the first decision. That officer can revoke it and make another order or can uphold the original order. If at that point the person still feels aggrieved they can go to the Administrative Decisions Tribunal and seek for the tribunal to review it. It has to be reviewed internally before it goes to that step. These are all safeguards that are well established and put in place.

CHAIR: But what is the expertise and the time factor in the resources involved for a person closely linked to the person you are looking after under section 39, those issues of being able to physically do what you say in terms of resources, capacity, time, geography—all those issues? What is the reality? Can you give us some examples of the reality?

Mr MARSHALL: That is a very good question. If we are managing an estate that has a number of interested parties who have all got different views we are obliged under the legislation to consult as widely as is appropriate. So we need to take into account all of those views. In a perfect world if we could just go out to people and say, "We need to make a decision in relation to the future of the property of the person under management and we would like to get your views in relation to that", we can then consider those views, we can then make a decision, we can notify the parties, we can advise them of their review rights and it can follow the process.

In reality, what often happens is that in seeking views what we get back is a lot of information about why we should not be taking the view of a particular family member because of all sorts of things that they may or may not have done in years gone by. We are left in the situation in which we do not necessarily have constructive views coming from the family members about what is in the protected person's best interests. That can sometimes take up a lot of time because we are actually trying to go back to them and say, "Look, we understand that those are the issues. However, what we are seeking from you is your views in relation to what is in the best interests of the person under management with relation to this specific issue about the property."

It can sometimes be a very arduous task, I suppose, to get the views of family members. When we are obliged to also consider issues, such as beneficiaries of estates and the impact our decision will have on that, that further complicates it. It is a very good question. It is one that we do struggle with.

CHAIR: Do you struggle with it from a conceptual point of view or from a resources point of view? Conceptually you are saying that I, as the son of the person you are controlling, become subject to your views as to what is in the best interests of my father. Subjectively, I have a strong possibility of maybe having a different view than you as a person who is controlling my father.

Mr MARSHALL: I suppose initially we do not have necessarily a firm view in these decisions. It is about seeking the views of family members to see what view ultimately we come up with as to what we think is in the best interests of the person.

CHAIR: Therefore, what is really being said is that I, as the son of a parent with dementia, am then feeling estranged from the decision-making process because I feel that you, as a person who is in control of my parent, are making a decision and not the family members. Understandably, there is a feeling of conflict.

Ms DODDS: That is one of the outcomes, often when the statutory financial manager is appointed, when the family may feel that they should have been appointed, but were not. It goes back to the point Mr Marshall was making earlier about very often in the early part, and sometimes right through the order, there will be quite a lot of anger expressed at times about the making of the order in the first instance. That can carry through. They are all complexities that we deal with on a daily basis.

You were asking about the resource issue. Of course, resources are a significant issue here. We know that we have an ageing population and we know that, to date—and I hope they hurry up—there has not been a cure for Alzheimer's found, and there are other forms of dementia. That is just one area of disability. We also know that, regrettably, acquired brain injury is increasing as well. The need for this sort of service is going to continue, even with the best promotion of pre-planning mechanisms. Our resources have been stretched, and the New South Wales Trustee and Guardian, in its budget bid, has put forward for increased resources now. They are all directed into client services in financial management. The outcome of that process is still in train.

The Hon. GREG DONNELLY: At page 13 point six of your submission, which follows under a heading on the previous page, "Summary of Recommendations", you state under (3):

> *The NSW Trustee may, at the discretion of the NSW Trustee, continue to manage the property and affairs of the person until …*

Then (3) has subparagraphs (a) and (b), and (b) has (i) and (ii). I direct you to (ii), which states:

> *or*
>
> *(ii) that The NSW Trustee considers that it is in the best interests of the person that management be terminated (even though the New South Wales Trustee is not satisfied that the person is capable of managing his or her affairs.*

I think the bracket should be closed there. This is one of your recommendations. Could you give us examples of what is behind your thinking in putting that forward as a recommendation for us to consider?

Ms DODDS: The New South Wales Trustee and Guardian has the capacity to review management orders at the moment under certain circumstances. When a person is discharged from a psychiatric facility and an order is made under the Mental Health Tribunal, it automatically comes up to me for review as well as when a guardianship order lapses and there is also a financial management order in place. That is reviewed by us as well to see whether it should continue. At the moment the only ground that I can give to not continue an order is regained capacity.

Under the Guardianship Act, the Guardianship Tribunal can review and revoke an order on two grounds: regained capacity or best interests. I am of the view, and my submission states, that I ought not to be doing this in the first instance. I think there is a fundamental conflict of interest with the organisation that manages the money saying whether you should continue to be under the order. I think that is the first point.

The Hon. GREG DONNELLY: Yes.

Ms DODDS: However, if it was to continue, I would really want to have that additional capacity to discontinue an order when it is not working—either it is not functional or it is in fact making things worse. I believe all the tribunals and courts should be able to apply that test. To give you an example, it is often the case that a person with a mental illness will be particularly unwell, and will require on the face of it a financial management order. Their life is chaotic. They are spending all their money as soon as it arrives. They usually only have a pension. It is all gone within days. Often they have a concomitant drug addiction. It is often going on the drugs. They are not paying their bills. It just goes on and on.

The intention of putting a financial management order in place is, with the best will in the world, to put some stability into that person's life and take what is a chaotic life and give it some order. For many people, that works; but for some, it does not work, and it makes the circumstances even worse. They could go out into the street and perhaps would steal to feed their drug habit or engage in other behaviours that will make life worse for them and lead them into the criminal justice system, or they become so distressed by the very presence of the order that it becomes functional. They do not deal with us, they will not deal with us, and they will not relate to us. It does not happen very often, but when it happens you want to be able to say, no, this is not working. The intention was good. Everyone was well intended in bringing the order, but it is not achieving its desired outcome. It is making matters worse.

The Hon. GREG DONNELLY: That is a good answer. I understand that. My last question goes to the final page of your submission, page 14 at point 8. I want to be sure I understand what you are proposing here:

> That the NSW Trustee & Guardian Act be amended to include the following statement in the preamble to the Act.

I admit that I did not go back and check the current preamble, but the first part of the proposition states:

> *In the operation of this Act the CEO and all persons with delegated authorities must in the performance of their duties observe the rights conferred …*

You then referred to the United Nations Convention on the Rights of Persons with Disabilities. What struck me is that the seminal human rights instrument is the Universal Declaration of Human Rights, which was established in 1948 upon which the Convention on the Rights of Persons with Disabilities and a range of other conventions are derived and built upon. I wonder why you would not be proposing that people would have reference to the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities?

Ms DODDS: Probably only because we were focusing specifically on the recently developed Convention on the Rights of Persons with Disabilities. There would be no objection or problem with the universal statement being referred to.

The Hon. GREG DONNELLY: It seems that the universal declaration scopes out very clearly the broad framework for the recognition of human rights. I put it forward as something worth reflecting upon.

The Hon. MICHAEL VEITCH: My question follows on from the last question about the convention. It also talks about assisted decision-making as opposed to substitute decision-making. What are your views on whether we should be moving New South Wales towards assisted decision-making as opposed to substitute decision-making? It is an important principle in those conventions.

Ms DODDS: Having reread my submission and everyone else's over the weekend, I am not sure which one said what.

CHAIR: I know the feeling.

Ms DODDS: The point is well made in a number of submissions that the guardianship legislation and, indeed, the forerunner to the New South Wales Trustee and Guardian Act—the Protective Estates Act—were developed at a point in history. The guardianship legislation in particular looked at the principles of best interests and substituted decision-making, which was leading edge at the time. Since then, thoughts, understanding and practice have changed across the globe and here in Australia.

In practice, I know from my time as the Public Guardian as well as the Protective Commissioner that the Office of the Public Guardian has been exercising assisted decision-making as far as possible. It is done in a number of areas on the financial management side. I think we need to do it better, and a lot of training and support has to go into that. We do need to bring in the principles of assisted decision-making. But it is a continuum and I think that is the important thing that people need to understand. It is a complex area that is really only just now being discussed and thought through at practice levels nationally and internationally in the adult guardian field. But, as a principle, I think it does need to be included.

The Hon. MICHAEL VEITCH: Are there any jurisdictions within Australia that have moved or are moving towards assisted decision-making as opposed to substitute decision-making?

Ms DODDS: I have not reviewed the legislation in that much detail for a number of years. I did for a masters thesis a long time ago, and it was not then. But law reform commission inquiries are being undertaken in Queensland and Victoria. It is a question on the agenda in Victoria and I believe that it is also being considered in Queensland.

The Hon. MICHAEL VEITCH: This question evolved from my previous line of questioning. Are there processes in place to penalise or to order compensation from private managers in the event that they are found to have acted dishonestly and are there processes to recover the loss if dishonesty is proven?

Ms DODDS: Like any other citizen, financial managers can take action against any person who has been found to have acted dishonestly. If a private financial manager has acted dishonestly and it comes to light, it goes back to the tribunal or court for the appointment of another financial manager. That could be another private financial manager or it could be us. Both would have the capacity to take action.

The Hon. MICHAEL VEITCH: Are those safeguards sufficient?

Ms DODDS: The safeguards to take action to redeem any losses civilly or criminally are sufficient. They are the same options that exist for anyone in the community. That is the broader question. It has been done successfully. Sometimes it is not successful and for very complex legal reasons. Sometimes both the money and the person are gone.

Mr MARSHALL: It can be very difficult to run a case on misappropriation of funds et cetera when the person who you really need to get the evidence from has lost capacity. I suppose there are two routes you can follow. There is the criminal route, where if the dishonesty or misappropriation is so apparent that the police may be interested in it. More often than not it is a case of having to take legal action on behalf of the person under management. You then have to weigh up the issue of whether the action is going to be successful and, if so, whether there will be any money to retrieve. As Ms Dodds said, it raises the bigger issue of how successful we are as a society in clawing back funds that have been misappropriated from any citizen where that person is no longer able to give evidence and say, "Yes, that person stole money from me."

CHAIR: I refer back to the issue of resources, the philosophies involved and how you match those philosophies with the required resources. Of course, there are various elements: section 39 of the Act; the options of substitute and assisted decision-making; the complexity of the continuous need to review; the human rights issues of trying to ensure that there is natural justice and an appearance of justice; and the need to continually review the capacities of the people you are looking after. In trying to come to grips with all those competing forces, the resources are limited. We need to make recommendations that have the capacity to be implemented. Are we able to address all those aims within the resources of your organisation?

Ms DODDS: There are two levels to the issue of resources. Obviously, there are the overall financial resources to provide the staff required to deliver what we seek as the best outcomes and training resources for the staff who are actually undertaking the work. I will start with the second issue first. The former Office of the Protective Commissioner experienced a high staff turnover in relatively recent times. There are a number of reasons for that. One of those was a move to Parramatta but it is not the sole reason. There is also an ageing profile in the workforce. There is a significant challenge that confronts me and my executive team in ensuring that we are able to have a staff that are skilled and understand the work that they are undertaking. A lot of the staff we have are very familiar with the work but the principles of assisted decision making are broadly a new concept that needs to be integrated into their work practices, along with a continual rota of training and awareness about disability issues. There are all things that are, for me, givens about the service going forward.

In terms of the number of staff available to provide the service, one reason, but not the only reason, for a move away from one-to-one service delivery historically, as I understand it, was the fact that the organisation could not at that time, and nor probably reasonably into the future, keep pace with the demand for service by providing one-to-one service delivery for all clients. If what is sought is a return to one-to-one service delivery for all clients under management as a best outcome, then we could not do that with today's resources. I am not of the view that it is essential for all clients though to have one-to-one service delivery. I am of the view that we need to provide that where it is essential and we need to be able to provide a quick and responsive service.

At the moment we are experiencing delays that I am not happy with in our regional teams. I cannot put my hand on my heart as I speak to you today and say precisely what that outcome will be when we move those services out to the regional offices, except I can say that I have asked for 17 additional staff, who are directly, as in those staff to go to the regional offices, or one layer behind providing essential client service support, are required in our current service delivery framework. So manifestly with that budget proposal we require additional resources. As I said to you, I do not know the outcome yet.

The Hon. MARIE FICARRA: We are told that New South Wales has no legislative provisions for advanced medical care directives. However, we are told that New South Wales Health provides advice on how to develop a document that would be valid at common law. With your previous experience and in your current position, what is your opinion about the status of advanced medical directives in New South Wales? Do you think that there is any need to introduce legislation covering this area?

Ms DODDS: As I indicated earlier, I confine most of my comments to the financial side. However, on this I would confirm that it has been my previous experience—and I see in other submissions and I concur with them—that legislative reform is needed. New South Wales is one of the few States, if not the only State, where advanced directives are not specifically provided for.

The Hon. MARIE FICARRA: How do you think this has developed? Is it just an oversight and we intended to do it, or has there been any body that has been leading the charge against it? Are doctors willing to comply with these directives? Why has this come about?

Ms DODDS: I honestly do not know. I do not know the history of it in New South Wales, partly because I am not New South Wales born and bred and was not here for those debates to know or working in an area close enough to them to know the history of it at the time. But other jurisdictions around Australia have it and have it under review. At the moment the nearest that a person can do is, through an enduring guardian instrument, give instructions to their guardian about their health care in the event that it is required but that is the nearest.

The Hon. MARIE FICARRA: Have there been any outstanding problems that you have seen in the operation of these advanced medical directives or any problem with not having legislation covering this area?

Ms DODDS: Personally, no, because in practice when I was the Public Guardian as well as the Protective Commissioner I rarely formally put that public guardian hat on, principally because the work load was quite sufficient in one side but I left that work to the director of the Office of the Public Guardian and only very specific issues were brought to me with that hat on. I could not give you anonymised case examples that others, I am sure, will be able to do, other than saying that the area has lacked clarity and there is a need for legislative reform.

The Hon. MARIE FICARRA: Have you heard anything such as doctors not willing to comply with these directives at all in the past or any body of medical opinion on these directives?

Ms DODDS: I can say that, with an enduring guardian instrument, yes we most certainly did hear of that. When I was the Public Guardian I assisted the office with some work that was conducted in collaboration with the AIDS Council of New South Wales in particular where enduring guardianship instruments signed by same-sex couples were not being adhered to and the rights and requests of the same-sex partner were not being respected.

The Hon. GREG DONNELLY: Was that just as a result of a question over whether in fact there was a genuine de facto relationship operating? That is why there was some contest over the position within the enduring guardianship instrument?

Ms DODDS: No, that would be irrelevant because I could determine, if I chose, to make Mr Marshall my enduring guardian, and we have absolutely no relationship whatsoever, other than a work relationship.

The Hon. GREG DONNELLY: I am curious. What was the cause of the issue at that time? I am interested about why these issues arise in the context of same-sex relationships.

Ms DODDS: Various comments have been made to use in regard to that because one of the roles of the public guardian is the support of enduring guardians. Those sorts of things have come to us after the fact and also reports through other organisations, particularly in the gay, lesbian and transgender community, that their experience had been that the instruments were not being recognised, specifically what happens right at the day. It is hard to know but we had been told of instances where the exclusion of the same-sex partner began at emergency and continued right the way through to the funeral.

The Hon. GREG DONNELLY: If I understood the import of what you were saying, the enduring guardian instruments have, in some circumstances, taken on a de facto advanced directive nature—it appears to have evolved that way. But could you explain to me, for my benefit, the enduring guardianship instruments themselves are not intended for that purpose?

Ms DODDS: Not specifically, no. They are to enable any adult who is able to give it the authority to someone to make whatever decision they determine, the same decisions that a guardian appointed by the Guardianship Tribunal could make—where I was to live, who I live with, certain medical care services I receive. So, it is much broader.

The Hon. GREG DONNELLY: So notwithstanding what seems to be the pretty broad scope such instruments provide for, you are still articulating there are good reasons to proceed and have some specific legislation to deal with advanced medical directives?

Ms DODDS: Yes, and they exist side by side with enduring guardianship in other jurisdictions.

The Hon. MICHAEL VEITCH: Is there a jurisdiction that has a preferred model, a model you would prefer us to look at?

Ms DODDS: No, I do not have a particular view on that, and I think others are better qualified to give you that advice than I am. I simply have not had the time to put that amount of research into it.

CHAIR: Because to do assisted decision-making properly—I am assuming, correct me if I am wrong—needs, as you indicate, a continuum and it is complex and there is a need to continually revisit the capacity of a particular person you are looking after under section 39. That would be time-consuming if you were to do it properly. How much time, effort and staff resources have been thought about for that?

Ms DODDS: That is not a question, the quantum, that we have turned our attention to vis-a-vis assisted decision-making. I made the point earlier, as you also addressed, that it is a continuum, because there are some people—quite a lot in fact—for whom substitute decision-making is going to be required, and that is not going to change. Most people are generally people who have a degenerative condition such as Alzheimer's, where their condition is past the point of their being able to engage in the process. So, that is one group of people, through to the other end of the spectrum, where we need to be working with people and being clear, especially into the future, where part of the estate is exercised from our management, which bits we are managing, for what reason, and does Imelda today lack the capacity to give me instructions about what she wants to happen on that issue? That is assisted decision-making at its top level, really. But, no, I cannot say to you we have been in a position to be able to look at the specific resources that will be required if assisted decision-making is introduced.

CHAIR: Would that also involve more contact and complexity, in terms of relationships, with close interested persons?

Ms DODDS: It will require more resources, without a doubt, and yes, it will, because you would need to be working with a person with fluctuating capacity, which is where assisted decision-making is very, very important. You would need to have good contact with them.

The Hon. MICHAEL VEITCH: The line of questioning is very good, very accurate, and it raises an issue. I spent a number of years working in the disability sector. Making a decision confers the right to make a decision that may be wrong as well.

Ms DODDS: Yes.

The Hon. MICHAEL VEITCH: That is a basic principle, is it not, of the assisted decision-making process, that people can be informed along the way to make a decision, but if the decision is not correct, that is their right?

Ms DODDS: That is probably one of the most challenging, ethical debates that one can ever have. It is around balancing competing principles, really. There is no simple answer to that, as you know from your own experience. But if a person is very unwell at the point at which they want to make a certain decision that the financial manager, private or statutory, considers to be extremely unwise and not to be in their best interests and to possibly place them at greater harm, then the competing ethical principles around that are, surely, I would argue, to not cause harm, to protect from harm. That may be when the right to make a bad decision needs to be overridden. But they are not snap judgements; they are very complex.

(The witnesses withdrew)

(Short adjournment)

GRAEME JOHN SMITH, Public Guardian, Department of Justice and Attorney General, level 7, 160 Marsden Street, Parramatta, and

FRANCES RUSH, Assistant Director, Advocacy and Policy, Public Guardian, Department of Justice and Attorney General, level 7, 160 Marsden Street, Parramatta, sworn and examined

CHAIR: In what capacity do you appear before the committee?

Mr SMITH: As Public Guardian.

Ms RUSH: As Assistant Director, Advocacy and Policy.

CHAIR: Do you want to make an opening statement?

Mr SMITH: I merely wish to reiterate what is essentially covered in the submission and say that this is an important inquiry at the present time given the ratification of the United Nations Convention on the Rights of Persons with Disabilities. That represents the potential for a change in the paradigm in which issues of capacity or incapacity are dealt with by law in New South Wales. The other two issues that I want to mention, which are consistent with that shift in paradigm, relate to the role of the Public Guardian in New South Wales which is out of step with the same role performed in other jurisdictions in this country and needs to be updated in that regard.

The third thing is that change in demographic, particularly in relation to the ageing population and the impact that will have on health and welfare services generally, and the role that government will play in relation to the provision of those supports, will also be felt in the way in which the law responds to the issues of capacity and incapacity. I have set out in the submission some very basic figures in relation to what we might expect in this State in terms of the impact of the ageing population. In that regard I want to emphasise the importance of the proposal that we have made in relation to the use of community guardians. They are the only opening statements that I want to make.

Dr JOHN KAYE: Will you clarify the reference in your submission to cognitive, mental and intellectual disabilities? Are they different? If so, what are the differences between them?

Mr SMITH: They are terms that are frequently used interchangeably. However, when one seeks to unpack those terms they can imply different levels of capacity or incapacity. A person with an intellectual disability in New South Wales would normally not be regarded in that way unless they have the disability prior to the age of 18. A person with a cognitive disability may be anyone who has suffered some sort of impact in relation to their mental functioning. The term "cognitive disability" is frequently used generally to identify those people for whom the issues of perception and reasoning are affected. They may be affected by a traumatic brain injury, long-term use of drugs and/or alcohol or disease, such as Alzheimer's disease. The term "mental impairment" is a generalised term that is usually used to cover the whole gamut of people whose capacity to understand, reason and articulate might be affected.

Dr JOHN KAYE: Mental incapacity is the generic overview term?

Mr SMITH: Yes.

Dr JOHN KAYE: I move onto the consequences of the amalgamations of the offices of the Protective Commissioner, the Public Trustee and the Public Guardian. It has been put to the committee that there is a potential to reduce accountability, to create conflicts of interest and it probably was not a wise move to have one body controlling the management of a person's financial affairs, their lifestyle and their health decisions. Will you comment on those concerns?

Mr SMITH: My first comment would be to say that it is not an accurate characterisation of the current situation. In fact, when the Attorney spoke to the passage of the New South Wales Trustee and Guardian Bill through the House made it clear that the role of the Public Guardian would continue to be separate and that the Public Guardian would report to the chief executive officer of the New South Wales Trustee and Guardian for administrative purposes only. That means that any decisions made by the Public Guardian with respect to a person's health or welfare, any decisions that are covered by the functions ascribed to the Public Guardian, would be completely independent of the New South Wales Trustee and Guardian.

The location of the Public Guardian administratively within the New South Wales Trustee and Guardian is an administrative device only, that is to say, we draw support of that organisation in order to support our functions but any decisions taken by the Public Guardian are completely independent and not subject to control by anybody else.

Dr JOHN KAYE: Do you have separate annual reports and to what degree are you separated? You say you have an administrative connection but what are the other separations?

Mr SMITH: It is proposed that we will have our own separate annual report, bearing in mind that prior to the recent changes the Protective Commissioner was also the Public Guardian and so the annual reports were amalgamated. It is proposed at this point that the Public Guardian will have a separate annual report. We are separated to the extent that we have a separate group of staff; the staff of the Public Guardian are under the control of the Public Guardian and their activities are controlled by the Public Guardian, not by the New South Wales Trustee and Guardian. There is a separation to the extent that we have our own ABN. We largely function quite independently but for administrative purposes, say, for example, in relation to the management of resources and our compliance with reporting requirements within the Department of Justice and Attorney General then that operates through the New South Wales Trustee and Guardian.

The structure of the Department of Justice and Attorney General is that the department is divided up into separate business centres. The Public Guardian is not considered by the department to be a completely separate business centre, it is considered to be a business centre within a business centre, if you like. There is some merit in the argument about separation in terms of perception. The general principle in the New South Wales Disability Services Act, in fact, says that all the aspects of a person's life should not be under the control of one body. In reality, the decisions of the Public Guardian and those of the New South Wales Trustee are separate decisions but administratively we are joined. From the perception of people on the outside it may appear as though we are acting together whereas, in fact, we are not. The name given to the New South Wales Trustee and Guardian has potentially sought to compound that perception and it was, in my view, an unfortunate name.

Dr JOHN KAYE: Do you advocate changing the name to the various bodies?

Mr SMITH: Yes, I would.

Dr JOHN KAYE: I personally find it very confusing. I left my cheat-sheet behind but normally I cover these meetings with one to remind myself who is who. Do you advocate a more separate set of names that would actually provide greater clarity to potential clients of the various bodies?

Mr SMITH: Yes.

Ms RUSH: I also think that people confuse us with what is now referred to as TAG—New South Wales Trustee and Guardian. They think that we are the "Guardian" within that group, and the name just completely confuses people.

Dr JOHN KAYE: Which, of course, you are not?

Ms RUSH: That is right.

Mr SMITH: That is what is confusing; people assume that the use of the term "guardian" in the name of New South Wales Trustee and Guardian in fact refers to us, but it does not. If you ask me why that name was tacked on, I would not be able to tell you why, but the use of the term "guardian" in that context refers to financial guardianship not to guardianship, but from the outside you can see where it would be confusing for people. And, in fact, having looked at some of the submissions, it is apparent that some of the people making submissions were confused about it.

The Hon. MICHAEL VEITCH: I want to follow on from that line of questioning in both regards; the definitional question and also where you see yourself residing in ministerial responsibility if there is a change. In your submission you advocate being moved from the ministerial responsibility of the Minister for Disability

Services and being brought in under the responsibilities of the Attorney General. Can you tell us what the benefits of such a move would be?

Mr SMITH: Our argument in relation to that is a focus more on the issue of policymaking and lawmaking. At the present time the Public Guardian is located within the administration of the Attorney General's Department but we have no direct reporting relationship to the Attorney. What we were really referring to in that submission was that the legislation is currently owned by the Minister for Disability Services, which means that it is quite difficult for us to get access to the legislation with respect to seeking amendments and so forth. Quite apart from that, it is an anathema for legislation that ought to be encompassing the civil law provisions in response to issues of capacity and incapacity to be located in the disability welfare policy environment.

The central thesis of our argument is that the passage of the convention represents a paradigm shift in the way in which we ought to be thinking about issues of capacity and incapacity; we ought to be lifting it out of the welfare policy thinking and locating it more in the way in which the law is structured to respond to issues of capacity and incapacity in a general sense; that is to say, that it ought not be just focused on people with disabilities. It ought to be focused on issues of incapacity whenever and wherever they arise. In terms of developing the law and the policy to support the law, it is our view that that would more appropriately be located in the Justice or Attorney General's area, as it is in every other Australian jurisdiction other than New South Wales, where its historical beginnings were in the community services-human services area.

If you look closely at the guardianship legislation in New South Wales you will see that it is focused on the welfare and interests of people, not about their rights to exercise their legal capacity, which the convention is all about. It is about governments, nations, States developing mechanisms to support people to exercise their legal capacity; it is not about protecting their welfare. So that is what that argument is about. In day-to-day practical terms we are located in the Justice portfolio but we retain this reporting requirement to the Minister for Disability Services. That has the potential to set up a couple of things.

It can certainly create the perception that the Public Guardian is not independent of the other services that are provided by the Minister for Disability Services, who in New South Wales is also the Minister for Ageing, and of course we cover both sectors, whereas if we were reporting directly to the Attorney, then I think it would be apparent to everybody that we are completely independent from the whole service apparatus that is designed to support people with disabilities. Clearly that would mean the Public Guardian was a more independent advocate, who could more openly and publicly comment on the effectiveness or otherwise of the service infrastructure.

The Hon. MICHAEL VEITCH: Thank you for that. In response to Dr Kaye's question around definitions of intellectual disability, mental and cognitive impairment, are the definitions used by organisations consistent with other New South Wales agencies such as Health or even Ageing and Disability?

Mr SMITH: No, I would not think they were. I think the Department of Ageing, Disability and Home Care uses the term "developmental disability". Developmental disability is a slightly broader term because it can encompass intellectual disability but it can encompass other disorders that occur prior to the age of 18 brought about by the later onset of disease or traumatic circumstances whereas I think Education, for example, uses the term "intellectual disability". In a sense, intellectual disability is a slightly narrower definition than developmental disability, because developmental disability could include people with cerebral palsy, who do not necessarily have an intellectual disability but clearly have a disability. That could be encompassed within the definition of developmental disability.

The Hon. MICHAEL VEITCH: Do you think there is an argument for consistency in definitional use across the agencies in New South Wales?

Mr SMITH: I think it would be definitely helpful. One of the issues that the Public Guardian confronts frequently is the issue of eligibility for access to services and the issue of inconsistent definitional use does create problems in that regard.

Ms RUSH: Because it can lead to exclude, although people use them quite interchangeably and probably quite loosely.

The Hon. MICHAEL VEITCH: And that leads to confusion about eligibility. That is why I wondered when you were talking a bit earlier, because my experience in the disability field is that it is not only New South Wales that has inconsistent use, it is also the case federally; it is even an issue with Federal services.

Dr JOHN KAYE: You are saying that within the New South Wales Government there is not a consistent definition; not just between the New South Wales and Federal Government?

Mr SMITH: Yes, I am saying within New South Wales there is also some inconsistency around the use of the terms.

Dr JOHN KAYE: I know that, for example, the Department of Education and Training has very formal definitions of various kinds of disabilities with set thresholds in order to supply support services within public schools to those people. Is it simply that one definition would not fit all or is it simply a lack of somebody taking a whole-of-government approach?

Mr SMITH: The latter.

Dr JOHN KAYE: Golly gosh.

Mr SMITH: There is a capacity to develop definitions that do capture all forms of disability but they are not currently in use by anyone.

Dr JOHN KAYE: And work for all contexts?

Mr SMITH: Yes.

Dr JOHN KAYE: Because it is not just the types of disabilities, it is the context in which it is being assessed and supported?

Mr SMITH: Yes, I am saying there is a capacity to do that but that is currently not the case.

The Hon. MICHAEL VEITCH: It is a big issue.

Dr JOHN KAYE: Clearly.

The Hon. MICHAEL VEITCH: That is why I was wondering whether it was impacting upon the role of Mr Smith.

Dr JOHN KAYE: I apologise for my incredulity.

CHAIR: That is all right.

The Hon. MICHAEL VEITCH: My last question is: in your submission you state that the Public Guardian "is a party to all guardianship tribunal hearings of an application for guardianship and that the Public Guardian may make an application to the tribunal for a guardianship order". Can you clarify what role the Public Guardian plays in tribunal hearings where it is not the applicant and do you perceive the potential or the perception of a conflict of interest if the Public Guardian is applying for a guardianship order?

Mr SMITH: There are two types of guardianship tribunal hearings. There are the hearings that take place in response to initial applications and there are hearings that take place for the purpose of reviewing an order that is already in place. In relation to initial applications, the public guardian plays no role. Notwithstanding the fact that we are automatically a party to those applications, we play no active part in the hearing process. With respect to the second type of hearing, we do play a role where we have been appointed as the guardian and the order is being reviewed and we provide evidence to the tribunal with respect to the conduct of that order for the period of time that we have been the person's guardian. In terms of conflict of interest—

The Hon. MICHAEL VEITCH: My question related to perceived conflict of interest.

Ms RUSH: If we were the applicant.

Mr SMITH: If we were the applicant. I do not think so, but, having said that, it depends on the role that the public guardian plays. If the public guardian were playing the same role that it was in most of the other jurisdictions, that is to say, a public advocate role, it is quite likely that the public advocate or the public guardian is likely to be in contact with the person prior to the application being made. In those circumstances, they are in a good position to determine whether or not this is a person who would benefit from having a guardian appointed. Having said that, once the application is made, they play no role in deciding who the guardian will be—that is a decision that has made completely independently by the Guardianship Tribunal. So there really is not any room there for conflict of interest to arise because we do not have any control whatsoever over the decision to appoint a guardian or, in circumstances where a guardian is to be appointed, who the guardian shall be. In fact in New South Wales it is fair to say there is a presumption in favour of appointing someone other than the public guardian where that is possible. It is a rebuttable presumption obviously, but the evidence has to be there to say that other parties could not appropriately be appointed as the person's guardian, so I cannot see how anyone could perceive there to be a conflict.

The Hon. TREVOR KHAN: Could I take you to pages 8 and 9 of your submission, which deal with the role of the guardian? "Acting as Guardian" is the heading at the bottom of page 8. The example you use repeatedly in that section is where a person should live. What further examples would you put forward of your role, relating to a person with I suppose a severe disability, beyond where they should live as an appropriate area for you to engage in as an active guardian as opposed to an inactive one?

Mr SMITH: I think it would be fair to say that typically a guardianship order will cover a variety of different areas of a person's life. The majority of the orders that we are given would cover where the person would live, the types of services that the person should receive; provide for the guardian to consent or withhold consent to medical and dental treatment, to determine who the person under guardianship can have access to and, in some cases, we are given an advocacy function in particular or sometimes we are given a legal advocacy function in order to facilitate access to legal services. The tribunal is not limited in terms of the functions it can give the guardian. The legislation essentially provides for a guardian to have any of the functions that a guardian would have at law or at equity, but they are the typical areas of the person's life where the guardian would be given decision-making authority.

The Hon. TREVOR KHAN: Let us suppose you are given decision-making authority in the area of medical treatment. We have been given an example recently in Western Australia of a gentleman who chose to make a decision not to accept food. Say a circumstance arises where one of your clients makes that decision. What do you do where you have a power relating to medical treatment in such a circumstance as that?

Mr SMITH: The distinguishing feature about that case in Western Australia—the Brightwater case—was that, first and foremost, the person was competent to make that decision for himself. In the event that we were given authority to make decisions with respect to a person's medical treatment or their health care generally, first of all, we would determine whether or not the person was competent to make that decision for themselves or not. The fact that we were given that function by the tribunal is already an indication that the tribunal believed that the person did not have the capacity to make those kinds of decisions, but, having said that, we would not assume that that decision-making capacity was set in stone. Some people's capacity fluctuates depending on the nature of the disability that they have, but we would seek to satisfy ourselves that the person was capable or not capable of making that decision. In circumstances where we felt that it was not in the person's interests for artificial nutrition and hydration to be withdrawn, we would not consent to it.

The Hon. GREG DONNELLY: You would not?

Mr SMITH: We would not consent to it where we did not believe it was in the person's best interests. At the end of the day, once a guardian is appointed we have a duty to always act in the person's best interest.

The Hon. TREVOR KHAN: That is the $64,000 question: what is in the person's best interest?

Mr SMITH: How we determine what is in the person's best interests would be through the analysis of the available evidence. Part of that evidence would be provided by the clients themselves, but part of that evidence would be provided by medical experts and other experts in the field and we would weigh that evidence and make a determination on the predominance of evidence whether or not it was in the person's best interest.

The Hon. TREVOR KHAN: As I understood the Western Australian case, although as I understand it he had to be fed through a tube, that was not an issue of artificial nutrition, it was in a sense that he just did not want to eat. If you have a client who simply refuses to eat, and taking into account that they are impaired, what is your position then?

Mr SMITH: It would depend on why the person is making the decision. There was a recent case in the Australian Capital Territory, quite soon after that Western Australian case, where the person was refusing to eat and the Department of Health in the Australian Capital Territory sought a declaration from the Supreme Court of the Australian Capital Territory with respect to whether or not they should adhere to the patient's instructions or should in fact override the patient's objections and force the patient to eat. What the court determined in that case, and it would be the same process that we would follow, was whether or not this was an informed decision made in the patient's own best interest or whether or not, as it was found to be in the Australian Capital Territory case, it was a decision arising from a delusional belief—and in that case the court declared that it was not informed consent on the part of the patient and a substitute decision should be made with respect to the patient's feeding.

We have had cases here in New South Wales where the person was in a persistent vegetative state being kept alive through, as you say, feeding through a tube and the request of the family was that we consent that the feeding should be stopped. The use of what they call PEG [percutaneous endoscopic gastrostomy] feeding is not without some significant medical difficulties: they block up and have to be replaced, and every time they are replaced it is a surgical procedure. In the circumstances of the case I am referring to there was no suggestion—this was after exhaustive medical assessment—of this person returning to any sort of functional life. In that case we took the decision to stop the feeding. That decision was appealed to the Administrative Decisions Tribunal and the tribunal upheld our decision.

The Hon. TREVOR KHAN: Who lodged the appeal?

Mr SMITH: Other family members.

The Hon. TREVOR KHAN: But it was not a circumstance where you initiated the proceedings before the ADT?

Mr SMITH: No, we did not initiate the proceedings. We made the decision to stop the feeding and the family appealed that decision to the ADT.

The Hon. TREVOR KHAN: Could I therefore, in the concept of medical treatment, raise another issue—reproduction? Where a client has a degree of compulsive behaviour that exposes that client, let us say a female in this case, to the prospect of pregnancy, do you have a position with regard to surgical intervention in those circumstances? I may have phrased it poorly but I think you understand.

Mr SMITH: I understand what you are saying. There are certain forms of medical treatment that are beyond the jurisdiction of the Public Guardian to make decisions. That would be one of them. That falls into the category of what is known as "special medical treatment" and only the tribunal in New South Wales can make that decision. If someone wanted to perform surgery on a person who did not have legal capacity to consent for themselves, and which would render them infertile, whether it be a man or a woman, it would require an application to the Guardianship Tribunal.

The Hon. TREVOR KHAN: Does that apply also with regard to the insertion of an intrauterine device [IUD] or the use of the pill?

Mr SMITH: Not necessarily the use of the pill, because that is something that can be withdrawn. It does not render a person permanently infertile.

The Hon. TREVOR KHAN: As with an IUD.

Mr SMITH: As with an IUD. There are other forms of long-term injectable treatment that would attract the category of special medical treatment in those circumstances. There was a practice in the past in New South Wales with females who were within that childbearing range where the department would routinely use long-term injectable contraceptives. These days that would require the consent of the Guardianship Tribunal.

The Hon. TREVOR KHAN: We will not deal with the long term. We will use the two examples of birth control that I have referred to. Are those matters that have to go to the tribunal or are those decisions that, being an active guardian, you and your office make?

Mr SMITH: We could, but it would depend on why they were being prescribed. If it was being prescribed for the purpose of rendering the person infertile that is an issue we would probably refer to the Guardianship Tribunal. However, if it was being used as a method of—

The Hon. TREVOR KHAN: Birth control.

Mr SMITH: If it was being used for birth control, that is probably a matter we would refer to the Guardianship Tribunal. Often the same type of medication is used for purposes other than just birth control—to regulate menstruation, which can be difficult to manage in certain circumstances for some people. We may be able to consent to that.

CHAIR: So the definition of best interest of the protective person can take different forms? If you are talking about the concept of assisted decision-making, the definition of best interest can take a different complexity, depending on whether you are talking about financial assistance, medical assistance or assistance in making a decision as to whether someone has a good time on a Saturday or Sunday night. Depending on which type of decision you are called upon to make, the definition of "best interest" can change if you are trying to bring about assisted decision-making.

Mr SMITH: Assisted decision-making is different from substitute decision-making because assisted decision-making is characterised by providing a range of supports for a person to come to their own decision. At the end of the day it is their decision and nobody else's decision. In substitute decision-making, where the issue of best interest is central, that decision is being made by somebody on another person's behalf. Within the context of assisted decision-making, if a person is making their own decisions they can arguably make decisions that are not always in their own best interests. Where a substitute decision maker has been appointed, that decision maker has a duty to act only in the person's best interests.

CHAIR: So they are not given the task of trying to head towards assisted decision-making?

Mr SMITH: We have argued that greater consideration ought to be provided within the scope of the law in New South Wales to facilitate assisted decision-making. To give you an example, I am currently the guardian for a young woman who was considered by her family to be in a persistent vegetative state and the family wanted me to authorise the removal of all life-sustaining treatment. As we have progressed with that matter we have discovered that not only is this young woman not in a persistent vegetative state but that she in fact may well be able to make certain decisions herself. The problem is that she cannot communicate in the normal way. Through the use of specialist intervention and advanced technology we have been able to construct methods through which this woman is in fact able to communicate with us.

Assisted decision-making is a concept that can be used to provide a range of different supports to help people come to their own decisions. Quite clearly, anyone who is assisting a person to come to their own decisions is going to point out what the problems are with a particular decision they are intending to make and point out where it may not be in their best interest. At the end of the day, it is their decision. In a substitute decision context, the decision is going to be made by a third party irrespective of what the person wants to do necessarily. In the case of medical treatment, we are frequently given not only the authority to consent to medical treatment but also to consent to medical treatment overriding the objections of the person.

The Hon. TREVOR KHAN: Mr Smith and Ms Rush, you understood, did you not, that I was talking about substitute decision-making?

Mr SMITH: Yes.

Ms RUSH: Yes.

The Hon. TREVOR KHAN: Following up what I asked, in the circumstance where the issue of reproduction arises, and you say that is more appropriately a decision for the tribunal, do you initiate the application or do you leave it to somebody else?

Mr SMITH: It can be either. If someone approached us, a family member, and said they wanted to have their daughter's tubes tied in order to prevent pregnancy, we would either take the matter to the tribunal ourselves or we would encourage the family to take it to the tribunal.

The Hon. TREVOR KHAN: How is the decision as to either/or made?

Mr SMITH: It would depend on whether or not the family had indicated a willingness to take the matter to the tribunal. If they were of a mind not to then we would probably feel duty-bound to take it ourselves.

The Hon. TREVOR KHAN: Do I take it from your answer that there is a preference for the family to remain engaged and initiate the action themselves?

Mr SMITH: Absolutely.

The Hon. TREVOR KHAN: If it occurs that the family takes the application, what role do you or your office take in respect of any subsequent hearing?

Mr SMITH: We would probably be asked for a view by the Guardianship Tribunal and we would provide a view with respect to what we know about the person under guardianship, their capacity, whatever emergent risks appear to be present in their behaviour and exposure. We would provide that sort of evidence.

Ms RUSH: And attend the hearing so we can be available further questioning as well.

The Hon. MARIE FICARRA: Can we go back to some issues raised in your introductory remarks? In the submission you made to the inquiry you state that a range of less formal, less intrusive options than guardianship have not eventuated in New South Wales. Would you elucidate those options? Are those options available in other jurisdictions? If so, how would you recommend that we proceed? What would be the benefits of having those less intrusive options for guardianship?

Mr SMITH: The options I was referring to predominantly fall into the area of advocacy. The capacity to advocate on a person's behalf means that we could negotiate with service providers to build a body of support around a person without resorting to guardianship. The other options include bringing to bear alternative dispute resolution practices, particularly where families are in dispute about what should happen with the person who is the subject of the application and so forth. That is the sort of thing I am referring to. They are less intrusive to the extent that problems may be resolved without actually having to make a guardianship order.

Having said that, that already happens to some extent. In New South Wales not every application to the Guardianship Tribunal results in an order being made. The Guardianship Tribunal retains a capacity to advise people that there may be other alternatives that they could pursue. In other jurisdictions that is often backed up by the capacity to refer the circumstances of the person to the Public Advocate who can then advocate on that person's behalf in order to gain access to services and support.

The Hon. MARIE FICARRA: There are other States that have that ability?

Mr SMITH: Most of the other States.

The Hon. MARIE FICARRA: New South Wales does not?

Mr SMITH: No.

The Hon. MARIE FICARRA: Is this a historical sort of thing? Is it just an oversight? How has this happened? It seems so logical? Why do we not have that ability?

Mr SMITH: I do not know the answer to that question. I was going to say it was historical but Victoria introduced their guardianship legislation in 1986, the year before it was introduced in New South Wales, and yet Victoria has always had a Public Advocate; so do Western Australia, South Australia and Queensland. The Public Guardian in Tasmania also functions like a public advocate. I do not know the answer as to why it was never brought in here in New South Wales.

The Hon. MARIE FICARRA: But it is an area we should look at?

Mr SMITH: Absolutely.

The Hon. MARIE FICARRA: I now refer to community guardianship programs. In your submission you recommend the development of a community guardian program. Can you explain that program? How would it operate? What would be the advantages? How would you build up that resource?

Mr SMITH: Community guardian programs currently operate in Victoria, Western Australia and the Australian Capital Territory, and they are about to commence in South Australia. In New South Wales there are three ways that a guardian can eventuate. One is that the tribunal can appoint a person after hearing an application. They have a choice; they can either appoint a family member or close family friend as a person's guardian—they are what we call private guardians. A competent person can make provision for the future by appointing someone close to him or her as his or her enduring guardian. So that is something that a person will do himself or herself. The tribunal can appoint a private person or they can appoint the Public Guardian.

The model we are proposing follows the Victorian model, which is a model where the Public Guardian, when appointed, can delegate their guardianship functions to another person. So there are two models of community guardian that operate in Australia. The Western Australian model is one where the Public Advocate recommends a person to the Guardianship Tribunal and they make the appointment. In Victoria the Public Advocate delegates their functions under an instrument of delegation. We prefer that model for a couple of reasons. One is that it is a stronger model in terms of the checks and balances. Because the person who is delegated by the Public Guardian ostensibly acts on behalf of the Public Guardian, any decision they make is a decision of the Public Guardian and is therefore reviewable. A decision made by an enduring guardian in New South Wales or a private guardian is not reviewable.

The other thing is that the system of delegation allows us to recruit and screen people, whereas private guardians appointed by the Guardianship Tribunal are not screened. In constructing the proposed model in New South Wales we work very closely with the New South Wales Ombudsman because that office currently engages community visitors and has quite an extensive screening process to make sure that there are no problems with the people they are recruiting. We would build on that program in order to screen people. We would then recruit them in the normal way. We would advertise for people. We would train them. They would have the benefit of being supervised by experienced professional guardians, whereas with private guardians we do not have that capacity. We do provide a support service to private guardians but we cannot directly supervise them.

Under a delegated model, if there were any problems with any particular community guardian we could revoke their delegation and we could revoke their employment contract—with private guardians that cannot happen. Once they are appointed, the tribunal can revoke the order but it has to come back to the tribunal and they have to have another hearing and so forth, whereas we could do that instantly.

The Hon. MARIE FICARRA: This would seem to be a better model to move forward. How do we get that out to the community to realise that possibility? Would it need enabling legislation?

Mr SMITH: No, we already have a provision in the legislation to enable the Public Guardian to delegate to a prescribed person or to a prescribed class of persons. We refer in our submission to providing a regulation that prescribes community guardians. You could build guidelines into the regulation as to the sort of person that could be recruited as a community guardian but the way the models operate in the other jurisdictions is that they are predominantly professional people—psychologists, social workers, nurses and so forth—who are prepared to take on this role, in the same way that community visitors do. In New South Wales we propose we would pay them a fee in the same way that community visitors are paid a fee.

The preference over, say, the Western Australian model is that we have direct supervisory capacity over them. The way in which we get it out is to run a campaign. After that campaign we would go into a recruitment process. It was done quite successfully in Western Australia, which is the most recent one, although, as I said, South Australia is about to commence the same program.

The Hon. MARIE FICARRA: One would envisage that that would be a better way to manage a client's needs moving into the future. But how would you get greater community acceptance and adoption of this process?

Mr SMITH: I think we would get that through practice. At the moment the system is two-dimensional: it is either family members or a public official. Our argument is that the community can become engaged in this process. Through an education campaign we could promote community interest in the same way that the Ombudsman did when recruiting community visitors. It would be used in New South Wales for people only where we reappointed. We have a high rate of reappointment in New South Wales relative to Victoria, for example. That means that, at any given time, we will have about twice as many people under public guardianship as they do in Victoria.

The benefit of community guardians is as follows. For a person for whom we have an ongoing protective and monitoring responsibility, a community guardian is able to form a much closer and more intimate relationship with that person and get to know him or her. The community guardian is likely to be located in the same geographical area and literally would be able to visit the person more frequently, be more aware of his or her needs, and respond to those needs. The Public Guardian has three officers but we cannot cover the whole State all the time. As I said, it is a way of bringing the community into the role of guardianship in New South Wales.

Ms RUSH: It is not necessarily for complex matters either. I make that point clear as some people perceive it that way. It is for that reappointment, often for people who are in nursing homes, for whom we provide a fairly limited service. It is that kind of community engagement.

CHAIR: You might already have answered this question. What is the incentive to become a community guardian?

Mr SMITH: There are two incentives. Some of the programs in other jurisdictions operate on the basis of volunteers. There is the obvious incentive that people who have worked in the aged care or disability field want to continue to make a contribution in that area. They might be retired social workers, psychologists, occupational therapists, nurses and doctors and they want to continue to play a role to support people with disabilities or older people. The other incentive in New South Wales is that we would provide a fee. Some of the other jurisdictions have not been doing that, but some of them are looking at going down that path in the future.

CHAIR: And you provide training and supervision?

Ms RUSH: Ongoing training.

Mr SMITH: That is right. The delegated model enables those people, in a sense, to be part of the Public Guardian's resources; therefore, they benefit from all our training, technology, policies and procedures and, probably the biggest thing of all, our intensive supervision.

CHAIR: And the ability to accredit or to take away accreditation?

Mr SMITH: Yes.

CHAIR: I assume also that that training would be across the board, or only in certain areas of capacity. Are you talking about looking after all areas of a person's incapacity?

Mr SMITH: We would probably be likely to try to attract people with specialist skills in certain areas. Let us say, for example, that we might have under our guardianship 20 or 30 people in a large institution such as Stockland. If we were to bring community guardians in to support that group of people we would be looking for people with specialist skills in the area of disability, whereas if we were looking supporting an elderly client in a nursing home in Broken Hill we might be looking for someone who had a professional background in aged and dementia care. It would work along similar lines to citizen advocacy in the sense that we would be seeking to match community guardians with specific clients.

CHAIR: It would be more of an advocacy role?

Mr SMITH: They would have both an advocacy role and a decision-making role.

CHAIR: How do you envisage them relating to family interested persons?

Mr SMITH: In the same way that we maintain contact with families and engage families in the decision-making process the community guardians would do the same thing. Let us say, for example, that we have to make a decision about an elderly woman who has been living in the hostel part of a retirement village but her care needs have increased and she needs to go into the nursing home area. A community guardian faced with that sort of decision would engage the family in a conversation about it. The family might say, "We have been happy with this place, but if she has to go into a nursing home we would rather that it was a particular nursing home." That would become part of the decision-making process.

CHAIR: I imagine that, in many cases, the community guardian would be the person running the nursing home?

Mr SMITH: No.

Ms RUSH: No, it could not be.

Mr SMITH: That could not happen.

Ms RUSH: You could not have that kind of conflict of interest.

The Hon. GREG DONNELLY: Today you traversed a couple of examples dealing with the matter of providing life-sustaining treatment. You referred to one case that ended up in the Administrative Decisions Tribunal [ADT].

Mr SMITH: Yes.

The Hon. GREG DONNELLY: If I recall correctly what you said in that instance, the family took that matter before the Administrative Decisions Tribunal. I have not read its decision but I will reduce it to this: your submission states that you were acting in the best interests of the person that you were representing in recommending that he or she not be provided with ongoing life-sustaining treatment and that the family members were arguing the opposite. Essentially, are those the arguments that were contested in the Administrative Decisions Tribunal?

Mr SMITH: Yes.

The Hon. GREG DONNELLY: Let us spin that around and look at the other example that you have given today. I think you used as an example a person that you represented in the past—I do not know how long ago it was—who was incapacitated to some degree. I gather from your evidence that that person was also in need of life-sustaining treatment?

Mr SMITH: Yes.

The Hon. GREG DONNELLY: That was the opposite sort of argument, was it not? Because of what you had come to understand about the person's state, you said that it would not be wise—my words—to remove the life-sustaining treatment, notwithstanding the fact that some family members might take the view that that would be the compassionate thing to do in the circumstances. Is that a fair summary of that instance?

Mr SMITH: Yes.

The Hon. GREG DONNELLY: Do matters such as this come up very often where you are put in a position of having to make a call—if I can put it so crudely—about one or the other? Is that something that happens regularly?

Mr SMITH: Yes.

The Hon. GREG DONNELLY: In some instances you are arguing the case for the maintenance of the life-sustaining treatment and in other instances you are arguing for the opposite. What mechanism do you use to make that call? How do you make what is, in effect—and I do not want to be overdramatic about it—a life and death call about treatment for that person?

Mr SMITH: It turns on evidence and the law largely. It would be only in those circumstances where the evidence is that any further treatment is futile and where the balance of burdens and benefits in relation to that treatment favour the discontinuation of treatment. It requires extensive medical evidence and analysis of the medical evidence. Unless we can see very clearly and unless the medical evidence quite clearly indicates that the balance of burdens and benefits favour the discontinuation of treatment, then the presumption is in favour of continuing that treatment.

The Hon. GREG DONNELLY: Would you acknowledge that is a very prudential judgement, a very fine judgement?

Mr SMITH: It is a fine judgement. But, as I said, it turns on the predominance of the medical evidence largely. For example, in the second of the two cases that you mention we have had no less than six medical opinions on that plus ethics opinions. There are a lot of professional assessments and opinions that we have to weigh up before we would arrive at that decision.

The Hon. GREG DONNELLY: If I understand your evidence correctly, you have just taken us through detailed considerations that you would reflect on and you take expert medical evidence to come to that decision. Can you explain how you take all that complexity and reduce it to the phrase "in the patient's best interests"? Further, with some precision, would you explain what that means? At page 20 of your submission you advocate what seems to be a significant change to what operates at the moment in New South Wales. Specifically I make reference to your proposed amendment to section 32 (b) of the Guardianship Act, which relates to the underpinning objects:

> The objects of this part of the Act are
>
> (b) to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and maintaining their health and wellbeing.

That is the position that currently operates, which, it seems to me, is underpinned by a medical principle of "do no harm". That is the way I would characterise it, in broad terms. However, if I understand your submission, you advocate something quite different. At the bottom of your second paragraph you want to replace section 32 (b) with a provision that would read, "for the purpose of ensuring the best interests of the person."

Mr SMITH: Yes.

The Hon. GREG DONNELLY: Given the complexity of making a significant decision of discerning what is in a person's best interests, how in black letter law do you define "best interests"?

Mr SMITH: "Best interests" has been defined by the courts in a variety of different ways. But, generally speaking, it combines elements of what I have articulated. That is to say, it combines elements of what I referred to as the person's critical interests. "Critical interests" is a term that is used to describe the person's stated wishes, desires, values and beliefs. All those things need to be considered.

The Hon. TREVOR KHAN: Would you repeat that set of criteria?

Mr SMITH: "Critical interests" refers to a person's stated wishes, desires, values and beliefs. In addition, "best interests" would encompass issues of whether or not medical treatment is considered to be futile. That is to say, no therapeutic benefit could be obtained from continuing this treatment. The third element—

The Hon. GREG DONNELLY: Do you define "futile" as being different from "burdensome"?

Mr SMITH: I was just about to move on to the issue of "burdensome". The third element would be where the burdens on the person generated by the treatment outstrip the benefits. For example, some treatments that are designed to prolong life or maintain the life of the person might include things like artificial nutrition and hydration, tracheostomy and artificial respiration. Even things such as dialysis can be considered a life-sustaining treatment. But in some cases these treatments actually generate more burdens than the benefits that are obtained.

The Hon. GREG DONNELLY: Would you consider that artificial hydration creates burdens?

Mr SMITH: It can do. Artificial nutrition and hydration, sticking a peg tube into someone and feeding them artificially is not without its problems. It can lead to frequent occurrences of aspiration pneumonia, which then requires further treatment and can generate this cycle. So it can be burdensome, but with no clear benefit to the patient looking into the future. It is those three elements, for the most part, that would constitute "best interests". The problem with the wording of the legislation at the moment, which is "promotes and maintains health and wellbeing", is that until recently it was interpreted by the Administrative Decisions Tribunal to mean that you cannot stop treatment. They could not see how you could withdraw life-sustaining treatment, which would ultimately lead to the person's death, and for that to be consistent with "promotes and maintains health and wellbeing". Therein lies the problem with that wording. That wording in New South Wales legislation is not repeated in other legislation around Australia. Other legislation and the common law uses the term "best interests" because there are circumstances where it is in the best interests of the person not to continue to burdensome treatment.

CHAIR: I am mindful of the time. We are now 12 minutes over time. Thank you very much for your attendance. We may need to call upon you again, at your convenience. We probably will have questions on notice that we will send to you in the next 2 to 3 days and ask you to respond within 21 days.

(**The witnesses withdrew**)

TERRENCE ROSS CARNEY, Professor of Law, Sydney Law School, University of Sydney, Eastern Avenue, Camperdown, affirmed and examined:

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

Professor CARNEY: I am a law professor, specialising in welfare law, which includes health and income security and those sorts of areas. I was a member of the Cox Committee in 1980 to 1982 in Victoria that invented guardianship Acts. The Victorian Act largely was copied here in New South Wales.

CHAIR: Would you care to make an opening statement?

Professor CARNEY: I am happy to take the questions, which I have here somewhere, the two sets. I did not have the time to write a submission. I am very happy to address the questions you have kindly forwarded to me or anything else for that matter.

Dr JOHN KAYE: Professor, welcome to the Committee. I direct your attention to the estimated 1.13 million people who will be affected by some form of dementia by 2050. In substitute decision making for this group of people, what sorts of provisions should we be making now in New South Wales to accommodate the increased needs of those people?

Professor CARNEY: It is a very interesting question. Indeed, it was one we discussed at the very first meeting of the Victorian Law Reform Commission in its two-year reference on this whole area. From the research we undertook back in the early 1990s—it is in the Federation Press book, *The Adult Guardianship Experiment*—I am not sure that a large proportion of that trebling or so of the numbers of dementia patients is going to feed through into the added workload of the Guardianship Tribunal. The reason for that is that our research demonstrated—and this is quite contrary to what the world expected; the world expected that guardianship legislation was going to cater mainly for people with intellectual disabilities—that, number one, almost exclusively the customers are the frail aged, that is, people in their late seventies/early eighties and, number two, people who are no longer able to live in the community. With the change in policy towards the care of people with dementia, that is, community-based care and family support, there will be some increase so far as the Guardianship Tribunal case load is concerned, but I do not think it will be as dramatic as people are forecasting. That is one part of the answer.

The second part of the answer is that the primary emphasis anyway is on mechanisms we have, enduring powers, and mechanisms that we should have in this State, advanced directives. Although advanced directives effectively are recognised by the common law, there should be a greater capacity in respect of advanced directives for people to be encouraged to write down in thin and thick form, short and long forms, what their views are about issues that might arise. That, coupled with the ability to delegate in advance by nominating your preferred holder of enduring powers, I think will be the area where the bulk of the attention needs to be directed. Finally, of course the United Nations Convention on the Rights of Persons with Disabilities, in article 12 (4)—I know this refers to one of the later questions—somewhat ambiguously but certainly to some degree emphasises supported decision making. It will be what I call private planning, those instruments—advanced directives, enduring powers and so on—rather than what I call the default public planning guardianship area that will be the primary focus. In respect of primary planning, one needs to work through to what extent supported decision making and other principles like that need to be drafted into the current arrangement.

Dr JOHN KAYE: Are you saying that of those 1.13 million people the overwhelming majority will have made arrangements that will not require them to be involved in some kind of public guardianship arrangement?

Professor CARNEY: Yes. They will have made those arrangements, though the maximum take-up rate seems to be about one in five. What happens to the other four out of five? The principle of guardianship legislation and, indeed, all the common law has been that where people are muddling through adequately and there are no serious problems arising in an informal arrangement that may have no legal basis at all, then there is no basis for the public guardianship machinery being invoked. Indeed, some jurisdictions—the very good table in the Queensland Law Reform Commission Report discussion paper in December last year, of which I have a copy—are now writing in that principle. One of the principles is that there should be minimal interference with informal arrangements that are working adequately.

Dr JOHN KAYE: Are you satisfied that those informal arrangements will protect the large number of people who are going to not have formal arrangements and who will be suffering from dementia by 2050?

Professor CARNEY: No. I am not satisfied that they are capable alone of protecting, but I do not see a significant—as I have indicated—added responsibility falling on the public guardianship mechanisms as they are currently constituted to provide the answer. Instead, what New South Wales suffers from most of all, more so than not having advanced directive provisions, is that it does not have a proper Public Guardian. In Victoria, South Australia and there is one other, do not quote me, it might be Western Australia, a proper public guardian as I describe it is a specialist ombudsman who has the ability to deal with any grievances and so on that are drawn to their attention, but also has the responsibility to be proactive in seeing how the welfare of the group for whom they are responsible is being advanced or not. They have a systemic advocacy role as well as an individual complaints-handling role. The problem with the New South Wales legislation is that the guardian only has responsibility for those who are the subject of an order from the Guardianship Tribunal. In Victoria, by contrast, the responsibility of the Office of Public Guardian is for all people who fit into the categories of vulnerability who are covered by guardianship.

Dr JOHN KAYE: Are you advocating as part of the mechanism for dealing with that projected 1.13 million people to give the existing Public Guardian responsibility to go beyond just those who are in a formal guardianship relationship?

Professor CARNEY: Yes.

Dr JOHN KAYE: To start advocating and intervening, or just advocating on behalf of the four out of five who do not have formal arrangements?

Professor CARNEY: To be able to do a wide variety of things from intervening of their own volition—that is a power in the Victorian legislation, which has been there from the beginning—the power to make representations to Ministers.

Dr JOHN KAYE: That intervening power is not in the New South Wales legislation?

Professor CARNEY: Not in relation to somebody who is not currently under an order. They would have also the power to make representations to government departments, non-government agencies, and to make media statements. It is an independent kind of ombudsman-like set of powers that the Victorian office is clothed with.

Dr JOHN KAYE: Do you see a conflict of interest between, on the one hand, being a traditional guardian, as in the New South Wales sense, responsible for those who are in a guardian relationship, and at the same time being a public advocate, part of the public debate as it were, on the issue of guardianship?

Professor CARNEY: There is that conflict of interest and it has been much debated, when the model was put forward back in 1982 and since. It is not by any means the only model. It is important to be a public advocate, but that person with those roles could be called a vulnerable person's health commissioner, on the New Zealand model. There are all kinds of other names that you could give to the institution, and in an ideal world you would try to avoid having a conflict of interest, of being also the default guardian and being responsible in some way for monitoring the adequacy or not of the way in which the default guardianship responsibilities are discharged. In the original design it was intended that—I was listening to the previous evidence—the default guardian would, wherever possible, deal themselves out of that responsibility in the shortest possible time.

Indeed, that is the genesis in Victoria of the community guardian. The idea was that sometimes you become the default guardian because while there are family, say, living overseas or they need some education support before they are prepared to take on the role or if, of course, as we have discovered with the frail-aged, by the time the orders are in place and a default guardian is needed very often any friends and relatives that you had are either dead or they are incapacitated and unable to serve. So the idea was that the conflict of interest would be only in respect of a small number of people.

The Hon. MICHAEL VEITCH: In a couple of the other submissions that we received—I am not sure whether you have had time to read through them?

Professor CARNEY: No I have not. A couple of them are referred to in the notes that were sent to me.

The Hon. MICHAEL VEITCH: In a couple of the submissions there are comments around procedural fairness and I think one of them actually says there is no reason why procedural fairness should not apply in respect of all aspects of the work of the Guardianship Tribunal. Could I garner your views on that statement?

Professor CARNEY: There is a basic procedural fairness obligation that is there whatever the legislation decides to write in. But, no, I think the informality and direction that exempt the tribunal from the strictures of rules of evidence, number one, and of the lawyer's gains, if I can put it that way, that can often be played under the guise of according procedural fairness, should not be permitted to have full rein. Maybe there is some compromise between saying that none of those rules apply, but certainly they should not apply, in my view, in their full lawyer-like traditional fashion.

The Hon. MICHAEL VEITCH: There are also some submissions that made comment around the person responsible provisions. Could you talk us through what you would see as some of the advantages of having more than one person qualify equally as a person responsible?

Professor CARNEY: I saw that in the question. I always stand corrected—we academics are into debate about points of view—but I thought the question was misconstrued. It is a hierarchy, and the Administrative Decisions Tribunal and the courts have made it clear that it is a hierarchy. I think subsection (5) of the relevant section indicates that, in the event of incapacity on the part of a person higher up in the list, the bases on which you can move further down the list. One of them is that a medical practitioner determines that the person higher up is incapable of adequately exercising a function.

If there is the possibility it is simultaneous, and I do not think there is, but the advantage of having that, or certainly the list, is that it provides a reasonable supply of potential decision-making. It is kind of the equivalent of the parliamentary will: that for the four out of five who have made no provision—or more at the moment—the Parliament is saying people who need to obtain authority to make decisions can quickly obtain it from this rough and ready list of people that broadly accords with community values and assumptions: it is the people closest to you first. In the same way that if I die without leaving a will the Parliament makes one for me in that rough and ready way of saying, "These are the people that you would have contemplated giving what little worth you had to, had you turned your mind to it".

The Hon. MICHAEL VEITCH: You mentioned the word "need", and one of the submissions goes on in depth about the legal interpretation of the word "need". Do you have any comments about whether the legislation, as it currently stands, adequately addresses the legal concerns of the word "need", or does it need refining?

Professor CARNEY: It needs refining is the short answer. In what way should the concepts be recast? I cannot give you chapter and verse on that, and I do not think anybody else in the country can either, but the underlying essence in thinking about answering that question is that guardianship legislation was designed to deal with functional need or incapacity and so the language in that section and any other section needs to be tested with any alternative wordings that people have against that criterion of whether this best encapsulates the proposition that intervention should occur if, and only if, at a functional level the person needs assistance or needs an alternative decision maker. "Need" was as good a word way back in the eighties as we could come up with.

The Hon. MICHAEL VEITCH: Mr Smith, the NSW Public Guardian spoke about the issues of definition, and particularly intellectual or mental impairment and cognitive impairment and how across agencies in New South Wales and even in the Federal jurisdiction there is a range of definitions and usages that make his job very difficult.

Professor CARNEY: It does, and there was a trade-off in the original design. We examined way back in the early eighties two models, and the purer, and I think preferred, model was functional need and functional need alone. Others in the administration in various departments, in the courts and so on, said that that was not going to be a robust enough way of setting the boundary line where it needs to be set, and we have had this long experience in legislation of setting the boundary line by reference to presence or absence of particular disabilities. In Victoria "senility" for about 50 years was the term used, and it was by far the largest, most predominant ground for what was an administrative decision by bureaucrats essentially to place people under control. Some of us, myself included, always had reservations about including the definition of "disability" because how long is a piece of string? I think the better definitions you tend to find now are in the Commonwealth legislation—social security, in those sorts of settings.

The Hon. MARIE FICARRA: Just taking you to the questions that you have already seen. In the tribunal processes section 14, part 2, of the Guardianship Act lists the factors that the Guardianship Tribunal has to take into account when they are deciding whether a person is in need of a guardian. Do you feel that these factors give enough assistance to the tribunal in reaching this decision? Are there any weaknesses there that you can see?

Professor CARNEY: It is a short list. In New South Wales it is the core, I guess. The comparative table runs over two pages in the Queensland report. I did not tally them up but I think there are about 20 in total, of which in 14 (2) there are just four. It is certainly fair to say that they are the most important of the four, but they reflect a rather paternalistic and older-fashioned view of the role of guardianship. Certainly they were not so old fashioned that they took the view that there should be plenary guardianship automatically and that it should not be reviewed.

There were significant changes made, but the idea of supported decision making, for instance, or the idea of co-decision making, just were not part of the agenda when the legislation was being framed and the principles to govern particular parts of the legislation were put together. When you look at the list in some other jurisdictions that have introduced legislation more recently, you find that supported decision making, minimal interruption with informal arrangements and principles of that kind, have been added. While I would not want to see a list of 20, yes I do think that it is time to revisit the quartet that appear in section 14 (2).

The Hon. MARIE FICARRA: Turning to section 25G on the list of factors for making a financial management order, do you have any comments on the adequacy of that?

Professor CARNEY: The first two are functional. It is the incapacity and secondly the need for somebody to manage—the matter that we were discussing in a way a short while ago. The third one in my opinion should not be there. I am not only not a fan, I think it is a nonsense proposition, "best interests". Best interest of the adult, best interests of the child is, as a famous now Secretary of State said, an empty vessel into which adult prejudices and perceptions are poured. What did Hillary Rodham Clinton mean by that? She meant that it is a conclusion-ary, debate-ending pronouncement. It does not indicate what factors, what reasoning process, one should enter into.

One answer to that is that in some jurisdictions the legislation says "best interests" and then goes on to list some of the factors, such as taking previous evidence, some of the matters canvassed in that medical decision making, and an end-of-life type of context could be written in. But the problem with the "best interests" is also of course that it is paternalism writ large. In constructing legislation, but this legislation in particular, the main tension is between autonomy of the individual and somebody else's view of what is best for Terry Carney. "Best interests" is squarely at the far paternalistic end. It has that old-fashioned ring to it, apart from being an unhelpful criterion.

The Hon. MARIE FICARRA: This Committee has also been asked to consider whether the New South Wales Trustee and Guardianship Act, which recently has been amended, should be amended to allow the relevant court or tribunal to exclude parts of an estate from a financial management order. How do you view such a proposed amendment?

Professor CARNEY: The short answer is "yes". The least restrictive alternative principle and others of that character come from international declarations that are now enshrined in the Convention on the Rights of Persons with Disabilities. It was a big change between the post-1980s and the pre-1980 several centuries, and that was being moved from plenary to partial guardianship. That happened in relation to personal guardianship where the tribunal must turn its mind to what aspects or kind of old-fashioned parental care of the child are going to be given to the person who is the guardian of an adult.

In theory in a number of the other States, a similar process ought to have occurred also with the State administration, but in practice it did not. In this State there are some legal barriers to what is taking place. So certainly I would 100 per cent support the amendment proposed. In fact, the only other observation I would make is that the amendment on its own is not going to bring about the desired result, which is to encourage as far as possible that people have some pocket money—something that they have a discretion to spend as unwisely as you and I unwisely spend our money, or as immorally as you and I spend our money today, pre loss of competence. In putting recommendations together, it would be important to emphasise the need for administrative training and other smart ideas to help reinforce that principle of the dignity of risk which, together with the least restrictive alternative, are the two important things.

The Hon. MARIE FICARRA: Can I also have your view on another amendment to the Act that the Committee has been asked to consider. Should it be amended to allow the Supreme Court or the Mental Health Review Tribunal to vary or revoke an order, even when the person remains incapable of managing their own affairs, on the application of a person who, in the opinion of the court or the Mental Health Review Tribunal, has a genuine concern for the welfare of that protected person? How do you view that proposed amendment?

Professor CARNEY: Yes, I also support that, but I would take it further. There are a couple of other observations about it. I think there is a serious case for saying that if it is possible to reopen and review orders of a public official, one should be seriously asking why it is that a guardian or administrator appointed under an enduring power is not equally able to have the exercise of their powers taken before the Administrative Decisions Tribunal [ADT]. If it is good enough for the public guardian, for political and other reasons—the relatives might bat many eyelids at that—in principle it ought to extend more broadly.

The second observation is that providing this power and, subject to the provision that the tribunal can refuse leave or can terminate the process peremptorily if they think that the person is just a busybody, providing wide standing for anybody else—such as a close relative, a neighbour who is noticed something to be able to apply for a variation that they think is needed—is the way in which you keep this legislation in tune with its underlying principles of, as far as possible, reflecting the wishes and values of the person, of least restrictive orders, and of adapting to the changes and fluctuations that happen in our ability to manage.

Ability to manage in medical literature is much less about some measurements of my intellectual processes and much more about whether I continue to reside in the place and in the environment that I am used to. Somebody with competence in a familiar environment often becomes quite incompetent when moved, without any change in their intellectual capacity, to a different kind of environment. Of course, changes in housing and social circumstances happen all the time, so that is why one needs that responsive mechanism.

My final point on this is that we are in print in last year's New South Wales *Law Journal* saying that there were two things wrong with the Protected Estates Act. The first one has been fixed in the Trustee and Guardian Act, which was that somebody with a mental illness used to be presumed, if detained, to be incapable of managing their property. The tribunal under the Protected Estates Act used to have to satisfy itself that that was not the case. That has been switched around. That was the first criticism we had about legislation from 1983. The second was that we do not believe it is a good idea to give the Mental Health Review Tribunal a job in which it does not have any great expertise. The expert on determining functional need for management of person or property is the Guardianship Tribunal. In all the other States, that is the way somebody with a mental illness has the question answered as to whether their property needs to be managed.

It is true that in South Australia they co-house the two separate tribunals in the same building. When we notice something about somebody who is severely mentally ill sufficiently that we are going detain them in a residential facility, should we not have a quick way of ensuring that their property is not at risk? Yes, but that does not mean that you should give the power to make that decision to the Mental Health Tribunal. Our view in the article that we wrote is that that should go to the expert—the Guardianship Tribunal.

The Hon. GREG DONNELLY: Thank you for appearing today and for providing extra testimony. I want to pick up on a couple of things you raised. You spoke about the Victorian model of which you have some real knowledge and the guardianship role, which is far broader than that provided for in respect of an advocacy role and deals with individuals who are specifically brought under the guardian, as happens in New South Wales via the tribunal. Is it your testimony that we should be looking at that model as we go forward?

Professor CARNEY: Yes. In practice the Guardianship Tribunal and the people appointed as guardians do a good job—about as good a job or better than is done in Victoria. But they are doing without the same degree of legislative guidance. For example, to encourage a substitute decision-maker to make not only formal decisions but also to be my personal advocate, it would be worth considering writing into section 14(2) that advocacy role and criterion when picking between potential guardians or administrators.

There are some things that can be done with the guardianship legislation and with legislation dealing with enduring powers of attorney, which tend to be very arid and bare and lacking in similar matching principles. If you were asking for one recommendation, the most important one for New South Wales would be to change the public guardian into an office of public advocate in the way I described. It is an alternative preventative measure. We were intrigued when we did the work for our book. We looked closely at the situations in New South Wales and Victoria. I heard the evidence that then and still New South Wales makes a much higher proportion of orders for administration of property than occurs per head of population in Victoria.

Why? Our book concluded that New South Wales lacked two agencies. One was the public advocate and the other was the disability review panel, which Victoria revamped in 2006 into a series of commissioners and other chief medical officers for people with intellectual and other disabilities. You can read about it on the website. We tended to find that in Victoria people say, "This person needs something done." In New South Wales at the moment, unless it goes to the Guardianship Tribunal, it does not get done. In Victoria, those cases often did not get to an application for an order in the first place because the Office of Public Guardian took a different route.

The Victorian Office of Public Guardian was headed up initially by Ben Bodner, who was a social worker and head of the equivalent of the Department of Community Services. He introduced a welfare-type mobilisation of informal community and family networks. It was a knitting together of the informal and formal services that might be needed for a person to supplement their situation such that you do not need to make these orders. That is why the Office of Public Guardian is so important.

The Hon. GREG DONNELLY: I refer to the matter of best interest. I share some concern about the fluidity or malleability of the definition of that term. You said that there is a continuum from recognising and respecting individual choice through to what can be seen as overt paternalism. That is a good way of describing it. Given the innate difficulty in defining it, how do you make some progress in providing certainty? You use the example of how you could within the definition list some examples or indices that might lead one to conclude certain things about best interests. Is there any way to define it with some certainty?

Professor CARNEY: There are some models. They started a long time ago in relation to best interests of the child and they have been adapted to adults. They are less than perfect, but at least they provide some guidance as to the kind of factors that the decision-makers should consider. The factors tend to be similar to the kinds of things you find on the list of principles that are written into other legislation—issues we have been discussing like not disturbing informal arrangements unnecessarily and paying regard to the wishes, values and lifestyle of the person as far as it is known. When you look at the table, you see that apart from Queensland, which has deleted it altogether, the solution that most other States have come up with is not to seek to define best interests but to add to the counterweights of other factors that are to be taken into account. Instead of looking at best interests in terms of section 25G together with functional ability being the two issues alone, you throw more of these other factors into the ring as principles to which the decision-maker pays regard.

The Hon. GREG DONNELLY: Are there any overseas jurisdictions that have legislation in this area that you are familiar with that you could recommend we should become familiar with?

Professor CARNEY: The one I think you should have the closest look at is Alberta's Adult Guardianship and Trusteeship Act 2008. It comes into operation in a couple of weeks. Why Alberta? First, Alberta's Dependent Adults Act 1978 was in some significant way part of the model for the Victorian and New South Wales guardianship legislation. Alberta has always been at the forefront of thinking about these questions.

A very extensive review was recently undertaken by Cindy Ady. There is information on the web about it. She undertook a great deal of consultation. She was a senior parliamentarian of cabinet rank but not in cabinet. Over about two years she and her departmental advisers consulted about what changes needed to be made in all the areas we have been discussing, from advanced directives to enduring powers and so on. I think they have done a pretty good job of grafting in supported decision-making, which is found in section 4 of their Act, and co-decision-making, to which I made reference in section 13. They are among many other ideas worth looking at closely.

CHAIR: If I understood him correctly, the New South Wales Public Guardian, Graeme Smith, indicated earlier today that he thought the advocacy role of the Public Guardian should be under the Attorney General's area and not under disability. I got the impression that you were indicating the opposite. Am I misunderstanding?

Professor CARNEY: No. Portfolio responsibility is important but advocacy, like any of the solutions to the kinds of social needs that give rise to consideration of these orders, is a question of resources. In some ways it is an important but slightly arid debate that we lawyers have all the time. Why do we prefer the Attorney General's Department? Because it is the most independent of the departments and is therefore likely to be best able to reflect, through whatever program and administration it is auspicing, to realise the values, wishes and advocate for the needs of the individual. That is the theory.

CHAIR: It is not because you are a lawyer.

Professor CARNEY: Yes, I do. I am sceptical of that argument. I think it is a minor consideration. The real issue is which administrative structure will deliver the largest resourcing, the highest fees, for the community guardian, the best and most committed number of public servants prepared to seriously go out and try to recruit them. With all respect, I do not think that is the Attorney General's Department. A good indication, in putting together the trustee and guardian legislation, although they adopted arguments, they did not do enough research to have a look at the New South Wales law journal to see an analysis, for better or worse, of the issue we were discussing in relation to the mentally ill.

This is not the first occasion when I have been concerned about the quality of advice or commitment or understanding that exists within the Attorney General's Department. I thought they produced a very silly paper about three years ago on the need for some kind of medical assessment of competence across every sphere of activity. It was worth looking at but their paper was a particularly poor one. So, no, I would not—I support some degree of independence, obviously, but the key issue is getting the job of work done and getting it done best.

CHAIR: What is the situation in Alberta?

Professor CARNEY: Alberta is extraordinarily rich with oil, and a conservative government there holds all but two, usually, of all the seats in Parliament. It is very much the American approach to governance: You have none of it if you can avoid it. They are interesting because of the way in which they seek to provide answers to these issues by cultivating and supporting civil society, and that is often neglected in the models that we construct. The idea of assisted decision making was first endorsed in Queensland in 1996. It has taken another 10 years before there has been any serious—at the time it was a government that made that decision because it just did not want a public sector answer to the question or significant financing of it. People were rightly critical of it at the time but it seeded the development of an important partnership that has now flourished between the government agencies on one hand and the community sector or informal civil society ones on the other.

(The witness withdrew)

(Luncheon adjournment)

SUSAN MARGARET FIELD, New South Wales Trustee and Guardian Fellow in Elder Law, University of Western Sydney, 330/243 Pyrmont Street, Pyrmont, sworn and examined:

Ms FIELD: I have been asked by Alzheimer's Australia, New South Wales, if I could appear on their behalf in respect of their submissions. I have explained to Jonathan just prior to this that I have only had a brief conversation with Lisa Langley, the policy officer from Alzheimer's, this morning about the additional questions. So some I may ask to take on notice.

CHAIR: Similarly, we are not in a position to be asking all questions about Alzheimer's New South Wales, so we might be giving you those on notice. Would you like to start with some opening comments before we go to questions?

Ms FIELD: First of all, I commend the Committee for holding this inquiry. My position in Elder Law is a unique one, not only in Australia but also internationally, because the whole issue of ageing is certainly on many governments' agendas these days. Associated with ageing but not necessarily mutually exclusive is the fact of dementia and people lacking capacity to make decisions, either on their own or, in some cases, with assistance. So, I have great pleasure in being here this afternoon.

The Hon. MARIE FICARRA: Starting on that very important issue of dementia and Alzheimer's, we hear that every 20 years we are going to have a doubling of people diagnosed with Alzheimer's and/or dementia. What provisions, if any, do you believe, New South Wales should be making to meet this likely increase in demand for substitute decision-making amongst this group of people?

Ms FIELD: Because, as you have quite rightly said, of the increasing numbers of people going to suffer some form of dementia, I think first and foremost there needs to be a standard definition of what we mean by mental capacity. New South Wales does not have one single definition. There are a number of varying definitions. For example, the Guardianship Act talks about a person in need of a guardian. Other legislation refers to someone requiring assistance. Because I was in Queensland for a number of years, I would have to say in Queensland under the Guardianship and Administration Act there is a definition of capacity. That is, that someone can understand the nature and effect of a transaction and communicate their response in some way. So, as a starting point, we believe there should be a definition of capacity.

I also believe, and the submissions is there, that there needs to be greater education, not only of professionals—and by professionals I mean medical professionals, lawyers and financial industry people—about the issues surrounding mental capacity or the lack thereof, and substitute decision-making. Of course, in the wider community there needs to be a concerted education campaign, because many people in the community, when they hear the word dementia, immediately assume that someone lacks capacity, that it is a global issue, whereas capacity is decision specific, and that point is not out there. When it comes to substitute decision-making instruments, that people, all of us, be encouraged to plan ahead and look at instruments such as enduring powers of attorney, enduring guardianship and advanced care directives.

The Hon. MARIE FICARRA: Do you think it is an area the public fears in terms of letting their control slip away from them? At point of diagnosis some people can be slipping into dementia over many years, or it could happen very suddenly. How is it picked up?

Ms FIELD: As to how it is picked up, quite often it may be there is a trigger to alert someone—who is on the lookout for it, of course—that the person's mental capacity is not what it once was. In that case we are talking about a gradual onset. Once again, it is an education process. Yes, I agree with you, many people, if we leave our planning ahead until later, panic at the thought that they will lose all control. It is a bit like a will, I suppose. Many people think you do not make a will, or, if you do, you bring bad luck upon yourself; whereas, if we are all educated we should be taking control of our own affairs by appointing someone of our own choice.

The Hon. MARIE FICARRA: You are talking about the definition of capacity as in the Queensland jurisdiction. This morning we heard evidence that the Victorian model is a very good model. Do you have any opinion on the desirability of changing the role or the direction of the Public Guardian into an office of Public Advocate, similar to the Victorian model, which is a more proactive type of assistance provided to clients—this idea of having a Public Advocate rather than the old traditional viewpoint of Public Guardian? Do you have any views on that at all?

Ms FIELD: The terminology does vary from State government jurisdiction to jurisdiction. I am familiar with the Victorian model. The term "public advocate" in Queensland means someone looking at the systemic issue because in Queensland they have an adult guardian who has far more powers and responsibilities, in some way, than what the Public Guardian would have here. I would certainly see room for expansion of the role of the Public Guardian to have a more proactive position. Whether it is then taken to encompass systemic issues in the institution as well as individuals, or whether there should be a split in the positions, I have not got an opinion.

The Hon. MARIE FICARRA: The Public Guardian has recommended that section 21A of the Guardianship Act 1987 allowing the Public Guardian to authorise members of the NSW Police Force to move a person under a Guardianship Order from one place of residence to another be amended to specify that police may use all reasonable force. Do you have an opinion on that proposal?

Ms FIELD: I discussed that with Alzheimer's this morning and they were of the view that as long as there were checks and balances and that it was in the best interests of the person, and probably the least restrictive means of physically assisting that person by the NSW Police Force.

The Hon. MARIE FICARRA: The guardian has recommended that the Guardianship Act be amended to allow the guardian to proactively investigate matters where it becomes aware a vulnerable person may be in need of a guardian. Will you comment on that?

Ms FIELD: We thought that was an excellent idea.

The Hon. MARIE FICARRA: What is your view of a recommendation for amendment to the Guardianship Act to allow the Public Guardian to assist people with decision-making disabilities without the need for a Guardianship Order?

Ms FIELD: We felt that considering it was decision-specific that each case was taken on its merits, yes, that would be a very good amendment.

The Hon. MICHAEL VEITCH: This morning Mr Smith, the New South Wales Public Guardian, said there were issues around the inconsistency of the definitions that are used for intellectual disability and mental or cognitive impairment by various agencies in New South Wales, as well the definitions between the various State jurisdictions and the Commonwealth. Do you have a view about how that could be tidied up? Do you think it impacts on the functions of the guardian?

Ms FIELD: Yes, I believe it impacts on the functions of the guardian. If I may point out that we were slightly confused by this committee's terms of reference. Subsection (1) refers to the management of estates of people incapable of managing their affairs and (2) refers to the guardianship of people who have disabilities. It could have been interpreted that in relation to people who lack capacity you are talking about financial affairs. It was unclear with disabilities whether you meant physical and mental disabilities. It was almost as if, reading these terms of reference, that guardianship just applied to people with disabilities but financial management applied to people who lacked capacity or who were incapable. There is confusion within every jurisdiction and, of course, we live in a federal nation so that exacerbates the problem.

Because of each State and each State within its various jurisdictions having differing views, it goes back to what I said, I think: there needs to be a standardised definition of what is meant by "mental capacity". The Attorney General's capacity toolkit, which was launched in March 2008, basically suggests that capacity is understanding the nature and the effect of a transaction. Therefore, when you look at capacity like that you have to take into consideration it is not a global concept. Many people, as I said at the outset, think you have either got it or you have not got it, and that is not the case at all. If it is an age-related dementia there is a continuum on which the person travels, but each individual decision needs to be looked at.

The Hon. MICHAEL VEITCH: In the submission of Alzheimer's item four on the last page refers to the recognition of the need for a standardised assessment tool.

Ms FIELD: Oh yes. There are many assessment tools that are used, some with greater skill than others and some perhaps with greater accuracy than others. I think looking at any assessment tool we also have to look at not only the veracity of the tool but also the skills of the person administering that tool. Guidelines quite often provide a better way to assist people to assess someone's capacity but guidelines, of course, probably take a bit longer to follow and do not give you necessarily a definitive score which some people would prefer to hang their hat on.

The Hon. MICHAEL VEITCH: The submission of the Law Society and a couple of others state there is no reason why procedural fairness should not apply in respect of all aspects of the work of a Guardianship Tribunal. I asked Professor Carney this question and he has a clear view of it, but what is your view about that statement?

Ms FIELD: I do not have the views of Alzheimer's on that so may I take that on notice?

The Hon. MICHAEL VEITCH: Yes. The Public Guardian recommended that consideration be given to expanding the legal authority of a person responsible for another person under the Guardianship Act 1987 but, in addition to making decisions regarding medical care, the person responsible could also make decisions relating to accessing services or deciding where to live. Will you comment on that proposal?

Ms FIELD: Yes, we have discussed that. In that case, yes, it should be expanded to look at where someone lives. It is very difficult when you are considering enduring guardianship would give a person that responsibility whereas the person responsible as it stands can look at the medical and health decisions. I would certainly see that expanded to encompass living arrangements as well.

The Hon. MICHAEL VEITCH: Do you think that persons responsible under the Act should be able to authorise withdrawal of life-sustaining medical treatment?

Ms FIELD: That was one we did want to take on notice.

The Hon. MICHAEL VEITCH: I dare say then you would also want to take on notice where the decision to withdraw life sustaining medical treatment should reside?

Ms FIELD: I will take that question on notice also.

The Hon. GREG DONNELLY: The Hon. Michael Veitch has asked some of my questions but I will read your responses to the questions taken on notice with interest. Thank you for coming along today and providing additional material for the inquiry. My first question relates to an element of the Alzheimer's Australia's submission and if you do not feel competent to respond to it, feel free to take it on notice and pass it on to the organisation. It relates to point 3 on the final page of their submission—the need to clarify informal decision-making processes. At the bottom it states:

> Alzheimer's Australia supports the need to investigate the mechanisms that will provide safeguards around informal decisions made on behalf on people whose capacity is limited.

Are you able to elaborate on what they are actually getting at there, or will you need to take that question on notice?

Ms FIELD: I think I know what it is but because we did not discuss that specifically—most of us have a standard view that—I would prefer to take it on notice and ask them to respond.

The Hon. GREG DONNELLY: That is fine.

CHAIR: What did you discuss?

Ms FIELD: We went through that. I looked at their submission the other night when they sent it to me and, to be honest, I did not pick up on that because I just thought, "Oh, that is the usual". The things that we discussed, we went through the extra questions that Jonathan sent through, possible questions for me and possible questions for all witnesses.

The Hon. GREG DONNELLY: Can I ask you to comment in light of your experience and position on point 3, which states:

> Often older people are pressured into handing over their decision-making power to a substitute decision-maker well before they have lost their full capacity to do so. In some cases family members may assume that once a diagnosis of dementia has been

> made the person no longer has the ability to make decisions for them and decision-making powers are swiftly transferred, leaving the person with dementia feeling powerless and frustrated.

That is obviously said in terms of their submission. Can you reflect on your experience and knowledge in this area and would you care to comment about whether you think that is accurate or whether you have observed something different?

Ms FIELD: No, I would totally support the statements in point 3. Much of my work is what we call community engagement so I am out at bowls clubs and RSL clubs talking to community groups. I constantly hear stories of an older person who perhaps has decided to make an enduring power of attorney, for example; it is usually the financial side of things, or they may have been pressured into it by a family member or a new friend, as we term it these days.

The Hon. GREG DONNELLY: Forgive me for not quite knowing that phrase "new friend".

Ms FIELD: Thank you for picking me up on that. We often find with older people that somehow someone has befriended them. It may start off with, "I am going to the supermarket. Let me do some shopping for you. No, pay me when I come back"; "I'm going to the supermarket. Yes, if you give me some money first" and then the change is not quite what it should be. "There is a document that you can fill out and it will save you having to go to the bank and do all that type of thing." We often see situations and the term generally is elder abuse. What happens is someone, it may be family, friends, new friend or whatever, may be appointed as an enduring power of attorney.

As it stands in New South Wales the choices for the donor or the principal of the power of attorney to say when they want the instrument to come into effect vary. One of them is "when my attorney thinks it is necessary". If you have a situation like that, then the attorney can just say, "Well, I think it is necessary that I start looking after all your financial affairs now." With an enduring guardianship, of course, if someone has appointed someone, that does not come into effect until the person is partially or totally incapable of looking after their personal and lifestyle matters.

The Hon. TREVOR KHAN: I know I am cutting across, but in terms of a power of attorney, if it has been granted, subject to issues of incapacity, the granter is capable of revoking the power of attorney?

Ms FIELD: Absolutely.

The Hon. TREVOR KHAN: So the circumstances you are talking about where a person holding a power of attorney seeks to exercise their powers lies entirely in the hands of the granter to revoke that power, does it not?

Ms FIELD: It does, most definitely, but if you have an elderly, vulnerable person, who is reliant on the care or the friendship of family, friends, whoever it may be, then it may be very difficult for them to revoke the instrument, and of course in this State there is no need to revoke in writing; it can be revoked verbally. You could say of course that would make it easier, but many older people who are on their own and, as I have said, vulnerable, may not like to upset the person they have granted the power of attorney to.

The Hon. TREVOR KHAN: My concern is that leaving the person in a situation with a lack of control may encourage people not to prepare powers of attorney, which, in itself, may do great harm to the individual if they become incapacitated?

Ms FIELD: I agree with you. As I said at the outset, there is a great deal of confusion in the community about the varying substitute decision-making instruments and many older people in the community confuse powers of attorney, be they general or enduring, and for financial matters, with enduring guardianship and, dare I say it, some people confuse both those instruments with wills. They do not understand the difference between any of the instruments. Some people think they are doing the right thing because someone has suggested that they make an enduring power of attorney, but that someone who has suggested it—and presumably suggested that they be the attorney—may not necessarily be the appropriate person. As it stands at the moment in this jurisdiction, and the others for that matter, there is no checking mechanism. You do not have to register a power of attorney unless you are going to engage in property dealings.

The Hon. TREVOR KHAN: That is right, but I suppose what I am inviting from you is if a power of attorney can be revoked, therefore a mechanism exists for the person who grants it to control it. What do you suggest is an appropriate and not too cumbersome mechanism that allows powers of attorneys to be created, for all the good that they do, and at the same time protect against the evil that you see?

Ms FIELD: And not just me.

The Hon. TREVOR KHAN: No, I understand that.

Ms FIELD: It is definitely a case of education. I argue, when appointing any attorney, that the person has to have integrity; they have to be available, both geographically and themselves, and also they must have financial acumen. So often people appoint an attorney for fear that it would hurt their feelings if that person were not appointed. Some people actually do not have anyone to appoint and this is why they may appoint now the New South Wales Trustee and Guardian. They may appoint a trustee company. We have to accept the fact that some people do not have family, nor do they have friends who would be trustworthy.

The only way around it is to educate people; there is the Guardianship Tribunal if someone has lost capacity whereby a power of attorney can be reviewed but someone has to make an application. So there is a mechanism in place if the donor has lost capacity. If the donor still has capacity—and there are many cases where the donor is pressured into appointing someone and then, of course, they are in an unequal position and not in a position to actually revoke the document. I am sorry—it is something I feel strongly about.

The Hon. GREG DONNELLY: Going back to point 3, and looking at this through your lens and not that of the Alzheimer's Association, the words struck me as very clear and firm: "Often older people are pressured." The word "often" suggests that it happens—

Ms FIELD: Quite often.

The Hon. GREG DONNELLY: More than infrequently?

Ms FIELD: Yes.

The Hon. GREG DONNELLY: I gather that is because of the inherent vulnerability of the person's predicament in terms of their capacity to represent their position and articulate through words how they feel and think about things or what their opinion is. Do you agree with the word "often" in that statement?

Ms FIELD: Yes, I do. As I said, I travel a lot, talking to community groups. I talk to aged care providers and, of course, they see situations such as this, and obviously I talk to my legal colleagues and other professionals who all have stories. You only have to look at the de-identified decisions and the Guardianship and Administration Tribunal website in Queensland where they put up all their decisions to see the number of cases that go before the tribunals where there has been abuse in one form or another of a substitute decision-making instrument, inevitably an enduring power of attorney, and it is usually left to a third party because if they have capacity they cannot go to the tribunal, so the tribunal is there for those who lack capacity. For those people who have mental capacity but for various reasons, because of their domestic situation, suffer financial abuse, it is about knowing where to go and where to receive legal advice. If you have been ripped off financially it is very hard to find the money to pay a lawyer $500 an hour to seek legal redress.

The Hon. TREVOR KHAN: You gave a definition that you thought was more suitable for "incapacity", which I take it was inability to understand the nature and effect of a transaction?

Ms FIELD: Yes.

The Hon. TREVOR KHAN: If incapacity means an inability to understand the nature and effect of a transaction, how do you deal with somebody who, through disease or stroke or injury or the like, engages in compulsive behaviours?

Ms FIELD: I think you would look at what we would call assisted decision-making. If we look at the approach of global capacity or incapacity in some ways it is very simple. You would say that someone lacks capacity, therefore all decisions will be made for them and we think we are making them in their best interests, and it is nice and clear-cut. If we look at it as decision-specific or domain-specific, someone may have the capacity to make health decisions, but not financial decisions, or vice versa. It is time-consuming to say we need to sit down and spend time with this person ensuring that they understand the implications of what it is that they are doing. Someone may well have the capacity to manage their pension but not, if they still have a share portfolio, to manage that.

The Hon. TREVOR KHAN: If we refine the definition of "incapacity" to an inability to understand the nature and effect of a transaction, in terms of a person who suffers severely from compulsive behaviours you potentially exclude people who are suffering a real problem from the definition of "incapacity" simply because they may understand the effect of what they are doing but still do it because of the compulsive component of their behaviour?

Ms FIELD: We would argue—and I cannot say Alzheimer's at this stage—how many of us in the community have not made a foolish decision at some stage in our lives?

The Hon. TREVOR KHAN: I do not argue that question with you, but I suggest a person could understand the nature and effect of a transaction and at the same time be severely affected by delusional components or behaviours. Would you agree with that?

Ms FIELD: Most definitely, but if we look at our own value judgements in certain situations, would we say that because someone wanted to blow the last of their pension on the horses or wanted to put it into the poker machines or wanted to give it all away when they had nothing themselves? We need to think very carefully what our views are in a situation—our moral values as well—and not impose them on other people. If we look at the least restrictive approach we would ask: What can we do to assist this person? Perhaps with assisted decision-making we can give them certain amounts of money but not all their money.

The Hon. TREVOR KHAN: I think we are talking at cross-purposes. I think if you use the racehorse example we are talking about compulsive behaviours as opposed to delusional behaviours—I hope—but the incapacity issue arose in a definitional sense. What I was asking you to do, in a sense, was address whether limiting the definition of "incapacity" simply to an ability to understand the nature and effect of a transaction was narrowing it to such an extent that you miss a number of incapacities, if I can use that word in a generic sense, which may seriously impact upon a person's ability?

Ms FIELD: No, taking it the other way, saying that the definition of "capacity" is understanding the nature and effect, so if you are saying—correct me if I am wrong—incapacity is not understanding the nature and effect then it may well be, if it is delusional, the person requires extra assistance. I think that taking that line would almost be using a global incapacity judgement that someone who is delusional cannot make any decisions. If we talk about decision-specific, notwithstanding that they are delusional, and if we look at the New South Wales case of *Easter v Griffith* where the majority held that she was delusional—it is just a pity that they said "delusional" equated to incapacity—nevertheless if we look at decision-specific, notwithstanding that someone is delusional, they can have the capacity to make some decisions. It may not be all of them. They may not be able to look after their money, but they may well be able to tell you whether or not they want a bath at a certain time of the day.

The Hon. TREVOR KHAN: Sure, but that would go to the nature and extent of the order made, not the threshold test of incapacity, would it not? You would have to go through two stages in any of these things—first, the finding of a need for the making of the order and then, having found the need, tailoring the orders made to the circumstances of the individual?

Ms FIELD: That is right, but you must always start with a presumption that everyone has capacity and because it is a presumption it can be rebutted, so we start off in this venue that we all have capacity. Someone would then have to rebut that and look for triggers in our behaviour or whatever it may be that would alert them to the fact that capacity may not be present. I suppose I disagree with you in that just because someone is delusional it does not mean that they do not have capacity for certain decisions.

The Hon. TREVOR KHAN: I do not think you have to disagree with me. I do not think that is the point I was making.

Ms FIELD: Then I am sorry I have misunderstood you.

The Hon. TREVOR KHAN: Let me go to the power of attorney issue because it is an important issue that you raise. You have raised the issue of education, but plainly these are documents that are entered into in the tens of thousands each year, I suspect, and there would be hundreds of thousands of them out there. Plainly, on what you describe, there is an issue that all that has been done in terms of education to date has not worked. Is there any other legislative change that you would recommend that may overcome some of the concerns that you legitimately express?

Ms FIELD: I hesitate to legislate for something unless it is absolutely necessary, however the system as it stands at the moment—you made a comment about the numbers that are out there; in one breath I can agree with you but we do not really know how many are out there because there is no mechanism. It is only in Tasmania that you have to register a power of attorney before it is a valid instrument. The rest of us can talk about it and say there is an incredible amount of abuse, but percentage-wise it is estimated at 3 per cent or something like that—

Dr JOHN KAYE: Three per cent of what?

Ms FIELD: Three per cent of the powers of attorney in existence are abused. Having said that, it is just an estimate. No-one really knows because we do not know how many are in existence. As for legislating for it, I think we have to look at the power of attorney documents themselves—these are my views; I have not discussed this with Alzheimer's Australia, and of course the Powers of Attorney Act is under review as we speak—and say that there is very little information on the document itself in this jurisdiction. In this State, witnesses are limited to about five different cohorts—a notary public, a lawyer, a court registrar, a trustee employee and a licensed conveyancer, if the latter two have done a prescribed course. In some jurisdictions a justice of the peace can witness an enduring power of attorney and that raises the issue of capacity as well, because when it becomes an enduring document the witness is actually certifying that the person appeared to understand the contents of the document that they had just completed.

The Hon. TREVOR KHAN: What benefits would you see in adopting the Tasmanian approach of requiring registration of the document, beyond the fact that we would know how many there were?

Ms FIELD: The issues associated with registration are such that once registered it becomes a public document and many people would be concerned that someone could access the document and see who they had appointed as their attorney, because some older people may well appoint one child and not want another child to know—

The Hon. TREVOR KHAN: I do not want to cut across, but I asked about benefits, not disadvantages.

Ms FIELD: The benefits of registration would be that the document was known to be in existence. I cannot see any other benefit.

The Hon. TREVOR KHAN: Do I take it that if we discount knowledge as being of any great benefit, registration per se is not going to overcome the problems you identify with the misuse of the power granted under the document?

Ms FIELD: No.

The Hon. TREVOR KHAN: Any there are other suggestions beyond that?

Ms FIELD: Apart from the education of the community, which needs to be a concerted effort be it on the part of Government or any other organisations—many organisations spend a considerable amount of time educating people—it may well be that the principal, the donor of the power, should always be seen alone—we would say that anyway as lawyers—to ensure there is no undue influence on their decision-making.

The Hon. TREVOR KHAN: In that regard, are you aware of whether there are any practice directions in New South Wales from the Law Society?

Ms FIELD: Yes, there are. In March this year the Law Society launched a booklet of guidelines for solicitors when the capacity of their client is in doubt. In 2003 or 2004, the Law Society of New South Wales produced guidelines for solicitors witnessing enduring powers of attorney.

The Hon. TREVOR KHAN: Does that form part of the legal practitioner's manual?

Ms FIELD: I do not think they are in the manual but they are the guidelines for practitioners.

The Hon. TREVOR KHAN: Would you agree that perhaps it might be a good idea if they were inserted in Riley's legal practitioners manual?

Ms FIELD: I think it probably would be a good idea.

The Hon. GREG DONNELLY: You gave a case reference in responding to a question.

Ms FIELD: *Easter v Griffiths*?

The Hon. GREG DONNELLY: Yes. Would you mind providing that reference to us? I am not familiar with that one.

Ms FIELD: Not off the top of my head. I will certainly provide that.

CHAIR: Thank you.

(The witness withdrew)

ANDREW BUCHANAN, Chairperson, Disability Council of New South Wales, 323 Castlereagh Street, Sydney 2000, and,

DOUGLAS HERD, Executive Officer, Disability Council of New South Wales, 323 Castlereagh Street, Sydney 2000, affirmed and examined:

CHAIR: Would you like to make any opening comments?

Mr BUCHANAN: Yes, please. Thank you very much for giving us the opportunity to speak to the members of this Committee. As you know, I chair the Disability Council of New South Wales, or attempt to, the official advisory body on disability in this State. It has been my privilege to do so for the past seven years, providing advice to four successive Ministers for Disability Services. With my colleague Dougie Herd, who I know has already spoken to you to provide some background from the Disability Council's perspective, I hope we will be able to answer your questions and add some value to your deliberations.

Let me preface our comments with what may seem to be at first an odd beginning. Asked to consider questions such as legal capacity; decision-making, good and bad, whether that is supported, assisted or substitute decision-making; the rights of people with a disability; what a person's best interests might be; and the many more complex, some might even suggest philosophical, questions the Social Issues Committee is being asked to wrestle with, one is drawn to the now legendary words of the incomparable Donald Rumsfeld, who famously observed, "There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. There are things we don't know we don't know."

I will start with what we know we know. On 17 July 2008, the Australian Parliament ratified the United Nations Convention on the Rights of Persons with Disabilities. We were one of many organisations that played a small part in urging the Parliament to reach that decision. The purpose of the UN Convention, according to its first article, is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

That places upon you, as lawmakers in a legislative body within a Federal system of government, not just a responsibility but a duty to rethink the status quo and to examine whether or not existing laws in New South Wales meet the challenges set by the United Nations convention and where it becomes apparent that our State laws may have slipped a little behind the times, so to speak, to take legislative action to return New South Wales once again to the forefront of legislating, let us say, as once it was, for example, with the Guardianship Act of 1987—now 22-years old.

Let me observe that we also know we know, for example, with the United Kingdom's Mental Capacity Act of 2005, that it is possible, entirely practical and, in our judgement, wholly desirable for lawmakers such as yourselves to discuss and enact enabling legislation built upon a presumption of capacity. Such lawmaking, it is clear, can be both cutting-edge in its character and consistent with meeting the best interests of people with disability, which must always be our goal. The question of capacity brings me, I must tell you, to what I think can be described as one of the known unknowns of life.

To remind you of Dougie Herd's recounting to you of the Jain parable of the exploration of an elephant by six blind men, capacity is something we all believe we know what we mean when we talk about it but in reality we understand, I believe, that defining capacity is anything but easy. Every one of us has varying degrees of capacity at different times in our lives and in different circumstances. The experience we acquire in life and the education we benefit from may equip us better in some areas of decision-making than in others. It is not uncommon for us all to seek advice, assistance and support in making all kinds of decisions. Sometimes we make the wrong decision in life. Every now and again we make some humdingers of bad decisions but that, we are fortunate enough to recognise, is life and we hope we will not make big mistakes too often. Unless I am much mistaken though, we know that no-one goes through life without making at least one wrong choice. That does not mean we lack capacity in that area or for our entire life or in every aspect of our decision-making lives.

It seems clear to us, therefore, that a necessary and desirable wish to protect and safeguard the well-being of sometimes potentially vulnerable people, people who have one or more of their decision-making capacities reduced, interrupted or destroyed in one or more aspects of their lives by some disabling condition, should not automatically or necessarily lead them to being determined or defined as incapable of decision-making in whole, or part, now, and possibly forever. We need a more subtle and sensitive approach to decision-making by, with and/or on behalf of people whose capacities may be from time to time, in varying matters and for varying durations, be sometimes prolonged, reduced, interrupted or absent.

We need a suite of instruments, agencies and mechanisms, which will include public advocacy and advice, supported or assisted decision-making, as well as substitute decision-making, and a rights-based framework to protect the interests of people with a disability who reach the decisions that may touch upon every aspect of their lives, such as these examples, and many you may think of too. Financial decisions ranging from how to budget on the disability services pension or invest an inheritance to guarantee, in as much as such a thing is possible, a nest egg for the future; where, how and with whom to live; how one may express one's cultural, spiritual, social and/or sexual self; and, dare one say it here and now, who to vote for in 2011. These are complex questions for any individual to consider and to answer with confidence. The questions that this parliamentary inquiry raises are no less complex and just as difficult to answer. But we are not wholly in the dark, and we are not starting entirely from scratch.

We have the United Nation's convention to guide us. There is here a genuine paradigm shift occurring. You are part of it, which may be a daunting prospect, but with the convention it assists us to see more clearly the way ahead and the decisions we must take. There are existing laws upon which to build. Reform is necessary—that much can be agreed or the Attorney General would not have sent this matter to your table in the first instance. The shape and scale of that reform may not yet be entirely clear to any of us. We, like other participants before you, believe that some of the interrelationships are so complex and interdependent that it may be necessary to initiate a broader review, perhaps through the Law Reform Commission, but we also believe there are changes this Committee could initiate now, and I hope that we may suggest some of those possibilities when we answer your detailed questions.

Thankfully, there is a robust and informed community of legitimately interested advocacy stakeholders with valuable ideas, understandable passion and a deep sense of commitment to the issues at stake. You have read their submissions and will hear their valuable evidence. You will not agree with everything they say, and different stakeholders will sometimes assert contradictory views. Nevertheless, the decisions you take following their input will have been assisted by their contribution to this debate. There are, of course, key agencies led by capable, compassionate and highly competent public servants, with insights that will commend themselves strongly to you. One thinks of Graeme Smith and his staff at the New South Wales Public Guardian, the team led by Imelda Dodds at the newly created New South Wales Trustee and Guardian, and Di Robinson, other tribunal members and staff at the Guardianship Tribunal. And there are people with disability, their families, friends and associates. All of them have something to say through this inquiry and beyond, as we reform our laws, organisations and professional practices associated with questions of capacity.

There are, and will be, unknown unknowns to be encountered along the path of reform, but I can leave them for now to be discovered and dealt with as we progress towards a new set of arrangements based on your deliberations on the evidence presented to you and the issues that arise from it. Can I sit here now and say hand on heart that I am certain of what the outcomes of all of this will be? That is, I fear, beyond my capacity to deliver. Let me conclude, therefore, by drawing finally on the wisdom of Cate Blanchett, for she and I are of one mind when it comes to some questions. She made the following telling observation—I cannot recall about what:

> Look, it is one of those great mysteries of the world. I cannot answer that question. I think I am vaguely blonde. To be perfectly frank, I do not know.

Thank you, Chair.

CHAIR: Thank you for those brief opening comments, which were very comprehensive.

Dr JOHN KAYE: We note that under section 18 (1A) (b) of the Guardianship Act that guardianship orders can be made for a maximum of five years, whereas financial management orders can be made for a period of indefinite time. Do you think there is an inconsistency? Do you think that difference is justified? Do you think we should change it?

Mr BUCHANAN: Before I go, Dougie? It is a change of Scottish brogue.

Mr HERD: We have prepared some answers, which we can read into the text and we can also provide them in writing for you, if that is helpful. I think the council's view is that the Convention on the Rights of People with Disabilities describes a landmark human rights treaty. We think this means that everyone needs to see the convention as something special. It defines a moment of fundamental change and our laws need to be considered within that new context. The convention is described thus by the United Nations. While many contend that existing treaties covered persons with disabilities along with everyone else, it was clear that without a legally binding treaty that spelt out their rights persons with disabilities faced being legally invisible in society and even in the international arena. The convention marks a shift in the way society views people, with persons being the key decision-makers in his or her own life. It makes persons with disabilities rights holders and subjects of laws, fully participating in formulating and implementing plans and policies affecting them.

Article 3 of the convention says that respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons is fundamental. Article 3 requires state parties, including the New South Wales Parliament, as part of a Federal Australia, to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination. It is difficult—perhaps impossible—to see how indefinite substitute decision-making would impact. Can I pause for a moment as I think I might be answering the wrong question?

Dr JOHN KAYE: You went further: you went on to answer the supplementary question that I was about to ask. What I really wanted to find out was whether you thought there was an inconsistency in the legislation as it stands at the moment.

Mr HERD: Yes, there is.

Dr JOHN KAYE: Is there an inconsistency in the five years relating to financial management, or the indefinite period that is allowed with respect to other guardianship matters?

Mr HERD: We have this in great detail. The short answer is: yes, there is. That inconsistency should be eradicated on the basis of what is in the terms and articles to which I was referring earlier. Ultimately, the convention states that any of these matters should be brought down to the least restrictive measure possible. In our view, anything that extends beyond five years seems not to comply with least restrictive.

Dr JOHN KAYE: Do you think that the administrative costs of bringing the matter back every five years is worth it in order to respect the human rights of the person about whom the order is being made?

Mr HERD: Yes. I would suggest that that is so for two reasons. If we continue to monitor the situation of people on a more frequent basis than indefinitely, it is entirely possible to imagine that we will intervene more appropriately in the lives of people who may be receiving an inappropriate service than we would over the life of somebody who may have been injured, who had an acquired brain injury at the age of 20 or 30 in a road traffic accident, and who will live with the profound consequences of that disabling condition for perhaps 30, 40 or 50 years.

We can imagine interventions over the period of their lives that might allow them more independent living, enable them to take an increasingly large part of some decision-making processes in their lives, and therefore be less dependent on a service system that will become more and more expensive as the years go by. Am I going to tell you that we will get a change to these things tomorrow? No, I am not. Do I think there will be savings over the lifetime of that individual? I think it could be suggested that there is a strong case to support that argument.

Dr JOHN KAYE: I refer to the factors that the Guardianship Tribunal has to take into account when deciding on whether or not a person is in need of guardianship. I refer specifically to section 14 (2) of the Act. Do you think those factors give sufficient assistance to the tribunal in reaching a decision? If not, how would you change it? What is missing? What is in the Act that should not be in there? What is missing? What should we have in the Act that is not in it?

Mr HERD: We have suggested that section 14 (2) of the Act would benefit from the addition of a reference to the United Nations Convention on the Rights of Persons with Disabilities. We require an explicit reference in the law. My reason for saying that is that section 3 of the Guardianship Act states:

> "person in need of a guardian" means a person who, because of a disability, is totally or partially incapable of managing his or her person.

Section 14 (2) of the Act makes specific reference to people with disabilities. Given that the United Nations Convention on the Rights of Persons with Disabilities makes sense of the clear inalienable rights in law of people with a disability, we believe that in addition to the three paragraphs in section 14 (2) relating to the views of the person, the views of the family—there is one other that I have forgotten—the convention should be a necessary requirement of consideration by the Guardianship Tribunal. The convention sets out all kinds of factors that should be considered when making that judgement.

The Hon. MARIE FICARRA: Mr Buchanan, I think you make a great act. You have a lovely radio voice, in case you want to moonlight.

Mr BUCHANAN: I can assure you that I am a "has been".

The Hon. MARIE FICARRA: In appearing before this inquiry you are aware of the Committee's terms of reference and the recommendations that it will eventually make for legislative change. Are there any glaring deficiencies that you think we should address? You might be aware of some of the other submissions to the inquiry. Are there any areas at which you feel we should be looking?

Mr BUCHANAN: Before Dougie responds I would like to state that the challenge you have is immense. I think that the challenge in the broad community in coming to terms with the whole issue of intellectual disability is daunting. A lot of people fear, and do not really grapple with, some of the issues involved. While we can have a framework it is important to have that framework or to have legislation. But the ideal situation would be if it could be a matter of interpretation rather than seeing it in black or white. Sometimes good commonsense has to apply in an area such as this. As a personal reaction, I would not like us to become too legalese over some of these things so that good commonsense does not prevail and, therefore, the bandied term, "the rights and the dignity of a person with a disability" is ignored.

Mr HERD: I am sure you will hear from others in their submissions—certainly in the submissions that I have read—that we should try to make a stab at defining "capacity". If we are to try to provide support, assistance and substitution for people with decision making because they are incapable, we ought to try to get some kind of understanding about what "capacity" means in law. Clearly, council and others will refer you to the Mental Capacity Act of the United Kingdom, which was passed in 2005, which makes a stab at it. It should be seen in the light of subsequent legislation around the Convention on the Rights of Persons with Disabilities.

There is the International Covenant on Civil and Political Rights and a set of United Nations principles around people with mental illness that I think are helpful in trying to set a context. That might need a clever draftsperson to come up with a definition that I suspect will always be imperfect. To have nothing on the statute books anywhere I think would leave a gap in our legislation. The reason it is important and the reason we all want to strife to achieve something is that there are those who have to take the difficult decisions about placing someone under guardianship or taking away their rights from them, with their best interests at heart because they might be about to harm themselves.

Because they keep making the kinds of compulsive mistakes that you were talking about earlier they need assistance and protection. The people who will make those decisions need some kind of guidance because they do not have the wisdom of Solomon. Solomon had wisdom but nobody else did. They are human beings in quite pressured service systems dealing with people in highly stressful situations who come with family members, friends and associates who are no less stressed than the people who are having the difficulties. Alternatively, they are dealing with people who have no-one around them, absolutely isolated in their lives, making dreadful decisions, or no decisions at all, about the circumstances that placed them in an invidious position.

I think those folk need help and guidance on where they should go and how they should reach a decision. They should also know where the line is. A point that I made before and about which I know council is concerned is that we should not rush down the road of taking decisions off everybody who looks like they might have some trouble at the first sign of that trouble. I have referred before to the wife of former Prime Minister Hawke. Mrs Hawke is perhaps the clearest public example of this.

Her journey into her new situation has been a long time in the making. It would have been wrong for anyone to remove her decision-making capacity on day one of her journey. There are many, many, many people with Alzheimer's who will follow a similar route who might need assistance with decision-making. They will ultimately lose all decision-making capacity because that is just the nature of the illness. The people who make the decisions about these people need some guidance from Parliament and in law about how they should act, when they should act and on what basis they should act. That is a long way of saying I do not know.

The Hon. MARIE FICARRA: It is a vexed issue.

Mr HERD: Can we be honest? I am being honest and Andrew is always honest because he is the chair.

CHAIR: Independent.

Mr HERD: Absolutely.

The Hon. GREG DONNELLY: And we are politicians, and we are always honest too.

Mr BUCHANAN: We have no doubt of that.

Mr HERD: I am glad I am here giving you evidence and you are on the other side listening to it because I think you have got a very difficult job to do. I have no idea, to be perfectly honest, how you decide somebody is capable in the real world. I just do not know, and I am glad I do not have to make that decision. But we do need a framework within which those who have got to make the decisions have some guidance as to how they should act. A lot of public servants are doing a very difficult job in difficult circumstances. Most of the time they probably get it right and sometimes they get it wrong. But the consequences for human beings can be grave. We need to try to find a way to move forward.

CHAIR: I am glad you said that, I feel better now. I was starting to worry; I thought it was just me who did not understand.

Mr BUCHANAN: I think we are all in the same boat. To answer your question again, part of the exercise in this area—and I say this not with some surprise—as I mentioned in the introductory comments, we are lucky in having public servants such as Imelda Dodds, Di Robinson and Graeme Smith because, with great respect, sometimes in government and in a bureaucratic sphere with disability that does not always occur. You have three individuals who are compassionate and who get it and who want to see it from the client's point of view. I do not want to draw comparisons, but in other States that does not always apply.

The Hon. MARIE FICARRA: I understand.

The Hon. TREVOR KHAN: In evidence earlier today there was discussion about due process. I am interested in the comments you make about what I take to be a warning of potential problems in a bureaucratic situation. In some of the evidence today there has been criticism about the Law Society's proposition of the need to ensure due process. Whilst I heard the criticism earlier, and I invite comment on this, one of my concerns is that the finding by a tribunal in these circumstances involves the removal of a person's legal rights and the placement of those rights in the hands of another. In those circumstances, I wonder whether the dismissal of a degree of formality and assurance of due process, because it is dealing with a person under some level of incapacity, in fact involves a denial of that due process component too readily. Do you agree?

Mr BUCHANAN: I do not think we can always say yes, but as a general reaction probably it does. Again, it comes back to—no matter who it is in law—a general fear of dealing with this issue within the community. We are not as sophisticated as perhaps we should be. We are not as emotionally mature as we should be. We make judgements without considering all the facts. There are assumptions about a person with a physical disability. If I am physically disabled and I go into a bank or I go to buy a new car it is assumed that I also have a mental illness or I am intellectually disabled. My kids may say that is highly appropriate for all three. But the reality is that assumption is made and, I think, sometimes in the community we do make assumptions that are quite dangerous.

The Hon. TREVOR KHAN: Mr Herd?

Mr HERD: I do not know. I want my cake and I want to eat it. I want due process to apply so that we can be sure that when we get to the decision to remove somebody's rights we have crossed every "t" and dotted every "i" to make sure that when we take that decision as a last resort it is the right decision and we have tested everything. But there is a bit of me also thinks that there is a human being sitting there. We said this elsewhere in answer to one of your questions, I think it is a furphy that people have got a right to take bad decisions and that we should allow people to take the risk that bad decision involves. We should have risk and people do take bad decisions. We all have a right to take decisions. Some of them are good and some of them are bad. We need to protect as much as we possibly can the individual and his or her right to make a decision which we would not always agree with, and we might not ever agree with.

In finding the balance between those two: the individual expression of oneself, whatever the hell that might be, and a legal process to ensure that vulnerable or potentially vulnerable people are protected, there is a tension there between two perhaps irreconcilable forces. Somebody has to reach a decision. I can understand why, obviously, lawyers want processes and social workers want protections and people with disability and their families want to know that they are safe and okay and a bunch of bolshie activists want rights. All of those forces are sitting around a human being who may not know how much he stuffed down the pokies last week, or a woman may be in difficulty of surrendering her sexual self to somebody that she is finally with, or some older person who has no idea what day it is. It is a big decision to take off any of those individuals the right to express themselves in whatever way they are going to express themselves. But we cannot leave people vulnerable.

CHAIR: You want the decisions they make to be informed as much as possible?

Mr HERD: Yes.

CHAIR: And you want the flexibility for decisions not to be binding forever? If you make a decision about taking away someone's rights by making a decision as to their capacity, it should not be a decision made today that lasts forever?

Mr HERD: Absolutely. I do not have this personal experience in my life but I know members of our council do and members of the community tell us these things. I was here in this room 18 months ago giving evidence to the Federal Parliament's inquiry into carers, and particularly around Alzheimer's the emotional stress that families find themselves in, whether it is in law or just their daily life. The person that they are trying to protect, they want protection for that person, they want to make sure that they are safe. I can quite understand why they would say to me, "Dougie, you are talking through a theoretical hole in your head about somebody's theoretical rights. I'm in tears." This is a real example. A woman, a single mother, who used to work for me—this is in Edinburgh before I came here—would tell me that at some point of her day working for us or preparing to come to work she had to choose whether or not to come to work or to tie her father into a seat to stop him wandering because she could not get the support that she needed. She had to come work—although, of course, I was a decent employer and accommodated her needs. She had her kids to look after and she had her dementing father to look after as well. She needed protection for her father.

The Hon. TREVOR KHAN: Following on with what the Chair just raised—I would not say that he verballed you—in a sense we went back to Dr Kaye's question dealing with the five-year versus lifetime dichotomy issue. You used an example of the dementia patient—we will not particularly label it as Alzheimer's—where the prospect is that the person, having begun to suffer the condition severely, is unlikely to recover. In fact, in truth we know that person will not. If what is suggested is a five-year order, nowadays with the level of care Alzheimer's patients may receive we know that they may last well beyond five years in that condition—in fact, 10 or 20 years. Knowing that their condition is not going to improve, is the mechanism to adopt in a sense your theoretical model of talking through the hole in your head to say that both the Alzheimer's patient but, more importantly, the family is to return each five years before a tribunal for reconsideration of the order that has been made? Is that going to advance the circumstances of that person?

Mr HERD: Yes and no. I know I am not giving you definitive answers here. Again, we asked ourselves a similar question in our response to the written questions you have given us, but using the example of the young man injured in a road traffic accident with a very profound brain injury, who has a life expectancy of 50 years, Andrew could tell you in response to other questions we have been asked in the past about the mobility parking scheme [MPS] of all things. When you are someone like me, who has been in a wheelchair for 25 years with spinal cord injury, you are not going to get up and tap dance away from your mobility parking scheme examination. Andrew, with lifelong polio, if he does not mind me mentioning that, and a double amputee, let us say, we all get our RTA MPS; we do not need to be asked every five years if we are still incapable of walking 100 metres. It really annoys you every time you are. So, the Government has been able to find a way to get round that with a list of clinically recognised conditions that do not need to be tested again and again.

I think the family of that young man with the brain injury does not need to be reminded of the trauma every 5 to 10 years or less, every 2 years or whatever, because we know that there is not going to be recovery. I think the systems we devise need to be sophisticated enough to test where appropriate to ensure that the rights of the people are protected and that if there is improvement or change, that that can be recognised and a decision can be rescinded, but not so onerous, frequent or intrusive as to keep bringing people back to the point of injury or loss because human beings just do not need that in their lives. I do not and I am relatively coherent, except when I am reading the wrong answer to a question!

The Hon. TREVOR KHAN: Is what you are looking for a mechanism initiated by the person-patient-client, family members or a public guardian, however named, that provides a ready mechanism for a return to a tribunal for reconsideration of the matter? Is that the most appropriate mechanism?

Mr HERD: Yes, it could be. The ability to rescind a decision or the facility to rescind a decision or reverse it or minimise it, change it from substituted to assisted decision making, ought to be no less difficult than getting into the situation in the first place. When one looks at questions of due process, it ought to be something that is possible without being fearful about engagement with the system again. Most punters are nervous. In an office with a professional, whether it is a lawyer, social worker or whomever, the power relationships are there. Ordinary people sometimes struggle in those circumstances to express their wishes adequately or well. The system needs to encourage them to exercise their rights, but they do not need to be hauled in every 18 months for the compulsory capacity-making assessment and confronted with, yes you are somebody with a 12-year history of dementia.

The Hon. TREVOR KHAN: One final question that arises from the concept of review, should you be starting with a position, there is an order made and we are reviewing the order made or should we be starting from the position that a person has capacity and, therefore, the matter starts afresh on the presumption of capacity? I hope I have not made it too hard.

Mr BUCHANAN: No. I think probably the latter is the more attractive choice.

Mr HERD: I think that is how the United Kingdom works. Whatever your situation is or whatever time you were assessed, the presumption should be in the examiner that capacity is there. If the history of decision making has shown that capacity in some way has been deficient or removed, then that ought to make the examination quicker.

Mr BUCHANAN: I think flexibility again is the key in terms of what you were asking. I think that old common sense approach that there just cannot be one rule for all is a matter of interpretation and flexibility. I can understand again without being too empathetic with you, as a Committee you are hearing differing views from different aspects of the disability sector, and that is even more confusing. But let me say without any ego or vanity, we are far more balanced in our approach.

The Hon. MICHAEL VEITCH: Speaking of the broad differences in the disability sector about a range of things, the submissions we have received contain a range of various definitions for intellectual disability, cognitive impairment, mental impairment et cetera. Even State agencies as well as the Federal bodies have different definitions. Today we have heard from a number of people that differing definitions impact on the way the Public Guardian and the Trustee conduct their affairs. How would this Committee address that as a recommendation of the legislative review?

Mr BUCHANAN: I think it is a very interesting question. As a disability council we stress that it is important to use appropriate language but not to get caught up and to be pedantic about the use of language, otherwise that creates issues. As an example, digressing slightly, when we were planning the International Day of People with Disability last year, somebody said, "Well, you can't really use the term 'amputee'. That is really passé. You have to really use the term that it is a person with limb loss." To me, personally, that is really being very pedantic and ridiculous. An amputee is an amputee. You and I conjure up and know what we are talking about, whereas a person with limb loss can mean anyone—me or you—in that situation. We have actually responded to you and we can give you a copy of that either in electronic or hard copy form in giving a description of what is cognitive, what is mental and what is intellectual disability, if that is of value to you.

The Hon. MICHAEL VEITCH: If you would please.

Mr BUCHANAN: I suppose in essence, the use of language is important, but we would be cautious and plead with you not to become pedantic and to lose again a sense of reality about it.

Mr HERD: One of the things I think is important to say is that in some senses the labels do not matter because if you begin with the premise that your decisions about whether or not somebody's capacity is impaired in some way and, therefore, a set of decisions need to be made about that, and end with the individual, you do not care whether or not they are in an intellectual disability category or a mental health category. It is Dougie Herd sitting in front of a specialist being assessed who says he has reduced capacity in these three areas. He therefore needs assistance or substitute decision making and he can deal with these areas to his full capacity. Some specialist in a hospital will have given me a categorisation of which group I am in, but those categories do not really make any difference to the question of whether or not that individual has capacity at the point at which the test is made.

CHAIR: Thank you very much for attending this afternoon. Your evidence will be extremely helpful to us in our deliberations. We had some questions on notice.

Mr HERD: Yes, we have answered them all.

Mr BUCHANAN: We can give you a hard copy plus an electronic copy.

CHAIR: Thank you, and we will be in touch with you about that. We may need to again call on your assistance.

Mr BUCHANAN: Thank you for having us, and good luck.

(The witnesses withdrew)

DIANE ROBINSON, President, NSW Guardianship Tribunal, 2A Rowntree Street, Balmain, sworn and examined:

CHAIR: Thank you very much for being here this afternoon. Would you like to make some opening comments before we go to questions?

Ms ROBINSON: I thought I might make a few very brief comments. You are probably aware already that the NSW Guardianship Tribunal is a specialist legal tribunal, a specialist disability tribunal. We operate as a court substitute. The job that we do has been done for some years by the Supreme Court of New South Wales but we do it in a way that is, hopefully, more accessible and more inclusive for people with disabilities. We try to be as non-legalistic as possible while maintaining all the fairness and other appropriate aspects of a legal process.

As you would know from my submission, we do a range of things. We appoint guardians and financial managers as substitute decision-makers for people with decision-making disabilities. We also review enduring powers of attorney and enduring guardianship appointments as a safety net to ensure that they are working appropriately. We also make a range of medical decisions when people cannot make those decisions by themselves.

I would just make two general comments. One is that I understand that this inquiry is taking place in light of the United Nations Convention on the Rights of People with Disabilities, and I think it is appropriate to say that I think we have got a very good human rights record in New South Wales and I think that our guardianship legislation is certainly consistent with those human rights principles. It is also, of course, a welcome time to be able to review them and revise them and improve them if we can. The other thing I thought I might say is that, having read all of the submissions that have come before the Committee, it is of interest to see that there is some discussion about various models of guardianship—a move from a welfare model to a rights-based model. In some ways, while they are useful ways of thinking about guardianship, they are sometimes, I think, a little bit simplistic.

Throughout the history of this kind of legislation—guardianship and mental health legislation—there has always been a tension between a welfare model and a rights-based model, and if you look at the whole history of mental health legislation you will see there is a cyclical change: sometimes we have got a welfare emphasis; sometimes we have got a rights emphasis. The worst aspects of a welfare model are, of course, that you get a very patronising, paternalistic approach where people are not heard or seen, and the worst aspects of a rights-based model is that it can be excessively legalistic and people can have rights but they do not have the facility or the capacity to access them or make them into anything real and substantial.

So what I would say to the Committee is that rather than focusing on these different models what we should be looking for is some balance whereby we use the best aspects of both and come to a situation where we can individualise the approach for people—look at people on a case-by-case basis and get an individualised approach and the best outcomes for people on that basis. That is all I would say by way of opening.

Dr JOHN KAYE: Thank you for that introduction. It was very useful. I want to ask you about two sections of the Guardianship Act, section 14 (2) and 25G. The former refers to the factors that the Guardianship Tribunal must have regard to when deciding whether a person is in need of a guardianship arrangement or guardian, and the second is in respect of a financial management order. Can you comment on whether you think those two provisions within the Act are adequate in terms of giving you the sort of guidance you want? Can you identify things that are in there that should not be in there, and identify things that are not in there that ought to be in there?

Ms ROBINSON: I will talk about section 14 (2) first and the guardianship provisions. I guess the thing to realise about that is that, as well as section 14 (2), there are some other provisions that are also relevant. Section 15, for example, also tells us that we should never make a plenary order when we can make a limited order and that we should never appoint the Public Guardian when we can appoint a private guardian. There is section 15 and there are also the section 4 principles. There is actually a range of other provisions, which also indicate to the tribunal when the appointment of a guardian is necessary.

Basically we operate on a least restrictive alternative kind of option. We only ever make an appointment when it is absolutely needed and as a last resort. In some ways the provisions that are there are currently adequate. They could be improved, I suspect, by possibly referring to some case law and indicating in greater detail some of the things that might be pertinent considerations.

The only other thing I would say is that because the tribunal tries to look at each individual case on its merits and as an individual person, it is very important that we retain an overall discretion—in other words, we are not bound by a list of factors that we can consider—because that, I think, would be too prescriptive and would not allow us to look at each individual person's needs. As long as we have an overall discretion based on need and the object and principles of the Act, I think that is appropriate. We could certainly expand on these from case law, but we take into account case law. I would not say it is essential.

Dr JOHN KAYE: Are most of your tribunal members lawyers?

Ms ROBINSON: No. There are three categories of member. Some are lawyers—about a third—and a third are professional members. We have psychiatrists, neuro-clinical psychologists, neuropsychologists, geriatricians, social workers, registered nurses and a whole range of professional people who are involved in the treatment and assessment of people with disabilities. Our third category is community members. There are some people who themselves have a disability and some people who are the carers or family members of people with disabilities or otherwise generally are familiar with people with disabilities. So we have three different categories of member.

Dr JOHN KAYE: And you sit as a tribunal of three members, one from each category?

Ms ROBINSON: We do.

Dr JOHN KAYE: Do you think that works well? Can you explain why it works well?

Ms ROBINSON: I think it works extremely well. The pivotal decision that we make is that somebody is not capable of managing their person or their finances because of a disability. That is a really crucial human rights decision because once we make that decision we are in effect vesting that right of decision making in another person. That should never be done lightly, or without appropriate expertise. So in the three-member panel, having a lawyer, a professional member and a community member—all of whom have disability experience—provides enough varying viewpoints and different levels of expertise for us to make a very informed and very competent decision.

I have very good people who know what questions to ask, know how to evaluate the expert evidence that we have coming before us, know how to talk to the person with a disability and how to engage them, and know how to make it as possible for them as it can be for them to present a view and participate in the proceedings. We do some reviews by single-member tribunals now, but always when we are making the initial call about a person's capacity, it is a three-member tribunal.

The Hon. MARIE FICARRA: In terms of resources that your tribunal would have for planing into the future and our ageing population—taking into account the dementia-Alzheimer's tsunami that is heading our way—do you believe that it is right for people to be alarmed about what is coming? Do you believe that you can cope with the future in terms of your current resourcing and resourcing into the future? What do you believe to be the situation? We have heard contradictory reports about how much to be alarmed about our ageing society.

Ms ROBINSON: The figures are alarming, are they not, when you look at them and when you look at Access Economics and the figures that are often produced by Alzheimer's Australia, for example, who released that recent Access Economics report. The rate of people with dementia coming into the Guardianship Tribunal has gradually increased, as you would expect. I am not terribly alarmed because I think the way to sort it is by having a really proactive and very well resourced community education/community awareness campaign. We are all able to appoint guardians for ourselves. We are all able to appoint financial managers and powers of attorney for ourselves now. That would mean that you do not have to come to the Guardianship Tribunal and ask us to do it for you at a later stage.

Some people have taken up these options, but I think quite honestly the majority of people do not really know how they operate. They do not really have access to the information. We run a community education branch of the tribunal, but if I had additional resources, what I would do is expand that very branch rather than do more hearings. I have to do hearings, as I am required to by law, but this is where I would put my money, if I had extra money. It would be put into developing a community education unit to get out there and talk to people about these things and have the community services branch out on the telly: Have you got your enduring guardianship appointment organised?

In that way, people can know. We need to approach culturally and linguistically diverse communities, a whole range of people, to let them know. We have to make these documents accessible. There are witnessing arrangements that many lawyers complain about and whether or not they are adequately accessible. Some of them have to be witnessed by lawyers in various ways. I think that is something that we need to look at as well.

The Hon. MARIE FICARRA: To simplify the process?

Ms ROBINSON: Yes. I think if we do that, we are there as a safety net, we are there for people who have not got those arrangements, and we are there to tidy up when those arrangements go wrong. I think that we need to continue to do that, but I think if we could get more people making these appointments in the first place, that would be the way to handle it.

The Hon. MARIE FICARRA: You said that part of your tribunal's responsibility is reviewing enduring powers of attorney. How does that actually work out? Is that something that happens automatically after a set period? What initiates a review? How adequate is that?

Ms ROBINSON: Do you mean a review of an enduring power of attorney?

The Hon. MARIE FICARRA: Yes, an enduring power of attorney.

Ms ROBINSON: We receive an application from somebody asking us to review, and we will then investigate. I have a unit of staff that investigates these applications. They will make inquiries, talk to the person with the disability first, obviously, and then talk to their family members and people involved in their care and support. They will gather evidence. The tribunal then will conduct a hearing in which we will hear the evidence and test the evidence and just see whether or not that document is working in the best interests of the person with the disability. If it is not, we can change it. We can revoke it, we can take out the attorney if they are doing the wrong thing and substitute another one, and we can have their records forensically audited. We have a range of powers under the Powers of Attorney Act.

The Hon. MARIE FICARRA: That can be quite comprehensive. In reality, from your experience, who initiates these reviews? Is it a family member who is upset, or a professional such as a doctor?

Ms ROBINSON: Both. Overall, half our applications come from professional people and the other half come from family members—primarily daughters, as you might expect.

The Hon. MARIE FICARRA: Yes.

Ms ROBINSON: So we are looking at doctors, social workers, people who are professionally involved, or close family members.

The Hon. MARIE FICARRA: You were talking about guardianship models and the welfare model versus the rights model. Do you feel that we are moving towards a better balance? Is there anything that this inquiry can do to assist that process in getting a better guardianship arrangement?

Ms ROBINSON: I think we have always actually had a pretty reasonable balance. Whether or not that has been as well articulated in the legislation as it could be remains to be seen. For example, we have always operated on the basis that there is a presumption of capacity. People are assumed to be capable until they prove to be incapable, but that is not actually stated in the legislation. That is just one small example. I think we could improve the written principles and objectives of the Act, but I do not know that it would make that great a difference to the way the system actually operates.

The Hon. MARIE FICARRA: What are the various ways that parties are represented at tribunal hearings?

Ms ROBINSON: Represented?

The Hon. MARIE FICARRA: What various ways are parties represented at tribunal hearings?

Ms ROBINSON: I would just let you know that when I saw that question, I sent to Jonathan a copy of one of our practice notes, which is about representation at tribunal hearings. You probably have not had a chance to look at that, but there is a comprehensive answer to that question in there. I will just summarise it quickly for you. People can be represented informally; that is, they can have a lawyer, an agent or a support person to assist them. That happens a great deal and we strongly encourage it. People can have a lawyer representing them formally as a legal representative by leave of the tribunal. People can also sometimes have a separate representative—that is, an independent lawyer. The tribunal will appoint that person when we think it is necessary. That is a little like what sometimes happens in Family Court proceedings. That is a reasonable analogy. There is a range of different ways, both formal and informal, that representation is available.

The Hon. MARIE FICARRA: Is it a requirement that all persons for whom an order is being sought from the tribunal are legally represented?

Ms ROBINSON: No, there is no requirement. One really practical way of improving our system would be the provision of additional resources to fund separate representation for all of those people. At the moment the Legal Aid Commission provides separate representatives for people. However, funding obviously precludes everybody being represented. To give the committee some idea, last year the tribunal dealt with 8,466 cases. We had 6,011 new applications and the rest were reviews. As you might imagine, the resources required to provide representation in all those matters would be significant. It would be positive and practical if we could provide more representation through the Legal Aid Commission.

The Hon. MARIE FICARRA: You would have to have criteria. I imagine that that would be onerous in terms of resourcing. Would it be possible to have criteria?

Ms ROBINSON: For when representation was most appropriate? We could do that. I have also tried in the past to organise pro bono support for people through firms. I cannot explain this in full, but I think that legal aid eligibility prohibits it. There is a problem in the system with my accessing pro bono support for people.

The Hon. MARIE FICARRA: That is a shame.

Ms ROBINSON: It is. That would be a great way to go and a practical thing we could do to improve the process for people.

The Hon. MARIE FICARRA: Is there some restriction at the moment?

Ms ROBINSON: Yes, a resource restriction.

The Hon. MARIE FICARRA: That is something to look into.

The Hon. GREG DONNELLY: My questions arise from some of the answers we received today from other witnesses. We heard evidence reflecting on the arrangements in Victoria. I am not sure whether you are familiar with the system in Victoria. However, as I understand today's evidence, the Victorian trustee's role is broader than that of the New South Wales trustee. I understand that the trustee, at least in part, plays a public advocacy role in explaining the importance of the issue of people entering into arrangements and representing people who may not have come to them via a tribunal as happens in New South Wales, whereby the trustee represents only those people who have come through the tribunal. Is that correct?

Ms ROBINSON: Yes.

The Hon. GREG DONNELLY: Which suggests a broader system in Victoria. It was put to us that that is a good system. The witness suggested that that gives Victoria some advantage over New South Wales. However, in your evidence this afternoon you suggest that things in New South Wales are satisfactory. I am not putting words in your mouth, but it appeared to me that you said that the New South Wales model seems to be robust and reasonable—notwithstanding resource issues that we can discuss separately. What are your views on the Victorian system vis-a-vis the New South Wales system, and even the arrangements in other States and overseas? Are there systems that we could look at and perhaps compare and contrast?

Ms ROBINSON: People often talk about the Victorian model. It is fair to say that we would be comparing apples and oranges, because they are very different. Victoria has different legislative and service provision frameworks. Some years ago there was a large influx of funding into disability services in Victoria. I now know that the Government has put money into disability services through Stronger Together and so on. The support for disability services has come later in New South Wales compared to Victoria. Having said that, if we took the best of the Victorian model and combined it with the best of our model, that would be fantastic. Unlike New South Wales, Victoria has a public advocate. That idea of a systemic advocate is something we need to examine. It would be a special ombudsman role. Somebody would be able to deal with those larger systemic issues and that would be very useful.

However, speaking from the tribunal's point of view, the New South Wales model works very differently from the Victorian model. Ours is a much better model and we would not want to lose that. About a year ago we had a visit from a team from Alberta, Canada who were reviewing their entire guardianship tribunal system. The team leader—a member of their Legislative Council—said to me, "You've got the Cadillac model." I guess that was her way of saying we had the Rolls Royce model. I thought that was terrific; they were very impressed with our system in New South Wales.

One of the things that we have that Victoria and other States do not have is that we provide written reasons for every decision we make. I hand down decisions that people cannot make their own financial decisions anymore. In terms of accountability and human rights considerations, it is most appropriate that there be a written reason for such a decision. That does not happen in Victoria or anywhere else in Australia.

We do a number of other things differently. One of them I have mentioned in my submission; that is, our tribunal has an investigation unit that investigates all applications. The public advocate does that in Victoria. If you look at their annual report you will see that last year they may have conducted 300 investigations. Last we conducted 8,466 because we investigate every application that comes to us. Every person we are dealing with has the opportunity to speak to someone one to one about the process and to get information. There is a number of very good things about our system that I urge the committee to retain. Nonetheless, we can take some good things from the Victorian system, with its public advocate and systemic advocacy model. A holus-bolus replication of the Victoria system would be foolhardy.

The Hon. GREG DONNELLY: That was a leading question to get your thoughts. It is not as simple as starting from scratch.

Ms ROBINSON: No, it is not. I think we need to take the best of both. That would be fabulous.

The Hon. GREG DONNELLY: I refer to the submission from Alzheimer's Australia, the last paragraph of which states:

> Often older people are pressured into handing over their decision making power to a substitute decision maker well before they have lost their full capacity to do so. In some cases family members may assume that once a diagnosis of dementia has been made, the person no longer has the ability to make decisions for them and decision making powers are swiftly transferred, leaving the person with dementia feeling powerless and frustrated. The current system has no checks and balances in place for situations of informal substitute decision making to address situations of abuse and exploitation.
>
> (a) Alzheimer’s Australia NSW supports the need to investigate mechanisms that will provide safeguards around informal decisions made on behalf of people whose capacity is limited.

Ms ROBINSON: Wow! That is very broad.

The Hon. GREG DONNELLY: I referred to this earlier today. The language is strong. Picking that up and reading it cold, it presents a pretty grim picture, almost chilling, that there are a number of elderly people out there often pressured into making decisions, of surrendering their decision-making power, and it reads on. I am not asking you to double guess the reasons they say that, but does that gel with your experience in your role as president of the tribunal and your general experience in dealing with the elderly?

Ms ROBINSON: Yes and no. Informal decision making is the foundation for our system. We receive a lot of inquiries. A lot of people come to us constantly with inquiries. If informal decision making is working well for them, we will say to them, "Well, you don't need to come and talk to us, off you go." Family members are making decisions for other family members all the time. What I would dispute about this is that in fact we are the safety net, we are the checks and balances that are in the system.

The Hon. GREG DONNELLY: That is what I thought.

Ms ROBINSON: Often people will come to us and say, "Look, granddad has lost capacity. We think he's got dementia and he can't make decisions. My sister has come in and she's forced him into a nursing home and she's sold all the furniture in his house and she's now doing X, Y and Z." If there is a dispute in the family about how the informal system is working, they can come to us and make an application. We can investigate that and then if necessary appoint somebody, either in the family or independently, to facilitate decision making. I think what they say is right. I think people do jump in and they do take over decision making for older people or people with disabilities. Why I said "wow" before is that if we start—I mean, there is a limit to how much we can do with informal decision making.

The Hon. GREG DONNELLY: Without cutting you off, other evidence today has been that—indeed, it is your point—that informal decision making is very significant in the whole process of managing this issue in society today. I have gathered from the evidence today that in large measure that seems to work from reasonably well through to quite well. There does not appear to be a large number of cases thrown up of abuse, for example, or people acting overtly against the interests of another person. The informal system, which seems to be large out there, seems to have a way of operating. When I saw that I thought to myself, "Gee whiz." What that is getting at is interfering in this informal decision making process. How do you do that, and what sort of resources and scope of activity would you need to have to compensate for taking away this informal activity?

Ms ROBINSON: Also I think we have to be really cautious about family members. Family members know what is best for their family member. To what degree do we interfere? We interfere as a tribunal when people are neglected or exploited or at the pointy end of things, but basically family members are generally doing the right thing. Those sort of things make me concerned about that sort of paternalistic busy-body role. I am just never sure how far or how you could deal with that problem. There are checks and balances. If service providers are concerned, if doctors are concerned, they can make applications to us in this kind of situation.

The Hon. MICHAEL VEITCH: A couple of submissions talk about the need for procedural fairness to apply in respect of all aspects of the Guardianship Tribunal. What are your views about that statement?

Ms ROBINSON: I think that is right. Procedural fairness is just a basic legal doctrine. Sometimes I know people raise it in terms of concerns about privacy and confidentiality. It is a tension that we have to deal with. If all of you came to a hearing at the tribunal just to be witnesses or observers and we had a bundle of private, confidential medical reports or financial statements we would not be showing them to you. We are not showing this material to everyone who turns up. But if you were a party, if you were wanting to be appointed as a guardian for somebody and you are saying, "Listen, I'm a good bloke, I want to be the guardian", and I have a report that says that this person is not of good character, they are X, Y and Z, of course I would be showing you this report. It would be fair to you to see what has been said so you could respond to it. So obviously it requires that some material is given to key people, but we are trying to balance that and make sure that we are not handing everything out so we are trying to have some sensitivity to people's very private medical and financial information. It is often a difficult balance.

The Hon. MICHAEL VEITCH: What safeguards are in place during tribunal hearings to minimise the opportunity for people to exploit persons lacking capacity by having themselves appointed in the substitute decision-making role?

Ms ROBINSON: I guess the safeguards come from the fact that we are undertaking a legal process. We are making the decision about the suitability of a person for appointment based on evidence presented, and we are rigorously testing that evidence. Say you came along and said, "Look, I want to be the financial manager for Mr West." I would be asking you about your experience and your knowledge of Mr West and his views, whether your finances are intermingled with his in any way and what your plans are for his estate. We would ask you a whole range of questions to make sure that you would be able to undertake this role.

I have this investigation unit who will have spoken to other people around you and around the person with the disability and if there is anything that is really untoward hopefully they would have identified that and that would be apparent to us. The other safeguard of course is that when you are appointed as a financial manager you are under the direction of the New South Wales Trustee. You are not on your own. We are not just giving you carte blanche and leaving you to your own devices. So there are a number of safeguards. Primarily the tribunal process is a court substitute tribunal. So we are hearing evidence, testing evidence in that way.

Dr JOHN KAYE: I have heard that expression, "a court substitute tribunal", twice this afternoon. Does that mean that you are acting on warrant from a court, or how does it work?

Ms ROBINSON: I am sorry, I use that expression to mean that we are different to some administrative tribunals. Some tribunals are reviewing administrative decisions of government. We are actually making judgments of fact, findings of fact and determinations at first instance like a court. It is just that we are doing it in a very non-court like way. We are doing it in a way that hopefully includes people with disabilities as much as possible. That is all I mean.

The Hon. MICHAEL VEITCH: You mentioned the investigation unit. Is one of their roles to determine whether applicants may be seeking to exploit someone for their own advantage? Is that part of the role of the investigation unit?

Ms ROBINSON: It is. That is not their primary role. Their primary role is to investigate the applications that come to the tribunal for hearing but in the course of that they will identify, and they have often identified, that. What they will do then is fast-track the application. They might, for example, discover that somebody's house is about to be sold from underneath them, so we will have a hearing that same day and organise for a caveat or something to be put in place to safeguard the person's property. It is, I guess, an ancillary role. They are not taking any direct action. They are not sort of doing anything themselves but they are facilitating the tribunal process so that we can make a decision to guard against or prevent that exploitation.

The Hon. MICHAEL VEITCH: Is the investigation unit the only mechanism you have, or are there other mechanisms to assess the risk of exploitation?

Ms ROBINSON: We have the investigation unit. We have an inquiries unit, but they would probably know less about the matter. Just the tribunal itself; the tribunal will undertake—we are not adversarial. We are inquisitorial. We are much like you where we are asking a lot of questions to get to the bottom of the matter. We will often also unearth some quite disturbing instances of exploitation, elder abuse in various forms.

The Hon. MICHAEL VEITCH: Going to the review of orders, and you mentioned what I thought was a staggering number of cases you deal with each year. It has been suggested to the Committee that financial management orders should be reviewed automatically at least every two years without the need for a request from the person under the order or the financial manager. It is suggested that that would increase the accountability for private managers in particular. From your position what is your view on that suggestion, particularly regimented review periods?

Ms ROBINSON: In principle, I can see the arguments for it. It obviously would require additional resources for the tribunal to do it. We could not do it within our current system. There are several systems in place for review now. People can request reviews, and they do. We can initiate reviews ourselves or we can order a review. So, what we have now is a system of review on a needs basis. To go to just general reviews, I would not be opposed to it, as I say, if I had the resources to do it. The only other thing I would say is that this is a legal process we are putting people through and many people are distressed by it, understandably. A lot of people with disabilities, when they come to any court or tribunal, they think they have done something wrong. They think they are in strife. So, to have a review that is unnecessary, there is an argument against that, but certainly in terms of principles of making sure that the order is there only for as long as is necessary, there is certainly that argument. But there are plenty of mechanisms to allow a review to take place now. Under our current system we review roughly about a third of all the financial management orders that we make, to give you some rough idea.

The Hon. MICHAEL VEITCH: If I was under a financial management order and I wanted to contest the order or suggest time has elapsed and my circumstances have changed and I am now able, in my opinion, to manage my own finances, how would I go about that?

Ms ROBINSON: You would ring us up and we would give you one of our investigation staff to help you out with the process. You would fill out your form and you would tell us why you think you can manage. Then our staff would assist you to get some evidence to support your application. Maybe they would say, "Why not talk to your general practitioner," or "Have you thought about getting a report from your doctor or your psychiatrist or whoever?" We would help you collect the information, explain what you have to prove, explain the legal rules and the process and then you would come along to the tribunal and present your case. It is hard to get an order revoked on the current legal standards because you have to prove capacity. If you have been under an order it is hard to prove capacity. Often we adjourn and we suggest they go away and ask the trustee or whoever is managing them to give them a little go on their own. They might come back after six months and they have had a trial run and then they have good, solid evidence that they can manage. So we assist them within the bounds of our role to make the best applications they can.

The Hon. MICHAEL VEITCH: I refer to an earlier response, I think it was to the Hon. Marie Ficarra's questioning about representation at tribunal hearings. If I am before a tribunal am I entitled to have only one advocate or could I have legal representation? Could I have, maybe, a social worker? Could I have a team of people with me?

Ms ROBINSON: You can have as many people as you wish. We frequently say, and very genuinely mean, this is your hearing, you can bring your entire family. We would accommodate that. You could have one or two. Some people bring solicitors and barristers. We have senior counsel appearing sometimes. You can have a range of representation and support as you wish.

The Hon. MICHAEL VEITCH: Is that recorded anywhere? Is it in the transcript?

Ms ROBINSON: We have an obligation to record all our proceedings, so we record them. We do not always produce transcripts, because of the 8,500. We only produce transcripts when there are appeals. But we have a record, and when we produce our reasons for decisions what happened at the hearing and what evidence you gave and what your representative said would all be recorded in those reasons for decision in our written judgement.

The Hon. MICHAEL VEITCH: But the team of advocates I bring would be recorded there?

Ms ROBINSON: You mean who they are?

The Hon. MICHAEL VEITCH: Yes, all the family members, whoever, would be recorded somewhere?

Ms ROBINSON: Yes they would. They would be recorded as people attending the hearing with you, yes, in the reasons for decision.

The Hon. MICHAEL VEITCH: With these financial management orders, it has been suggested there has been inconsistency in the matters that must be proven before a financial management order can be made by the Guardianship Tribunal, on the one hand, and before the court and the Mental Health Tribunal on the other. Under section 25 of the Guardianship Act, you must satisfy a list of things.

Ms ROBINSON: Yes.

The Hon. MICHAEL VEITCH: Do you agree there is inconsistency between the Mental Health Tribunal—

Ms ROBINSON: Yes, it looks inconsistent, doesn't it? I think it is only understandable historically. Historically the mental health legislation was such that immediately upon you being admitted to a psychiatric hospital your estate was automatically vested in what was then the Master in Lunacy, now the New South Wales Trustee. There was no hearing, there was no discussion, it was automatic. Then the Protected Estates Act evolved and it got a little bit better, a little bit more liberal and human rights oriented. Of course, then the guardianship legislation came after that. We have articulated I think that you have to prove that you are incapable of managing, that there is a need for an order and that it is in your best interests, whereas the other jurisdictions only talk about being incapable. What it means to be incapable is explained not in the legislation but in the case law. An enormous number of cases explain what that means. So, in a sense, we are all operating under the same system. It is in the case law what we are looking at.

The Hon. MICHAEL VEITCH: What should we do then to resolve the inconsistencies or perceived inconsistencies?

Ms ROBINSON: If you could make everything like the Guardianship Act. I sound like I am joking but if the provisions that affected the other tribunals and the court were the same I am sure that would just standardise things. They are not that dissimilar.

CHAIR: In terms of the case law you are talking about, you indicate that your tribunal is not a court of record as such. Where is the case law coming from?

Ms ROBINSON: The case law is coming from the Supreme Court. There are a series of cases in the Supreme Court that set out what it means to be a person who is incapable of managing your affairs.

CHAIR: So it is Supreme Court case law?

Ms ROBINSON: Yes.

The Hon. GREG DONNELLY: Has case law through the Supreme Court of New South Wales or in other jurisdictions dealt with some clarity with the issue of best interest?

Ms ROBINSON: Well, yes. They have dealt with it. It is a difficult term, isn't it? It is so value laden.

The Hon. GREG DONNELLY: It is. I was not meaning to put you on the spot but, I am sorry, I feel I have put you on the spot. It is just that in evidence earlier today we were looking at different aspects of this consideration and obviously the question of the best interests of the person has been raised. I must say, for me anyway, it is a term that troubles me in trying to get some clarity around its precise meaning. I was wondering whether or not you can give us any insights into whether there have been successful attempts to find best interests for the purposes of the issues we are considering.

Ms ROBINSON: Yes, there have been. There is the case of *Holt v The Protective Commissioner* that Justice Michael Kirby, when he was President of the Court of Appeal heard some years ago, in which he gave a very useful judgement. He talked about a person's best interests. This was an application to get rid of the Protective Commissioner as financial manager. He asked when that would that be in a person's best interests. He spoke about, for example, the fact that family would usually always make a better decision for somebody than a government manager. But, when would that not work? When, for example, there might be a conflict of interest. What would a conflict of interest be in these circumstances? He spoke about the family relationship and the support, and so forth. He gave a whole list of considerations that we might look at in this area. That is just one example. Yes, there have been discussions in the case law of these sorts of things.

CHAIR: And the definition of capacity?

Ms ROBINSON: In terms of financial management, heaps.

CHAIR: In terms of case law and the whole definition of the word "capacity"?

Ms ROBINSON: There is a great deal of it. Would you like me to talk about it? I can if you would like me to.

CHAIR: You are saying there is a great deal there. You might take on notice if there is any chance of getting some enlightened information?

Ms ROBINSON: Yes, I would be more than happy to talk about that.

The Hon. GREG DONNELLY: Does capacity and consent mean one and the same thing or do they overlap or are they different issues—to have capacity to be able to consent?

Ms ROBINSON: I guess they overlap. We talk about consent often in a medical context—can somebody give informed consent? Usually at law that means that you understand the nature and the effect of the treatment that is proposed for you. So you really have the capacity, in a sense, to have that level of understanding. One is a bit of a subset of the other, I guess.

CHAIR: Can I go quickly back to the questions that were asked by the Hon. Michael Veitch in regard to the review of orders and the indication given that, of the roughly 8,000-odd orders each year, roughly a third were up for review, and there was that resource issue. Can you give us some very rough, ballpark figures as to the cost that would be involved if you were required to review the other two-thirds, if you were required to review the 8,000-odd each year?

Ms ROBINSON: Can I clarify that we do review every guardianship order now? At the end of its term we review it. I was only referring to financial management.

CHAIR: If you review every two years, as per question 11, review of audits—

Ms ROBINSON: If I could take that on notice I could look at the numbers and do that for you more sensibly than I could right now.

CHAIR: That is fine. Your evidence has been very helpful and vital for the Committee to come to grips with this matter. We will forward you some further questions on notice. We trust that you will be available should we need more assistance?

Ms ROBINSON: I would be absolutely happy to do that.

(The witness withdrew)

ROSEMARY KAYESS, Associate Director, Community and Development Disabilities Studies and Research Centre, University of New South Wales, affirmed and examined:

CHAIR: Do you want to make an opening statement?

Ms KAYESS: In the way of opening I wish to acknowledge that my evidence today and my opening address will be brief as a reflection of the submission that we made. Our area of expertise is in the international law context of this inquiry, in particular, the interpretation of Article 12, equal recognition before the law, of the Convention on the Rights of Persons with Disabilities. We believe that New South Wales and Australian jurisdictions generally are reflective of some of the most progressive guardianship regimes in the world, but that does not mean that there is not room for improvement both in New South Wales and within the other Australian jurisdictions.

The Australian jurisdiction still works on a presumptive model of capacity or lack of capacity, and that guardianship is a process of substitute decision-making. We believe that international law, and the enormity of content of international law, has moved on from that presumptive structure and that now the challenge is to develop mechanisms and legal legislative frameworks that embrace notions that recognise the varying modes of capacity in the exercise of decision-making for people with disabilities. Whilst that is easily said, it is not very easily achieved. It is a complex process and it is a combination of distributive justice, through allocation of public resources, and also having a solid understanding of the lived experience of persons with disabilities. We are talking about a group of vulnerable, socially isolated people that are very disempowered in this process. Opportunities like this to be able to engage in forthright discussion about how those mechanisms may change are very welcome.

The strength of any guardianship regime, or any regime that supports a person to exercise their legal capacity, must reflect the will and preferences of the individual. International human rights are built on the notion of human dignity, and it must be the sole objective of any legislative framework to support persons with disabilities in exercising their legal capacity. I was intimately involved in the development of Article 12 of the Convention on the Rights of Persons with Disabilities. I was a member of the Australian Government delegation to the negotiations in New York and, believe me, this was not an easy article to negotiate. It was contested and controversial from the word go and it places a significant challenge before legislators, before the legal profession and also before the community about recognising a paradigm shift in the way we think about legal capacity and how people can exercise their rights.

The article is not perfect; it is a negotiated piece of international law, but I think it is a strong reflection of where we should be heading. The strength of the article is that the presumption is capacity, and that the mechanism by which support is balanced is the proportionality—proportionality in the level of intervention and proportionality in the safeguards. At the moment in New South Wales you are either under guardianship or you are not under guardianship. You either go through the process of the full tribunal or you do not. There is room to shift that balance. There is room to recognise that people who have decision-making difficulties may require greater support in some decision-making areas but not in others. We believe the opportunity is with us now to be world leaders, and to create a system that has the objective of achieving human dignity through supporting people to the level that their vulnerability needs protecting.

Dr JOHN KAYE: Do I take it from what you said that you would therefore support amendments to the Guardianship Act to allow the Public Guardian to assist—rather than take over—people with decision-making disabilities without the need for a Guardianship Order?

Ms KAYESS: If the mechanisms can demonstrate a proportionality in terms of the intervention required, and the safeguard mechanisms that are required, I think a variety of support mechanisms could be put in place, and a variety of mechanisms would be dependent upon demonstration of the level of need, and the level of protection—that is the wrong word. We are talking about legal safeguards, checks and balances.

Dr JOHN KAYE: But also a range of supports from complete intervention through to assistance?

Ms KAYESS: From very informal to very formal.

Dr JOHN KAYE: So you see the range of needs, as it were, as being on a spectrum and hence what we should be focusing on as presenting a set of options that are proportional to those needs, which therefore means that we should be talking about a spectrum of responses. On that spectrum of responses the Public Guardian has made a recommendation to us that members of the New South Wales Police Force be authorised to move a person who is under a guardianship order from one place of residence to another—that power currently exists—but that the police may use all reasonable force to achieve that outcome. Clearly what is being envisaged here is a person being in a place that is deemed to be inappropriate for that person and the person not wishing to leave that place. The question is: Should the police, under those circumstances, have the right to use all reasonable force to move the person to a place deemed to be more appropriate?

Ms KAYESS: That is a question of the level of need and whether the person is under a guardianship order because of a demonstrated level of capacity that requires complete substituted decision. If it is a complete substituted decision process then it has to go through the process of guardianship. If it is something that has been deemed by that substitute decision-maker, that they can demonstrate that it reflects the will and preference of the individual and that decision meets the level of proportionality of the intervention warranted, I do not have a problem with the intervention. I do have a problem with the intervention if it can be demonstrated that the person does not require that level of intervention in their decision-making.

Dr JOHN KAYE: So you can envisage situations of police using all reasonable force to move somebody from one place of residence to another?

Ms KAYESS: Well, it is very difficult to answer that unless I know what the decision-making issues are for the person and whether they require that level of substituted decision-making.

Dr JOHN KAYE: I guess where I am coming from is can you envisage a situation where it would be appropriate? Is it inherently wrong for the police to use all reasonable force to move somebody?

Ms KAYESS: Well, it depends on whether the police can demonstrate that there is risk to harm or others. There is a duty there of the risk of harm to others to be demonstrated and that it is not an arbitrary intervention by the police in terms of the use of force.

Dr JOHN KAYE: How do you respond to the idea that the Public Guardian should be allowed to proactively investigate matters where it becomes aware of a vulnerable person who may be in need of a guardian? I would like you to address two aspects of that. One is: is this unreasonable intervention and, secondly, is there a conflict of interest for the Public Guardian to behave in that way? They are investigating something with the idea that they are going to become the guardian of that person.

Ms KAYESS: Again, it is the proportionality; it would depend on what evidence there is to justify that investigation, so there would need to be a threshold at which they could have that authority to be able to investigate. Again, I would say it comes down to the proportionality test, so if there is a threshold level at which they can demonstrate that they have evidence that there is a risk of harm to self or others and that intervention is warranted and you can demonstrate that it is proportional to a person's level of vulnerability or need, I feel that if those mechanisms could be in place, yes, the Public Guardian could have that power. Hypotheticals are very difficult to answer sometimes.

Dr JOHN KAYE: I am realising that. Thank you very much.

The Hon. MARIE FICARRA: On the issue of responsible persons, the Guardianship Act provides a hierarchy of people who may be considered as a person responsible for another person and who must be contacted, for instance, a medical practitioner or for dental treatments, to obtain substitute consent for treatment. We are told in this hierarchy that more than one person being equally considered the person responsible could potentially lead to difficulties if there is a disagreement with the treatment that is being suggested. Are there any advantages to having more than one person qualified equally as a person responsible?

Ms KAYESS: I will answer this not from my professional experience but from my personal experience. In the last two years I have sadly lost both my parents. My mother had early onset Alzheimer's and my father probably cared for her way longer than he should have, which put his own health at risk. We are a family of four, and yes, having two responsible persons, or even three responsible persons, would have been a significant benefit because the load gets left with one person and it becomes difficult. As my father became more frail, one brother had the responsibility of both parents. But then again, that means that the role is then divided. You need to have checks and balances that there is communication between the two.

The Hon. MARIE FICARRA: At the moment there are moves to amend the Act to ensure that there is only one person who can be deemed as the responsible person. Each individual situation is different. It is hard to get the balance.

Ms KAYESS: It is really hard unless you have an understanding. As I said before with the hypothetical questions with Dr Kaye, it is very difficult when you do not have all the information because that will give you an indication of the proportionality of the intervention and the requirements of the situation.

The Hon. MARIE FICARRA: Absolutely. Is there any area that you believe we are failing, from your own personal experience, in talking with others in the field of disabilities, having been overseas and negotiating Article 12? Is there any area that you believe we should be looking at with a view to improvement, or any other jurisdictions?

Ms KAYESS: I think the Victorian jurisdiction; I think the role of a public advocate is something that is desperately needed in New South Wales. I believe that systemic advocacy and much of what the Guardianship Tribunal and Public Guardians do in all Australian jurisdictions is advocacy. I believe strengthening community organisations in their advocacy roles; they are stretched beyond belief in trying to be able to support the number of people who are in need of advocacy. I think that would take pressure off the system as well; a public advocate, who could take on a lot of the systemic advocacy issues or an ombudsman-type structure, but I favour a public advocate. It might be splitting hairs in terms of names, but I think there are subtle differences between the ombudsman structure and a public advocate. I think the systemic advocacy role is incredibly important and I think that is one thing that the Victorian jurisdiction does well.

I also think we are a bit top-heavy in terms of our structure. I believe if we went down a proportionality road that we could look at one-member tribunal sittings for cases that were not as contested or as complex as other cases. So if you are looking at proportionality in terms of legal safeguards, you could be looking at proportionality in terms of the tribunal approaches. We are talking about contested public resources and three-member sitting hearings are very expensive. If we are to meet the resources of having a broader array of mechanisms available to people and yet still have a very top-heavy substitute decision-making structure it is going to be difficult to see how that can play out.

The Hon. MARIE FICARRA: You believe that, in the right circumstances where there is minimal controversy, there can be guidelines and criteria?

Ms KAYESS: There would need to be threshold tests that would need to be achieved before you would have a single or maybe two-member tribunal or the requirement for a three-member panel.

The Hon. MARIE FICARRA: We have heard lots about the model in Alberta and the resourcing and provision of disability services and decision making there. Do you have any thoughts about that? It would be nice to learn from international experience where they do have systems that operate well.

Ms KAYESS: Australia and Canada are put forward as most probably the two progressive guardianship regimes in the world. Canada has looked at what they call assisted decision making since the early 1980s. I cannot say that I am intimate with the Alberta jurisdiction. My understanding of a lot of the Canadian jurisdictions is, like Australia, they are provisionally based. Their assisted decision making looks very similar in lots of respects to the threshold tests for our guardianship, but there is most probably greater flexibility in terms of the application, so again it is coming back to a requirement of reflecting will and preferences and proportionality in terms of the level of intervention and who can be appointed as not a substitute decision maker but as a mentor in decision making for people who have decision-making capabilities but who need support in certain decision making.

The Hon. MICHAEL VEITCH: I would like to ask you a couple of questions around restrictive practices.

Ms KAYESS: It is not my area of expertise, but you may ask me.

The Hon. MICHAEL VEITCH: The reason I ask is that earlier you talked about the need for a public advocate—not so much the ombudsman role but the systemic advocacy role. Do you see that that function would in some way go to negate or reduce the use of restrictive practices?

Ms KAYESS: One would hope so. I even think the public advocate or a public advocate could enter debate about whether we still need mental health laws in Australia and whether all the mechanisms under the Mental Health Act cannot be applied through a guardianship structure.

The Hon. MICHAEL VEITCH: You are obviously quite passionate about the United Nations Convention—

Ms KAYESS: No, no, not passionate, I just have a nervous twitching because of some articles. Australia was very involved in the development of this particular article.

The Hon. MICHAEL VEITCH: Dr Kaye referred in his questions to the spectrum, but I gather from your response that you are looking at some sort of intermediary process. At the moment one is either under guardianship or not. I spent 15 years with family members with disability, so I am quite intrigued about the process that allows people to say, "I can make decisions about the majority of my life, but there are a couple of areas that I can't quite manage." How do you see the intermediary role, with regard to the Convention, being played out in a legislative framework?

Ms KAYESS: You are going to get sick and tired of me saying this: It is being able to demonstrate the level or proportionality of intervention, so it would become a threshold element. It would be the demonstration of where the threshold cut-off is for this type of support mechanism. There would need to be appealable avenues if people thought that people were no longer coping under a particular structure, so there would need to be articulation across various mechanisms so that if people's decision-making capabilities deteriorated they were not left vulnerable. Legal construction might be my interest, but I do not know whether it is my forte. Us international lawyers get away with that sort of stuff. The legislative framework would need to be able to establish how the threshold mechanisms would operate, who would have power to establish those threshold mechanisms and where the right to appeal would be based.

The Hon. MICHAEL VEITCH: I am interested in your use of the word "appeal" because earlier today—

Ms KAYESS: I do not mean the Full Bench of the Criminal Court or Court of Appeal.

The Hon. MICHAEL VEITCH: This morning Ms Dodds was talking about appeal versus review.

Ms KAYESS: Yes, review and appeal—it depends whether you are coming from the applicant's or the tribunal's perspective. If you are coming from the applicant's perspective you might be wanting to appeal their decision, but it could also just be a periodic review. That is a mechanism that I believe should be in place. The periodic review is something that should be in place; it should not be left until things get to crisis situation.

CHAIR: Where would the periodic review take place and who would determine the period?

Ms KAYESS: If it were periodic, it would be a set periodic review, and that would be determined. Again it comes back to my much trotted-out word of the afternoon, the proportionality of the intervention. The level of intervention would dictate the level of review and most probably the period of review because the threshold would need to establish the protective stability of that decision-making capacity. Some people may be in a situation where that will be very stable for a very long period of time and it may not change until they go through certain life transitions. For someone with Down syndrome in their early 20s it may not be an issue until they transit into mid life or older life, but it could be a situation where somebody has a deteriorating disability and the situation may change much more regularly.

CHAIR: Have you attempted to define "proportionality" and "capacity"?

Ms KAYESS: We did. "Proportionality" is not defined and it has not got any normative framework at the international level. I suppose it would come down to what evidence there was in previous jurisdictions and within the common law. It would be interesting to go back to some of the common law case law that is available in terms of guardianship and look at what has been said about proportionality, but no, it has not been articulated in terms of normative conflict.

CHAIR: So you would see those words like dignity, capacity, proportionality—

The Hon. GREG DONNELLY: Best interest.

Ms KAYESS: I do not know about best interest.

The Hon. GREG DONNELLY: I will ask you about that when I get a chance to ask a question.

CHAIR: You would see those words being effectively defined on a case-by-case basis in the tribunals?

Ms KAYESS: You would most probably find that there is a body at common law that defines a lot of these terms. As Di was indicating previously, there is a lot of case law and a lot of that has been compiled in terms of recognising capacity and understanding capacity, and also the mechanisms by which guardianship and the public trustee operates here in New South Wales. It has been distilled and put forward with lots of clarity in the Attorney General's tool kit, the capacity tool kit, so there are definitions out there, it is just whether they would still be upheld if different principles were included in the analysis.

The Hon. GREG DONNELLY: Thank you for coming along today. Yours is a very good submission. I was not aware that you participated at such a high level in terms of the development of article 12. I congratulate you on a tenacious effort to get a very important development that will benefit many people in the future. I want to take you to page 4 of your submission, point (3), and specifically the second paragraph. I have not read the cited report in your reference No. 17, so that is probably something I should do. You say, "One area highlighted in the report was guardianship laws with respect to the absence or ineffectiveness of procedural safeguards." That is the first point. Secondly, you say, "The failure to implement in some cases the principle of the least restrictive alternative." Finally, "The failure to ensure the effective promotion and support of alternatives to substitute decision-making." Obviously we can go to the report and read it where those points are cited in some detail, but would you like to comment on any or all of those points?

Ms KAYESS: Okay. With the first point about the absence or ineffectiveness of procedural safeguards, this is not directed just at the New South Wales jurisdiction. This was a national consultation, so the comments made may or may not have been directed at the New South Wales jurisdiction. I could not cross-reference the people who made the comments that led to that being in the report. But I think the other two points can be adequately looked at and considered reflective of the New South Wales jurisdiction. In the case of the principle of the least restrictive alternative, New South Wales has the highest level of guardianship in Australia. Just those simple figures suggest that it is not embracing of the least restrictive alternative and there should be concern about why the numbers are so significantly higher. Even on a percentage basis they are higher than other jurisdictions.

Secondly, in regard to the failure to ensure the effective promotion and support of alternatives to substitute decision-making, the crowning glory of our guardianship regimes and their progressive moves are looking slightly old and are being shown for what they truly are—just another form of substitute decision-making. So we have not gone beyond making enduring guardianship powers and advanced directives, yet they have been around for a long time. The issue of supported decision-making and the need to move beyond the binary system of capacity or lack of capacity—so, substituted decision-making or fend for yourself with informal mechanisms—is way behind us and we should be taking more proactive steps to establish alternative mechanisms.

The Hon. GREG DONNELLY: I have a question relating to a submission from another organisation. You may not have a copy of it, so perhaps one could be provided to you. It is from Alzheimer's Australia, and I refer to paragraph (3) and recommendation (a). I will give you a chance to read the paragraph and recommendation (a).

That is obviously from an organisation that is specifically dealing with people with Alzheimer's. What is your reaction to reading that? Does that statement surprise you? Does that statement equate to your experience in terms of dealing with the issues arising from this inquiry?

Ms KAYESS: It equates to my personal experience and also equates to my professional experience. My personal experience is that I have lived through this experience and, yes, it is a situation where people have capacity to make certain decisions for a lot longer than the original diagnosis.

The Hon. GREG DONNELLY: The issue of pressure being brought to bear is picked up in the first sentence. Does that accurately describe what happens either on an infrequent basis, from time to time, or on a regular basis? They use the phrase "Often older people", which suggests it happens quite a bit. Do you have a view about that?

Ms KAYESS: As I indicated earlier, this is not my area of expertise and I will answer purely from my personal experience with my parents. Families react in a variety of ways. Sometimes they react overprotectively. Our natural instinct is to protect our parents and do the best we can for our parents. Our parents have done that for us and so our natural instinct is to try to protect our parents. But you have to be very strong not to take on that suffocating parental role yourself. You have to recognise that your parent is still a human being and that they still have rights and that you can be too protective of them.

It is not an easy time in a family when someone is diagnosed with Alzheimer's or dementia. It is not easy at all. As I was saying before, a lot of what Guardianship should be doing—I will support Di Robinson's position, but community education and community support is desperately needed for the families that are going through this. Informal decision-making support could be very beneficial for most people and cover most decision-making needs, but people need to have access to information and they need to be able to access support. There is nothing worse than being the person that has to make the decision to end someone's life, especially when that person's life is your mother's. I do not care what anybody says, I made that decision. I was part of the people who decided to stop giving her food and water, however right that decision was. I still played a hand in the end of my mother's life.

It is not easy. Parents would feel pressured because they know their children love them. Some may feel pressured because their children are bullying them. Families can be very good and families can be bloody awful. I mean, I was incredibly lucky to come from a family that was very loving and very supportive but my experience within the disability sector is that that is the exception; it is not the rule. There should be mechanisms out there if one sibling feels that another sibling is not doing the right thing. Here I go ad nauseam again but it needs to be proportional to the level of intervention. So there needs to be community education and there needs to be access to support people who are taking on these informal roles. As I said, it is not easy. You take these decision-making jobs on and sometimes they become incredibly hard decisions to make, very painful decisions to make. Forgive my emotions: it still quite painful.

The Hon. GREG DONNELLY: No, thank you very much for your explanation.

CHAIR: Would you like to make any final comments before we close?

Ms KAYESS: I suppose the main thing I would like to suggest is that we really do have an opportunity to be world leaders in this respect. The world is crying out for a jurisdiction to do some progressive things. I do not know if the Committee is aware but last week Hungary made dramatic changes to its legal capacity, to its legislative structure in guardianship and substitute decision-making. Now basically all they have done is bring themselves in line with most Australian jurisdictions but in terms of continental Europe that is a huge step—especially for eastern continental Europe it is a massive step. The world is actually looking for leadership on this. So we have an opportunity to do something very special because if we start the ball rolling I can tell you that there are many, many countries poised that might follow. So it may not just be the people of New South Wales who will benefit. It could provide significant benefit for a much broader population of persons with disability. Thank you for your time.

CHAIR: Thank you for your time. There may be some questions on notice that will be sent to you.

Ms KAYESS: That is okay, but please note I will be overseas until 6 November. I am going to do some work in Brussels and then I am going to Geneva to the day of general discussion around Article 12.

Dr JOHN KAYE: When are you leaving?

Ms KAYESS: I am leaving tomorrow week but I am still available on email. Jonathan has my email address and I will still be receiving emails if you do wish to post any questions on notice.

(The witness withdrew)

(The Committee adjourned at 5.15 p.m.)