

CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into powers of attorney

Melbourne — 30 March 2010

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Mr T. Worsnop, Chair, Victorian Coalition of Acquired Brain Injury Service Providers, and
Ms K. Stringer, Community Partnerships Manager, Summer Foundation.

The CHAIR — I welcome Tom Worsnop from the Victorian Coalition of Acquired Brain Injury Service Providers and Kerry Stringer from the Summer Foundation. Thank you very much for appearing before the Committee today. You have received a copy of the terms of reference. I need to advise you that this hearing operates under parliamentary privilege. This means that things you say that might cause offence to people outside are protected but, clearly, if you say those sorts of things outside the confines of the hearing you will not be afforded protection. Hansard is recording what we discuss this morning and you will be sent a transcript later. You can make minor changes to that transcript.

We received a submission. Thank you for that; it is very helpful. We have 30 minutes for this hearing, so we will hand over to you to talk to us about your submission and address yourself to the terms of reference. We have some questions to ask you then.

Mr WORSNOP — Just in terms of opening, we represent a particular group, who are people with brain injuries. We are largely a service provider and policy body but we work closely with a group of people with brain injuries as well. The whole idea of acquired brain injury and the consequences of that is that we need to think of people in a rehabilitative framework in consequence of their brain injury. Brain injuries vary significantly from minor glitches in people's capacity right through to catastrophic injuries, so we are talking about a wide variety of people's needs post-injury. The key thing we consider all the time is the rehabilitative framework. After their injury and their rehabilitation from then people's capacities are changing consistently. That can vary from fairly rapid change and improvement in capacity right through to what we call slow to recover, or long-term slow recovery with significant capacity changes at the beginning and improvement over a long time.

Recovery is unpredictable. Despite the fact that there is a lot of pressure on the acute system to be able to give a prognosis early on, our experience in the sector is that it is very unpredictable. Some people with catastrophic injuries improve rapidly; some people with very minor injuries have significant capacity issues for the rest of their lives.

Communication ability is one of the key issues in regard to powers of attorney. The capacity to make decisions is often clouded by the capacity to communicate effectively. Just because somebody is not able to easily communicate their wishes does not mean that their ability to frame their wishes is changed as well. Being able to work with people with significant injuries and to unearth what is their capacity is probably one of the main areas of concern in acquired brain injury work

We work mainly within a human rights and citizenship framework along the lines of the Disability Act in Victoria, so we assume that people have capacity unless there is some sort of indication to the contrary. Being able to assess that is one of the key challenges. The area where we do most of the assessment is neurology, medical assessments around people with the medical capacity to make those decisions. I guess neuropsychology as a key profession is part of what we work with in terms of being able to decide what people's capacity is, so some of the issues about being able to support people are around trying to work with the professions that have the most knowledge in that area.

There is lot of pressure on families around decision making when somebody has a brain injury. That is assuming there is a family involved. Young people, and young men in particular, are the main group of people who get brain injuries. They are not traditionally a group of people who have even thought about the future. They are mainly in a framework of immortality at the age when they get the brain injury, so thoughts about powers of attorney and stuff are the furthest thing from their mind. Therefore, families are often in a position where they are having to gather around to make decisions on behalf of young people. That is traumatic, particularly for families who are going through major issues about the future of their child as well.

Making decisions under duress is a key feature of the time after a brain injury, both for the person with the brain injury and for the family — and, for that matter, the medical system around them, too, with people having to make decisions in acute systems when there is pressure on moving people out of beds. The capacity for people to make decisions is often a very slow one but there is a lot of pressure on people to be able to make those decisions quickly.

Ms STRINGER — We were speaking to some family members a couple of weeks ago. One of them said that when they came to talk to him about turning off the life support system for his son it occurred to him that it

had taken him longer to teach his son to ride a bike than they were giving him to make a decision about turning off the life support system.

Other examples of duress are when people say, 'You choose a nursing home or we will choose the nursing home'. Again, the capacity in our system to provide space and time and appropriate support to the people in it just is not there. We do not have the same sort of rehabilitation models in Victoria that they have in New South Wales, where you can give people the opportunity, the time, the resources and the support to undergo the sorts of rehabilitation they have available to make those sorts of decisions.

We also have a fairly diminished advocacy and information network in our sector. We have two advocacy positions and two services that provide information. In Victoria I think there are upwards of something like 10 000 injuries per annum, so clearly support around information and advocacy is not available to most people in this situation.

The CHAIR — Thank you very much for that. Perhaps I could start by going back to the point you opened with, which related to the assessment of capacity. You described capacity as having a functional and time-specific dimension that can change over the course of the development of the person who has the acquired brain injury. We have, of course, given some time to thinking about this, but could you talk to us about what you think should be the key elements of the capacity test and who should administer that? For example, should there be doctors with specific types of qualifications involved in such a test?

Mr WORSNOP — It is complex. Certainly neuropsychology is probably the profession that actually is geared up towards this most effectively. They have the training and skills to assess people's brain function capacity. I think the neurology profession actually is under a lot of pressure, so being able to make informed decisions when you have actually got to observe somebody over a long period of time to see how effective their communication and their decision-making capacity is is a real challenge for somebody who is doing medical-appointment type approaches to these things.

The CHAIR — Could you give an example of where you think a capacity assessment has worked very well and perhaps where it does not work so well, so that we can get a sense of where you are coming from on that?

Mr WORSNOP — One of the key people that we both know is a young man with a significant brain injury. He is in a nursing home. He has a good family and friendship network. His capacity to communicate is very limited. Now, 13 years after he was injured, he is able to blink a yes consistently, and that has been going on for a while.

What has been going on there are decisions about his life and about how his services might be set up, which have been done in consultation with his family members and a group of friends around him, but they spend a lot of time talking to each other about interpreting his will. That is a really effective way, but it is a very resource-intensive way of actually being able to find out somebody's own opinions about things.

It has been working effectively for a long time, under a lot of pressure, because the system is still difficult to set up around him. They consult with neurologists regularly and they consult with various allied health workers to assist them with how to effectively understand communication and how his communication might work, but it takes a long time to be able to do that. This is somebody with a significant injury, but the key thing about it is the time that it takes to be able to actually really understand this person's ability to communicate and to express their will.

In contrast, one of the things that often happens is that somebody may be in receipt of a service, like a rehabilitation service, and the service itself might actually want to reassess whether or not the way in which that service is being delivered is the most efficient and effective. What will often happen is that there may be divided opinions about that and it will be referred through to a neurologist to make the final decision.

Classically what happens then is that that neurologist will have a one-session time with the person to be able to understand how they function. They will have had a lot of reports and stuff, but they will have to make that decision fairly quickly and probably in a majority of times they can only make a fairly good estimate of what the capacity or decision making is.

Ms STRINGER — In other areas, when you are a practitioner, often people we work with fall through the gaps in terms of long-term case management and those supports that are picking them up sometimes six, seven or eight years post injury where their lives have fallen apart and, as a practitioner, it is about how they are functioning and the risk. It is not necessarily the degree of disability.

I have worked with people with what would be considered a mild to moderate acquired brain injury who make poor decisions which put themselves and other people at risk, and you are basing it not so much on the neuropsychological assessment but what is happening in their day-to-day life. I think that is particularly around the area of alcohol-related brain injury where someone may in fact be continuing to abuse alcohol and drugs.

Again, you are making those decisions on a continuum. You want to allow people to, as Tom said, within a rights framework, have as much say as possible around their lives but not to the point that they are at risk or put someone else at risk. You are really basing your decision making around capacity on the risk taking and their capacity, with support, to minimise that risk. In that way you would use the neuropsychological assessment to determine what approach your support would be, or what resources you need to put in rather than the degree of disability.

For me, when I am working, it is about not just what the medical profession or the neuropsychologists are saying but what you actually see that person doing. Over the last couple of years I have worked with a man who had spent 12 months in a locked unit at St Vincent's Hospital because he was HIV positive and abused heroin. He was discharged from there and provided with accommodation in a rooming house with a particularly supportive manager who supported him to pursue other kinds of interests. He has been drug-free for 12 months and is not practising sex, but if he did he would be practising safe sex because the supportive education has gone in. Now, 12 months before that, it was deemed that he should not be allowed to be in the community. That kind of stuff happens quite a lot if you can put the appropriate support and resources around someone and find the right place for them to be.

Mr CLARK — Can I come back to the point you made earlier about the pressure that decision-makers are often put under in an acute context? Are there any improvements that you would propose or could see done to relieve that situation? Is it a question of giving greater rights to attorneys or holders of powers of attorney or other decision-makers? Is it a question of better protocols in an acute setting to make sure that people are informed and have the time to make decisions? What would you like to see changed?

Mr WORSNOP — The key people around somebody at the time of brain injury are usually in crisis and it is about their own friend or family member or whatever. Being able to actually make informed decisions at that time is very difficult. People do rely on the medical profession significantly. I think there is a lot of trust in the community that the medical profession can actually make finer solutions to these things, but there is a lot of pressure on them, as I said, to be able to do this stuff efficiently and quickly.

What we know of is that there are what we call slow-to-recover places where people can actually be given more time in which to make these decisions. I guess that is the core to it: to be able to assess whether somebody may have the capacity but it is going to take a much longer time to be able to get to that and therefore the transfer out of acute into a much more time-available system is probably what is required. I am not saying that the neurologists and so on do not have the capacity to do it, but they do need more time to be able to do it effectively.

Mr FOLEY — I refer to that notion of power-of-attorney holder abuse and the pressure involved. You talked about the pressure for the medical profession and other institutional players and your submission also notes that particularly in rehabilitation circumstances there is some power-of-attorney holder abuse. How does that play out? Are there any particular issues associated with ABI that work through that as a difficulty? I get the impression from what you are saying that the family and time is the key issue to try to get through the difficulties from the institutional side of things. How do you see the potential for the abuse that apparently happens being dealt with similarly?

Mr WORSNOP — One of the things is the reviewability of decisions and being able to be realistic about it. Some decisions have to be made and therefore people are making them as well as they can, but a lot of those decisions can fix people within a place that they actually then no longer are going to be in.

An example of that is probably the issue of nursing homes, as Kerry mentioned, needing to be able to make the decision about where somebody should go. If that is being made done efficiently, it is almost like abuse because you are actually forcing somebody into a place where, six months down the track, they may no longer need it but because they have actually been assessed as requiring it, it then takes a lot of effort to get that assessment changed.

Another example which affects families, which I think is a really important one, is that, particularly when there is a compensation-type of case, the ABI system is divided between people who are compensable through things like the TAC and those who are not, but where there is a payout families are often in a position where they have to make significant decisions about investing money for somebody. One of those things might be that they actually then set up a room in their family home for their young member of the family. The money is then absorbed into that system and if the young person later on needs to be able to make a different decision, it is sort of locked. Their capacity to make a different decision is locked because of the investment advice that they have had. I am not quite sure whether I got to what you are after.

Mr FOLEY — If I am the holder of a power of attorney, financial or otherwise, in that sort of circumstance and the person has their capacities returned, how does that play out? Does that lead to abuse of the person who has the acquired brain injury, or can it?

Mr WORSNOP — Young people's capacities to make decisions might return. Their ability then to live the life they want to live might be then restricted by decisions that have been made earlier on around where they live.

Ms STRINGER — We had an example recently of a young man who is in a locked unit in a specialist residential aged care facility whose father has power of attorney and who has retired interstate. Our view is that that young man could live somewhere else. Again, I do not think there is any malice or intent around the decision making. The parent likes it where he is because he is safe. He does not have to worry about him. He is not getting those phone calls at midnight. He kind of retired. Our view is that if the young man were given the opportunity to look at alternative accommodation and spend some time out in the community, he would be able to make a decision about an alternative place to live.

Mr FOLEY — If I can extend that, the father is making, from his point of view, some risk-based decent assessments. Because you are approaching things from a human rights-based approach and wanting to support the person with the injury, there is a real conflict there.

Ms STRINGER — Absolutely.

Mr FOLEY — You are happy to support that there is a default position of the younger person making those judgements even if it brings it into conflict with the person who holds the power of attorney?

Ms STRINGER — It is incredibly difficult to have that person moved without the support of the family. It is easy for the system to support the family, because it is not easy to find alternative accommodation and provide the resources that are needed for that young person. One of the key things about the family, that Tom talked about, who support their son is that they are also very strong advocates. They are advocates for the system about that person having the most normalised living opportunity, whereas there is no advocacy for the young person who is in the residential aged care. It does not matter how hard we go at it, unless we have got the support of the family it is not going to happen.

Mr WORSNOP — I guess these complex situations can be set up. It needs resources to be able to support both sides. We need to be able to recognise that families are under a lot of stress. Being able to support them to be able to make decisions and have faith in the system is actually a real challenge. Not everything is available for what they need. So being able to actually make those decisions about what somebody's capacity is is really quite tough. That is where you need the time for somebody with a neuropsychology background or something who can assist with professional understanding of what capacity actually is.

Mrs VICTORIA — Would it be of any benefit, especially in the area of acquired brain injuries, to say there needs to be — and I do not know how this is mandated — an ongoing assessment criteria at certain intervals, but there also needs to be a review of a power of attorney, so that one goes hand in hand with the other, that is, an assessment of capacity. But rather than going, 'This chap is going to sit in residential aged care because that

is where his father deems is fit for him for his own peace of mind living up in Queensland', is that necessarily in the best interests of the young person? Then should his capacity be reassessed and the power of attorney be taken, for example, from the father and the young man being able to continue on with his life or give his power of attorney to somebody else?

Ms STRINGER — Yes. There needs to be checks and balances within the system to ensure we are working with the best information we have got at a given point in time.

Mrs VICTORIA — Can you suggest what those checks and balances may be?

Ms STRINGER — Again, I work in a framework of the less restrictive to the most restrictive option. I think it is advocacy, support and education at that lower end. What is good about this is that we even know that that person exists, that we visit them and that there is some sort of external scrutiny around what is going on. It is from that level right through to some sort of formal intervention around a review and assessment.

Mr WORSNOP — I guess the key thing we keep coming back to in the sector is the rehabilitative framework. Just going back to the rehabilitative framework, if somebody makes a power of attorney, is injured and capacity is assessed at a certain level, and if that injury has the capacity to recover, then we actually need to be able to put in a framework which allows the reassessment of their capacity over time. Within that rehabilitative framework is the key to it — that is, being able to recognise people's capacity to recover abilities over time.

Mrs VICTORIA — Then going back to I suppose a situation where you are saying that accommodation is found within the family home and there are adjustments made, whether that comes from compensation or whatever, should there be some sort of a time frame? As you said, it is hard to predict who is going to recover and to what extent, certainly in the acute stages. But should there be some sort of a hold on what is spent, because there is no long-term prognosis that you can assess immediately and would that then safeguard the person with the ABI later in life?

Mr WORSNOP — I think the problem with this is that one size does not fit all in these circumstances. I agree with you that in some circumstances that would be really important, because major decisions are made which lock people into lives that they cannot escape in a sense. The difficulty is actually at the early stages being able to understand what the prognosis is going to be. It needs to be applied variably according to circumstances. I guess one of the key things again, going back to my earlier comments, is that assessments at any particular time need to take into account the fact that it takes quite a while for people to be able to understand what capacity is at any time. Being able to make the decisions efficiently is working against good outcomes for people.

Ms STRINGER — In the disability sector we talk a lot about person-centred planning but often pay lip-service to that because what we do is we plan for the existing resources and supports that are available. If we truly do person-centred planning, that plan would accommodate the differences that you see.

The CHAIR — I am conscious of the time.

Mr BROOKS — Just quickly, your submission talks about most people you deal with, or the sector deals with, being younger people and probably those least likely to have considered the need for a power of attorney. Is there a mechanism or a way you think can be addressed to get younger people to think about these things? It is a difficult topic.

Mr WORSNOP — It is hard. My thoughts on that initially were how do we educate young people generally, because this group of people just happens to be one part of that. I guess the health promotion type of approach is the only one that really is going to be effective here. You have to educate the community to be able to get to these young people. They are relying on their families often to be able to help them with these sorts of decisions. Keeping it simple is probably the only thing that will get through to that young group of people too in a sense, because they like things to be matter-of-fact and straightforward. But it is clearly not an easy thing to get young people who are thinking of themselves as immortal to make wise decisions about powers of attorney just in case they have a massive brain injury that might actually affect the rest of their lives. I do not think there is an easy solution.

Ms STRINGER — It kind of seems a logical extension to some of the public health and information around drinking and violence. As someone watching that, working with people and having adolescents of my own, there seems still to be this kind of gap between even the notion that these injuries can occur and the long-term impact of that.

The CHAIR — We are out of time. I thank you both again for your submission and for spending some time with us today. As I said, you will be provided with the transcript of the Hansard recording of our discussion. I hope you will be open to Kerryn or Kerry contacting you about any further information that we might need.

Mr WORSNOP — Thanks for the opportunity.

Witnesses withdrew.