CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into powers of attorney

Melbourne — 17 December 2009

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Witnesses

Ms G. Pierce, Manager, Policy and Research,

Ms P. Paul, Coordinator, Carer Consultations, and

Ms M. Dalton, parent carer of an adult with a capacity disability, Carers Victoria.

The CHAIR — Thank you very much for attending this hearing today and for your submission. Hansard will be recording our conversation this afternoon. You will receive a copy of the transcript subsequent to the meeting. You can make minor editorial changes but not changes to the substance of it. The discussion this afternoon is held under the Parliamentary Committees Act. That basically means that if you make remarks here that somebody may feel are actionable, you will be protected by parliamentary privilege, but if you make the same remarks outside this hearing, you obviously would not be afforded that protection.

As I said, we have received the submission. I will give you a few minutes to set up and maybe talk to the submission or the terms of reference. Then we will open it up for some discussion and matters that we would like further information on.

Ms PIERCE — Thank you for the opportunity to present to the Law Reform Committee. I will say a few things about Carers Victoria. Carers Victoria is the statewide peak organisation which represents the needs of unpaid family carers to governments, service providers and the like. We are a membership-based organisation governed by an elected board.

I am Gill Pierce, the program manager for policy and research. This is Penny Paul, who is part of my team and goes by the title of Coordinator, Carer Consultations. She consults with families on issues that are important to them. Marianne Dalton is the mother of Kate, who is a young woman with disabilities. We are all going to have a bit of a say, if that is all right.

The CHAIR — Excellent.

Ms PIERCE — In our submission we have not looked at issues around enduring powers of attorney across all our constituents. We wanted to draw the attention of the Committee to the need to extend mechanisms for enduring powers of attorney, be they financial, medical or guardianship. This is to allow ageing families and other parents of people with lifelong intellectual disabilities to work with their son or daughter to put plans in place for future decision making. We estimate that currently in Victoria there are about 3000 ageing parent carers of people with an intellectual disability or a psychiatric disability. With the bulge of the baby boomers those numbers are going to probably quadruple. We will have to think about that. Most of those families care for their son or daughter in the home, but obviously their needs can change by sudden illness or disability or death.

Currently there is no framework in which ageing parent carers and their offspring can plan together for how they want future decision making to be done. People with a disability are commonly regarded as lacking capacity to appoint people to have the various enduring power arrangements, but many people with a disability have strong views about who they would like to assist them, both currently and in the future, when their parent can no longer do so. Ageing parents themselves can appoint enduring powers of attorney or guardianship for themselves, but they cannot make anticipatory appointments regarding the ongoing support of their son or daughter.

There are innumerable catch 22s in the current system of substitute decision making for people with a disability and their families. They do not have access to the mechanisms to appoint people to act on their behalf, and thus we feel they are disadvantaged relative to people who have capacity. Substitute decision-makers are generally appointed after a crisis attendance at VCAT. A more preventive and anticipatory approach is needed.

We have submitted the views we are expressing here today to the Law Reform Commission’s review of the Guardianship and Administration Act and also a modified version to the review of VCAT. What we want to do is ensure that all the people undertaking all the inquiries are aware of the needs of this particularly vulnerable group of Victorian citizens.

The process we are going to use is that Marianne Dalton is going to outline some of the dilemmas by describing her lived experience as a mother and then Penny will provide a summary of our position about what should happen.

Ms DALTON — Thanks, Gill. It is significantly difficult to be a parent of a person with an intellectual disability. Our daughter, Kate, is over 18 years. She would normally have legal rights, but because she has a lack of capacity she does not have legal rights. That has led us up some troublesome paths really. She is now 30 years old.

I will tell you a little bit about Kate so you get a bit of a picture. She was okay until she had some epileptic seizures at the age of four, but initially that was not a big problem. Her early view of her life was that she was going to go to university and go travelling. Things were pretty rosy for Kate. Initially she did well at school, but over some years the epilepsy became quite intractable. By the time she was in her teenage years she was having between 8 and 30 catatonic seizures every day. She wore a helmet, but the number of falls and the number of seizures actually damaged her brain and left her in a reduced situation. It has taken Kate a long, long time to accept what has happened to her. I think she has done very well. If I had 30 seizures a day, I do not think I would get up, but she never stops. She never took a backward step.

She is still very keen to participate in life as much as possible, but it is limiting for her. It has left her with permanent brain damage, which has resulted in something like an intellectual disability, psychiatric disorders and short-term memory problems. Life is tough for Kate. She still has daily seizures — not as many, but she still has them every day.

As parents we decided we would like Kate to reach her potential as much as possible, and for about 10 years we argued to get her some accommodation so she could get a bit of independence from us. It is a long story, and I will not go into it, but finally she is housed very nicely in a residential unit in Geelong. We live in Balnarring on the Mornington Peninsula, and Kate comes home for the weekends on the ferry. That is all possible because the ferry staff were trained in epilepsy first aid and Kate was travel trained to make that trip. That is probably the highlight of her life. She comes off the ferry with a big smile and says, 'I'm just like normal people, aren't I, Mum?'. At present she is doing what she can with her limited capacity.

We speak to her at least once or twice, or maybe even more, on the telephone every day, and she usually finishes the conversation by saying she is sorting out her life. 'I think I'll write letters to friends and family, and I'll make them a cross-stitch. Then I might go for a walk around the block to be healthy'. We hear that conversation over and over. That is where Kate's life is at.

On any day she has fluctuating abilities according to her mental health status and her seizures, but she is always trying to do something for herself. But for all the positives she has a very tough and challenging life. At times she needs someone who knows her really well to help her negotiate the complexities of life.

I will tell you about some of the problems we have experienced. On a family holiday in Cairns Kate had some psychiatric difficulties and was admitted to the Cairns hospital because of them. She was delusional, she was having seizures and she has an intellectual disability, but she asked to leave the hospital in a strange city and they just let her go. They did not inform us, or anybody really. Luckily we found her. It was that episode that led us to apply for guardianship when Kate turned 18.

Some of the other problems we have had are that on two separate occasions Kate was organised to go to aged care. She had not been asked, and neither had we. We managed to keep her out of aged care on both of those occasions. At another time her medication was changed by a new doctor, who probably was too busy to read the long history. That put Kate in hospital for a fortnight. Had we been rung we could have told him that we knew all about the drug reaction. You run into these problems along the line because no-one has legal status here. I think it puts Kate in a very vulnerable position.

I think sometimes authorities act in their own best interests rather than in Kate's best interests. If there are pressures on beds in hospitals, or whatever it is, they are able to act in their interests rather than Kate's because legally she does not have any rights really. It is not how you want the world to be, and it is not like that 99 per cent of the time, but that 1 per cent of the time it is not right; it is not good. I think it can lead to abusive situations. Since Kate turned 18 authorities have not routinely involved us in decision making. Sometimes they do and sometimes they do not; it just depends. We do not know that we are definitely going to be advised and included, and as a mum it is not a nice position to be in.

I will talk a little bit about the current guardianship and administration orders. When Kate turned 18 we applied for guardianship, and the tribunal officer, Mr Julian Gardner, was very familiar with disability and was very supportive. It was a lovely meeting. We all came out of it feeling supported. Kate was there, and we were given guardianship. I guess we wanted guardianship to defend Kate against the sorts of problems that I have outlined to you. But you have to go back after three years, and in that time something happened. There was some change, and the next time we went to the three-year review the presiding officer said, and this is a quote, 'It is now important for people to be independent', and he said that a guardianship order was unnecessary, 'because in a crisis you can get temporary guardianship in 24 hours'.

We rang to get temporary guardianship regarding one of the aged-care placements, and they did not ring us back. The lady on the phone said, 'There are no consultants here at present. They will return your call', which they did five days later. In the interim we had contacted the minister's office. I did not want her going to aged care. The minister's office intervened, and she did not go. That does not seem to me to be the most sensible way to run things.

Because we had guardianship and then it was taken away, we were left with administration orders. We have probably never really felt we needed administration orders. Kate trusts us completely. Someone with a lifelong intellectual disability does not have assets; any she has come from us. We have administration orders, which means we have to do a whole lot of very detailed accounting which we are not particularly interested in. We give Kate $100 every week, and I do not care if she buys books or ice-creams; I could not care less. To ask her to keep all the receipts is just nonsense. Every year she has to pay an annual fee to have our accounting audited. It is sort of like an insult to me. We just detest it. We cannot get out of administration orders without handing Kate's financial affairs over to the State Trustees. We do not want to do that. We are quite happy to care for Kate and assume financial responsibility and use family money for her needs, but it is all this looking over your shoulder and auditing and paying — horrible!

The order itself is reviewed every three years, and we do not take Kate with us any longer. At the first encounter with Mr Julian Gardner, he really had an idea about disability. I do not think the presiding officers since then have had any clue about the complexities about disability. They certainly do not demonstrate that they do. The whole thing for our daughter is so distressing as it is like a reminder of all she has lost. They are sitting up there, physically removing themselves by sitting at a higher level and she comes out of there distressed, so we do not actually take her, which is not what we normally do. We normally involve Kate in everything. That is not a pleasant experience, so between the bookkeeping and going to the hearings this is something we are pretty reluctant to hand over to our son. We will not be able to hand it over; that is the other thing. The tribunal will decide who to hand over to, and that is pretty horrible.

There is a presumption at VCAT that it is acting to protect Kate from our mismanagement. I know that in some cases they have to do that, but with most families caring for intellectually disabled people, their whole life revolves around this. You do not get any real interest taken in Kate or in you. Most importantly I think they do not have any understanding of all the complex issues around disability. I guess it is planning permit one day, disability the next — I do not know. You do not feel like you are understood at all. I think it is demeaning to disabled people and I think it is demeaning to their carers to limit the legal interest taken in those people with an intellectual disability to basic accounting and nothing more, when it is actually legal status that those people require.

I am interested in this, because for the last 11 years of my own father's life I acted with his enduring power of attorney — or powers of attorney — so I am familiar with what goes on there, and I can tell you no-one sent him to aged care or anywhere else without contacting me. Why cannot my daughter have those same rights as my father did? I think it is wrong. My dad had the advantage of someone in his family who loved him and who knew him well and could help him get the best quality life he could get, and I cannot get that for my daughter. I think that is really wrong. I think what we need for our family is a system by which Kate has a legally sanctioned right to an advocate. Providing Kate with the opportunity to appoint people to act as her enduring attorneys would go a long way to giving her the same security that my father enjoyed in his later years and a right that is afforded to all other people in the community who are fortunate enough not to have suffered an intellectual disability. That is really what I wanted to say. Thank you.

The CHAIR — Thank you.

Ms PAUL — Carers Victoria believes that individuals with a capacity disability are deemed to lack the capacity to appoint an enduring power of attorney and are conceptualised in law as perpetual children. The failure of current laws to provide a mechanism whereby individuals with capacity disabilities can appoint substitute decision-makers has left substitute decision making to family members, service providers and friends who are undertaking this task in an unregulated, underdeveloped and poorly conceptualised manner.

The problem with the Victorian Guardianship and Administration Act 1986 is that it appoints a substitute decision-maker, an inherently restrictive appointment, and so guardianship orders are rarely made. So we have the situation that arose for Marianne and her family where many people have no legal status and no recognised right to an advocate or designated advocate to act with and for them.

The achievement of a good quality of life for individuals with capacity disabilities who cannot represent themselves and who depend on the decisions of others requires legal support. In our opinion it is not reasonable to assign families, friends and service providers the role of substitute decision-makers without guidance and a common rationale supported in law.

This submission recommends that the Committee could best progress the rights of people with capacity disabilities and put in a place a succession planning mechanism for ageing carers by: firstly, expanding the scope of enduring powers of attorney to include a mechanism by which adults with capacity disabilities can appoint; secondly, developing a definition of ‘capacity’ that is decision and context specific; and thirdly, enshrining the principle of assisted participatory decision making — that is referred to in other jurisdictions as things like supported decision making or co-decision making. The province of Alberta in Canada has introduced a co-decision making order for people with significant impairments. Enduring powers of attorney founded on assisted participatory decision making would, we believe, support the autonomy of the individual to make decisions they can make.

In the United Kingdom the Mental Capacity Act 2005 defines ‘capacity’ as depending upon the ability of the person to make the particular decision that has to be made, so there is no static notion of capacity. It depends on what decision is required to be made.

The United Nations Convention on the Rights of Persons with Disabilities and the Victorian Charter of Human Rights and Responsibilities Act both emphasise that people with a disability should not be subject to special laws. So, laws must be reformed and altered so that they are universally accessible.

We feel that the two most protective mechanisms available to people with capacity disabilities are: firstly, relationships, hence assisted participatory decision making aimed at supporting and validating relationships as well as to some extent formalising them; and; secondly, education about rights, how to enact them and how to protect them. We are seeking a framework that provides for the ongoing education of people with a capacity disability and the education of their family members and friends, service providers and the wider community. This could be done with the production of a handbook along the lines of the UK mental capacity code of practice. It should explain the rights of adults with intellectual disabilities or capacity disabilities, explain capacity — how, when and in what circumstances it needs to be tested — how to undertake assisted participatory decision making and where to go for support.

The CHAIR — Thank you for that. We have just about eaten up all our time.

Ms PIERCE — Yes; sorry.

The CHAIR — No, do not apologise at all; it is just the way it has played out in this particular situation. If I understand you correctly, you are saying that in a situation like Marianne’s the law should be amended to accommodate a situation where Marianne could appoint another person who has a power of attorney for Kate in the event that Marianne is no longer able to fulfil that role.

Ms PAUL — From my point of view what I would like to see is enduring powers of attorney having a separate add-on bit that would make it possible for Kate in a round table meeting to actually make an appointment herself through the mechanism of assisted participatory or supported decision making. It would be necessary for somebody from OPA or from VCAT or a government statutory body like that to be present to sign off that that is not a coercive thing. But within the enduring powers of attorney that we have now — certainly in the *Take Control* book there is a list of principles which attorneys should adhere to — we need a more formalised understanding of the principles to which whoever Kate appointed would have to adhere to ensure that all her decisions were made in a participatory and supportive way, that she would make every decision she can make and would receive help with those that she cannot.

The other particular part of enduring powers of attorney as they are now is that people can appoint a substitute attorney. If something should happen, if Kate appointed her mother, Marianne, and something happened to

Marianne, there would at the meeting have been appointed the substitute attorney. Presumably in Kate's family's case it might be her brother. He would be present at that meeting and understand the responsibility that he would be taking on.

The CHAIR — And you are saying that there are precedents for that in law in Alberta, Canada, and the UK?

Ms PAUL — Alberta, Canada, has just embarked on this type of mechanism — October 2009. I do not know if there have been reviews of how it has gone. With the UK there is not so much. In the UK you still need capacity to appoint an enduring power of attorney, but I think the really interesting thing about the UK model is the code of practice that goes with their act.

The code of practice is meant to be read by every person who has contact with people with capacity disabilities, and it should inform their dealings with them. If it does not, they have to, should they go to their VCAT, explain why they did not act according to the way it is written about in the UK capacity code of practice. I really recommend that publication to you because it is very informative.

Mr CLARK — I think you have given us one of the most powerful and innovative submissions we have received during our entire inquiry, because you are breaking into new ground for assisting people with intellectual disability to take more control of their lives as an alternative to VCAT making guardianship orders. I suppose the alternative point of view people would say is, 'Well, the risk is that someone with an intellectual disability will be bundled before VCAT and persuaded to sign away all of their capacities', to which I imagine your response is, 'Well, no, because they would not necessarily give all powers under the EPOA; they would give only certain powers'. Is that correct? Or would you envisage, under your model, that there would be a range of things that the person with a disability may or may not authorise the appointee to do?

Ms PAUL — Thank you. I think that is an interesting question, because certainly if there was a member of OPA present at the signing off of an enduring power of attorney and it was uncovered that the person with a capacity disability has significant assets or might be expected to gain significant assets, certainly limitations could be written in by them as a safeguard. Say they were to inherit a house from an uncle and there was property to be sold, that decision would have to go back to VCAT. So you can put in all sorts of safeguards. That is another lovely thing about the enduring powers of attorney as they are now: you can write in clauses as required. And in this case, obviously, that would be a very useful mechanism that exists.

The CHAIR — Perhaps for the moment we will call it quits at that. This conversation will probably continue in one way or another; that is quite clear. First of all I thank you all but especially you, Marianne, for your contribution telling us about Kate. It is not an easy thing to do to come along and talk about yourself so personally in a public forum. I am sure I speak on behalf of the Committee when I say that we appreciate that very much.

Ms DALTON — It was going to be my husband, but he was Santa Claus today at the library.

The CHAIR — Thanks very much. I thank all of you for putting that submission together; it has been extremely stimulating. Kerryn and/or Kerry will probably be in contact with you, and you will receive a copy of the Hansard transcript. Thank you very much.

Ms PIERCE — We have only just found out about the Alberta mechanism, so should we formally present that?

The CHAIR — We would be very happy to receive that, yes; absolutely.

Ms PAUL — We would also like to offer the opportunity for you to meet with any of our constituents if you would like us to organise that for you.

The CHAIR — We can see how we go with the inquiry into next year, and we will see how that works out. Thank you very much.

Witnesses withdrew.