CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into access to and interaction with the justice system by people with an intellectual disability and their families and carers

Geelong — 20 March 2012

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Ms J. Pierce, individual.

The CHAIR — Thank you very much for coming today. This is a committee set up by Parliament to investigate things that need looking at in terms of law reform. This is our second inquiry. We are pretty informal. We would like you to talk us through your submission. It helps us most to focus on our terms of reference — access to justice for people with intellectual disability — and we will ask questions as you go. You are covered by parliamentary privilege in the room but not outside. We record everything. Could you start with your name and professional address and who you represent, and then launch into what you want to tell us?

Ms PIERCE — My name is Jacqui Pierce. I am here in some ways as an individual, but I am also currently a project manager, so I have put that in my background, which I have brought copies of for people to take. I am contracted by Karingal to project manage a service for them which focuses on people with a brain injury.

The CHAIR — Just to be clear, are you representing Karingal?

Ms PIERCE — I would say no.

The CHAIR — Your personal experiences at Karingal inform your view?

Ms PIERCE — Yes. I started working in disability services in 1987, so I am 25 years on, and for the last 8 years I have been specialising in the area of ABI. I suppose my particular interest today in terms of your terms of reference is to see where we have put in ABI and neurological conditions. I suppose what the last eight years have taught me is we do not yet have a level playing field in Victoria, so some of the services and supports afforded to people with an intellectual disability are not being applied to people with a brain injury.

The CHAIR — For the purpose of clarifying, could you give me your definition of what the difference is between the two?

Ms PIERCE — Intellectual disability generally is from birth, and it means that the person will have a lower IQ level than the norm. People with acquired brain injury, either from a trauma — so where there has been a particular injury to the brain — or from progressive neurological conditions where there will be a slow decline in cognitive ability — do not have an IQ lower than yours or mine. What they have is impaired ability with their cognition — their thinking processes, their planning processes, their ability to organise things in their mind and come out with a coherent answer. As a really good example, in a police interview if they keep being asked the same question over and over again, they will start to think that what they are saying in answer is wrong, they will get confused and then they will start to sound like they are not telling the truth or something, but it is not because their IQ is low. They understand the question but they have started to get their thinking processes confused, so it is a fundamental difference. Ultimately it is a cognitive impairment, and that is where, among other things, we need to move away from.

What I have done on page 3 is try to focus on some of the solutions that I see after 25 years of working in the field, the last 8 in ABI. I have put in there: move away from the aetiology. Let us start talking about cognitive impairment. The cause might be intellectual disability, brain injury or multiple sclerosis as the journey goes on, but ultimately there is a level of cognitive impairment there for people. What that means in terms of accessing and interacting with the justice system is that a range of supports need to be put around those folks to make sure that they are getting a reasonable outcome in the justice system.

I suppose my first recommendation was that we need to move away from causation to looking at cognitive impairment generally. The current systems that are in place generally work well, like the Office of the Public Advocate and the independent third person, but again it is very ID-focused currently. It is very underresourced and run by volunteers generally, and a lot of people do not know it even exists, so they would not necessarily call on it for support when they have come into contact with the justice system, so it is not well known in terms of an awareness campaign.

A real concern to me — I put that in my statistics at the start — is the percentage of prisoners who have an ABI. I would like to see a real commitment by the government to reducing the number of prisoners with ABI currently in the prison system. My fourth dot point is a review as to whether or not prisoners with severe ABI should be in the prison system at all. What are they actually doing there in the first place if they have been classified as having a severe brain injury? I would like a review done similar to what we do with intellectually disabled offenders. We do not necessarily put them into the prison system; we have another correctional service for them. Again, making the playing field level for people with a brain injury would be one of the things I would like to see.

An increase in ongoing ABI training for all relevant workers in the justice system. A really good case study of that is a young man I support. A few years ago he had been robbed and attempted to go to the police and report that. He knew his rights — he knew he had the right to go and do that. Because of his progressive neurological condition, his slurred speech and his uneven gait — whatever — he was perceived by the police as being drunk or drug affected and was basically told to bugger off and not worry about it — you know, ‘Because you are obviously another druggie off the street’. Thankfully he rang his father and said, ‘This is what has happened, Dad. I took my money out of the auto-bank and tried to report it to the police and got sent away.’ His father came down to the police station with him and explained to the officers. That ultimately ended up in a formal apology from the police, but the fact was that they responded that way in the first place and made the assumption that he was another druggie off the street when he had a progressive neurological condition. Again, it is not the police’s fault; just a lack of awareness and a lack of training. I do not think a one-off session in police cadet time is enough. It is about an ongoing awareness and training for police generally.

The CHAIR — On the issue of police being aware of who they are dealing with, have you considered whether some sort of identity card would be of use to address that issue?

Ms PIERCE — I am coming at this from a human rights framework, and I have mentioned that in the first couple of pages of what I have written here. I suppose an identity card for me could potentially be a human rights issue, because we are trying to move away from labelling and diagnosing people and trying to move towards celebrating diversity and difference in all its human forms. I suppose that would be my first question: are we labelling people by handing them a card? What are we achieving? I think it might make us feel better, because we have said, ‘We have had this new system that we have rolled out. We have spent all this money on these ID cards’. I think people with a brain injury generally would put the card in their wallet, and in five years time — if that is when it happened — they had contact with the police when they were stressed, upset and worried, they would not even remember the card was in their wallet. Personally I think it would become a white elephant. I think people with an intellectual disability similarly would not necessarily remember, ‘This is the point I need to pull out my card’. I do not know that that processing would happen in a stressful situation.

The CHAIR — If we are not going to recommend that idea, how do you alert police to the issue of somebody before them who they need to know more information about? Are there any other ideas that could work?

Ms PIERCE — I have attached a very simple brain injury screening tool. If we are talking about brain injury specifically, I think one of the challenges for police at the moment is they can come across as being drug or alcohol affected because of the slurred speech and the uneven gait — all of those things I mentioned. With this tool, for example, you do not need any qualifications to do this. I could walk in here today with one of these and go through this process with you. It is really very simple. It is what we call an initial screening tool. If the police had some concerns and thought, ‘Gee, I am not sure whether this person is drunk or drug affected’ or whatever, this is a one-page tool where they can get their heads around whether there is another underlying issue. To me, that puts the power in the hands of the police as an initial screening tool to do that very basic assessment. They might then say to the person, ‘Have you got, or have you ever had, some sort of brain injury? Do I need to get some additional supports in here for you?’. Something like that takes the pressure off the people with the brain injury or the intellectual disability to pull out a card, if they remember they have even got it in their wallet.

With people with a brain injury the other thing to remember is that with short-term memory issues I could say to person X sitting here, ‘Here is your card. Put it in your wallet’. In an hour’s time they will have completely forgotten I even gave them that card.

The CHAIR — Can you generalise to that extent? Surely there would be some people for whom it would be the focus of their attention that they have this card?

Ms PIERCE — For some people. I am not saying do not do the card thing. I think it needs to be a choice.

The CHAIR — It might work for some people but not others.

Ms PIERCE — And particularly people with a brain injury, if their short-term memory is affected, they will not even remember they have got the card — literally in and out; some people 5 minutes. I could say, 'Can you show me that card?', and they will say, 'What card?'. I will say, 'The card I just gave you 5 minutes ago' — nothing!

The CHAIR — So of the people we are considering in this review, what percentage would be in that cohort of people who would not even remember if they had it?

Ms PIERCE — Loss of short-term memory is fairly common, and capacity to learn new skills. Long-term memory is often there and still fully intact. The vast majority of people with a brain injury would have some short-term memory issues unless there is repetition, like constant retraining of the brain, and that would mean workers saying on a daily basis, 'Which card are you going to pull out to show the police if you have contact with them?', which again is a resource issue.

The CHAIR — This screening tool — has this been given peer review or given the tick by anybody? Is this a good thing to use or — —

Ms PIERCE — This is one I recommend to a whole range of agencies. If a youth service says to me, 'We have a kid coming in, and we are not really sure about them. There is something else underlying, and we cannot work it out', I will shoot them that and say, 'Start with this' because they are such easy questions: 'Have you ever hit your head or been hit on the head? Yes or no'. An untrained youth worker can go through this with a young person and go, 'Gee whiz — we have possible brain injury here. Let's follow it up further with proper neurological and psychological testing'.

What I find is that because brain injury people get overwhelmed and think they need to call in the professionals immediately and whatever, this tool works incredibly well with just an untrained workforce. You do not have to be a neuroscientist to implement this.

The CHAIR — Who is using this at the moment?

Ms PIERCE — I recommend it to anyone who contacts me for help.

The CHAIR — Other than you distributing it, is anyone else distributing it?

Ms PIERCE — I am not sure. I know an OT locally does the same. She uses this one — an OT that gets a call about brain injury. It is one that we found via the internet, and it is an American-developed tool. We could probably Australianise it a bit if we wanted to, but it is fairly generic and, as I said, fairly simple. I send it to secondary schools. Again, I often get calls from secondary schools saying, 'We have this kid in year 10 who was recently involved in an accident and was not diagnosed with a brain injury but is not the same', so I will send this out to the youth health nurse at the school and say, 'Go through this process with the student. If you get the yeses, get a neuropsych assessment done'. The youth health nurses love it because there might have been a kid who might have had a really brief period of unconsciousness following a car accident and have come back to school different but was not diagnosed — they had their broken ribs treated in a hospital or whatever but nothing was done about the mild brain injury.

The CHAIR — Vathani, could you just make a note that if we are going to recommend something like this, we need to look at the copyright issues or anything else connecting it to who produced it?

Ms PIERCE — I think what that does is take the onus as well off the person with the brain injury or intellectual disability, who may not remember they have their card in their wallet or whatever the issue is at a time of stress, and puts the onus back on the system to potentially identify whether there is a subsequent issue. I thought that was worth considering.

The other thing for me, I suppose, is what I see. This is whether it is a compensable brain injury or non-compensable. What I mean by that is that we have all the folks who get TAC and WorkCover support because their brain injury was via a car accident or work related versus people who were assaulted on the street and got their brain injury or had an accidental drug overdose. Neither of those systems is doing well in terms of early intervention and proactive, preventive services. What I constantly see is that we start with the brain injury following the road trauma or whatever the issue is, and then we have this massive downward spiral into drug and alcohol misuse, homelessness and the justice system. I see that often — where that is the trajectory. I think we can do a whole lot better in this state — particularly in the compensable sector, because the funding should be there for that, but also in the non-compensable sector — in stopping that trajectory so we actually prevent people getting to the justice system.

What happens is that you have the brain injury. People with a brain injury are four times more likely to develop a mental health issue, so we get that on top — we get depression from the loss and grief and trauma of the brain injury. Then we get the young 21-year-old guys starting to self-medicate the brain injury and the depression with alcohol, which worsens the brain injury of course. Then we get the young 21-year-old having the brawl in the local pub, being picked up by the police and not having any anger management strategies — because the frontal lobe has been damaged — so then we end up with resisting arrest and everything on top. There is this real downward spiral with people with a brain injury, particularly young men, because young men are two-thirds of the brain-injured population and two-thirds of brain injury are sustained under the age of 24. So we have a truckload of young men in which we see this downward spiral.

The problem for families is that they will often not call the police. They will often choose to call the ambulance, and that is not just for ABI. I experienced that back when I was working predominantly in the intellectual disability sector. Families are worried about the type of response their family member — their loved one — will get from the justice system and the police, so they will often call an ambulance rather than the police, because they do not want the person necessarily charged or in jail; they want them taken care of and looked after and supported. Because families are fearful of what the response is going to be if they make the 000 call to the police, they will ask for an ambulance instead. That is something I think we can do a whole lot better at, and that economically is much more sensible, because $10 000 spent on early intervention and proactive, productive, preventive stuff is better than $150 000 spent trying to react to a massive crisis. In terms of economics, I think that is a really important way forward for Victoria.

The other issue is equity of access. As I said, we have people with cognitive impairment from other aetiologies, and we need to at least make that a level playing field with what happens with people with intellectual disability.

Ms GARRETT — In terms of early intervention, do you have a thought on how that would work? You have young men, and however it comes they end up with a neuropsych assessment that says, 'You have an ABI'. What would normally happen in that situation, and what do you think should be changed?

Ms PIERCE — The biggest chasm we have at the moment with ABI is that you start your journey in the health system, so you have point of impact and point of injury. You have your ABI, and you start your life in the acute hospital system. Often you go from acute hospital to subacute and maybe rehab, and then you are discharged. When you are discharged, you are often discharged to float or sink on your own. That is where the chasm is. Under the recent COAG initiative around My Future My Choice, which was young people who were stuck in nursing homes, that is exactly why they were generally stuck in nursing homes: because at the end of rehab there was nowhere really to go, so it was into aged care. Often they are young people with brain injuries.

I talked about the fact that I think in Victoria — and I have a service model paper around this — it is a matter of trying to find out how to get this funded. Basically we have a fantastic system — the Victorian maternal and child health nurse system. We do not discharge a baby from hospital without referring them to a local community agency, that being a maternal and child health nurse. We have no expectation that this new mum actually knows what the heck she is doing and will cope. We put in place a safety net immediately. I have said that that service model is adjustable to people with brain injury, so what should happen is that when you are discharging a person with a brain injury from the health system, there should be an automatic alert to the local community health centre — the local community health centre is probably logical — so there is a practitioner there who picks up that individual and that family so there is no chance that they are going to fall through the gaps in the system.

I developed that service model, and I was hoping originally to get that piloted under that Young People in Nursing Homes National Alliance COAG initiative that has recently just finished its five years of funding, but again people were not focused on preventive, proactive early intervention; they were into building more shared, supported accommodation. That is desperately needed — I am not saying it is not — but, again, you can prevent the need for shared, supported accommodation if you can support the person to move back home, being the family home if they are young enough or, if they were living independently in a unit, supporting them to get back home by having a safety net. I have a service model already developed for that, which I could send to you if you want it. I did not bring it with me because I did not think of its relevance to this, but it is definitely a way of doing that early intervention well.

Ms GARRETT — It is a very interesting point that you make when you roll out those stats — two-thirds young men and two-thirds under 24 — and that that is compounding the issues, which is very common —

Ms PIERCE — Yes.

Ms GARRETT — particularly with drug and alcohol abuse and anger management. It is a well-worn path.

Ms PIERCE — It is a well-worn path, and the scary thing is that even in the compensable sector — because a lot of my work is done with individuals and families — there is not a huge difference between whether you are TAC-funded or not. In the past we have often had this perception — and I probably had it too before I started this work — that they were the 'lucky ones', because they had access to TAC funding. When you talk with families and individuals, they will go, 'There is nothing lucky about it; we are just fighting a different system. You are fighting with the Department of Human Services to try to get funding through that system; we are fighting with TAC'. Really, from a family and individual perspective, the outcomes are not that different whether they were compensable ABIs or not.

The CHAIR — It would be useful if you could send that through, please.

Ms PIERCE — I can do that for you, yes.

Mr NORTHE — Jacqui, just in regard to the ITP, I will not say there were conflicting submissions, but I guess there are ideas around the adequacy of that, and the notion has been put forward a few times of ensuring that there is a family member or somebody familiar there who is part of that initial discussion in consort with the ITP and police. What are your thoughts around that?

Ms PIERCE — I think it depends probably on the issue itself. If the person was attempting to raise an issue of abuse against a family member — so you would almost have to make a call on what the issue is at the time. I think it is incredibly important to have people familiar with the client because often people who are familiar will pick up on communication that is not necessarily verbal that the ITP would not pick up on because they do not know the person well enough. I think, generally speaking, as long as the allegation or the issue being investigated was not to do with family issues, probably that would be very useful. I think the ITP, as I said, is a great program, incredibly underresourced and incredibly unknown. They are probably the issues that I find with them. I do not think its effectiveness is necessarily to do with the service model but the fact that people do not even know it exists, particularly the people with a brain injury. They would not know because it has very much been in the ID field up until now.

Mr NORTHE — So from a practical viewpoint, how do you extrapolate that out and get that message out there further?

Ms PIERCE — That the program exists?

Mr NORTHE — For people to obviously understand that the program exists.

Ms PIERCE — I think a huge community awareness campaign has to happen, and I think that has to be targeted. You have all your peak bodies — you have peak bodies for people with disabilities now, plus the carers, and Carers Victoria is the peak body for carers. I would be trying to get families empowered about that information because I do not know that families often know that. The service providers are the third, through National Disability Services, the peak body for the service providers, again a big campaign. But there is no point campaigning unless you increase the resources, because ultimately what will happen is we will drown ITP. Particularly people with a brain injury — who often are much more in tune with their rights, because prior to acquiring their brain injury they were people like you and I sitting around this table — would start using that if they knew it was available and existed and they found themselves in need of that support. They would probably be more likely to use it than even people with an intellectual disability because they have a greater awareness of their rights.

Mr NORTHE — And another one, if I may. Obviously you have given a lot of thought and consideration to such things as a screening tool. If it was advantageous, if somebody has called into the station and an ITP is there to assist, who is that person — that family member or somebody who is familiar with the person? How do we from a practical sense understand who that person or persons to assist might be? I am picturing that the police might be there scratching their heads — —

Ms GARRETT — ‘Who do I ring?’.

Mr NORTHE — ‘Who do I ring?’. How does the system deal with that? If the Committee does come up with a recommendation for example to say, ‘Well, we think that is a sensible approach to go down this path, having somebody familiar with the person’, how do you do it as a process or procedural matter?

Ms PIERCE — That is a really good question, because most services still close their doors between 5 and 9. That is one of the really big issues, and it is one of the really big issues for people with a brain injury, and often that is why they do fall through the safety net. Look, I think there are probably a few options. I know — and I am presuming it still exists — there is a nationwide abuse and neglect hotline, or there was at one stage. I think that is still operational. That is just in my memory; I have not had contact with them for a while. Getting back to your card idea — which, as I said, I am not completely for or against — I am just wondering whether it would be another one of those wonderful things that we do that are well intentioned and it does not actually achieve the results that we need. Whether that is almost an in-case-of-emergency-type card as well — so not just declaring, ‘Hey, guys, I’ve got a brain injury’, but an in-case-of-emergency type thing, where there are contact details on that — that might make it a tad more useful.

Mr NORTHE — The previous people giving evidence spoke about a card, which would be of a voluntary nature.

Ms PIERCE — Yes.

Mr NORTHE — My understanding of that is that one could note their disability or intellectual disability or whatever it might be and that would go to the departments and the police, so the police, you would have thought, would have a record. Say if Russell Northe has an intellectual disability and I want to note that to the relevant authorities, then the police would have that on file and maybe as part of that you could have your familiar contacts, who they are. I do not know.

Ms PIERCE — Yes. The problem we have, too, is that we have no real one-stop shop because — again, getting back to the old difference between ID and ABI, for example — a lot of people with brain injury still are not even using DHS. You could not even rely on DHS’s records to have these people registered, because a lot of them will not be because they have not necessarily been told that since the legislation changed in 2006 they are eligible for services. There is a real communication gap between those areas.

The CHAIR — Thank you very much; that was very helpful. You have good ideas.

Ms PIERCE — Thank you very much. Sorry, we are one copy short there. I thought there was no point me coming in here and just grumbling to you; how we move forward from here is most important. That is a bit about ARC support as well.

Ms GARRETT — Sorry, just before you go, in terms of people not accessing services for a range of reasons that you have identified, is there also sometimes a failure in diagnosis for people to say, ‘You actually do have an ABI’ or an issue with acceptance, both individual and family?

Ms PIERCE — All of the above. One of my biggest bugbears at the moment — and it is something I am working on locally but I would hope, again, it could go statewide — is this. Even within Barwon Health, for example, a person may come in who has been involved in a car accident and may have had a period of concussion, but because the whole focus in A and E is on the other stuff — the broken leg, the broken ribs, the whatever it is — that is all dealt with, and unless it is a really significant, obvious head trauma where they have to respond medically, we are not even doing well at screening for brain injury at that point. One of the best examples I can give you, and it is something that, again, we need to work on as a state, is the number of people who have survived suicide attempts but in fact have hypoxic brain injuries. They have had a period of unconsciousness, not breathing, and therefore the hypoxic brain injury has occurred.

They go into A and E, they are triaged for psych services because it was a suicide attempt, and we discharge them. We have not even screened them for a brain injury, yet we know they were unconscious for 10 or 15 minutes. Whatever it was, they were saved — their lives were saved by the paramedics — but six months later that trajectory I am talking about has already happened and the family is starting to say, ‘My son is not the same as the son that six months ago attempted suicide. Yes, the depression is under control, but there is all this other stuff’, and mum and dad, not being medically trained, are going, ‘I don’t even know who this person is anymore’. It is then that often the crisis response has to come in. So we are not even doing well screening at the health end for brain injury. We are discharging people with brain injuries not having been diagnosed. Often it then gets misdiagnosed as a mental health issue or a drug and alcohol issue or whatever, and that is why I find that HELPS tool so often useful. The drug and alcohol person will come to me and go, ‘We are really struggling; we’re dealing with the substance abuse issue but there’s all this other stuff’, and I say, ‘Ask these questions. Do the screening and find out’. Often it is an underlying brain injury that came from either a fight on the street or a suicide attempt or something but was never diagnosed.

One of my big things at the moment is the health system making sure, before anyone is released, that if there was any chance of a brain injury, they get it screened and diagnosed. The second part of that is what I call the forgotten casualties, which are the children and families, because this person is sent home, and if it is mum or dad who all of a sudden has major anger issues because they have damage to their frontal lobe or whatever, there are kids at risk under that. One of the other things Barwon Health does not screen for is this. I say, ‘Well, how many kids does that man have?’ and they go, ‘What?’ and I say, ‘Well, you have discharged him to home, he has got a significant brain injury and there are all these other issues. How many children are in that family?’ — ‘Oh, we don’t ask that question’ and I say, ‘Well, these are the forgotten casualties that you are discharging the person home to with no supports in place’. That is that chasm again between the health and community services sector, and it is huge. It puts a lot of families under huge amounts of stress, and they will not find the services they need sometimes until absolute rock bottom has hit — until dad has ended up in jail or dad is whatever. It is a huge issue.

The CHAIR — Thank you very much.

Ms PIERCE — Thank you so much for your time.

Witness withdrew.