C O R R E C T E D V E R S I O N

LAW REFORM COMMITTEE

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

Melbourne — 21 February 2012

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The CHAIR — I am Clem Newton-Brown, the chair of the Law Reform Committee. This is one of three inquiries we are working on at the moment. The process is that we gather information and then meet with people and produce a report which then goes to the Parliament. Everything you say here is protected by parliamentary privilege, but nothing outside the room. Please start with your name, professional address and who you represent, and then launch into your submission.

Mr RUSHWORTH — My name is Nick Rushworth. I am the executive officer of Brain Injury Australia. We are located at the Royal Rehabilitation Centre, which is in Ryde in Sydney.

The CHAIR — So you are a national organisation?

Mr RUSHWORTH — We are referred to as the peak of peaks. I sit at the apex of a small triangle of state and territory organisations, and we have members in every state and territory bar the ACT, and those individual member organisations are in their jurisdiction the peak advocacy outfits for people with what is called an acquired brain injury — family members and carers. So I am the closest thing you will see to a national-level lobbyist on behalf of people with an ABI.

The CHAIR — Okay. Perhaps it would be helpful if you could start by assisting us with a definition of what an ABI is.

Mr RUSHWORTH — It is quite simple. It is any damage to the brain that occurs after birth. The only — and recent — exception to that is foetal alcohol spectrum disorder. So things like stroke, trauma, alcohol and other drug abuse, infection and diseases like Parkinson's, for example, would be classified as acquired brain injuries.

The CHAIR — So as far as the range of disability as a result of an ABI goes, does it range from so mild that most people would not even be able to pick it up to being at a state where you cannot communicate at all?

Mr RUSHWORTH — It is everything from a Saturday afternoon concussion at a football game right through to catastrophic injury. In terms of the consequences of the disability and in terms of what people's experiences might be like, broadly speaking there is what is called cognitive disability — people would have problems with attention, concentration, memory and so on and so forth — physical disability, paralysis, problems with vision, hearing disturbance, lack of coordination and so on and so forth, and what is referred to by some people as challenging behaviour and by others as behaviours of concern, which are things like irritability, impulsivity, disinhibition, and verbal and sometimes physical aggression as well. Broadly speaking as a generalisation, the more severe the brain injury, whether it is traumatic or non-traumatic, the more likely it is the person will experience a greater severity in those consequences.

The CHAIR — Of the range of ABIs that are possible, is there any pattern as to people who have issues with access to justice in terms of the type of ABI they have?

Mr RUSHWORTH — I am not so sure about that. What I can tell you, and it is certainly one thing I say in public forums regularly, is that many of my colleagues in the sector will say that brain injury does not discriminate. If you are in the injury prevention business, you want to try to capture as many pairs of eyes and ears to your message as possible by including as many people as possible within the ambit of the risk of the injury you are trying to prevent.

The truth of the matter is somewhat different from that, so to give you a good example — I am from Sydney, so I will give you a Sydney geographical answer to your question. Half of the traumatic brain injuries that occur in the young traumatic injury space, as it were, in the Sydney metropolitan area occur between Parramatta and Penrith. What I say as a matter of regularity and as evidence to bear this out is that those people at the greatest risk of acquiring a brain injury are drawn from exactly the same populations as those at risk of any injury. Broadly speaking they are from areas of social-locational disadvantage.

The CHAIR — Why do they have a high propensity to ABIs?

Mr RUSHWORTH — Because of, for example, particularly in that young traumatic brain injury area — so 18 through 35 — risk-taking behaviours, motor vehicle accidents, assaults, drunken falls and those kinds of things. What is really important about the life course of the disability in terms of the paper you have that formed

my submission to the Committee is that, if you think about it, you have people from a background where there is a greater than average level of contact with the criminal justice system to begin with. Then you add to that a traumatic brain injury, for example. The part of the brain most vulnerable to the most common kind of head injury — what is called a closed head injury, where there is no direct impact to the brain from an external object but there are forces of acceleration, deceleration and rotation applied to the brain — is what are called the frontal lobes of the brain. That is the part of the brain that controls impulses, regulates behaviour and so on and so forth.

The CHAIR — Is that mainly car accidents where — —

Mr RUSHWORTH — Car accidents, assaults and falls. Again, the most common kind of head injury across all external causes and age groups is what is called a closed head injury, where there is no direct contact with the brain per se but the brain is accelerated, decelerated and rotated in its casing. For whatever reason, and there is good anatomical evidence for this, the part of the brain most vulnerable to that kind of head injury is the frontal lobe — the part of the brain that is more likely to regulate behaviour, control, impulses and so on and so forth.

The CHAIR — Does the brain repair itself?

Mr RUSHWORTH — It depends again. It is a question of severity. It is a question of the age at which the injury occurs. What is called the optimal change point for recovery from brain injury is 29 years of age, so every year you add after 29, your chances of a quite good outcome from that injury are reduced. The overarching point of the paper I guess is that if you think about brain injury in those terms, this is a population at some of the highest risk of reoffence and reincarceration from a history of one or more head injuries and loss of consciousness.

Ms GARRETT — Does New South Wales have a similar approach to Victoria in delineating between ABI and ID in service access and the way in which the justice system responds?

Mr RUSHWORTH — I am not so sure that I know the answer to that particular question. What I can tell you, though, is that as a generalisation, as an observation that again is made in the paper, when it comes to the understanding and applying services in terms of eligibility for detainees/offenders with ABI, I think it is fair to say that Victoria is ahead of the game. I think there is a greater level of understanding. It probably almost extends from the work of one particular person called Peter Persson from the justice department here in Victoria. He has been very active in trying to get the concerns of prisoners with an ABI understood and recognised.

I notice from the appearance of an earlier witness to this committee that the research she referred to was conducted by arbias, which is a specialist brain injury service here in Victoria, on a sample of 117 adult prisoners, I think. What they found, conducting neuropsychological assessments on those prisoners, was that roughly 40 per cent would screen positively for an ABI. That is where that reference comes from.

One of the points that paper seeks to make and that I think is really important to emphasise with the committee is that this is a competitive business. Often disability types or diagnostic groups compete with each other for attention, for recognition. Engaging in competition with other disability types, other diagnostic groups, I think is sterile and unproductive, but it is the case that traditionally, as a matter of history, those kinds of services and supports in the criminal justice system that are forensic and are disability based have largely been targeted at intellectual disability and mental health, for fairly obvious reasons. The only claim the paper seeks to make is that, given the high level of criminogenic need in the ABI population within the criminal justice system, ABI be included in a genuine needs-based approach to disability, rather than relying on diagnostic criteria, for example.

The CHAIR — There is discussion here about the propensity of the number of people reported as having a head injury and being unconscious. Is that a fairly common thing with a head injury, to lose consciousness?

Mr RUSHWORTH — Yes. It is a reasonably good index. Obviously diminished or loss of consciousness is an indication of the severity of the impact involved. It is no great surprise that a lot of people who report one or more head injuries and loss of consciousness have backgrounds of multiple assaults — histories of child physical abuse, for example — mixed in with motor vehicle accidents and so on and so forth. I think at one

point in that paper I make reference to the fact that these are the injuries that they can recall in a survey conducted often by a complete stranger.

On that 60 per cent figure that is mentioned in that paper, there was a really good what is called a metasurvey conducted in the United States last year, I think, or the year before, that arrived at a 60 per cent figure as an average prevalence of traumatic brain injury particularly in prison populations around the world. I think it is reasonable to say that that could probably be an underestimate for a whole variety of reasons, one of which is difficulty, with a lengthy history of comorbidities and multiple assaults, of people in recalling the number of head injuries they have experienced. There is a whole range of really powerful disincentives for prisoners to disclose that they have a disability across the board, but particularly an ABI as well, if they have behavioural issues or problems with thinking, memory and concentration. Most of the estimates in that paper would probably be on the conservative side; that would be my guess.

Ms GARRETT — You have heard some of the evidence here today. According to people working every day in the field, there is a quite significant underdiagnosis of intellectual disability.

Mr RUSHWORTH — Yes.

Ms GARRETT — Is that similar in ABI? Because the nature of ABI means people have clearly acquired an injury. They have had a catastrophic injury or an assault or extended drug use and so someone has told them, 'You have an acquired brain injury'. Do you find there are a lot of people who perhaps do not even realise they have an acquired brain injury?

Mr RUSHWORTH — In answer to your question, both, I think for a whole variety of reasons. One of the submissions to the committee came from the Victorian Coalition of ABI Service Providers; I know they gave evidence here earlier this morning. Most of the ABIs involved in the sample in their submission were from 20 years back, so again, we are talking about people who may have had a motor vehicle accident in their teens, who went to hospital and received some treatment and were then discharged home. They may not even know they have any manner of disability. What I have found in my experience, in the kinds of awareness-raising presentations that I give, is that often in a crowd — in an audience — you will see a light globe going on in someone's head because they suddenly realise that the reason why Uncle Johnny was never the same was because of a motor vehicle accident in his late teens or early twenties.

I think we are better now at capturing brain injury, for obvious reasons, with better trauma care and better diagnosis, but there are a whole range of individuals in the criminal justice system who have lengthy histories of multiple assaults combined with a motor vehicle accident and drug and alcohol abuse who may not know they have an ABI or who may go undiagnosed for a whole variety of reasons. I think at one point in the paper it says that the gold standard in diagnosis of ABIs is neuropsychological assessment and can cost anywhere from $250 to $2500. They are not cheap. One of the recommendations of the paper is for a nice, plain English, user-friendly ABI-screening tool. One of the frustrations of being in this business and having a national view of acquired brain injury is that government agencies and government departments will often devise their own screening tools from scratch without first checking what has already been done.

It would be nice if there was a collective approach to these kinds of things, but I think that probably one of the most important things to say, and one of the most important points made in the paper, is that it is pointless to be screening prisoners for an ABI positively unless there are services and supports for them downstream. One of the points made in the paper by someone in Victoria, who works in precisely this area is, 'Please do not give me a screening tool and ask me to apply it unless I know that there is something positive for the person I screen positively, something that will address the unmet needs and the impairments I discover in them'. Does that make sense?

Ms GARRETT — Yes, absolutely.

The CHAIR — You give an example here of somebody who asked about a notice card or a publication showing they have an ABI, because the police thought they were drunk — —

Mr RUSHWORTH — Yes, it happens all the time.

The CHAIR — Are you aware of any national system of identification that people use, or do they just make up their own if they feel the need?

Mr RUSHWORTH — There are. Certainly one of the things on my wish list of things to do would be to establish something user-friendly and acceptable, in the broadest sense of the word — so acceptable to consumers; people who are living with an ABI — because there is a whole potential for another kind of stigmatisation of those individuals by carrying around a card. Many of them would perceive it in a similar way to being microchipped, if that makes sense. But certainly it is a great idea. I am meeting with the New South Wales police tomorrow to discuss the contents of this paper, and it is certainly something I will be raising with them, because the most frequent complaint I hear is about at that first point of contact with the criminal justice system, a police van or individual police and them mistaking someone's spasticity for being drunk and disorderly in public. That is very common.

The CHAIR — Those who are concerned about being stigmatised for carrying a card do not necessarily need to carry it; it is a matter of having the option there of there being a card — —

Mr RUSHWORTH — Yes, absolutely.

The CHAIR — Whatever state you are going to, the police know what it is.

Mr RUSHWORTH — As you would imagine, doing that and doing it well — so you have a high level of carriage of the card — would take quite a bit of work.

The CHAIR — It is incredible that it has not yet been done.

Mr RUSHWORTH — I am not sure about other disability groups. I think there are similar kinds of cards — in the mental health area perhaps — but it is not something we have gone down the road with. It is certainly on my work agenda.

The CHAIR — Are you able to make any comment so far as the access to justice goes and the difficulties for ABI people as compared to people who have a — what is the other term?

Mr RUSHWORTH — A psychosocial disability or — —

The CHAIR — No, other types of intellectual disability other than ABI.

Mr RUSHWORTH — Again, do not forget that they are different, so there is no overarching group. ABI and intellectual disability are two distinct disabilities; they do not sit underneath each other. I think there was some discussion in the earlier session about that. I guess part of the problem that the paper identifies is the regular confusion and conflation of intellectual disability and ABI in legislation as well. Certainly on the part of the nation's, dare I say, police, lawyers, judges and magistrates and so on.

The CHAIR — Do you think so far as access to justice goes, our recommendations need, in essence, to split into two, or more than two, to deal with the different types of disability, or is there some commonality that we should be looking at?

Mr RUSHWORTH — It is no surprise to me that given the traditional focus of disability advocacy, not only in this country but throughout the Western world in intellectual disability, physical and sensory disability, that you will find in legislation around the country, when it comes to access to justice and diversion for example, that there is embedded legislation for mental health and intellectual disability — that is one obvious thing to say. I think it would be ideal to reflect the way that disability policy is going more generally so that rather than relying on diagnostic groups or disability type, dare I say, legislation, access to justice, access to therapeutic jurisprudence, access to rehabilitation programs is not legislated by disability type or by diagnostic group but generally by unmet need or whatever kind it might be.

While I lobby for a particular constituency by diagnostic group, it would be ideal if legislation reflected the new way of thinking about disability and certainly the way that a national disability insurance scheme will think about disability — which is on the basis of unmet need rather than diagnostic group. Again, what you find time and again referred to in the paper is that Brain Injury Australia did a pretty comprehensive scan of offender rehabilitation programs right around the country. There was only one here in Victoria — at Port Phillip jail —

where people with an ABI were directly eligible. More often than not we found that the programs were only available to people with an intellectual disability or a mental health problem. Again, given the high level of criminogenic need in the population in my constituency — people at the highest risk of reoffending and reincarceration — there should be a much more generalised eligibility criteria based on whatever you choose to call unmet need overall or criminogenic need specifically.

Ms GARRETT — Are you able to expand or speak to the part of the submission regarding bail, fitness to plead, sentencing, et cetera.

Mr RUSHWORTH — If you are going to ask me to do a whip around, a lot of that work was conducted by the law firm Blake Dawson.

Ms GARRETT — Okay.

Mr RUSHWORTH — The overarching point right across those various areas — so bail, sentencing, fitness to plead, defence of mental impairment and diversion in general — is that most of the provisions in legislation are made for mental health, psychosocial disability and intellectual disability and not for ABI. Diversion or access to different kinds of sentencing options is not ordinarily available to offenders with an ABI, and that is a matter for some regret.

Ms GARRETT — Given the range of manifestations of ABI symptoms, are there identifiable characteristics within the ABI spectrum which would require particular attention in relation to accessing justice questions? I know what you are saying about not being bogged down in diagnostic — —

Mr RUSHWORTH — No, I think it is important. I think we are talking about the behavioural end of the spectrum. Whether you choose to call them challenging behaviours or behaviours of concern, I think one of the most important points made in the paper, when you think about the kinds of life experience that I described to you earlier — that young traumatic brain injury from somewhere between Parramatta and Penrith — involves the behaviour.

There is a reference to a study done by the brain injury rehab program in New South Wales, and it is my experience that that program is probably the most sophisticated of any in the country. They did a survey of 760 of their clientele and found that 50 per cent screened positively for behaviours of concern or challenging behaviours — things like irritability, poor impulse control, verbal and sometimes physical aggression and so forth. So rather than issues of physical disability per se or problems with cognitive disability such as memory, concentration and attention — and they are also very important when it comes to interacting with the justice system and understanding what you have been charged with and turning up for a bail hearing, those types of things — but in terms of contact with the criminal justice system and with police and that offending behaviour, clearly the behavioural aspects of the disability are the most important.

In fact one of the recommendations in the brain injury rehab program study is that, surprise, surprise, probably one of the least serviced parts of disability services in this country is stuff in the general behaviour management area, or positive behaviour support as it is sometimes referred to.

Ms GARRETT — So these are people who would be able to perform an IQ test, would not be defined as intellectually disabled, nonetheless their acquired brain injury has led to loss of inhibition et cetera, which has — —

Mr RUSHWORTH — Yes. You asked me earlier to reflect between New South Wales and Victoria about how they differentiate between ABI and intellectual disability, and this is the best I can come up with: one of the curiosities of the programs that are available for people who are about to be released from prison in New South Wales — something called a "Community Justice Program" — is that the only group eligible for that program is people with an intellectual disability.

If you look at some separate research done by Statewide Disability Services of Corrective Services in New South Wales, with over 700 clients who screen positively for acquired brain injury, 40 per cent of them have an IQ of 80, and a further 31 per cent have borderline IQ between 70 and 80 points. None of them, even though they might have behaviours of concern or are in need of positive behaviour support, whatever you call it, would be eligible for those kinds of programs. So if I can reinforce one particular point, while there are some

similarities between the manifestations of intellectual disability and acquired brain injury, particularly in behavioural settings, they are very distinct, different types of disability, and most importantly, in some ways, people with the disability think of themselves very differently.

I cannot tell you the number of mistakes I have seen where service providers have tried to provide social support to people with an intellectual disability and tried to combine them with consumers with an ABI and it has not worked because the lived experience of someone who is born with a developmental disability as opposed to an 18-year-old man who acquires his disability by virtue of a motor vehicle accident means very different life experiences that are difficult to conjoin. Does that make sense?

Ms GARRETT — Yes, absolutely.

The CHAIR — Thank you very much for that. It is very helpful.

Mr RUSHWORTH — It is a pleasure. You all have a copy of the submission.

Ms GARRETT — Are you heading back to Sydney?

Mr RUSHWORTH — Yes.

Ms GARRETT — Thank you for making the effort to come and talk to us.

Witness withdrew.