

Corrected

REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO DISABILITY SERVICES

At Sydney on Friday, 19 October 2001

The Committee met at 9.30 a.m.

PRESENT

The Hon. Jan Burnswoods (Chair)

The Hon. Dr A. Chesterfield-Evans

The Hon. Amanda Fazio

The Hon. I. W. West

ANNE THERESE CROSS, Director, Strategic Development, Community Resource Unit, Queensland, sworn and examined, and

JUDY ELLIS, Committee Member, Family Advocacy Unit, New South Wales, on former oath:

CHAIR: You have received a summons?

Ms CROSS: I have.

CHAIR: You know the terms of reference for our inquiry?

Ms CROSS: I do.

CHAIR: You have not made a submission. It might be better for us if you open by telling us about the things you do and, because of your knowledge and expertise, give us some ideas. I think probably that is why we did not prepare any formal questions, because we felt it was much better for you to tell us what you think it would be good for us to know.

Ms CROSS: I do not often get that opportunity, so thank you. In the way you framed the letter to me you said you were interested in innovation, especially in accommodation services, so what I thought I would do is start to talk about where I think we are up to in the field more broadly and what that means about innovation and what some of the strategies and issues are that would help drive some innovation and change.

Broadly, as I understand what is happening in New South Wales, it is very similar to what I am seeing in most jurisdictions, at least in Australia, and that is that the struggle to try and keep up with unmet need and crisis related stuff is, in a sense, impeding any further evolution of the solutions that we need to find. I think also it is really concerning that, despite the fact that over the last decade or two we have had very broad legislation which offers a lot of promise, policies which offer a lot of promise, by and large what we are continuing to deliver are quite standardised solutions, and what we are finding, of course, is that those solutions, which in the accommodation area are group homes, are not going very far to meet the overall parameters and the problems and issues that people are facing.

That difficulty has led me in the work that I do to look at what we are doing, the assumptions we are making here, and what is that leading to in terms of the kinds of solutions.

The whole evolution of the group home as a model, of course, is the post-institutional solution, it is the solution that we came to when we decided that we could not have the big institutions any more, and we have not quite settled that question but still the dominance is the group home, as you know. What research is showing is that group homes are struggling and indeed do not deliver on most of the promises of our legislation and policy very well. In fact, unless numbers are very small, research shows that unless we get numbers down to the one, two, three type mark then in fact we do not do very much about most of the institutional practices, which were our concern in closing the institutions, they are just being replicated largely in the group homes, and research across the world is bearing that out, so that is a concern I think and should be a concern for the field more broadly.

I think the second thing is that what is still operating as a major assumption in terms of how we meet the problem is that we largely are evolving systems where families and their friends hand over to the care of either the non-government or government sector a family member, so that we still largely are operating a model which passes the care and responsibility from family and community to the service system and, while inevitably there will be a need for that, there will not be solutions for everybody outside of that, it seems to me that it is a fairly flawed assumption to make because, as we know, people with disabilities come from families across the whole socioeconomic perspective. In a sense the families offer the whole range of human potential that is there - the good, the bad and everything in between - and yet largely what we are offering is one solution. When you think about that, people's lives and the way we all evolve our lives, of course, while there are a lot of similarities, there are also many, many differences.

So part of the issue of innovation is how can we drive some sense of finding a range of solutions that allow us to use the whole range of potential that exists within the community, what

exists amongst families to find long-term solutions for their family member, that exists within communities to find some of those solutions, and indeed what services, so I think we have invested all our babies, all our bucks, into one kind of solution and the very nature of the crisis means that we are just replicating and expanding that one solution, by and large.

In the last decade I suppose my interest has been in looking at: Can we move this on at all? Can we deliver on the promise of the legislation in any way? I think to do that we have to actually look at ways that can capture and work in partnership with the potential capacity of families and communities to evolve solutions and so my work has been particularly interested in looking at how we strengthen, support and resource families and communities to find solutions that are safe, that are sustainable in the long-term, et cetera, that are of high quality and that are, of course, in the domain of ordinary lives.

Because of the crisis, I think what happens is that even when there are good intentions at the legislative and bureaucratic level people just get tied up in the crisis and they never get to it, so what this means I think is that the very acceptance of the need to drive innovation has to almost be a mission type question for bureaucrats, for policy, that we have to actually make it part of the core business, albeit a relatively small part in my view, but you just do not get it unless you pay attention to it, unless you put in some effort and put something on the table that does it.

One example of that in Queensland was the development of the Community Resource Unit in 1988, so it is 12-13 years ago now. Queensland was quite stuck in its service delivery models - it was the earlier phase of this current crisis, if you like, it was the wave before this one when the system was stuck, the Government was stuck, it could not get any movement - and a group of families and professionals got together and conferenced this issue. What emerged out of that was this notion of developing an intentional strategy to drive change and innovation within the State and, in a sense, Community Resource Unit became the focus for that; but I think the first issue was that it was agreed that there needed to be an intentional strategy. The second thing was that the Government of the day at the Commonwealth level - because this was pre-CSDA days, but the State were partners in it - also agreed to fund such a strategy to provide some resources to try and drive some innovation; and then, thirdly, to make some funds available for projects that might help us deal with this question of innovation. So, thirteen years down the track, Community Resource Unit has been working across the state and has supported the development of a whole range of initiatives and projects that are trying to deal with this question: is there some way that people can get decent lives in an individualised way within their local community, where their families and friends are still part of the solution, so that they are part of it. There are lots of projects that exist. It might be helpful to describe a few of them.

CHAIR: Yes, some examples would be good.

Ms CROSS: Some of them would be where, say, a group that I have had connection with for over ten years, where a group of, say, ten families in a local area in a couple of suburbs of Brisbane came together with the purpose of trying to help their sons and daughters get a home of their own. Their sons and daughters were people who had multiple disabilities, significant autism, a range, across the spectrum. Two of the people in that group of ten are people who have had quite lengthy institutional and group home kind of experiences, where their families have in fact brought them home because of the neglect and abuse that they suffered in those settings. There are ten families.

This group of ten people initially were auspiced through the Community Resource Unit, so it became a host body to them, but they became incorporated in their own right, so they are a community association, albeit a small one. They work collectively to support each other to evolve homes for each of their sons and daughters, so the ten people are all now living in their own places, not together, and in a wide array of circumstances. In some situations someone is living in a house that their parents bought for them, some people are in public housing, someone else is in a co-residency, public/private tenancy arrangement. There is a range of options.

CHAIR: But none of the ten is living with anyone else of the ten?

Ms CROSS: No. The collective is at, in a sense, the broader community level around the ten people; it is not in the living arrangements for each person. Because it is local, quite a few of the people live within a block or two of their family, they live quite close, so people have been able to either find a place there or negotiate with public housing to get a property close to where they live; and the group operates from the assumption that the major responsibility for evolving this is the

responsibility of families and their friends.

The funding for it, each of the individuals has some funding. One person got a significant package because they came from the institution, so as part of the institutional devolution arrangements got a significant package. All of the remainder are operating within the arena of 35 hours to 50 hours or so of support per week, so it is very much within the normative range of support dollars that are available to people or that in theory are available to people – not everybody gets it, of course, but it is certainly not extreme packages – and there is a small amount of infrastructure dollars in the form of a coordinator for the ten people; so there is a service arrangement, but in all circumstances the arrangements are shared, the care arrangements and support arrangements are shared between the paid support and the families and friends of the people.

It is now ten years down the track. The ten people are doing superbly and in many respects have surpassed most of our expectations about their capacities and their growth and development.

CHAIR: What is their age range, roughly?

Ms CROSS: The youngest would be in their early 20s through to someone just turned 50, so it is largely the middle-aged/younger middle-aged group of people. The families mirror that, and so there would be some families who are still in their 40s, most in their 50s, but one mother who is in her early 80s, so right through that kind of spectrum.

What that group has been able to do that we have never cracked in our group home systems is that they put a lot of effort into building the supports and networks around the individual as well as at this kind of collective level. When I first started meeting with this group of families we used to meet in a pretty ordinary school room in a local school, because one of the parents was a teacher, so we used to go and meet there and it was just five or ten people. While there were amongst that group of ten a couple of parents who had quite clear visions about inclusive lives for their sons and daughters, and some of them had come through the system, so had rejected clearly group homes as an option because of what they had seen happen to their sons and daughters, the rest of the families were the typical range of families that you would meet. They were people who knew they did not know what was on offer and they were, like all families, worried about the future and worried about the long-term care of their sons and daughters; but over the period of time we were able to agree on a whole set of principles and assumptions about that people would be safest if there were people in their lives, that that is what keeps people safe and, so, in terms of building for the long term security for a person, that certainly had to do with service, but it had much more to do with the networks and supports around the person. A lot of effort has gone into that.

The ten year anniversary last year, I was telling family advocacy last night there were over 200 people that were personally connected to the ten individuals that were present at that gathering, so from a group of a pretty ordinary five or ten families who were all feeling fairly isolated in their own personal struggle, we go to this kind of gathering ten years down the track of a couple of hundred people all of whom are connected to those people. Structurally you have a small community association that has made decisions to stay small. Lots of families want in on this, as you could imagine, it is a very attractive option to families and families actually get very attracted to the notion that they are not handing over the care, that they are part of the solution, that this is part of the long-term way of sorting something out for people. One father would say very clearly, “I don’t know what’s going to happen to my daughter when I die, but I know I’ve done everything I can, I know there’s people in her life who care about her, we’ve got all these things in place including some financial matters”, so they started to look at issues around her long-term financial security as well, and they have done a lot to help her evolve her own life and gain as many competencies as she can.

This is a young woman with severe autism, with quite significant intellectual disability they think associated with that autism and her capacity to even be in a social situation ten years ago was extremely difficult. I can remember one time I was at a social situation and she had to be out, you know, up and round and out all the time. Now she has poise, she has capacity to be in a social situation, she is a pleasure to be around; so her getting a life and getting some control over her situation has been enormously – I think it has just given a lot of solace to the parents in thinking about her, because not only have they got people around her that will look out for her, but she herself has grown and developed, so they feel clearer about her capacities. She had never used a phone. She does not have much speech at all, but she now knows to pick up the phone and press the pre-dial number, so in a sense she knows how to get hold of somebody if she feels she needs to. On one

occasion when a support worker had not turned up, she did precisely that, so she actually had learned how to problem solve her own situation. This is something people would not have expected of her ten years ago.

That is one example of community association, government funding, more or less within the same range as what anyone would get. In fact, this would be operating at a cheaper rate than what the average cost in a group home is. That would not be the case all the time, but in this situation across the ten people this is not average. In Queensland the average cost in group-homes is about \$76,000 per person and they would not be operating anywhere near that level of funding.

They have been able to in a sense put together the resources of government, public dollars, with family resources, with community resources, so you kind of value-add in that sense, so even from a cost point of view this looks to me like a better option. I think as we look at all of the unmet need it is fairly scary when you translate that into the dollars that that would take and I do not believe we can afford it, apart from anything else, so I think we both need to find ways of working with people that should be in their own community and help them evolve their lives, but also that help us use the full range of resources that might be available to them, because when you think about disability coming from across the socioeconomic perspective, this is not a silly option. Not everybody has got nothing to contribute here. Even families who are much poorer – and this group, there is a mixture of financial situations; there is one family who did buy a house, take out a mortgage to buy a house for their daughter, but by no means could other families afford that, so it allowed the option of people being able to put in what they are able to put in to help secure their future for their sons or daughters.

There are examples of these small collectives of families who are either in small community associations or who are in hosted arrangements through another organisation in many locations across Queensland. There would be groups in most of the regional centres. In Brisbane there are several.

For instance, this group is a pretty good example of the model and families want to be part of it; but they made a decision that, no, if they were going to stay true to the ten people, they actually had to be quite self-interested, it was quite a co-operative kind of model in a sense, they had strong interests of looking out for the people they were concerned with, but they kept a list of people who contacted, and then Community Resource Unit with that group of families called a meeting of the families who had made an approach and we invited some other families who are also known to us and there is another group that has been forming and working together for several years now, in order to try and evolve another group that is like this. I heard on Friday that they just got some infrastructure dollars from the department, which will give them some co-ordination dollars. Two of the people have individualised funding, but there is no capacity to make this happen around people.

Co-ordination dollars will both help that happen around people who have got dollars, but also allow them to start working with the other eight to ten families to start to do what is possible now to keep building people's lives, because people's lives do not start when you get dollars. In a sense what you can do and how you can do it, you need to take every opportunity all the time and to put support into the families to keep working towards that, to use little bits and pieces of one-off dollars. Homes West, the group I was talking about, did not feel right that people would just go from a home to the home of their own, because people did not quite know what would work for them, so they did quite a few years of people going off and house-sitting other people's places, going and staying in furnished apartments, trying it out for a month at a time, but they also, through their networks, offered this house-sitting service to people, so people with disabilities with a support worker would go and spend time in other people's homes, so the families built up a much better view of how environment might affect what their sons and daughters were able to offer, so they built it up and the notion in this new group, River North, is to do exactly the same. As I said, I was pleased to hear that they got some of the structure dollars the other day to evolve that.

There were other groups in Brisbane coming out of the devolution of institutions where two people were living in a group home that was under the auspice of a non-government agency. That was not going well for their sons, in this case, and so those two families in fact formed a small organisation and the funds were transferred to that organisation and the families now run the group home, so part of what we are working on with them is the long-term sustainability issues.

CHAIR: When you say they now run the group home, is that for two people or for the two people plus others?

Ms CROSS: Just for the two at this point. They have not made a decision about whether they will expand that or not. That has now been happening for about two years and is operating with all of the typical accountability and industrial and occupational health and safety kind of arrangements and is operating well. A review was just done and people feel it is coming up very well. The people are doing well and the families are far more involved and close, so again the resource of the family as a safeguard, as being part of the solution, is built into the model, but there are many options.

The Hon. IAN WEST: I am trying to come to grips with a couple of issues. One is the issue of funding at a State level and how you come to grips with the resources that are needed; how do family advocates get the expertise to be advocates and be involved. The next question is the question of responsibilities and how you overcome those issues of occupational health and safety, industrial relations issues, being the employer, et cetera. The final issue is that of the diversity in the group, how you actually get a group together, how you determine what a group is?

Ms CROSS: If I can start with your second point, which was really about how do the families get to be competent in this, and relate that also to the question of how they come to be a group, there is absolutely no doubt in my mind that you need to build into your system the support and technical competence to be available to these small groups to enable them to flourish, so in putting up a model we are not just talking about A being the only option. It is always, in my view, A plus B, and the B bit is the competence to help people sort through those issues, to connect them into the various legal and other things that they need to understand and to help them through the processes of thinking through, well, how do we not just repeat what other people have done?

If this is truly about innovation then you need to build in something that supports people to actually bite off something that is a bit different and to try some other things, so you need to build in at a systemic level the capacity to support these small groups. In Queensland that has largely been Community Resource Unit. There has been other money available as well, but over a very long period now there has always been available within the system dollars to support this level of activity, so quarantining some dollars, and when you think about the budgets we are talking about, I am talking about a very tiny proportion of this. I think that is the other thing to remember, that to drive change, at least initially, you actually only need relatively modest levels of dollars because in a sense what you are doing is saying let's take some resources, take them out of the mainstream of the system and put them on the edge of the system to create some new possibilities and options, low risk, but really invest there, so take it out of the mainstream, position it with families and people with disabilities and make that available. To quarantine some resources to enable that to occur is important.

Secondly, to understand that ethical, moral and technical expertise required to develop these services the families will not necessarily have, but it is not that hard to get it to them if you have a strategy for supporting that to occur. For 12 years Community Resource Unit would have worked with many, many of these groups at that level, so helping people sort out who they were, what they were, who was in, who was out, as well as the technical expertise around employment responsibilities, industrial responsibilities, accountability responsibilities, financial and audit responsibilities and so on, and of course there are lots of resources available around those matters. What I have found is that families take this very seriously, all these matters, and in many respects I think they have proven to be as good and better employers than many of some of the non-government agencies - maybe I should take that off the record.

CHAIR: I think we might have heard comments like that before.

Ms CROSS: Well, at least in Queensland when you look at low rates of pay and all those sorts of things, there were far more abuses within the systems that were largely built on strong charitable models, people were very lowly paid in our major agencies. The advent of the awards within the system, and of course all of these small groups and agencies have been gathered into the award process so nobody has escaped that, so people are all paid according to the award system, but the large agencies have done a whole lot of enterprise agreements and in some of those I think people are not getting as good a deal as if they had stuck with the award, whereas all these small groups are largely working with the awards, and especially the Australian Services Union award, the SACS award. On the industrial front I think people are doing okay and on the technical side of stuff that relates to accountability and financial matters there have been no major kinds of crises or difficulties or fraudulent stuff, and I always say it is much, much easier to track what is going on within an agency that is running a budget of \$200,000 than it is to track what is going on in agencies that run budgets of

\$30-50 million, which some of our large agencies are.

Going back to your question, when you think about trying to get innovation happening, you have to quarantine dollars. You also have to recognise the need to put in some technical competence or advice for people. I think if you want this to be outside the mainstream, given that the mainstream is so busy with trying to just keep a modicum of quality going within our major service systems, then you have to situate at least some of that also with the families and people with disabilities.

CHAIR: In Queensland what would be the rough breakdown of what you call the mainstream and what you call these more flexible and innovative--

Ms CROSS: It has become muddier in the last few years with individualised or so-called individualised funding. Most of that, of course, is going back into the major agencies, but going back about two or three years it had grown to being about 30 percent of the overall budget that was going to the non-government sector, so if you took out the DOCS type components, it was going into quite small efforts and projects, so it is a significant part of the sector in Queensland. There are these small consumer family-governed projects. Also Queensland has pioneered - it has been done in many other places in the world - funding through small companies, not for profit companies, so there are some individuals self-managing their funds through a company arrangement.

Ms ELLIS: And that is funded by the Queensland Government, by the department.

Ms CROSS: Yes and that, of course, has a higher level of formality than what you see happening in Western Australia where the self-management of funds has much larger numbers of people and people are not required to incorporate in order to self-manage funds within Western Australia, so they have found ways of dealing with the accountability issues within the current system. Of the 7,000 or so families in Western Australia who are supported through Local Area Coordination - I am not absolutely sure of these figures - I believe in the region of 3,000 or 4,000 people are self-managing some levels of funds, and as the working model families who are in the adult arena that includes significant packages of money where that has been self-managed.

In Western Australia they have had 13 years of Local Area Coordination and there is a significant body of literature available, many evaluations and Productivity Commission reports that are available about that scheme, and my understanding of that going back to some of the industrial matters and things is that the commission has been in court about twice in that whole period of time over matters related to how families have employed people, so very low incidence. The level of any misuse of funds has been tiny, so it has not caused them any significant problems at all. So in a systemic sense there is some very good material and evidence to look at through the Western Australian scheme.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Can I take this a little further? It seems to me that governments are always reluctant to fund smaller groups because they are harder to manage. If you are a timid little manager, you are much happier to give it to someone who is church based and big than a lot of little people because you do not know what they are doing, you do not know them and talk to them, it is hard to keep track of them. The other thing perhaps is that, putting it in to human resources and facilitating, they cannot see it, whereas if it has gone to an institution for beds or food or wages, you can see that we looked after so many people in a bed for so long and it cost so much, we can compare it easily. In a sense it is a distrust and an inability to manage small things and the combination of the two ends up being missed allocation, so group homes are less efficient per person, per bed, than big institutions and if you created a whole lot of little institutions you would actually be perpetuating the problem, although you would call yourself progressive, and I think that is where we are stuck, is it not?

Ms CROSS: Yes, absolutely.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: To put it really bluntly.

Ms CROSS: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: And it is a question of getting someone in management a little more daring. I mean if there was someone a bit more daring and you said let's do a daring experiment, we've got six facilitators who just wander around the countryside putting groups

together, groups of people who will manage their children, partly government funded and partly trusts or whatever from their own intrinsic resources, we will set those up rather than X group homes, which we could do with the same amount of money, presumably you would have six facilitators at a cost less than a group home by quite a margin - I do not know what it would cost, but you probably do - but we do not seem to be able to do that in New South Wales. Is that your bottom line?

Ms CROSS: Well, in a sense legislatively you can.

CHAIR: But conceptually you can not manage it, managerially.

Ms CROSS: That is right and in a sense this is a problem in many jurisdictions at the moment. The first issue is to go back, this absolutely has to be on the agenda, because if we make this a focus and say that one stream of our core business, albeit a small one, has to be to drive innovation and change because we are stuck, then that opens up the possibilities. You then, of course, do need the leadership, the daringness, if you like. At a risk level, when you look at the evidence within Australia and overseas, there is actually very little risk in most of these models; and you can still count the numbers, so if you are funding ten people you can say there are ten people who know they have a home of their own and what is happening for them, so we can still chase, we can do evaluations, we can still do reviews and all of these groups are subject to those levels of quality control and accountability. There are no different expectations.

I do think we have to struggle with how we make sure those accountability requirements are not overly onerous. That should be true across the system. I think there is a different level of accountability that is required in the different circumstances and at the moment, of course, we have standard accountability as well as standard solutions; but by and large I do not think there is much risk. You do need a daringness, you do need a capacity to say, "we can get through this" - just like we closed the institutions, or that we knew we had to, and we have in fact done that successfully in many places - we can get through this problem as well and we will find some solutions to it.

I think you do need to think about situating the requirement quite senior in Government. I think the question of where you locate the resources to support this is a more open question and in my view in Queensland it has worked far better putting it into a community association that is related to families. We have had a very close partnership with Government now over twelve years, I was the director for twelve years, so we have worked solidly with people and worked with agendas and things. I think you can do that in partnership with Government, and put it out there.

Ms ELLIS: I think it would be good to spend a little bit of time on the Western Australian stuff, because there are large numbers, there are 7,000 registered.

Ms CROSS: This is Local Area Co-ordination, which I guess is the model that local support co-ordination here and Local Area Co-ordination in Queensland are based on. It started in 1987 in Western Australia. Essentially what they decided in their system is that if we were truly going to empower people with disabilities and families, then again we have to put information and resources and supports close to them. You cannot say we are going to do it and then put all of our efforts into the service system, because families continually tell us they are not empowered by the service system. This is a moral question, but it is also this practical question at a financial level, I think, because if we cut families out of the picture then we are just creating huge burdens for the public, for a very long period of time. Just as the people in institutions ended up costing enormous amounts with very poor outcomes and abusive outcomes for people, we are now creating systems which are going to cost the taxpayers and everybody as much and more for a very long time. The cost in group homes is going up, we are having to add more numbers into them. There is nothing in research that would tell us that that is going to deliver some outcomes with it. We know of all these problems.

What Western Australia decided to do was to develop through pilots what is now known as Local Area Co-ordination and they now have state-wide coverage of people who are out in local communities. It is in a directorate of the commission that is separate to the direct service delivery and their funding arms and their policy arms and everything else; and the role of the local area coordinators is to work directly with individuals to support and strengthen them in their role as parents or, if they are individuals, in their own right, to make decisions, to get access to resources, to find ways around things, to help them use their own networks, to help them think through situations such as if the aunt is not feeling like she can help because she is afraid of the disability issues, well, how would you struggle with that within a family situation? And really being there to support families, keep their own

networks as strong as possible and to do some of the community building type work, community capacity building at a local level.

It has been evaluated on numerous occasions. It has won an award through the Productivity Commission for cost-effectiveness. I visit and work with them about four or five times a year and across the country from Kununurra to Broome, you know, to metropolitan Perth, so it is a model which has good promise in lots of areas. I think it does have the promise of helping keep families less isolated but with more autonomy, you know, less dependant, even if they might use the resources of the system, but feeling that they can make decisions and that they can work with that.

The Hon. IAN WEST: Am I understanding it correctly to say that that model has achieved the objective of getting away from big government to community to ownership at a local level?

Ms CROSS: I think it is a promising strategy, yes.

The Hon. IAN WEST: But has it not also attempted to address the fundamental problems of shifting the responsibility, the legal and financial responsibilities, on to the family and the parents? Has it addressed that issue? Am I understanding it correctly to say that the Local Area Co-ordination still is responsible for the legal issues and the employment issues?

Ms CROSS: Where families are self-managing funds and in a technical sense become the employer, then the families or whoever they buy the supports from – if families have funds, then typically of course they are buying supports and sometimes that will be through agencies, so they become the employer, so in a sense it is a mixed model and the responsibility would or could in some instances be Local Area Co-ordination if they are the employers, but it might be families or it could be agencies, so just as in any system there is a mixture of employers here, depending on the nature of the actual relationship, whether it is an employer/employee relationship that exists; but they do fund families. You might like to talk with some of the people there, but there have been very few industrial disputes that have arisen out of that model. As I have said, they have ended up in the court I think a couple of times to my knowledge in a 13 year period, so this is not a high incidence of industrial difficulties.

The Hon. IAN WEST: I am more interested in the overall principle than the incidence rates.

Ms CROSS: Just in the sense of the principle and then in practice does it work. I think when we get ideas it is whether we can make them practical that is part of the puzzle that we are dealing with.

CHAIR: I do not know whether you are familiar with this matter from the Government end. When we started this inquiry in 1999 we were in the group homes devolution argument, in that phase of it, the Committee visited the community accommodation support team in Newcastle and then later on we also visited BASS in Ballina and I have just been thinking while you were talking that they are models which have some similarities but I suppose basically DOCS provided fairly flexible support teams for a number of individuals. The difference may be that I think they were probably with the least levels of disability, but I know for instance when we talked to the people in Newcastle, the mix of support workers and clients and so on, that we had people all living in their own accommodation in a mix of public housing and rented units and so on and with the workers relating to them I think and providing the services in the way you are talking about. The one big difference in my recollection is that the adult clients seemed to have no family support, seemed to be separated and that is I think partly the historical accident of Newcastle, which had such an enormous number of people in institutions. Most of these people had been devolved; but I am just thinking of it as something that in fact DOCS, and everyone, said “this is working really well”, but it was very much a DOCS initiative, rather than a family initiative, but perhaps achieving somewhat similar results.

Ms CROSS: Where we have seen this in the public system, and in most jurisdictions there would be some examples of this, in Queensland, Victoria, Western Australia there would be examples of this, by and large they were models that were developed for people with lower support needs who were thought to be able to live on their own with drop-in support, so it was a model that was developed and largely fills that end, so its limits largely relate to that, to the level of perceived disability of the person.

The other thing that has been difficult with government services - and I will come back to the issues around local supports co-ordination and Local Area Co-ordination – is that to maintain a level

of quality in a widespread way becomes very difficult because essentially these are add-ons to the group home system and often the culture and the issues that relate to group homes, be that rules or staffing matters or occupational health and safety issues, start to permeate the community end of things as well. It has been very difficult to maintain this as people's homes rather than an extension of the group home kind of model and the workplace of the staff.

In all accommodation support there is a real tension around maintaining this as someone's home and the issue of the fact that it is in fact a workplace for staff; huge tension. Where these are models that are built on to the group home assistance, over time unless they have had extraordinarily good values based leadership they have tended to become more and more like the rules that operate in the group home tend to operate more and more in people's private homes; so in a sense we lose some of the essence of the model.

CHAIR: But can that not also happen when families are for instance buying services from the agency in the way you described earlier, where the culture of the agency comes to dominate the kind of service that is provided?

Ms CROSS: It absolutely can. The advantages of developing these smaller models is that they deliver the services themselves and they separate that from the major agencies, so the culture of the major agencies, the negative cultures of those larger agencies, you are more quarantined from that, but it is always a tension. Anyone, whether it is someone getting in home support – I am getting in home support at the moment for my father – you struggle with those questions. It is always tense. You cannot get rid of the tension, but how you manage it and what are the principles that guide your decisions about whose home it is and how you make that work is very critical.

It is very hard in the larger systems to not have the broader interests of the system dominate over the individual, so that the promise of people doing it either as small collectives or individually I think is that we quarantine some of that. In any system we have the problems of safeguards. The degree to which you keep local support co-ordination or Local Area Co-ordination or any of these things in a sense oriented to honouring and respecting the culture of the family and the local community is really important.

One of the things they have done in Western Australia is that Local Area Co-ordination has operated as a separate stream outside of their direct services and they have paid a lot of attention to values based training for their staff, the kind of leadership they have, they have evaluation review built in; so they have a lot of mechanism that helps keep this system operating. Families are quite involved in that.

For a Government system – they have just reviewed their charter of Local Area Co-ordination - they had families involved in all of the weekend retreats doing that. That is a bit unusual in Government, to be bringing in the families to be part of trying to think those things through and that is because they have safeguarded it well, but it is unusual. In most government systems that is quite hard to do, even with good intentions, so I think the limits of the models really are around the people with milder needs, lower support needs.

CHAIR: But, in theory, it could be extended to people with higher support needs?

Ms CROSS: Well, it could be, although with people with higher support needs - I now have close to 25 to 30 years of experience in this field - I actually think to support them in individual lives in the community, families and friends have to be part of the mix. I think where systems do it we inevitably come back to either these highly staffed houses which are too expensive or we get back into group models.

CHAIR: Does that mean that, for the majority of people, we need to start with younger people with disability in their families, whereas with de-institutionalisation in many cases the family is in effect no longer in existence and therefore it is very much harder with older--

Ms CROSS: Yes and no. I think if we are thinking about driving change over the long-term it makes most sense to work with people who are still embedded in their family and their networks where that is part of the clear strength of the arrangements that exist and there will be some people I think who have spent more time in institutions and group homes where it will be quite difficult to retrieve those people and they will largely be dependent on the professional paradigm, models of care through

the typical service system, and that will be part of the mix, in my view, in the system. There will be some people where we will not be able to achieve it. It does not mean we should not try.

The other thing though is that I think that we have been surprised at the capacity of some families to reconnect with their sons and daughters even when they have been institutionalised and the Community Resource Unit has just published a little book on a project that we were involved in with the families in the Challinor Centre, one of the institutions in Queensland, where we spent a couple of years just talking to families, taking them around to show them options, helping them think about the possibility of bringing them together, really helping families make up their minds and become active decision makers again in the lives of their sons and daughters and I would have to say that was one of the most inspiring pieces of work I have been involved with because it blew away all the stereotypes that exist about families who are disconnected from their sons and daughters. Many of them were disconnected from their day to day lives, but they were not disconnected emotionally from their sons and daughters and the capacity to rebuild that has been quite marked. We launched the book just last week and there are only a dozen or so families who are narrators within that book, but they were all there with their family members and honestly, when you think about where they were five or ten years ago, you would not believe it was possible. So I think, while it makes good public policy sense to invest in people who are still within their families, we have to be careful not to stereotype the other families as well, and again they offer a whole range of human potential, but we will still need some of the professional models for those people where that is not possible, and even within the families in the community, of course, there will be some families who will not do this, who will not be able to do it.

CHAIR: Certainly we found in some of the institutions, the large centres we visited, the passion of families.

Ms CROSS: Yes, absolutely.

Ms ELLIS: And you can build on that. If I could just give a quick example of a very current issue that did exactly that, not stereotyping everybody, like people go into institutions one by one and what we say when we do devolution and policy is, well, they are all the same, so we lose sight of the potential that Anne is talking about that might be there to build on the passion and emotional affect between people. If I can just give an example of somebody I know very well who has been disconnected, he says quite clearly, from his son for over 20 years, now with devolution he has moved back home to be closer to the institution where his son lives, but what he needs is some technical support to help him. He cannot think that he could be his son's carer, he cannot think that he could do certain things, but he does want passionately to govern, to have the real say in what his son's life now looks like. This is a man aged 24, but the only thing that New South Wales will give him is a group home and he is wanting to say: I can't do it all, but I have something and I want to work with people to help me find out what it is that I can do and I might manage this or do that or live close or be a backstop. His son might have very, very, high support needs, so what will face this young man now is that he will go into probably a four, five, or now six bed group home in New South Wales - they are talking about even larger group homes - and still remain totally disconnected with his father still feeling as disempowered and as separate from his son as he has been. What Anne is describing is thinking about how do we find ways to get the range of things in place for that young man and for his father.

Ms CROSS: And use all of the capacity and resources that are available.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: This cannot be completely new.

Ms CROSS: No, not at all.

Ms ELLIS: No, we have a lot of experience with it.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Well, we have to ask why this model has not progressed faster. It is one thing to say that bureaucracy is hopelessly conservative but, in a sense, when an organisation behaves conservatively it goes for what it knows and the churches have this respectability about them and history of institution and, to some extent, home support, although I do not know what, but how much has it been that groups like yours have not been able to tender and market themselves effectively? If you said, look, give us X dollars and we think that within X time we will be able to get this many people looked after - maybe the Government did not want to know about those people because they were not getting much and you might discover unmet need and that creates costs. How much is it that you have not had the ability to get a team together, a model, and say, yes,

we will find some unmet need, but we may be able to de-institutionalise within a framework and some of the people who we are linking together will be able to put money into trust and take control - "control" I suppose is a bad way of putting it - or manage their relative rather than have the Government manage their relative and thus de-institutionalise, so that you may actually cut the institutional costs even though you generate costs in people who are in unmet need categories. Has there been a problem in having respectability, for want of a better word? In other words, this is a respectable model, we are not just going to fritter your money away holding meetings and talking and doing things you cannot account for. In other words, have the legitimacy to compete, in terms of dollars, with institutionalised and more conservative funding models.

Ms CROSS: There are two parts to the answer. I think there are many layers, but I think one of the things we are dealing with is the "stuckness" of the field across the world, so that the nature of where disability services are across the world is in the group home. You see this everywhere, even though there are many examples of other options and other possibilities, so it is something about the time we are in, just as at a previous time we were largely in an institutional era and nobody could see past that and it took the actual development of some strategic home intent to try and move beyond that. So that is part of the answer, I think a broad context is not conducive to it.

The second part of the answer is just talking about the Community Resource Unit, because we did establish as a community based agency within Queensland, our focus was Queensland and we actually have not looked to do work in any substantial sense here. As a consultant I have done lots of work in other places but, in doing this grassroots work, we have kept that in Queensland, so we have not actually tried to market--

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You live in Queensland?

Ms CROSS: I live in Queensland, so in a sense that has not been part of the agenda that, as an organisation, we have had.

The third part is that the very scale and expansion and increased complexity of the field in this last decade means that no one is putting their head up and looking beyond what is under their nose. This field is hugely more complex than it was a decade ago. I can certainly remember a time in Queensland where I thought I knew everybody and every major agency would know all the players, would understand what was happening. There is no way in the world, given the scale of expansion that has gone on in the last decade, that that is the case now and this has been mirrored in every jurisdiction.

We are not doing much about unmet need at all, but the systems have become incredibly complex and much, much larger, and to some extent the degree of complexity of the systems is stopping people just looking beyond the sheer management of those kinds of systems. Ten years ago I would have said we were in community services, the professionalisation of services. Now of course we have introduced all the technocratic systems where processes are driving everything that is occurring. People spend their whole life trying to manage these very complex processes, so families fill out these huge forms and they go into this lottery system and panel system and in some remarkable way people end up - a few people, a very small number - actually getting any dollars out of it, but the amount of resources we put into it - so I think that we have not developed a strategic intent of acknowledging what the problem is that we have and trying to do something about it. If in fact there was that acknowledgment then you would have groups like CRU or any number of other people, I am sure, who would be saying we have some expertise, we can help with this. I think that it is just understanding where the field is at, the complexity that we have, and there are some other features about New South Wales itself.

Ms ELLIS: Yes. It is a mistake, as I am sure you are aware, to believe that the large agencies do not spend as much time in meetings and assessments and reviews and whatever, and I think the Western Australian model, because they have moved outside the box and are on the edge pushing some innovation, the accountability--

Ms CROSS: Is much simpler.

Ms ELLIS: It is not process driven in that sense. Could I table a document that we provided to the Director General of the Department of Ageing, Disability and Home Care yesterday about the sorts of things that Anne has been discussing and the way ahead maybe in New South Wales? It is

quite short.

Document Tabled

Ms CROSS: I would like to leave you with one of our publications. We have many, but this is one that just collects together largely stories really from our newsletters which would speak to many of these examples and I thought you might be interested in that.

Document Tabled

(The witnesses withdrew)

MARGARET PATRICIA WILSON, Vice President, Brain Injury Association, 17 Macquarie Road, Auburn, and

KEVIN MICHAEL MARRON, Executive Officer, Brain Injury Association, 17 Macquarie Road, Auburn, sworn and examined:

CHAIR: You have the summons and you know our terms of reference?

Mr MARRON: Yes.

Ms WILSON: Yes.

CHAIR: We have your submission. Do you want to start with an opening statement or should we start with our questions?

Mr MARRON: We would be happy to start with the questions.

CHAIR: The first one probably covers making an opening statement because we have asked you to briefly outline the main activities of the Brain Injury Association.

Mr MARRON: The Brain Injury Association is the peak body in New South Wales for people with acquired brain injury, family, carers, service providers and interested people and so on. We provide an information referral service, an advocacy and lobbying service and a self-advocacy service for individuals to develop self-help groups around the state.

Our board of management is entirely comprised of people with an acquired brain injury. The organisation has been in operation since 1979. We have essentially been receiving government grants to run our services since the early 1990s.

Maggie, could you expand on the role of the network of the self-help groups?

Ms WILSON: Yes. As a person who has had my own brain injury, not a traumatic one, I found that the self-help groups are much more rehabilitative than the professional rehabilitation services and I think they provide a level of care support for people, all of whose brain injuries have been different in cause and effect; but they are a really egalitarian, supportive system of rehabilitation.

We have recently, at the end of September, had a combined women's picnic for women who have had an acquired brain injury and we had not done it before, we did not know how many people were going to turn up. It was not large, it was only 17 people I think, but the amount of interaction that went on there was really high quality and I think it is the one-to-one peer support that is the most vital function that the Brain Injury Association provides.

CHAIR: Are you the only staff person, Kevin?

Mr MARRON: No, we have five people on staff: a full-time executive officer, a full-time information referral worker, two part-time workers in community development work and myself, advocate/liaison work and administrative support and bookkeeping support as well.

CHAIR: Are they based in Sydney and attempting obviously with some difficulty to cover the state?

Mr MARRON: Yes. The information referral service is essentially a telephone and internet service, so we can and do receive calls from all over the state from people wanting to know, one, information about what is a brain injury – and we have an extensive library and resources there that we can copy things and lend out information resources to people – and also people making inquiries about where services are around the state; so we have a reasonably good idea of what is available around the state, both brain injury services and generic services that can provide services for people with a brain injury and then appropriately refer people.

With our self-advocacy project, we support and resource a number of self-help groups around the state and we are trying to set up those in areas where there is a need for that. We try and

get out and visit those groups at least once a year and stay in contact with those groups by phone and mail at other times and from time to time when the need arises support those groups with skilled development training programs in terms of developing people's personal skills and also their advocacy skills, taking action on issues for themselves in the local area.

CHAIR: Our next question was designed to give us, if you can help us, something of a profile of the population of people with acquired brain injury, because I think it is not an area that is very well known really in terms of how many people, how specifically can they be defined in terms of where they fit in the general population, age, gender, etc. Can you cover some of those for us?

Mr MARRON: We certainly can.

Ms WILSON: Could I interrupt? I want to add something really relevant to this particular disability. One of the almost inevitable consequences of surviving an acquired brain injury is short term memory impairment and I was talking to someone last night who said a member of her self-group has only just remembered that he did not fall out of a window to sustain his brain injury, he was actually hit by a car. The statutory limitation period has expired, so he has not sought compensation, nor has he been included in the statistics and I think that with increasing survival rates from brain trauma it is a growing population, whereas with antenatal screening things, intellectual disability as a disability will be reducing, whereas the brain injury will keep growing.

CHAIR: There is a similar sort of effect happening with the increasing survival rates of very premature babies affecting the population.

Ms WILSON: The memory loss.

CHAIR: Yes, it is a huge issue. I was on the Law and Justice Committee which did the inquiry into the motor accidents scheme and I remember talking about some of these issues and listening to the evidence in relation to that a few years ago.

Given that we accept the limitation of the statistics, what do we know about how many people have acquired brain injury?

Mr MARRON: We draw our statistical information from the 1999 national report done by the Australian Institute of Health and Welfare on incidence prevalence of acquired brain injury in Australia. From that report it is estimated that in New South Wales there is probably approximately about 114,000 people with an acquired brain injury and that is what was identified at that particular point in time; but the other probably more relevant and pertinent statistical figure is the incidence rate of brain injury, which we now estimate in New South Wales to be approximately 45,000 a year; and that is people from sustaining both a traumatic brain injury and obviously through motor vehicle accidents which are probably the more recognised and more profile means of the general public understanding what brain injury is, and assaults and workplace accidents, to non-traumatic brain injuries, which essentially occur through stroke, aneurisms, periods of lack of oxygen to the brain, drug and alcohol abuse, poisonings, tumours and so on. Statistically of that 45,000 about 37,000 people acquire a brain injury through non-traumatic events.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is that included in the 45,000?

Mr MARRON: That is included in the 45,000; and then about 7,800 through traumatic events, so motor vehicle accidents or assaults or workplace accidents or whatever. That is a fairly high yearly incidence figure.

The report does make some estimations of those figures in terms of: of all those people who acquire a brain injury how many may have mild, moderate and severe injuries, and they make some sort of estimations of categorising people into those groupings.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Of the 114,000, if that is a cumulative rate, then most of the 45,000 have recovered so they do not go to that 114,000.

Mr MARRON: I guess that is the question that needs to be debated or needs some investigation, because the 114,000 is a snapshot figure, based on various reports that the hospital separation figures acquired through the 1980s and 1990s. That was a snapshot figure, I think, that they

drew from the latest hospital separation figures for 1996/1997.

Ms WILSON: But there are two statistics here. One is the annual incidence of ABI and the other is the ongoing population which of course will be added to each year.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The cumulative population or the prevalence is 114,000 and the incidence is 45,000. Presumably both of those are total figures and within that there is a range of degrees of impairment and the hospital separation figures of course are only the acute state, so presumably some of those who are fairly bad six months later might be at least able to function and not appear in the statistics if their social situation is such that they do not require much support.

Mr MARRON: That is right and with that 114,000 people figure, that would have been people who at that point in time would have been identified or identified themselves as having an acquired brain injury. With Maggie's example and many other examples within our organisation, we have one or two people on our board of management who did not identify their acquired brain injury until many years after the actual injury occurred, so they spent many years not knowing what was going wrong and what sort of impairments they had and relating it back to an event or an injury that occurred six or seven years ago.

CHAIR: Would it be true to say in the sorts of statistics you have given us that the bulk of the non-traumatic acquired brain injury would be amongst the oldest segments of the population, you know, the strokes and so on, whereas the traumatic element is mostly a much younger population group?

Mr MARRON: Yes, that would probably be right.

CHAIR: One of the reasons I am asking that is that there is an increasing overlap, I guess, between disability services and aged care and while we are conscious that there is an overlap and a complexity in there, but I am guessing that a lot of the people you are talking about would normally be regarded as in the aged care group than in the disability care group.

Mr MARRON: From that same report and in that 37,000 figure that I quoted, those under the age of 65 were approximately about 7,000; so that assumption is certainly a fair one from that point of view.

CHAIR: For the traumatic group is it, as people tend to assume, mostly motor accidents, sporting accidents, workplace, et cetera?

Mr MARRON: That we have not been able to ascertain. I was speaking to somebody yesterday, a researcher from a television program, who had actually contacted the Motor Accidents Authority to try to obtain that information and they were not able to provide that, so trying to get a breakdown of that figure into the type of injury is very difficult.

It is probably a fair assumption to make that a majority would be through motor vehicle accidents, but we have not got it and I do not know of a particular source where we could acquire that information to find out exactly the type of injury that people sustain, in that figure.

CHAIR: The remaining and, in a way, the most important question in that group is: What are some of the ways that acquired brain injury can impact on people's lives?

Ms WILSON: I will speak from personal experience. I think initially for me - and I was very lucky - it was the loss of the self-confidence that you previously had in your ability to function and, because you lose confidence in your memory, you tend to lose all general confidence. You not only lose that self-confidence, you lose autonomy in your life. I was kept in hospital for much longer than I wanted to be, I wanted to be home. I could not do that. You become very much subjected to other people's intervention, well-meaning though they might be. It is almost as if you have to start becoming an autonomous adult again. I was not dragging a limb or that sort of thing, and at the same time as you are going through this, people are looking at you and saying: What is wrong with you? You haven't got an ABI. My children used to say to me, mum, you don't have short-term memory problems and I would ask why they said that and my son would say because you never forget to tell us, so it is a no win situation and it takes a long time to convince yourself that you are going to get through this and

get out and help other people.

CHAIR: So if you do not have any overt symptoms, any signs, it is in some ways worse--

Ms WILSON: Yes.

CHAIR: --because it increases the psychological pressure on the person?

Ms WILSON: Yes, and I am, seven and a half years on, still going through the legal issues of worker's compensation for my matter and my worker's compensation was cancelled in February this year because they said I do not have an ongoing disability and I sort of thought, well, thank you, wouldn't it be nice to wipe it out with the stroke of a pen? It is a back-foot reaction most of the time. I do not have, as far as I am aware, any bizarre behaviours, but I am aware that I do not have the confidence in my short-term memory. I function cognitively slower, but I can still get there, it just takes so much more effort. The things we take for granted when the sun is shining and everything is right with the world and we never express gratitude for, that is something I have learned to say - thank you.

I have just had a piece published in the association's newsletter which was written on a book about women with disabilities written by two academics. They had intellectual disabilities and their overwhelming message was that they found the social discrimination impacted much more on their lives than the disability itself. That says a lot and that sort of attitude is what informs the support services for all the disabilities that the attitudes towards the disability rather than the disability impacts much more.

CHAIR: That would be particularly true for the group with acquired brain injury, do you think?

Ms WILSON: The ones with the invisible--

CHAIR: Yes.

Mr MARRON: I guess in many cases, not being able to go back to one's previous occupation or employment is also a major impact on individuals. It is one of the things that we pick up through the office, through callers that speak to us and so on, and also the impact on families, spouses, parents, siblings and so on, especially when you are living with someone who has an acquired brain injury, can be very great as well. As a disability it is a very unique thing in the way it does impact on and affect individuals.

One of the points I wanted to make earlier when we were talking about the statistics and the incidence rate of 45,000 and the Australian Institute of Health and Welfare trying to then sort of classify people into categories of mild, moderate and severe injury, what may be judged by other people as someone who just has a mild injury to that person may still have a very significant impact on their life in terms of changing their employment. They still may be able to function independently in terms of personal self-care; they still might be able to support their own relationship and their own family and so on, but their whole direction in life may have changed, particularly with their course of employment or their course of study, and to them that is a major change. Although you may not need very highly structured community based support services in terms of attendant care services and community access programs to facilitate social reintegration and things like that, for that individual it is still a major impact on their life and they still need some form of support service available to them for an indefinite period of time to help them manage that change.

CHAIR: Would this be a good place for you to give us some indication of the range of effects of injury? I mean obviously there is a very wide range and, taking into account what you have just said, the perception from the inside might be rather different from the perception from the outside.

Mr MARRON: Absolutely. The range of injuries or the range of effects can vary from someone who has cognitive and physical deficits, someone who also needs attendant care services in terms of mobility or personal care and so on, to the range where, on the outside, a person may appear not to have a disability and appear to be functioning well but, on the inside, issues such as memory loss, mood swings and behaviour changes and things like that, not being able to manage frustrations and getting stuck on particular ideas and modes of thought, and I guess not being able to understand how to sort of laterally think around issues and solve problems and so on, which again a lot of us take

for granted in terms of cognitive thinking and which are all things that you cannot see on the outside and you may only observe in someone from their particular behaviour, which may be interpreted as someone who may have a mental health problem or someone who is just having a bad day or not being understood at all by the lay person.

Ms WILSON: Can I add something here which I am finding and that is that people tend to think people with an acquired brain injury are malingering. They cannot see anything wrong, we are just being lazy, because there is no physical energy, you have no physical energy, and that is something that I find particularly frustrating. People do not understand why I am not normally out of bed before 11 o'clock in the morning - I just do not have the physical energy to get out of bed - because they see me as functioning as I did before, because how do I prove that I am tired? It is like chronic fatigue syndrome. How do you prove it?

Mr MARRON: That is one of the misconceptions or the perceptions in society about brain injury, one of the misunderstandings about brain injury. It is not a high profile sort of disability, it is probably a very misunderstood disability. It is difficult to get some media attention or media spotlight on to the issues that people face. It can be a bit of a taboo sort of subject - a bit like mental health - most people don't want to know about it, it is too hard, people who have a mental health disability are too difficult to work with and so let's stay away from them. I think many people in the community just do not understand what having an acquired brain injury is until you have one or until a member of your family has one.

The Hon. IAN WEST: But there is a much wider understanding of that difficulty, is there not? I mean is there not more funding coming through?

Mr MARRON: Not really, no. Even within disability services and Department of Ageing, Disability and Home Care, it is very much a poor relation disability to the others and it is an area that, since I have been in my position for two years, I have found the department very much wants to keep at arm's length because it knows that to give some adequate resources and to further develop some specialist services in the community that can support people with a brain injury is going to cost more money, and Treasury is not going to wear that and they do not have that within their budget, so again let's just stay away from it. That is a very frustrating thing to deal with from a disability sector's point of view from a government department that has carriage and responsibility to provide services to people with disability in the community.

CHAIR: Are departments like the Department of Housing of relevance too?

Mr MARRON: The two key players are the Department of Health and the Department of Ageing, Disability and Home Care. The Department of Health developed and still funds and manages brain injury rehabilitation units. There are 13 of those set up around the State of New South Wales, three in Sydney that operate out of Liverpool Hospital, Westmead Hospital and the Royal Rehabilitation Unit at Ryde. There are two specialist paediatric units, one based at Westmead and one based at Prince of Wales at Randwick and then in rural New South Wales there are eight regional brain injury rehabilitation units in various places around the State. Those services, and certainly in the city, primarily are about supporting people who sustain a traumatic injury, so they come through the hospital system after a traumatic injury: They are in acute care; they are in the brain injury rehabilitation unit; they may spend some time in that unit before discharge, particularly with therapy services and rehabilitation services before being discharged, and those units will also provide some support upon discharge in terms of community rehabilitation.

CHAIR: So it is residential at first but then there is a later stage?

Mr MARRON: Yes, in terms of the metropolitan units, apart from acute hospital ward settings, they do also have some transitional live-in units, so some people who need that can reside in those for X number of weeks before being discharged either back to their own home or back to their parents' home or, in some cases unfortunately, to nursing homes. In the rural areas they are a little bit more flexible in terms of the clientele they can see. Those services will also provide ongoing outreach support services to people who have a non-traumatic injury, essentially because there is nothing else in those local communities to support those people.

CHAIR: So they are more flexible because there is nothing else or more flexible because there is not quite the pressure?

Mr MARRON: They are more flexible because there is nothing else and because the Department of Health has said, well, okay, with the resources you have, if you have some existing capacity to provide services to people with a non-traumatic injury then by all means go and do it, and so those services have developed some capacity and have provided services to people with a non-traumatic injury. In the city, though, I think it is much more strict in terms of the Health Department's guidelines in saying it is traumatic injury only, that is your clientele group and that's it.

CHAIR: Is there a problem with shortage of therapy services? This is an issue that has been raised with us in relation to other groups; or are there enough services to go round, if you can get into the unit in the first place?

Mr MARRON: That I am not really sure. That particular information we do not have any solid information on that from our association in terms of therapy services. My guess is that there probably is a lack of appropriate therapy services, but we do not have any particular evidence.

CHAIR: Physiotherapy and occupational are the two?

Mr MARRON: Two aspects, yes. Physiotherapy and occupational therapy are the main two, yes.

Ms WILSON: But I think within our membership there is no consensus about whether the knowledge that the professionals have is as relevant as the knowledge that the people in the self-help group share in an egalitarian fashion. It is this structure of "those who know up there, we down the bottom just receive what they think we ought to", you know, what our prognosis is. In lots of cases it is not accurate. There seems to be some sort of time lag between the curriculum content that those out there with the power in the field are imposing on we survivors and often it is inaccurate.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think that the fact that people would take you if you are traumatic and not if you are not traumatic relates to the fact that traumatic are funded either by workers' compensation or by third party insurance? Is it as simple as that?

Ms WILSON: No, not necessarily.

Mr MARRON: No, it would not be as simple as that. The development of the brain injury rehab units came about through money from the Motor Accidents Authority and the Department of Health. I think they were the two primary bureaucratic sources of money, so because the MAA was involved then, yes, you may be right in terms of the categorical definition of clients may be limited to people with a traumatic injury, because that is the part of the clientele group for the MAA, these people who are affected by motor vehicle accidents and nothing else; so my guess is that is probably the reason.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: That is the historical origin and it may have gone into a bureaucratic definition.

Mr MARRON: That is right.

CHAIR: Adequate health. Housing? Home modification? Department of Housing tenancies? Is it of relevance?

Mr MARRON: Yes. Certainly a number of people with acquired brain injury are tenants of the Department of Housing. I am not sure, I do not think the Department of Housing would give any particular priority of waiting to people with acquired brain injury as opposed to anyone else on their waiting lists, but certainly a number of people with ABI are tenants of the Department of Housing and as such other support services can then come in and provide certain accommodation type support service as well.

CHAIR: Do they become tenants of the Department of Housing, it is hard to separate the reasons, I guess, but because of a difficulty in earning income, or because of a difficulty in maintaining relationships with families and spouses and so on? I am assuming then they are probably not originally Department of Housing tenants, but it becomes necessary for an income reason which may be a result of non-employment but may also be related to difficulties in relationships.

Mr MARRON: To be honest, I would not know the reasons why people become Department of Housing tenants. It is probably more to do with income and if you have acquired a brain injury and you cannot return to work and therefore you are then on a disability support pension and if, sure, if you are in a relationship or in a family and that breaks down and you need to move out, then I guess your only option is Department of Housing; so it is probably a combination of both, to be quite honest.

CHAIR: Our next question deals with the types of accommodation and support services that people with brain injury need and obviously we are conscious of the huge range of brain injury you have talked about, but I guess we are relating more to the major, the extreme end of the injury.

Mr MARRON: At the extreme end, we estimate that there is probably in New South Wales at least about six to seven hundred people under the age of 50 with an acquired brain injury living in aged care nursing homes, and that is probably at the extreme end, that is probably the particular area where we are most concerned at this point in time. They are in there because there are no facilities or services, or more appropriate facilities or services for people to move into after discharge from hospital and so often it is people who are going straight from the hospital system acute care into nursing homes, because there is no other option.

CHAIR: Do they therefore essentially get no rehabilitation types of services?

Mr MARRON: That is right, yes. They get no rehabilitation.

CHAIR: Is that because someone decides it is not going to do any good, or is it because if their condition is that bad they sort of bypass that and get in effect parked in the nursing homes?

Mr MARRON: It is probably a perception that if they are in a nursing home then that person is probably not going to improve and because nursing homes do not have any rehabilitation services for that population, they are just not going to get any, unless a family member can pay for that and organise that for themselves, which is quite rare anyway; so often people who will have some capacity – and that capacity is always a question mark in terms of rehabilitation and re-acquiring most skills – it is just completely lost and no opportunity gained at all and that I think is a bit criminal.

CHAIR: So you estimate 600 or 700?

Mr MARRON: Yes.

CHAIR: I assume that is growing year by year, it is not diminishing?

Mr MARRON: There is a real political football here. The Commonwealth position is that obviously younger people just really should not be in nursing homes. However, they are not actively doing anything to provide some alternatives to do that, apart from saying that they give the states a certain amount of money through the State Commonwealth Disability Act and it is their responsibility to provide services. The state will say, “We have not got any money to do that”.

From what I understand, the Commonwealth is trying to put some pressure on the states and I have heard in the last couple of weeks that a particular edict from the Department of Health and Aged Care has gone out to aged care assessment teams to say under no circumstances are younger people with disabilities to be admitted into aged care nursing homes, so they are trying obviously to shut that gate and put the pressure back on to service workers at that level.

The problem with that is that there is still no alternative. You can shut the gate but there is no alternative, and so those people at the front line are just going to be in more of a dilemma and often ring us and say “Where can we place people?” and we end up saying “There is nowhere”.

Ms WILSON: It is impacting all the way through the system. If you have aged care beds being occupied by people with disabilities, those beds are keeping out other people in the general hospital list because those beds are not available, so how do you break this vicious cycle?

CHAIR: What is your wish list? What should we be setting up as a community for the six or seven hundred people you are talking about? Where should they be and how can we achieve it?

Mr MARRON: We do not have a particular model that we would be presenting to anybody to say: this is the sort of thing you should have. Because brain injury is so unique and people's support needs can vary from one individual to another, we cannot really generalise too much. What really needs to happen is there needs to be some commitment for resources to start off with, say, we will put X amount of resources to address this particular issue, and then for each of those people currently in a nursing home, being able to go to those individuals and their families and say, well, what sort of set-up, what sort of structure, what sort of service model is best going to meet your particular needs?

That may result in a number of people in some small form of congregate care whose levels of dependency and attendant care needs are quite high and whose therapy service needs are quite high and obviously in terms of best use of resources those needs would be best met in some small sort of congregate care sort of model.

Others, though, it could be a certain amount of support living back in their own home with their families; that still may be the best option. Other people may be able to live on their own or with one other person in a particular type of accommodation. It is a very variable sort of thing. The first thing would be some commitment for resources and then the second thing would be to individually negotiate that with each of those people who are in nursing homes, so there is a quality of service there for people to move into and not just to move into the next worst thing.

CHAIR: Do we know anything about the relative cost? Nursing home care is expensive, is it not? We had this discussion with our previous witnesses as well, about people thinking sometimes the more flexible and family based care may end up costing more but, in fact, sometimes the evidence is that it does not, that the costs in the more institutional form of care can often be higher than other costs.

Ms WILSON: Over time, especially if there is a rehabilitation focus on enhancing residual abilities, the level of need might actually drop; therefore to put someone into the top end of the cost thing, nursing home, forever and a day, because there is no evidence that acquired brain injury shortens people's lives once you have survived the initial trauma, it does not necessarily mean you are going to cark it at 60 instead of 77 or whatever, so I think there is a lack of co-ordination and a lack of vision and also I think there is a lack of input from the actual recipients of those services, so that it is not in anyone's interests at the moment to empower the people with disabilities to participate in their own solutions.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think, though, that if the level of need declines, the people giving out the money do not have confidence that that money will be returned, that people will say, "I do not need that much now" and therefore the principal concern is to stop people getting on any sort of benefit from day one which is basically leaving unmet demands unmet, thank you very much.

Ms WILSON: But I am not talking about the overall pool of money reducing. What I am saying is that individuals within that system, their level of needs might still drop over time.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Presumably a number of people who need more care are not getting it and they are not in nursing homes presumably so therefore they are probably not getting much, are they? Therefore, even if you are getting home support you are getting more than they are getting now and therefore you would say let's keep the unmet need unmet, that is our ambit position.

Ms WILSON: It is like a dog chasing its tail. You are never going to catch up. You started off with a gap, an unmet need and the client group is growing each year, therefore that gap between needs meeting and unmet needs will blow out.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is this worse than it was? Has this not always been the situation, that this need has never been met? There are a few being added to it each year, but car accidents are not as bad as they used to be so presumably brain injuries in car accidents are not as bad as they used to be.

Ms WILSON: No, but more people are surviving car accidents these days, because of the

advances in medical technology.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Because of seat belts they are getting head injuries instead of dying of chest injuries.

CHAIR: Will air bags make a difference? I remember there was talk when I was on that inquiry into the motor accidents scheme and there was a lot of optimism that seat belts produced higher survival rates but increased the incidence of those with brain injury who did survive.

Mr MARRON: It is an interesting statistic that I would like to get our hands on in terms of in the public domain there is always a lot of attention given to road toll in terms of death, but not in terms of injury. You do not really know whether, sure, there may be less people dying on the road, but there still may be a larger number of accidents and people sustaining injuries and severe injuries; they are not dying, they are not going into that statistical basket, so no-one sees that, so you do not get an accurate picture of those records.

Our other witness who was going to come today, Kerry Stafford, who could not because of a client crisis, manages the only brain injury specific accommodation support service in New South Wales, so she could have answered those costing questions because she has had many, many years' experience in running that service.

CHAIR: Perhaps it would be possible for us to contact Kerry later and see if she can help us.

Mr MARRON: Yes, because she was certainly more than happy to come today.

CHAIR: Question 5 I think is a crucial one and the questions about respite and the extent of unmet need. We have talked about it as we have gone on, but I guess we have not done much to quantify it.

Mr MARRON: Well, in our submission where we detailed quite a bit of statistical and figurative information, nothing has changed from that picture, and this was written in January 2000, nearly two years ago. Nothing has changed on that at all. To move things along a bit and get to the crunch of what we, as an association, really want to see as the first step in addressing this, what would be a very useful and helpful step for our sector is if the department responsible, being the Department of Ageing, Disability and Home Care, and through the MAA and the Department of Health, if a brain injury action plan could be redeveloped for New South Wales and some deliberate attention and focus given to the particular issues and needs of people with an acquired brain injury in a structured developmental plan across the State. If that could be redeveloped, that would be a significant start in looking to address some of the unmet need.

In 1994-95, under a Liberal Government, such a plan was developed. It was a two or three year plan. From that the Motor Accidents Authority put in some seeding funds which gave the association some additional funds as a peak body. It also helped to set up two or three additional community access programs, brain injury specific community access programs, and of course prior to that it had kicked off the brain injury rehabilitation units. With such a plan a bit more evolution happened in terms of community based brain injury specific services, so there was some structure out there in the community that (1) people with an ABI could access for support service and (2) other generic services could take a lead from and acquire some knowledge from in terms of providing services themselves.

Since that time nothing has happened across ABI and, as I said earlier, the current department (1) really has no capacity to develop any sort of plan across disability services and (2) really wants to keep at arm's length acquired brain injury, so if this Committee had some leverage or some impact to be able to kick start or I guess, in a sense, force the department to redevelop a brain injury action plan for New South Wales, then we could start to address some of these outstanding significant unmet issues. I mean nothing would be solved immediately--

The Hon. IAN WEST: Which department?

Mr MARRON: Department of Ageing, Disability and Home Care. You would not immediately solve anything but you would at least start to develop a plan to try and solve it.

Ms WILSON: I think we need overt commitment to this as a disability group whose needs

are being disproportionately recognised in funding. Apparently the incidence rate of acquired brain injury is about the same as intellectual disability, but we get less than two percent of the funding, and that is an inequity and that has to be acknowledged. I think that is the priority, that is the way I would look at it: Recognise the unfairness of it. I mean this is the social justice committee, is it not?

CHAIR: Social issues.

Ms WILSON: I am not having a shot, but if there is an analysis of the facts and where the money is going, who is getting a fair share and who is not, start from that, because that is not subjective, that is empirical, and I think, from that, commitment. We do not cease being citizens because we have an ABI, and we still vote.

CHAIR: Is there any other State or States dealing with the needs of those with acquired brain injury better than New South Wales is? Are there models elsewhere that could help in developing that action plan or is the situation similar everywhere in Australia?

Mr MARRON: I am not aware that any other States have a particularly structured action plan to address acquired brain injury services and unmet need.

CHAIR: Do they have models of services that New South Wales could emulate?

Mr MARRON: No, I do not think so.

CHAIR: It is a pretty dismal picture right across--

Mr MARRON: Right across the country, yes. I suppose in Victoria the one positive thing they have is that, through their sort of compensation scheme, they have a no fault system in terms of motor vehicle accidents, a no fault system, so if you acquire an injury through a motor vehicle accident there is no question about whether it was your fault and then you get compensation and get some services or if you were at fault then you get no compensation and then you are at the mercy of the community service system if you want some services.

CHAIR: And Tasmania is the same I think.

Mr MARRON: You could be right, I am not exactly sure, but I know Victoria certainly has that. Less than 50 percent of the people with an acquired brain injury receive compensation. The majority who have an ABI do not get any form of compensation, and again that is probably another misconception or conception in the community, that people with an ABI are people who have been in an accident and will get some money for it, so they have plenty of dough.

Ms WILSON: It is only the big cases that hit the headlines.

Mr MARRON: Yes, and it is not true.

CHAIR: I was just looking at the recommendations in your submission. Recommendation 6 talks about funding contracts which expired in June last year. Were they refunded?

Mr MARRON: Yes. Had to fight, but yes, they were refunded.

CHAIR: So at the moment they are continuing through to 2003?

Mr MARRON: Yes, they were given recurrent funding grants in June of that year, but we had to fight for it, it was not automatic. It certainly was not in the budget that year and both those programs had to kick up a bit of stink to get the department or the minister to agree to that, so number 6 actually has been addressed.

CHAIR: On the various range of needs for services and so on, can I just ask specifically about respite services which your submission mentioned? In relation to, say, intellectual disability, this Committee has made the point several times that respite services are a good investment, apart from all the other things, because if you have adequate respite services you enable families and carers to cope and therefore it is in everyone's interest. It is cost effective, but emotionally and psychologically successful as well.

Mr MARRON: Sure.

CHAIR: So I would assume the same points can be made or are people with acquired brain injury different and have different needs?

Mr MARRON: The need for respite is certainly still there and still quite acute. In terms of service types around, there is only one respite facility, a brain injury specific respite facility, that exists where people can go for respite. That is at Baulkham Hills.

CHAIR: Who runs that?

Mr MARRON: It is called Gem Hill Cottage. I think it is run - not by Baulkham Hills Council--

Ms WILSON: I think it is pooled funding, I think it comes from a couple of sources. I am not sure.

Mr MARRON: It is called Gem Hill Cottage and I am pretty sure it is a community based service.

Ms WILSON: But often people who are entitled to respite are not aware of it. Norma Thomas found out last year - and her daughter's accident was 35 years ago - that she was entitled to respite and yet she had been told by one source, no, you are not entitled. She found out years down the track, inadvertently, that she was entitled, so people have to know how to access, what is available--

CHAIR: And where it is?

Ms WILSON: It is a community information system that really needs to be out there.

CHAIR: Does a respite service, for instance, need to be specific to acquired brain injury or can generic services serve just as well?

Mr MARRON: Generic services could do it, but the problem there is that at this point in time they do not have the staff or the skills or the knowledge to actually work with people with an ABI and that can be a real issue, so some sort of home and community care like HACC that pays for respite services may not take people in with a brain injury and may categorise them out of their type of group, but in the long term that is more about an investment in training and developing those services to have that knowledge and skills and that competence.

I think there need to be geographically around the State some specialist services (1) that can provide the direct respite themselves and (2) can then provide a resource and training service to other generic services to have that capacity as well.

I guess the other problem with respite is that people with an acquired brain injury over the age of 18 are not accessible to any Department of Community Services respite service because strictly they are there for intellectual disability, which I think is a bit discriminatory in the disability service network, that you have an entire government department set up specifically only servicing one disability population group. Under the age of 18 there is more flexibility and more scope to receive DOCS services, but once you are over 18--

Ms WILSON: But that is an inequity in itself because the younger you are in life when you acquire your brain injury the more you fit into an intellectual disability guideline because you have not acquired the skills that you would have if you had your brain injury when you were an adult, so if you are two when you have your acquired brain injury you are going to have a lot of the deficits that an intellectually disabled person would have.

CHAIR: Would someone who does acquire a brain injury at the age of two be likely to be categorised as having an intellectual disability and therefore have access to those DOCS services?

Mr MARRON: Historically they would have.

CHAIR: But is that changing?

Mr MARRON: Well, in the last ten years since the paediatric brain injury units were set up and you have at least got those units that can actually correctly diagnose and identify an acquired brain injury in a young child, and they are also there to provide ongoing support services to families throughout, but certainly pre-1990 that probably would have been the case, yes.

CHAIR: I guess what I am getting at is there, in a sense, a disadvantage in that the more exact the diagnosis - does that very diagnosis then rule someone out of services that might be available?

Mr MARRON: In this day and age it probably does, yes, although I am pretty sure the Department of Community Services, regardless of the disability diagnosis, if you are still a child you can still access their respite services.

CHAIR: But to take up Maggie's point, if the injury occurs when you are so young that that inhibits you from the normal developmental skills then you may well continue to be categorised as having an intellectual disability even over the age of 18?

Mr MARRON: Yes.

Ms WILSON: Yes.

CHAIR: Even though it may be a misdiagnosis, it might be quite useful for that person and their family?

Mr MARRON: Yes.

The Hon. IAN WEST: And that would be up to about what age, up to about five?

Ms WILSON: I would say adulthood because we develop gradually emotionally, socially, intellectually, and if you have had an early brain injury you are going to exhibit a lot of these symptoms that are straight-out intellectual disability without the brain injury. If you had your acquired brain injury at the age of 13 when you were just entering adolescence, there are many social and emotional skills we will acquire between 13 and 21 - 13 and 50 - so those people still have slower development compared to normal.

CHAIR: Well, I think we have probably covered it. We can contact you, I hope, afterwards if we realise there is something we have not covered adequately?

Mr MARRON: Sure.

Ms WILSON: May I table, not for the purposes of my writing but as a resource, the book I mentioned earlier, *Women With Intellectual Disabilities*, because it was told from the perspective of those people and it went into finding a place in the world in families, relationships, work and community. There were 25 women interviewed in the book and they discussed a range of residential options in Canada and in the United States of America and I just thought it was a riveting resource, which was an academic textbook. I would like to refer the Committee to that.

Document Tabled

(The witnesses withdrew)

(The Committee adjourned at 11.45 a.m.)