REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO DISABILITY SERVICES

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At Sydney on Monday 10 September 2001

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The Committee met at 10.00 a.m.

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PRESENT

The Hon. Jan Burnswoods (Chair)

The Hon. Dr Arthur Chesterfield-Evans
The Hon. Amanda Fazio
The Hon. Doug Moppett
The Hon. Ian West

TREVOR KENNETH DAVIS, Executive Officer, Australian Council for Rehabilitation of the Disabled, New South Wales Division, 24 Cabarita Road, Cabarita, sworn and examined:

CATHERINE EDITH DICKSON, Divisional Manager, Disability Services Australia, 76 Harley Crescent, Condell Park, and

ROBIN WAY, Chair, Accommodation Subcommittee, Australian Council for Rehabilitation of the Disabled, affirmed and examined:

CHAIR: Did you each receive a summons signed by me?

Mr DAVIS: Yes.

Ms DICKSON: Yes.

Ms WAY: Yes.

CHAIR: Are you conversant with the terms of reference for this inquiry?

Mr DAVIS: Yes.

Ms DICKSON: Yes.

Ms WAY: Yes.

CHAIR: You have provided the committee with a new submission. Do you want that submission included as part of your sworn evidence?

Mr DAVIS: Yes, please.

CHAIR: I sent you a copy of the proposed questions. I note that we did not begin by asking you to tell us about the Australian Council for Rehabilitation of the Disabled [ACROD] because we have spoken to you on a previous occasion. If you would like to refresh the Committee's memory and make some particular points in relation to these questions you might begin by making an opening statement.

Mr DAVIS: Thank you very much. I would like to do that, only in so far as positioning the organisation to make the submission. I would like to firstly note that Robin Way, who appears here today, is the Chair of the Accommodation Subcommittee of ACROD New South Wales, and Catheryn Dickson is the Vice Chair of that particular committee. On the last occasion Robin appeared before the Committee she was the Chair of the entire ACROD New South Wales division. The reason I wanted to restate that was simply to put into perspective that we are the funded and recognised peak body representing disability service providers across the State.

It is important to note that when we make submissions we are coming from a very heavily structured State, in terms of our members and the service providers we represent. We have a structure of some 13 committees which include specialist committees, such as accommodation, day services, children and youth services, and so on. We also have six regions of throughout New South Wales. Like the office bearers here today, we have elected office bearers in six regions of the State. It is a consultative process that we have undertaken since July 1999 when we expanded into regional representation, something of an extension of the subcommittee process. We ensure that there is geographic, as well as specialty, representation. It is from that basis that we consult with our members and we come to you with a submission endorsed by that framework. I think that is the important point to make on the day, so that it is not seen as a isolation reference.

CHAIR: Thank you. I note that your submission contains some rather critical comments in various places.

Mr DAVIS: It does.

CHAIR: It is useful to the Committee when people do not beat around the bush, but make comments about issues.

Mr DAVIS: We certainly believe in being candid. My two colleagues will be making the primary submissions to the Committee today and I am here in support of them.

CHAIR: Shall we go straight to the questions? Do either of you want make any preliminary comments, Robin or Catheryn?

Ms WAY: I think the questions will lead us through the comments that we believe are important.

CHAIR: I would mention, for the benefit of members of the Committee, that ACROD has referred to the Committee some suggested issues they want to take up, not all of which our questions specifically cover. We have agreed that we will probably manage to cover them one way or another before we finish. The first question is what might be referred to as simple but not simple. Would you briefly explain the current role of non-government organisations in providing services? How and for what reasons has this role change it over recent years?

Ms WAY: Perhaps I could lead off on that aspect. It is important to put in context the environment that disability organisations have had to deal with over the last period of time. If we were to go back 10 years, just prior to devolution of the non-government sector to the State, there was a distinct vision about disability services operating at that point. That was based on a social justice model which said that people with disabilities and their families should receive the support they need from organisations; that, inevitably, their best interests would be served by people living within the context of their community; and that people should have a real job with real money.

That’s simplistic, but it took quite a bit of doing, the sector was moving into that. It had moved away from a fairly institutionalised custodial model, if you like, of the past where institutions were the prime gathering place for people with disabilities. I guess today the vision has been replaced by a system which largely sees people with disabilities as outcomes of the service delivery system. They are not equal partners any more. Their families have been displaced from the very organisations in fact that they helped establish. People now get a few hours a week in different areas of their lives, if they are lucky enough to have been able to access the system at all in those areas.

People might get a couple of days in a day program. They might get somewhere between eight and 16 hours a week in work preparation under the Adult Training, Learning and Support program [ATLAS]. If they are very fortunate they have an accommodation service which may or may not the appropriate to their needs, but at least they have a coverage there. We have an array of what I refer to as "silo" programs, that is, they focus on particular aspects of a person's life and there are no bridges between those programs. That, I think, is the distinct difference that has emerged over the last five years in particular, that people's lives are perceived to be dealt with in one way and not holistically.

We have moved away from seeing a person with a disability as having a lifelong need for services. It is almost as though the system believes that it is a crisis approach and people with disabilities are taking from the system rather than being empowered through the system. The system is about how do we spread the dollar further to more people, which means that everybody ends up with less and the dollar gets stretched. On paper it looks as though more people are being served, but the reality is that we are fracturing people's lives and we are causing enormous stress to families.

Two sets of parents spoke to me recently. One, who had been rejected by the service access system [SAS] system, said, "I thought that I would have to kill myself and my son. Now I am sure about it." They saw the SAS system as being the last way in. They have been told that this was the way you got services. To be rejected from that and referred to the Carers Association said to them that they would never get services. The other family said to me—and I think that this is a very sad statement—that they wished now that they had put their son into an institution when he was a child because that would mean that now, as they were ageing, that he would at least have a service. They did not know where he was going to go and they did not know what would happen.

Everything now is tied up with whether you have a funding package. If you do not have a funding package you cannot access services. It is very shortsighted, because what we are seeing is that there is the loss of people able to actually contribute to the community. You have families who are locked at home, looking after their people. It is cost-effective for government, but it is destroying the social capital of our community and I think we are not well served by that at all.

The current system of service delivery is about making do, I guess. The non-government sector, I would have to say to you, is extremely demoralised. It is probably also extremely passive, which is useful for government and the bureaucracy, but I know that they are fundamentally saddened by what is going on. People who provide services wish to provide services. They want to have the relationship with the people who have disabilities, and with their family members. That is the way the sector has always operated. At the moment the processes prevent those things from happening.

Ms DICKSON: Just to add to Robin's point, one of the major changes over the last 10 years is that, prior to devolution to the State and with a much more focused role for non-government organisations, we were the designers of the system for certainly a major player in the design of the system. We are now just tools of government to deliver pre-designed programs. We are not in partnership with government in the designing. That is a real shame because we believe we have an enormous amount of skills and expertise, and a great deal of history, that could be very valuable in the designing of the system for now and the future.

The Hon. DOUG MOPPETT: That is a most striking submission you have made. I know analogies can be misleading, but it sounds to me as if you feel you have been moved into the role of the suppliers who put products on the supermarket shelves.

Ms DICKSON: Indeed.

Ms WAY: Absolutely.

Ms DICKSON: Absolutely.

The Hon. DOUG MOPPETT: And somebody else giving access to people to come and take a packet that you are providing. Is that too harsh?

Ms WAY: We do not even get an opportunity to be a part of the designing of the package. We are more or less just a retail broker. We are not getting a part in the design of the product, and that is a shame because we are the closest you will get to those who are going to be using the services.

CHAIR: You have put your point more strongly than you have in your second or third submission. Are you saying that until 1991 non-government officers had a fairly independent role?

Ms WAY: They were recognised as being centres of specialist expertise.

CHAIR: State and Commonwealth government funding came to NGOs to provide those services?

Ms WAY: During the 1980s there was a sense of enormous optimism about what was possible for people with disabilities. The Commonwealth entered into a series of demonstration projects of pilots which they offered to the sector and people could put up their hands and design their own demonstration projects and take them to the Commonwealth. If they fitted whatever guidelines the Commonwealth had established, those projects were funded and put in place. That led to an enormous amount of diversity in the non-government sector. You had small organisations evolving to take one particular aspect, but they had linkages to other organisations who would then deal with this sort of aspect so there was some overlap process.

At the moment we have what I call homogenisation of disability: that disability is disability is disability, you treat it the same way—a person with a physical disability receives largely the same amount of money as a person with an intellectual disability. Their add-on needs for attendant care, housekeeping services and provision of technological equipment is largely ignored because it comes from a different pot of money, whereas previously—

CHAIR: Ignored by whom?

Ms WAY: Ignored by particular bureaucracies who look only at direct support needs. Technology comes from health so it is not their concern. Again it is the silo effect of funding as well as service delivery. I guess that the organisations themselves felt that if they were able to identify a set of needs in their particular region or in their particular grouping of disability they could put up their hand and say, "These are the things that we think are important" and they would enter into some degree of funding arrangements with the funder which would allow that to come forth. The positive benefit that happened in the late 1980s with the Commonwealth pilot programs was that they were researched. The most successful of those received continuity of funding and some of the others dropped off. There are echoes of those services still in existence today but there are precious few of them.

Now it is largely built around three or four distinct programs, and that is about it. There is no entry point into the bureaucracy to say, "I have got this whiz bang idea that I know will work" and to be able to say, "Here's our submission" even if that is in concert with other organisations. I have been working with a group of organisations on collaborative processes. Part of our stumbling block is that we know how we can increase capacity across a regional base but there is no way that we can access the pot of gold that we need in a regional area to allow us to take that forward. That is the frustration of service delivery.

CHAIR: On the other hand, it could be argued that a smaller number of people with disabilities were catered for and that now a larger number of people are catered for than the system you are describing was able to do in the 1980s?

Ms WAY: For less time.

Ms DICKSON: But ACROD members still feel that we can play a major role in the design of programs. We do not feel that we are getting that at the moment.

CHAIR: What do you say about the number of people?

Ms WAY: It goes back to the assumption that disability is an enormous drain on the community.

CHAIR: It is certainly argued that the raw number of people catered for under the old system was less: a lot more people were getting no services?

Ms WAY: That is probably true, but the increased numbers of people mean that now most people are getting less delivery service.

CHAIR: People are getting some service.

Ms WAY: They are not having their needs met which actually means that you end up with further pressures and crises as people progress through their lifespan.

The Hon. IAN WEST: Have the overall number of hours being delivered increased or decreased?

Ms WAY: I do not think we can answer that. One of our problems is that there is very little information that comes to us from the department about those sorts of things.

The Hon. IAN WEST: Is it argued by anyone within the advocacy groups that the ability to have knowledge of the delivery hours that are available has diminished since the late 1980s.

Ms WAY: The quality of life of people has diminished. I am not certain whether you can measure that in terms of hours of service.

The Hon. IAN WEST: Anecdotally do you believe on the evidence that less hours are being delivered overall, but more people are being given a service—a little bit like underemployment?

Ms WAY: It is very akin to that. If you measure the people in employment on their half hour of employment in a monthly period then I think you could say that similarly with the ATLAS program and with the day programs, that is exactly what is happening.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: When I campaigned against smoking some years ago the department would rotate staff working in the position that dealt with smoking. You would get reinvention of the wheel with 20-year-old ideas that did not work being massively funded—not by their standards but in terms of the resources of the non government sector absolutely massive—doing basically silly things and being totally impervious to any ideas one might have for a more effective use of capital. Is that an analogous situation for you? Do you have a loss of expertise and a change of staff at various grades within the public service?

Ms WAY: Absolutely.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is there a lack of wise spending of resources?

Ms WAY: Part of the problem is that the bureaucracy has no history in disability.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Yes, that is exactly the problem.

Ms WAY: They have no real interest in exploring this. For example, I sat on the working party for the first ATLAS report a couple of years ago. It became very evident that it was being moved in the direction of a time limited experience for people with disabilities. The community grouping within that working party was so appalled by what that meant longer term for people that it put in a separate submission to government saying that this was wrong. We went back and provided some material on the old activity therapy centre model which was very prevalent in the 1980s. We looked at why it was not useful to see employment services as some sort of training continuum, so that eventually if you got to 89 you would end up in employment because you had been in the training process for so long. But the department did not have any understanding that any of those things had ever existed or why they had failed. So a lot of the processes that they were suggesting within the ATLAS program were exactly what had failed in the ATC, with a lack of any systematic training processes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Was the lack of corporate memory a huge problem?

CHAIR: Question two is about the amalgamation of disability services in ADD and DOCS. A lot of what you have said relates to the past and to the operations of the Commonwealth which we will continue to come back to. We have some familiarity ourselves with what you are saying about employment programs. Let us move through them and keep in mind your overall philosophy as we go through the questions. Would you comment on the amalgamation and its effect on the members of your organisation?

Ms WAY: It is very difficult because it is a very new process, apart from anything else, and they are two different systems which largely do not connect. Traditionally non-government organisations have gone down this pathway. They subsidise government with their discretionary income that they raise and put into services. They are underfunded in comparison to DOCS, which has a whole array of access to resources which the non-government sector does not have. Largely they traditionally have not had a lot to do with each other. People with physical disability, for instance, would see them as totally irrelevant to their needs. The problem with the amalgamation lies more in the restructuring of the department. Restructurings inevitably mean that you have another hiatus period when nothing happens because you have got a whole lot of new people, different structures coming into play and the whole array of new departments within the department and everybody has to work their way through them.

CHAIR: What you said initially relates to DOCS but it does not relate to ADD. The non-government sector previously had a lot to do with ADD even if it did not have a lot to do with DOCS.

Ms WAY: Yes, we are still connected with what is now called the DADHC. That is our focus point rather than DOCS. That being said, however, Catherine has a comment to make about the interface between direct supports DOCS staff have with some aspects of the organisation.

CHAIR: I take your point about the lack of contact with DOCS because DOCS basically ran its own services and focused on intellectual disability, but that point does not relate to ADD which was and still is obviously a funding body, a supervising body, a planning body and so on?

Ms WAY: Sure, but it muddies up the funder-provider split as well.

CHAIR: The point you are making about no contact does not relate to ADD but it relates in the past to DOCS?

Ms WAY: Yes, even within mega departments at this stage there really is not a great relevance to the non-government sector of a restructured department except the additional problems it is likely to bring to the sector.

Ms DICKSON: There are two major issues; two parts have come across with the amalgamation. The disability workers within the Department of Community Services [DOCS], who are under the DADHC [Department of Ageing, Disability and Home Care], obviously will boost their numbers on the ground. The other sector that has come across is their service provision, that is the large institutions and the group homes. As far as extra resources for disability workers within DOCS, it is early days yet, but our front-line contact at this point clearly indicates that those workers are ill informed as far as the Ageing and Disability Department [ADD] systems and processes are concerned. They are very unsure of their role and how they connect with new processors that roll out quite quickly. That has added to the confusion.

Families who are used to seeing DOCS workers as caseworkers now do not understand where their DOCS contact sits. Some families actually saw them as independent from ADD and, therefore, able to advocate for them. Now, of course, they have become part of the department so there is confusion. It is very early days and we understand that there will be a time at which we expect the department to bring those people online and better inform them. It is a shame that they are out there now, and a lot of confusion will be created in the meantime.

CHAIR: Do you think that the amalgamation has positive aspects in the longer term?

Ms DICKSON: I suppose, if it increases the number of people who are available for the department to use, to act as a contact. But until the NGO [non-government organisation] sector has an understanding of how ADD thinks its structure is going to work, it is very difficult to comment. It is hard to make a judgment on whether it will be effective or useful if we have no idea of the vision. That is one of the problems that comes through much of our comment today. The NGO sector has no idea of what its vision is. We are second-guessing all the time.

Mr DAVIS: I refer the Committee to the section on page 8 of our written submission which is headed "DADHC Administration and Relationships with the Sector". That tends to describe the current relationship. I highlight that to illustrate the point further

CHAIR: You are referring to your new submission, the members of the Committee do not have a copy of that. However, as your submission has become part of your evidence the members will be able to read it. Would you comment on your experiences in the changes in service delivery, particularly the use of the EOI [expression of interest] process. Can you give what I assume will be negative comments on that?

Ms WAY: In our submission we have gone into great detail about this. As you say, our comments are negative. Our member organisations do not regard the process highly. It is extremely costly and time consuming and does not really support the relationships between people with disabilities, their families and the organisation in the way that we envisage it would when we were part of the original working party. The processes are confused, the communication is appalling and it does not meet the needs of the people for whom it is targeted because of the tiers funding approach.

We get back to the notion that people can only have their lives divided up into programs such as the Adult Training, Learning and Support programs or accommodation programs. It does not take into account the holistic nature of a person's life and how the various programs will link. I ask Catheryn to cover some of the details of the EOI processes.

Ms DICKSON: Our members believe that the tender process, or the EOI process, has done a considerable amount of damage to the relationship with the funding body and NGOs. The 300 places tender process, which was the first roll out of that tender process, left a bad taste, if you like, in the mouth of the NGOs, because it was capped funding. The viability issues that were created through that process damaged, to a great degree, many organisations and left them with financial burdens. That was after many of them were already carrying financial burdens after not getting any transition funding through the devolution process from Commonwealth to State.

I believe that that has moved many organisations to be sceptical about entering into the tendering process. In some instances, particularly the small organisations, they are not very well equipped because the infrastructure has been absolutely eaten away over time. Therefore, they cannot be participants in the process. A good demonstration of the impact that tendering has had over the past seven years is the latest expression of interest process for housing and supported accommodation. That was to see organisations go on a two-year eligibility list to be able to be part of helping the department with devolution and the 197 list.

The Hon. IAN WEST: What is the 197 list?

Ms DICKSON: Blocked respite beds. Out of 250 organisations, only 69 are now registered. That is a clear demonstration of how many organisations either did not understand the outcome of that tender by not putting in an expression of interest, that they would not be able to be part of the process, and that is because it was not clearly communicated prior to the tender going out that this was growth funding. If they did not apply, they were not going to be there.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Only 69 organisations applied? The others did not apply, but should have because they had beds, they were providers?

Ms DICKSON: We know that 69 organisation are currently listed as eligible. I cannot give you the numbers of how many organisations actually applied, but we are suggesting that many organisations did not apply because they did not understand the implications of the tender.

Ms WAY: In part, it came out just before the Christmas holiday period and it was very badly phrased. If you read it you would not be sure what you were tendering for. Many organisations said that if that is the sort of generic tender for ever and a day, they did not know what it meant to them if they put their hands up for this one. In fact they might need to look more specifically at what support needs they could not provide for people who might be the subject of the tender.

Ms DICKSON: You also need to realise the disillusionment of organisations with that tender, and other tenders. The tender process did not give them the resources that they needed to maintain their organisations to get rid of viability problems. It was just new growth. While they may have entered into the process of new growth with crisis accommodation, they were still working with viability problems that they had carried with them. So you had a financially weakened group of organisations that are not necessarily in a position to take yet another risk of whether this will be a viable process.

Ms WAY: Because funding, inevitably, is fixed you cannot put your hand up and say that this person's needs have changed and we need additional funding to support that person. If people's needs change the organisation has to provide for that, through its discretionary income. Because infrastructure costs are no longer funded as part of the organisations subsidy, the majority of organisations are very cautious about putting their hand up when they cannot visualise what is going to happen 10 years from now. It is a bit akin to saying to the ambulance service that you will fund them for the patients they take to hospital but we will put up for grabs who will pay for the petrol and the servicing of the ambulance.

Part of our problem is that organisations are perceived to have to provide the infrastructure funding themselves. It is a ridiculous notion, it is actually destroying the quality of service delivery that they were previously using their discretionary income to add to.

The Hon. DOUG MOPPETT: You all seem comfortable using the word "tendering" rather than the phrase "expression of interest". Do you see it as more akin to a commercial tendering process? The Committee has heard some benign interpretations of what "expression of interest" means.

Ms DICKSON: Up until the supported housing and accommodation tender, all previous tenders included costing, and estimation of how much it would cost. Quite often there was negotiation after the fact, once it had been approved; for instance, "You got through that process, but we do not like your figures and we will go into negotiation". Decisions were taken on the basis of those negotiations. Most of tenders, before that time, included having to cost outcomes. More often than not we were actually doing costs on people on paper, without meeting the client and without having any idea of the complex needs. It is to be remembered that all the tenders have been for the highest complex support, for service provision. It was a very difficult process to ask how much it would cost to provide for this person for the rest of their life on the basis of that snap and a little bit of a profile.

The Hon. DOUG MOPPETT: Do your members regard this process as basically that to secure the commission you need to be a competitive tender and beyond that that you are entering into a contract, so to speak. Does it have those commercial overtones? We have heard it described as being a matter of assessing where the resources are.

Ms WAY: No, it is much more commercial and competitive and we are moving more and more towards the process.

CHAIR: Question 6 essentially asks how you would run the system. The Committee has a fairly good idea of your criticisms, although not in detail. Your comments about silos is akin to our question about the criticism of predetermined service models and so on. How would you allocate funds? What sort of system would you set up?

Ms WAY: We need to move to an holistic approach again. We have to view people as having lives that start at birth and end at death.

CHAIR: Could I be devil's advocate for a moment and say that no-one with a disability is treated like that by the Commonwealth or State governments.

Ms WAY: They can expect that they will have an education that will take them through childhood to adolescence.

CHAIR: But that is run by either the education department or a private school?

Ms WAY: Yes, and we are suggesting that there needs to be a whole-of-government coherency approach to this. Disability is not really the auspice of one particular department, or should not be. Disability should be about the particular needs of the life cycle of a person at a particular time. It might well be that you can draw in resources from other departments through that life cycle as you can expect to happen.

CHAIR: So how would you fund that?

Ms DICKSON: That is dialogue that we need to have and we have not had. We have discussed this at some length. It may be a mix of a block funding, pilot funding and individualised funding. It will depend on what target group or what group of people you are trying to provide services to. But underpinning all of that is that you need a healthy and financially stable NGO system to be able to support government to deliver those services. We believe that there is a requirement for government to have those discussions with us rather than making decisions without us.

CHAIR: But you do not have a model? A lot of what you said is critical of existing ways of doing it.

Ms WAY: There are many models that we should be exploring and embracing. As I said, one of the ways that the Commonwealth addressed this problem was to institute a series of demonstration models and pilots that could then prove whether they could exist in the longer term. I think the system is in such disarray at this stage that there is no one model. There is no one shoe fits all type of service arrangement for disability. People with disability are just as varied as all other members of the community.

Mr DAVIS: Can I add there, Robin, apart from saying the reference is at the bottom of page 8 and page 9 of our submission of today, it goes to the issue of building first of all a recognition of the role of the NGO; it goes to the relationship that is yet to be created after many, many years. In that relationship, the definitive role of consultation, we can go to the sections we have called equal partnerships, the holistic approach and building sustainability. It is the appropriate allocation of funds to underpin programs to meet the needs as expressed. We can contribute far more significantly than we are currently allowed to do.

Ms WAY: It also requires that there is some sort of infrastructure and interface between the Commonwealth and the State governments that is effective. We are not seeing any evidence that there is any real intent that services can move across those barriers easily.

Mr DAVIS: Where they do exist they are called bilateral projects. They are rare and only for specific needs, short-term. We believe that some of those projects lack vision and continuity.

CHAIR: Robin, you made the comment earlier about the system being in disarray. Is New South Wales worse than the other five States, better or the same? If you are going to stress the good things that the Commonwealth was doing in the 1980s in terms of pilots, there are obviously huge implications for State-Federal relations, but it also raises the issue of, whatever the Commonwealth was doing, nevertheless the administration was fundamentally at a State level.

Ms WAY: Absolutely. That has been one of the significant shifts for the sector over the last 10 years. Part of the problem for New South Wales—

CHAIR: But surely the administration, if it existed, was always at a State government level?

Ms WAY: No.

CHAIR: Some NGOs might have been more independent—

Ms WAY: The non-government sector had very little to do with the State Government.

CHAIR: But at that time they also had very little to do with the Commonwealth Government.

Ms WAY: No, they were funded by the Commonwealth Government.

CHAIR: But there was very little in the sense of administrative relationships.

Ms WAY: The first funding to disability came from the Commonwealth Government in 1972 under the Handicapped Persons Assistance Act.

The Hon. IAN WEST: But was it not administered by the State?

Ms WAY: No. it was administered through the Commonwealth right through until devolution happened. Non-government organisations were funded by the Commonwealth until 1992 when we devolved to the State.

The Hon. IAN WEST: And you are saying that Federal money has always been administered by Federal people?

Ms WAY: Yes.

The Hon. IAN WEST: Are you sure of that?

Ms WAY: Yes, absolutely.

CHAIR: We are talking about the non-government sector, an essentially charitable sector operating with limits, whereas the administration we are talking about now is more to do with State government administration of service access systems—who gets what share of the cake.

Ms WAY: That has been part of our dilemma. The relationship with the Commonwealth was never wondrous. I am not trying to paint a rosy glow picture here. There was enormous turbulence in the 1980s as well as we moved through the change of model. But at the same time the organisations knew what to expect from the Commonwealth and the non-government sector was not all that fussed about devolving to the State. They saw it as a waste of money, to be perfectly frank. However, having had that happen, we were then faced with a bureaucracy that knew nothing about the non-government sector. They had not had a relationship at State-level with the non-government sector disability organisations apart from the odd contribution to good works, education and some health issues. But the services themselves were funded and supported through the Federal Government until that time.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The Federal Government basically cannot manage anything can it? It tends to give the money and let someone else manage it. That is its model as it relates to the States.

Ms WAY: It is now.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But it always has been. It tends to be pretty hands off. It says, "Here's the money. We will get a few performance indicators to see how you are going and you can get it again."

Ms WAY: It was not that way in the 1980s.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Whereas the States, having run their own organisations, then presumed to be able to run yours. Is that not the difficulty you are having?

Ms WAY: Yes, it is.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: They think they know, whereas the Commonwealth did not.

Ms WAY: Yes, I would agree with that.

Ms DICKSON: To go back to your question about how we would see it being funded better, it would be very difficult for us now to come up with a model. We need to be having that conversation with the Government as it is and across government departments too.

Ms WAY: And with other stakeholders. One of the things that is very lacking at the moment is the capacity for all the stakeholders to come together to explore the issues. If we are serious about being innovative as a sector we have to address how we will interface with each other across the sector. But in the last five years in particular the lack of trust and the suspicion between stakeholders within the sector has increased markedly, particularly since the group home devolution process.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is there an overall picture of what is happening in the sector? Is there plenty of information? Who is getting the money? How many people are they looking after? Is this information available publicly? What programs are there? Where are those programs? If one is trying to look at an overall system one would have to have some data. Is that data available and is it available publicly? If not, why not?

Ms WAY: We provide data to the department about every part of our activities. I suspect that there is a cupboard somewhere in ADD where all that data goes. Every year the minimum data survey results come out. But that is one day in the life of an organisation each year. It does not actually give you a very clear picture as to how many people have been supported into housing through a particular tender process or how many people are in daily programs. Indeed, many of the organisations fund their day programs and do not receive any funding through government from that. So there is no clear picture about which programs are in existence, because the sector provides a lot of the funding itself and provides programs to people that are not government funded.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It seems to us a nightmare of acronyms and programs. Getting an overall picture of what is going on is extremely difficult. Until you get an overall picture that people can discuss you will never get any serious progress.

Ms WAY: Yes.

Ms DICKSON: And in the meantime there are some urgent issues in the sector that need to be addressed, including the huge backlog of people waiting for service.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It may be that we do not want to define what we have because then we would have to define what we do not have.

Ms WAY: Absolutely right.

Mr DAVIS: I have asked the last two successive directors general directly on behalf of our members for statistics that will help us to assist them to plan for the future. That information has not only not been available but it has been declared to be too difficult to produce.

CHAIR: That probably is a good point, to get onto the service access system. It is probably time that we got into the specifics of what is happening at the moment or the plans. It is obviously meant not only to deal with some of the problems of collecting data and measuring need but to set some priorities and make it help. What is your comment on that?

Ms WAY: I guess our great concern is that it is early days and our fear is that it will turn into some sort of gatekeeping mechanism which excludes people. Part of the problem is what will happen to people who are excluded from the SAS system, as I gave you that earlier example from the parent who has been knocked back through SAS. Catheryn is working with that on the ground so I think she is the best person to cover it for you.

Ms DICKSON: I suppose our major comment on the SAS system at the moment is that it has not been broadly communicated to the NGO sector as a methodology for providing access for families. Nor has it been communicated to those community groups that will be the first contact point for people needing to go into the system. If we look at it just as a crisis process, many families or people will not go into the system because they may not be at crisis at that point of making contact with someone who may know about the SAS system. But if you were to extend the communication so that everyone was aware that this is a way of getting your lottery ticket or perhaps your chance for future service, if that was broadly communicated, then it may provide the information that government, NGOs and the community at large would need to plan better. But as Robin said, it will depend on how well that system is administered and managed or whether it is just used as a gatekeeping process and a prioritising process.

CHAIR: What is your comment on how it is shaping up so far?

Ms DICKSON: Up until two months ago we saw very little action and suddenly we have an enormous number of inquiries from people who have seen our organisation's name on the eligibility list and think we have got funding and want to make inquiries about our organisation. There is no way that we are going to be able to cope with the demand that has come within the last two months.

CHAIR: So that I can get it straight, you are talking about organisations that have received funding?

Ms DICKSON: No, on the eligibility list, and families who have been prioritised and get through the gate to say that they are going to receive funding. The numbers of those people, while in broad terms it is very small, will put enormous pressure on organisations on those lists to provide services. You have to recall that many of those same organisations will be part of devolution and part of respite bed blockages. It will be extremely difficult now because suddenly we have enormous requests for growth and to provide services. We do not have the staff. It will be extremely difficult to get the staff. We do not have access to housing. There has been not enough work. There has been some work but not enough work to ensure that there will be the capital to purchase housing or that the Department of Housing has been prepared adequately to cope with the influx. And that is just to deal with the people who have been let through the gate.

Ms WAY: This goes back to the 69 organisations—

CHAIR: These are people currently living with their families, presumably, because they are not people currently in the system. So you are talking about people for whom new accommodation has to be made available?

Ms DICKSON: And that brings to mind the other important issue that for the SAS system to be a real indicator of what the needs are it must go broader than those living at home with families. It must also take into consideration those people who have been accommodated in the past but their position has broken down, the relationships have broken down, there are viability issues because of increased needs. It must capture all that need as well. It is an enormous amount you are asking of the system and I do not think the system was set up to do that. It may be able to be expanded to do that but that expansion needs to be looked at carefully to determine what is its aim.

CHAIR: You seem to be talking about growing pains or implementation pains.

Ms DICKSON: Yes.

CHAIR: But you are also saying that the system is in fact producing people who have been let through the gate and it also has lists of providers.

Ms DICKSON: Yes.

CHAIR: So to what extent are those two sides being brought together or is it too early to say?

Ms DICKSON: It is too early. We are dealing with families making inquiries of organisations on the list. They are making choices and, interestingly—it has come out of our conversations when developing the submission—many families are choosing larger organisations that they know the name of or have had some history with because of their misgivings or fear that smaller organisations are not going to be able to provide the security that they need.

Ms WAY: So you end up with a self-fulfilling cycle of large organisations growing larger and the small and medium organisations are likely to disappear.

Ms DICKSON: That would lessen the diversity and nature of the whole NGO sector and, as important, one must question the ability of medium to large organisations that have a reputation for quality because of their sheer size, whether they have the capacity to actually cope with the roll-out of the new funding. As a medium-size organisation we are battling to keep ahead of the workload and that means we have to then draw on new people who do not necessarily have the history that we need them to have, when you will have 250 or more organisations out there that could be sharing that load when it comes down to 69 that are on eligibility list.

The Hon. DOUG MOPPETT: In the context of marrying up resources to demand, about 12 months ago the Committee heard evidence to do with the department's survey of the total needs. It went around the regions and had a system to try to evaluate not only the current demand but the potential demand out in the community. Did the department contact you?

Ms DICKSON: Yes, as a regional organisation as well as a metropolitan organisation we have been part of regional planning, which is, I think, what you are referring to.

The Hon. DOUG MOPPETT: Yes.

Ms DICKSON: Whenever possible, as far as our resources go, we have tried to be a part of that process.

Ms WAY: But the majority of organisations do not get that information. Unless you are actively involved in the process you are out of the loop and you stay out of the loop. It is part of the lack of coherence in communication within the sector from the department.

Ms DICKSON: And there is a degree of scepticism about the value in the sector and by that time there was considerable backlash to the new processes.

The Hon. IAN WEST: Do you sense that certain stakeholders in the system do not really want you to know what the demand is?

Ms WAY: I think that organisations know the levels of demand. We get phone calls every day from people who are truly desperate about how they get a funding package. If you do not have a funding package you do not get into the system. The organisations are well aware of that. The dissemination of information across the sector in terms of planning framework is non-existent and it is the big picture framework that nobody seems to have access to and certainly the department will not talk about.

The Hon. IAN WEST: Access to it. You say it exists.

Ms WAY: It may well be there but we do not know about it.

Ms DICKSON: That is not to say that the information that has come out of the regional planning process is not integral or accurate. Having reviewed many of the prioritising in regional areas I would suggest that even though NGO participation was fairly low and in some cases non-existent, the priorities are fairly clear, the volume perhaps is missing.

Mr DAVIS: As a peak representative, we welcomed the opportunity for peaks to be separately consulted in the field activity and the correlation of those two sets of consultations did come closely together, as one would expect. However, what we asked for was not just a report but an understanding of how the outcomes went to service provision. There have been no outcomes that have been measurable from our input to the report.

The Hon. IAN WEST: Returning to the question of what you would do if you had the chance to do whatever you wished, how do you think you should be able to match the wish list with the cost effectiveness?

Ms WAY: If it is a whole-of-sector approach then that is possible because you are looking at organisations being able to define what it is that they do well and marrying that with the needs of the people in their specialty area of expertise or within their regional area. One of the concerns we have had from members in the rural and regional areas is that they do not even get to discuss their needs about what is good for their person—any service for them.

The Hon. IAN WEST: Are you saying that in terms of economic cost effectiveness, the question of ownership, relationship and the core partnership between stakeholders in the system and those who are interested in the dollar. There should be no reason why the information is not shared. You are aware of the need for cost effectiveness.

Ms WAY: The system at the moment is so fragmented that everybody is only operating within their area of vision and the lateral spread of information is just not occurring. That is the first thing that has to be addressed. There needs to be a vision about what disability services is about in the first instance. There needs to be a process that enables the sector to come together in real terms, not in rhetorical: "Let us all innovate together" but "What is the hard work we have to do here?" One of the other issues is that there are many disability groupings which are not even getting a leg-in to this. For instance, the Deaf community does not get very much funding in the way of service delivery because many of people within the community are embedded within the community and those people are dying because they do not have access to people who can provide assistance into the health system. Doctors cannot communicate easily about their health needs and misunderstandings mean that people may develop cancer and they may not even know what that means because there is no way of placing the dollars to address those needs.

People with multisensory disability, if they are very fortunate, will fall within a specialist organisation. If they are not, they are mostly left in institutions or at home. We need to have some decent debates about those needs and there also needs to be equal weighting with people in the middle of the bell curve, if you like, who are within the system because they are relatively easy to meet needs. It is the people on the fringes who are missing out. We also have people who have what are defined as low support needs who are not allowed into the system because ADD made a decision in 1997-98 that they did not meet their needs and that they could manage within the generic system. Many of those people end up in gaol because their needs are fragmented and they do not have coherent service delivery coverage.

Mr DAVIS: As my staff and I travelled around the State there are a couple of expressions that are common when we ask, "How are you going? Are you getting what you need? What's happening?" The two comments would be first of all that the department's relationship is, one, would they invite us to be reactive on isolated issues and/or our input seems to only complement preset agendas. We regret we have to say there is negative things but this is the view of our members across the State. We are not inclusive in the planning or consultative processes on the comprehensive basis that Robyn just outlined.

CHAIR: You have reminded the Committee that one area we did not cover of whether it is true that people with physical disability are underrepresented amongst service providers.

Ms WAY: And it is difficult to know that because the information has not come out from the department to tell us whether that group now is receiving more attention but I would suspect that if you spoke to the relevant specialist organisations they would tell you that it is no different to the rest of the sector.

Ms DICKSON: In a system where you are funding people with support needs, the sensory, the physical, people who are not necessarily considered in the same degree of crisis as a family with someone who has high complex support needs, there is no entry point in the current system. Globally NGOs feel they are not trusted, respected or part of the system and that the resources they have collected over many years as far as knowledge are not being utilised to the best benefit and there are many organisations that are now not actively participating in the work that is needed to be done and that is a shame.

CHAIR: Do you mean gradually closing down?

Ms DICKSON: They may, as their capped dollars continues to shrink. That may be an alternative for these organisations.

Ms WAY: It is occurring in two ways. They are also withdrawing from they see as a futile process.

CHAIR: Which is why so few of them are registered.

Ms WAY: Take the sparse resources that are available to be part of something that everybody feels is tokenistic and has already been determined prior to the consultation. The other problem is just staying alive. It is extremely difficult now for organisations to fund-raise. Competition for the dollar is increasing. We are part of the new brave world of tax. Compliance issues are increasing. All of us have had to expend a lot of the resources that would once have gone into quality of life issues now going into compliance and regulatory processes so within the organisations themselves, their structures are being forced into more and more formalised processes rather than immediately responsive processes that can attend to the needs of people with disabilities.

Ms DICKSON: We think that there is a future. We are born optimists.

CHAIR: What would you like to see come out of this inquiry?

Ms DICKSON: NGOs have evolved out of an idea of optimism that problems can be resolved, that there are solutions out there. We believe NGOs have an enormous amount to offer as far as providing the outcomes that are needed but we do need to be considered as equal partners and our resources called upon to come up with some guidance as to what would be the best way to do things. We need financial support as far as our infrastructures are concerned to actually survive during that process, not just medium and large organisations but small and specialist organisations, the migrant resource centres, those organisations that target specialist areas that need the financial structure and stability to be able to survive.

Ms WAY: The other point, though, that needs to be made is that this is not just about money. As I said before, the sector has actually subsidised government. There would not be a disability sector if the non-government organisations had not got together and decided that they would do something about these needs that the Government would not have a bar of. The sector has largely financed the underpinnings. It is run down at the moment and badly needs an injection of funds to lift the infrastructure issues but, collectively, it is still able to harness its interaction with the community. That is its greatest strength: its interaction with the people around it who support a particular cause or organisation. They build the resources within our communities. It is not just about money. If the sector is able to pick up and run with the vibrancy and the energy that it has shown in the past I think we could end up with a very coherent disability service system. However, as Catheryn said, it has to be an equal partnership.

Mr DAVIS: This was an offer to government from the industry to contribute to the future of disability services in the State. It is based on a great deal of skill, experience and expertise. To give effect to my colleagues' statements, we want to be inclusive philosophically and in reality in planning for the future.

Ms WAY: Thank you for this opportunity to appear before the Committee.

CHAIR: Thank you for coming. Are you happy for your most recent submission, which answers are questions, to be published?

Mr DAVIS: Certainly.

(The witnesses withdrew)

MEAGHAN LESLEY SWEENEY, Advocate, Family Advocacy, 7 Lansdowne Avenue, Wagga Wagga, 2650,

ALEXANDER FRANCIS PURVIS, Environmental Scientist, Family Advocacy, 5 Vincent Street, South Grafton, and

JUDITH VALENTINE ELLIS, Advocate, Family Advocacy, PO Box 502, Epping, sworn and examined:

BELINDA EPSTEIN-FRISCH, Advocate, Family Advocacy, PO Box 502, Epping, affirmed and examined:

CHAIR: Thank you for appearing before the Committee today. Did you each receive the summons issued under my hand?

Ms ELLIS: Yes, and we are conversant with the terms of reference of the inquiry. We have submitted a written submission to the Committee and we have a handout that we would like to leave with you. We would like that document to be included as part of our evidence. We will elaborate on our submission and make a statement. We have tried to think of some solutions, which we will focus on in our presentation. It will be a guide to some solutions about which we will be happy to answer questions.

Mr PURVIS: We will try to address your questions throughout our presentation. However, there will no doubt be other points of clarification.

Thank you for this opportunity to appear before the Committee. It is greatly appreciated. Your Committee is in a prime position to start making a difference in New South Wales to try to move from a system in crisis to a system of prevention. Our entire organisation has a considerable amount of experience, and the people you see before you have experience in senior levels of the State and Commonwealth public service. We have past and present members of the Disability Council and members at senior levels of various task forces, boards of management of service providers and community visitors. We are all parents and advocates.

A key point—we will probably reiterate this in our presentation—is that we do not believe spending additional resources on the traditional way of doing things will change the current system, which we believe is in crisis. We are trying not to focus so much on the problems—I am sure you have heard a lot about them—but to suggest some practical solutions regarding how we can move forward from our present position. We have had some preliminary discussions with the acting director-general about some of the things that we will discuss with you. We have gone away and refined our ideas and we will tell you today how we are moving forward with our notions of how the system could be better. In our presentation we will discuss how we can adapt the existing system to function more effectively. We will give some examples, both local and from overseas, about how things can work in the real world and some principles that we think should be embedded in the system. That will give you an idea of where we are trying to head.

Ms ELLIS: I will use the overhead projector for my part of the presentation. I will be happy to answer any questions. To revisit what Alex said, we wanted to give a presentation that we thought might lead to some solutions. My part of this presentation—and hopefully any questions that Committee members might have later—will outline the first part of the solution that we see, which we think has been lost. We want to revisit the legislative mandate and the legislation that we have in this State, the Disability Services Act 1993. We believe that we also need to revisit a particular part of the legislation—revisit it all, actually, but, when we are thinking about structures and the way things might happen differently, in particular to revisit section 10.

The short extract of section 10 shown on this overhead is obviously paraphrased from the legislation. It shows that financial assistance can be approved to individuals, their family or carer. That is contained within the legislation; it can be approved to eligible organisations for the provision of service; and it can be approved to individuals or eligible organisations for research and development. What we would have to say about this is that policy direction over recent years has resulted in that very wide framework that the Act of in thinking about the lives of people with disability has been narrowed very considerably. I think that the evidence you heard from ACROD previously shows that that is the case.

We face a situation today where, generally speaking, funding is provided through a very restricted part of this, which is, eligible organisations for the provision of service. We would have a view that this area (indicated) has been very actively discouraged by the bureaucracy and this area (indicated) we have not seen very much of. But these actually are the two areas that might give us some better frameworks for thinking about how to get some solutions are into this area. I have copies of these overheads to hand out. I think this is what the Committee heard earlier and I do not propose to dwell on it, but what we have now is that funding for services is primarily being approved—you heard the way it is being done by expressions of interest and competitive tendering—to non-government specialist disability agencies who support a very large number of individuals in one or two geographical areas.

I might say now, and I am probably going to come back to add to it, is even those agencies are being pushed through the process to get bigger and bigger and to expand to other geographical; non-government specialist disability agencies which support a large number of people in very widely dispersed geographical areas; non-government agencies that provide support services to a wide range of disadvantaged people—we also face the fact that funding for people with disability, for children and for adults, is now being provided to organisations that provide services for homeless people, people with mental health issues and youths in trouble. I think part of that phenomenon is the agencies that can best write expressions of interest; and church-based agencies that serve a wide range of disadvantaged people.

The common features that our organisation would say have arisen from this are that over the past five to six years, despite a very innovative Act, ended up with large traditional management structures with decision-making in the hands of people who are extremely far removed from any individuals. We have the management of facilities and outlets, whereas human services are about support to individuals, but most agencies that we know about and are in touch with are forced into the management of facilities, outlets or branches. They employ increasingly casualised work forces. One of the things we absolutely know about people with intellectual disability, particularly those with high support needs, is that they need consistency. They need people who understand them, and form a relationship with them in order to support them.

I know that my son needs that. I am aware that most of the people I meet need that consistency in their lives, particularly as support services are about very intimate day-to-day aspects of people's lives. What we have as a result of this is a highly casualised workforce of people who are there one morning and not there the following morning. They come and go. The other common feature is that the agency and people are removed from personal knowledge of the people being served. There are also very high administrative costs. While it is interesting to hear some of the rhetoric around the expressions of interest, from what we understand some agencies have to expend more than 30 per cent of the funding in administrative costs. That comes from someone's package that has presumably been assessed at some place.

As I said, they have very high administration costs and, we would say, provide quite outmoded forms of support services. Some of those agencies have received adverse reports from the Community Services Commission or from the Audit Office. The 69 eligible organisations that ACROD spoke of include some about whom the Community Services Commission or the Audit Office has reported adversely in relation to their capacity to support the lives of individuals.

Conversely, section 10 (1) (a) gives us some possibilities that could be different. I have paraphrased some of the things under section 10 (1) (a) and 10 (1) (b) that could be possible. The Act allows the provision of funding to individuals who can manage their own affairs. There is nothing in any evidence anywhere to suggest that an individual is not as accountable as a non-government organisation for their money, or that an individual could not have the same kind of monitoring arrangements. That Act provides funding to an individual through a member or members of that person's family; and it provides funding to an individual through members of that person's family or personal network.

In section 10 (1) (b), rather than the very narrow interpretation of that section there could be some things I am sure that the Committee has heard about. A trust could be established with the sole aim of supporting an individual. There could be a company limited by guarantee with articles of association limited to meeting the needs of one individual. There could be a microboard. I believe the Committee have seen some of the reports and has heard extensive evidence from British Columbia about the establishment of microboards. Those microboards have developed further I believe since the Committee received that evidence.

There could be non-government generic agencies, for instance, substitute care, local family support agencies, community health and resource centres, neighbourhood centres et cetera. With some funding and some encouragement there could be a non-government specialist disability agency which would manage the funds for the sole benefit of an individual. It is interesting that only here do you find the specialist disability agencies. The rest could be a whole variety of different agencies. The common features come back to a focus on the person, bringing different expertise to bear on issues, and interest in building relationships and a real life for people, as opposed to the management of outlets and facilities. We would argue that that would lower administrative costs at the level of support services.

Those are just some of the agencies. I had proposed, but have decided not to in the interest of time, to think about ways in which the Government could have provided support through section10 (1) (b) to individuals or eligible organisations for the purposes of research and development in its broadest sense, which I think you heard about that earlier and which we certainly want to talk about. That is, how do we encourage people to think about innovation? How do we trial things? How do we examine things? We would say that, unfortunately, through the narrow definition of policy, we have ended up with a very constrained and limited way of thinking about the lives of people with disability. And it is not working.

Ms EPSTEIN-FRISCH: I want to talk about the role of the department and of government in getting something more innovative, and responding to the crises and moving towards prevention. We say that government has a significant role in leading the way. It is up to the Government to go from the narrow definition of what is possible, to lead the way to innovation. The Committee has heard an excessive amount about the chaos. We are saying that the Government is the body to take us forward. The Committee heard a great deal of evidence from ACROD this morning about the chaos. It is not possible to both work through the crisis-driven system at the moment as well as think of ways to do something different.

The crisis means that consumers the bureaucrats are not able to free their minds to think about something different. What we are asking the Committee to recommend and what we say is important, is to separate or quarantine within the department some new funds that will be used for the purpose of thinking about doing things differently; to provide the scope and the opportunity within those quarantine funds to think about different ways and to be responsible for getting some innovation onto the ground. This kind of quarantine area would think about expanding ways to get support to individuals; it could work with selected agencies to start to help them to think about the way in which they might reshape themselves are around support for people. That is what fundamentally we are talking about.

ACROD talked about developing relationships with non-government organisations; that non-government organisations felt out of the loop and out of the partnership. But the people who are even more disempowered are the people with disability and their families. We need to think about and find ways to share some of the power and responsibility for people who have the most intimate and greatest desire to make things work for families and people with disability. Through these quarantine funds we could start to think about additional information and education to consumers. We have to help people to see some different ways. We have to establish pro-active strategies that will link that innovation ultimately to general service delivery. We have to allow the people who are thinking about innovation to work together and share ideas because some of these ingredients are missing in the current system. Ultimately those kinds of innovations need to speed back into general service development and general policy.

Ms SWEENEY: Judy spoke about parts of the legislation that have been neglected as far as funding is concerned and have been actively dissuaded. Some families who are familiar with the legislation have requested individualised funding and have put forward to the department ways that would be administered, but it has been actively rejected by the department in favour of only traditional disability-specific services getting funded. In order for those things to actively happen we need to have a section of the department that solely looks at that type of thing, rather than just crisis. By laying out these things, it is the role of the department to find that niche within DADHC that can look at innovation and individualised funding and changes to congregate care. We had announcements about the devolution of our large residentials within this State and very few people have come out of large institutions, even though the funds have been allocated and the money is there, because the department is in crisis. There is crisis management but no-one solely focuses on how to do something different.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you suggest a research department?

Ms SWEENEY: It is more or less like a quarantine section of money that does not get sucked into crisis management; that is left to do the work around change, and looking at doing things differently. Some families who have family members in those institutions want them to come out, and are actively seeking it, but they do not want them to go into the traditional six-bed group home somewhere in the other side of the State.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you talking about a research or audit department or one that has a fair budget for seed funding or pilot programs?

Ms SWEENEY: That is right.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It cannot be one that is just reading literature?

Ms SWEENEY: It has to be active. We believe that one of the problems with the department is that people have really good ideas, they want to do things differently that are absolutely contrary to within the department and eventually they leave. Good staff who have wonderful ideas and a great passion to make changes in people's lives get stifled because of the bureaucracy and they end up going elsewhere.

Ms ELLIS: The basis of why we are suggesting that the department should actively think about the things that we are suggesting here is that we absolutely believe, and we have seen, that there is chaos and crisis—your evidence and your reports show that. You cannot have the same people in the department having to try to solve that crisis and think about new things. It is different skills, different expertise and at the moment everybody is sucked into the sorts of things that you have heard from ACROD throughout this whole inquiry. The department is probably in the best position, given that there is a new director general and there has been an amalgamation, although that has enormous ramifications, and it is time to say "Can we invest in seeding, thinking and encouraging a different way to do things? That will, we believe, see a solution—there are no simple solutions but it is a way of thinking.

Ms SWEENEY: Part of the problem in New South Wales is that people ask, "What could be different?" There are so few examples of how that looks in our State that it is hard to say, "It could look like that." It is hard to take it on board if people have seen it in a research paper or from overseas. People want to look at the service providers and at other families and see it working to see how it looks. In New South Wales we have very few of those more innovative sort of things happening. There is very little opportunity for that to happen in the way that our bureaucracy is handled in this State.

Ms ELLIS: That is extraordinary if you refer to the Act which gives a wide mandate for innovation in this State in 1993, and in 2001 very little—

Ms SWEENEY: Because the way bureaucracy works it does not allow for it. We think that there needs to be a quarantine section within the department that focuses on parts of the Act that have been neglected in the past. How can that work and get funds out in individualised smaller projects which we will talk about, and get some of these pilots, and some things, actually happening where people can say, "Look, this is different. It can work differently."

The Hon. DOUG MOPPETT: Apart from the need to encourage people with innovative proposals, to what extent is it important to pursue this idea of evaluation and strategic planning for unrolling the services that we already know about? Our biggest issue which comes back is unmet need. There are heaps of people out there, and although there have been steps taken to quantify that and say that by the year 2010 this demand will be on-line, that seems to be singularly the most obvious deficit in the Government's approach. We all understand crisis management which probably has to go on for a while but the problem is that no-one can say when the end of the crisis will be?

Ms SWEENEY: That is right. There is no focus in the department on what we are talking about which is prevention of crisis. This idea of quarantining someone to look at supporting families who want something different, or families who are not in crisis now but see a need for some type of service provision—not even service provision, support—in their family member's life and getting that on board and making it happen. In order to do that you are setting the building blocks to prevent the crisis that the same family will be on your crisis book in 10 years' time if those things are not in place now.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you suggesting two separate departments?

Ms SWEENEY: No.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: If you are talking about a huge number of other programs you have to have a research department which says, "We will fund these and get results" and then presumably that research would have to encompass what the department was doing elsewhere. It would have to be an audit department as well, would it not?

MS EPSTEIN-FRISCH: From the perspective of families to refer to it as research sounds too academic. We need the opportunity to set aside a certain proportion of funding to authorise and give responsibility to that section to provide innovative ways—some of which might be getting people in crisis—to look at things that are different, that are allowed within the legislation that make a difference. Of course your report is going to talk about the importance of strategic planning and positioning and dealing with the crisis. We are saying that let us have something in a recommendation that says we also need an opportunity to try to think through how we are going to do things differently so that 10 years time we are still not following a crisis-driven mechanism. Let us look at some things, pilot them and try them out, and then make sure that they feed back in to general service delivery and policy and they inform the sector in general.

At the moment there is no opportunity for that development and there is certainly no opportunities for people to share ideas and thoughts and with the authority to do something with those ideas and thoughts. This is the preventative stuff. This is looking forward to the future to say, "How are we going to make sure it is different in 10 years' time and not just the same crisis responding to crisis?"

CHAIR: This morning ACROD talked about the role of the Commonwealth in the 1980s in funding pilot programs. There was discussion arising out of that and we might come back to this when you finish because some of the same issues we raised with them apply to what you are talking about.

Ms SWEENEY: You referred to rolling-out—which seems to be a popular term at the moment—of traditional service structures that we know do not seem to be out there, but one of the things I will tell you about is that there are many families that want something different to those traditional service structures. I have three children and my middle daughter has an intellectual disability. I do not want her to live in a group home and work in sheltered workshops when she is an adult. I have a very different future in mind for her. She is currently in a local State school in the neighbourhood, in a regular class, getting integration funding. Currently if you look at the education system and the change in demand there are now equal numbers of children with exactly the same profile of disability in regular classrooms in ordinary schools on integration funding as there are children in support units in special schools. Now that is a huge shift in thinking. It is a change in direction.

Families that are asking for the regular class at the local school are not asking for a group house respite for a week of holiday at Christmas time for the child, but are asking for support for the child to go to Brownies or Scouts or to join in the local swim class like every other child in their family does. There are many of those families now whose sons and daughters are in high school years, and they are looking for different things. They do not want to go into traditional day programs. They have been through ordinary high school. They have peers, friends and relationships in their local community. They are looking to get some different supports to help their family member join in, maybe, doing a combination of volunteer work, some paid work, some development skills and things like that. At the moment there is very little scope for any of those things that I have mentioned. We only have scope for traditional models that many families like my own, even if it were offered to me, reject because it does not fit in with my way of thinking about how the world looks now. I know some families, like my own, still get told by service providers, "Beggars can't be choosers".

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: As bluntly as that?

Ms SWEENEY: Yes. I find that notional absolutely appalling living where we are today, and that families still have to be grateful for whatever they get offered by government or service providers in the way of support for their family members.

The Hon. IAN WEST: Is there a big difference in dollars?

Ms SWEENEY: Without a doubt to get support for my daughter to go to Brownies or Girls Guides is heaps cheaper than sending her to a group home somewhere for respite. It is not so much even the dollars for support, the way I see it for Jocelyn to go to Guides, for instance, I would not see a worker going with her to Guides. I would see someone helping Guides think about how they can support her there with their own people. Getting someone who has gone through Guides and is now able to come in so they have got more of their own people to help support her to join in and be part of it. On the ground there may not even be any wages involved once it is setup but it is having someone that can help them think through how that could happen.

The Hon. IAN WEST: Why do they say "No"?

Ms SWEENEY: At the moment there is no "someone". At the moment in service provision, if any of that sort of stuff is happening, it is generally the families that are doing it—for example, they are going to Guides and saying, "This is what I would like. How about we do it?" At the moment I am doing that at school, at church—

The Hon. IAN WEST: I understood they told you that beggars can't be choosers?

Ms SWEENEY: No, service providers. They do not do that.

Ms ELLIS: It is an example of everything being channelled into specific specialist disability services to get bigger and bigger. As a result of getting bigger you look inside to technology and to disability staff and you lose sight of your role in the community and many disability-specific organisations. I am not criticising the people in there as there are lots of people who are trying hard, but they do not have the view of how can we support ordinary, everyday things in the community. If we could get the model of funding to be wider, to think more laterally, then some of the things that Megan is talking about can be resolved.

Ms ELLIS: Before Megan continues, I need to say that I do not believe that our proposal necessarily commits everything to just the change in demand on families. The Government and this Committee should think about that very important role. Quite a lot of the unmet need can also been resolved with families and people with a disability having a broader range of things to think about, rather than what ACROD said that more families ask for the same thing, because that is all that they know.

Our proposal does not mean that we are ignoring the unmet need. We are saying that you cannot deal with a crisis in unmet need with people who think about change. The unmet need would be better dealt with if a major part of the department focused on their crisis. We are not asking for a huge role, just a significant role in the department. It is tiny at the moment and I do not know what it would look like. I would not want to divide one from the other.

Ms SWEENEY: The next point is looking at how it would be if it were different, if the things that we talked about were not to happen. We need to ensure that regionalisation or decentralisation does not become a branch control from the centre. Typically, one problem is that all the decision making is done miles away from the individual. Decision making is not that hard, but it is stifled because no-one knows the person involved. They have a piece of paper with a profile of a person and have to make a decision that makes a difference to someone's life. People talk about consulting, and ACROD has spoken about how lame they felt that the consultation process was.

ACROD acknowledged that the decisions were made before the consultation. Advisory boards offer consumers a place, but often it is tokenistic. That is not what we are talking about with decentralisation of decision making; is more that being part of an advisory board. We need to involve people in the decision making. They should be focus on ways to forge genuine legitimate partnerships with service users and the families. Partnerships must include shared authority. One thing that people find it is when they ask for something different from a traditional service provider they are often told that beggars cannot be choosers; you take what we offer or you get no service.

What we want for our family is seen as utopian, unrealistic. It is trivialised. That is not an example of shared authority. What we want for our family should be respected by the service provision, governments and funding bodies to make it a reality in someone's life. Real shared authority is a mutual respect for someone's life and what should happen in that person's life.

The Hon. DOUG MOPPETT: You appear to be pointing towards the British Columbian model in which basically the role of government is to make some sort of assessment, and we hope that it is a sympathetic one, to provide funds. It is then up to the family, the carer, a microboard, right down to the people concerned with the person, to then procure the most appropriate mixture of services, depending on their availability. Does your organisation see that as at a practical example in New South Wales?

Ms SWEENEY: Yes, I do. It sounds like that puts a lot of pressure on families to do that, and some families will not want to do that. There is still a role for traditional services that can provide a lot, or procure services on behalf of an individual. If we have more examples of that family-based decision making around someone's life and get different things happening to keep people based in the community to do ordinary, typical things according to their age, there are more examples of that for traditional service providers to look at and acknowledge that they can do that too. For the families that do not want to administer it themselves, the traditional service providers are being urged to do better things.

The Hon. DOUG MOPPETT: What if it is developed to the stage of funding of a core amount that went to existing and identifiable service providers and then a discretionary amount which, in your case, would enable you to get someone totally outside the service to provide that help?

Ms EPSTEIN-FRISCH: We need the opportunity to try out different things, because there is not just one model. In our innovation we are not talking about one new alternate way. We need to have the opportunity to trial different options.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You may not want to answer this question. When I was working in occupational health, big organisations tendered out all their rehabilitation for the whole State or country to one centrally-based organisation which had absolutely no idea of the rehabilitation needed by a person in Woop Woop. They could not deliver the service in country towns although there were excellent people in those towns who could have done it. Because big organisations can deal only with big organisations, they assume that to be the case. The most tokenistic nonsense was put together as they tried to find someone to deliver the service. To what extent is the problem that big organisations deal only with big organisations? To what extent is it a problem that you cannot get recognition of the level services that are outside the main stream?

Ms SWEENEY: That is exactly where we are at when we talk about innovation being stifled. There is no environment for that innovation to be respected, to be seen as legitimate.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It is not even innovation, is it? It is the inability to deal with too many providers. It is bureaucratic inability to deal with small providers as well as the lack of innovation?

Ms SWEENEY: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Big organisations cannot deal with a lot of little people.

Ms ELLIS: Some of the examples we will talk about will pick up on some of those questions.

Ms SWEENEY: Feeding into general policy helps innovation come about and provides examples on the ground. It has to feed into the big crisis-driven situation to get it changed. It cannot go on on its own, it needs to be respected so it can create change. We need proactive strategies for information and education for families and people with disabilities—it is vital. Often information is available through training courses and conferences to the service providers and government. Often family members who deal with disabilities have no way of participating in those things because they are cost prohibitive, and the people do not have the resources to travel.

The families and people with disabilities need as much opportunity as the service providers have to think differently about what is happening to their lives. People ask for what they know even though they know it is not so good. But they do not know what else is available. That quarantined area would also have a role in linking people doing good things around the State. Quite often if you are doing something different on your own, somewhere out in the bush, no-one knows about it. That good work will be transferred elsewhere. Also it is very isolating for people who are doing it themselves. In city areas some very good stuff is happening, but no-one knows about it. A role within the department would be to link people who are doing things differently so that they can bounce ideas of each other and iron out some of the difficulties. Once it is fixed it can feed into the greater policy of the department.

Ms ELLIS: We can give some examples. We were asked whether we were focusing on the family or the microboard. I draw the attention of the Committee to the range of ways that different families, different communities and different connections, can run things around a family member, not just through a microboard, although that is one way, and not just through the individual family. All the knowledge that I have in this area leads me to believe that we are not proposing something that means that only middle-class, articulate families can access. Most of innovative things that I know about are the families, workers, my connections and links, and a family can procure help.

For instance, through a more innovative way of providing services, a family can employ someone to do some of their work for a short time. Maybe the family could think about how to employ staff, or access something. This is not just models, and that is a very important point that Family Advocacy would make. I guess it comes through experience; it is rejected because people think that we are suggesting something for only a small group of families.

I want to speak about the 30 Massachusetts family- and consumer-governed projects. The experience drawn there is not through a microboard or a family. There is the British Columbia and other ways of looking at individual families or microboards. This model relies on both generic, existing family agencies, such as the ones mentioned on the overhead, and sometimes disability-specific. Under those projects, the families do not want to manage but they want to govern what is happening around their son or daughter. Those projects range from groups of families coming together and some families are able to access funding as low as $1,000 or $1,500 a year for a particular need.

Other families can access tens of thousands of dollars for a high-support accommodation or meaningful day activity, small business, et cetera. The families come together in 30 projects and the agency brings the money down and shares in the authority and the governance with the families. They manage what their son or daughter needs. One example I can think of brings in cultural backgrounds. One project funds a group of about 20 families from an Hispanic-speaking background. They share and decide on the sorts of things that they want individually for the families that are different from the mainstream in that State. They have a different view. Some things that they have a different view about are derided in Anglo communities.

They have a deep suspicion of government and non-government agencies and having their child or their adult removed from their culture into an outlet facility-led disability service. Therefore, they can manage within themselves things that are cultural to what they perceive as important in their lives. Another group of families governs the way they view respite, a break away; we consider respite to be something completely different. They would use their funding to decide amongst themselves what their family needs for a break. It might be the guides, or something else. The non-government agency may give them technical assistance on how to go about that.

It does not prescribe the respite home, or the overnight stay. Recently in New South Wales there has been a whole list of respite services. The Massachusetts program does not prescribe that, but allows them to do what they want with their money. It tells them that they will not have any more money that year and tells them to manage it in the best way that they can. That is another thing: This has been tried over many years and there is a lot of evidence about how these things can work differently, they provide much greater consumer satisfaction and they prevent crisis.

The Hon. IAN WEST: The question that arises in my mind is how you determine the dollars, all those industrial relations issues of who the employer is, training of the staff. With respite, how do you establish and govern whether the money is just put in the poker machine or drunk, whether there is substance abuse or whatever? I assume that you are overcoming all those difficulties.

Ms EPSTEIN-FRISCH: They are absolutely important and we understand where you are coming from. You would not expect us to give a trite answer but if you were to recommend to the Government to quarantine some money for innovation these issues would obviously need to be dealt with together with the centrality of providing support to individual people with disability. But we need an opportunity to trial them and to work out how we can respect all these laws of the land and what have you but at the same time provide something that people with disability want.

Ms ELLIS: My experience of the Massachusetts model is that nobody has rorted any money. In fact, what they found is that families give the money—

The Hon. IAN WEST: With all due respect, I find that very hard to comprehend.

Ms ELLIS: There is plenty of written evidence about it. The money goes through channels. It is as accountable as any other money.

The Hon. IAN WEST: I am not against what you are saying.

CHAIR: We can do more exploration on this. This comes back to our discussion with ACROD just before you are arrived. Parents in particular keep saying to us that they need certainty, guarantees. I am not saying that they are mutually exclusive with pilot programs but clearly there are problems. Historically that has been the case and I guess it is now. If you try something new do you therefore give with it the guarantee of lifetime funding at a certain level? How do you manage the funding and that need for families to be sure that a bright idea will not be given up in two years time?

Ms EPSTEIN-FRISCH: There are ethical issues about certainty to be provided for families. ACROD spoke about phone calls from people looking for a package and looking for certainty and they are not able to provide those sorts of services and people disappear in the ether. What we have lost is any sense of community and any sense of connection and the relationships and someone taking a more active interest. I am a member of the board of Jewish Community Services. In that capacity I chair the Disability Services Committee.

I would like to talk to you a little about accommodation and some of the innovation that is possible even within the existing system when you look at it from the perspective of individuals rather than outlets and what have you. I can think of five or six other organisations that do it in New South

Wales. But I perceive that they are able to do it because they are relatively small and they know the people. That is a model of co-residency. Perhaps you have heard about it in your deliberations over the time. In Jewish care no people live in a house with more than one other person with a disability. Some people live individually. We do it within the kinds of funds provided through the 300 places and the other packages and for some people who have no packages and no support provided by government. In a model of co-residency a person without a disability is recruited and supported to share the accommodation with a person with a disability. It is a contractual arrangement because there are certain responsibilities faced by the person without a disability. They get rent free or very reduced. It depends on the individual circumstance.

In many situations they have a commitment to sleep there every night. Support to help people get out of bed, to work on their budgeting and do the practical lifestyle things that people with disability might need happens through paid workers. But the co-resident provides that sort of security. In most of the houses if there was not a co-resident there would be a need for an overnight carer, which would be probably $35,000 a year or perhaps an awake carer, which would cost even more.

There are many benefits. First it contains costs, which government is obviously interested in. It helps the person with disability to be a more integral part of the community. They are living with other people. Their friends pop in. They might say, "We are all going to the club or restaurant tonight. Would you like to join us?" It is like a housemate situation. There has been relative stability of some co-residency relationships having lasted in excess of five years. Some only last a year. But in house sharing things that can be okay as well. So you have an organisation that is in there and trying to think about how to support ordinary relationships in the community.

We have other people who have very high support needs and challenging behaviour. The DADHC response is to put two, three or four people together. Their challenges only increase the need for support, whereas in some situations we have used semis. These are for people who do need an awake carer because they have needs that arise overnight. With the semis each individual has their own privacy and their own space. But you can share some of the staffing and reduce the cost without compromising the lifestyle of the person with a disability.

CHAIR: We understand the variety and flexibility but the issue that you have not addressed is the level of funding and the guarantee of funding perhaps over a lifetime. What you are talking about is essentially based on government funding making the innovation and flexibility possible. Some of the people who have spoken to us might be dubious about that. Some people clutch the traditional solutions because they feel safe with them. They do not want to be faced in two, three or 10 years time with their child suddenly not having a place or that awful prospect that the parent may die and the child will be left.

Ms ELLIS: First of all, I am a parent of a 30 year-old who has very, very high support needs. Secondly, I was the Director of the Commonwealth Office of Disability when the Commonwealth did what we call the demonstration programs in the mid-1980s. I think there is the opportunity to learn from the mistakes. In terms of the perception of no guarantees, talking about pilots is not the way to go. There are tried and true ways that do give longevity to a support service that are not just going to be trying something for two years. We have had the experience in doing something different, using a much wider range of doing things, using families, using generic agencies, using disability agencies in a different way which would not give rise to the thought that it is just a pilot and it will go away in two years.

Some of the so-called demonstration programs did. In fact, the co-residency model was one of those demonstration ways of trying to do things which has lived on but for which we cannot seem to get past the very large service provider mentality of the six pack and the four pack that you have heard about throughout this inquiry. We—not Family Advocacy—in New South Wales have the capacity, the experience and the knowledge to think about all those things and not set up things that are going to fail or that people will not have faith in that they are going to go on. On the issue of refinement, the existing services have constantly been refined—unfortunately, we think they have been refined the other way—over time anyway. While the Government has given a guarantee of ongoing service to people who are currently in institutions, I do not necessarily—other people might correct me on this—believe that people through the SAS system are being told that they have a guarantee for ever. That is not being said. We are not in uncharted territory here. What we are looking for is a big emphasis on doing something different.

Ms EPSTEIN-FRISCH: And none of it builds community. The people who are knocking on the doors of a whole range of large non-government organisations, go away when the door is not open for them. Where do they go? In Jewish Community Services there are many people, and it is a community. That makes a difference. Many people do not have government funding and, under the crisis model, are unlikely to get government funding. But they knock on the door and there is someone who will take a continued interest. It is not just a case of, "If you have a parcel we are interested." It is "Yes, there is not a parcel of funds, but what can we do? How can we think about what you need within your life that—

CHAIR: ADD is saying that the things it is doing at the moment in relation to respite would meet some of the sort of criteria you are putting before us, that they are enabling a whole variety of flexible and community-based models. Would you agree with its optimism about the—

Ms SWEENEY: The rhetoric sounds good but in practice you will find that it is fairly traditional. One of the highlights of that is that the only organisations eligible to receive funding are disability-specific large service providers.

CHAIR: I thought with the respite program starting from about a year ago that there was more flexibility for the non-traditional disability organisations.

Ms SWEENEY: To do some brokerage type of things. But we often find that the guidelines of those things are quite rigid. That exact thing has become available to a colleague. She has $1,500 a year to use on behalf of her son who is 18 and still lives at home. But the only way she can use that money is to pay for a motel room and a carer. She does not want her son to go to a motel in town for a weekend. She would rather use the money to provide someone to come to the house. He goes to the local high school. He has very high support needs. She would like some of his mates to come out to the house to spend a weekend with him and have a paid carer there while she and her husband go away. But they cannot use the money for that.

CHAIR: Who has made her use the motel model?

Ms SWEENEY: That is the guideline of that respite funding that came out that was innovative.

CHAIR: But of the department or the organisation?

Ms SWEENEY: The department's guidelines. The organisation is constrained by the model.

The Hon. IAN WEST: With your experience, can you make a guess as to why that is?

Ms ELLIS: It is easier to manage.

Ms SWEENEY: Yes, and some people want that.

The Hon. IAN WEST: Have you delved into trying to break down those barriers. Obviously, the department has this management problem that goes to all those other issues we talked about.

Ms EPSTEIN-FRISCH: I think there is a lot to do with the role of the department. The department has a rhetoric that says that it wants to use generic services, it wants to provide flexibility, it wants to do what it takes and recognise that the needs of different families are different. But they put out one message, a unimessage, and it does not cultivate different players to take a role.

The Hon. IAN WEST: Yes, I understand that. But my question goes to the issue of why you think that is. I am sure the department has expertise, and it must have a historical reason for that policy. Have you delved into the reason? Can you give me the department's reason for that?

Mr PURVIS: Because in a crisis situation they do what is easiest, they do what they know, they deal with people they have dealt with before. They are not prepared to consider that there may well be some other ways of doing this that may be much better for the child and much better all round.

The Hon. AMANDA FAZIO: But do you believe that there is too strong an emphasis with respite care on the focus always being on the person with the disability being removed from the family home for respite rather than at-home respite being provided?

Ms EPSTEIN-FRISCH: I think that they are moving on that but not moving strongly enough and when they are talking with the specialist disability services there is a certain kind of boxy view. Whilst the department has talked about supporting generic agencies, which are possible under the DSA, what happens is that they do not actually see a role in going out and negotiating. Family Advocacy had discussions with the Family Support Services Association at a senior level of that association and they were most interested to be involved in getting some of the funds and providing some of supports in an ordinary way in the community. But ADD at that time saw no role for itself in helping the Family Support Services Association to help its members to have a different view.

CHAIR: Is that because they see themselves only really dealing with specialist disability organisations?

Ms EPSTEIN-FRISCH: I think that is the case.

CHAIR: We will take these issues up with them because last time they talked to the Committee they put considerable emphasis on, as they saw it, the flexibility of the program that started about a year ago. We have run out of time but if we need you to answer some of those specific questions we might do that by phone or in writing. Otherwise, the Committee has a fairly good idea of the philosophy that you are suggesting. When Alex or Judy spoke to me as well as mentioning the Massachusetts examples, they mentioned some positive things happening in Queensland.

Ms ELLIS: I think it was Alex and Libby.

CHAIR: That is right, yes. We might chase that up with you again because I do not know whether anyone besides me actually had access to those sorts of examples, unless there is something that you can leave with us today.

Ms EPSTEIN-FRISCH: We have a range of information to share.

CHAIR: Perhaps a Committee member can move that that be accepted by the Committee formally.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I so move.

Ms ELLIS: We have a few comments in summing up.

Mr PURVIS: We have highlighted the need for something different to be done. There is considerable dissatisfaction in the current system and it is fairly clear there are lots of examples of crisis out there. We need things that actually make a difference in the life of individual people with disabilities. The legislation allows for a wide range of service deliveries but for a whole range of reasons we have only chosen a very narrow way of dealing with that and I think part of the way to the future is to be much more expansive in how we interpret what the legislation allows us to do.

The Government needs to lead. We think that there is a need to quarantine funds and people to move them away from the crisis situation in order that they can think clearly and do different things. Also, there is a clear need for a mechanism to bring back what is learned to the mainstream rather than sitting out there withering on the vine.

We have given you some examples. We do have many more examples which, unfortunately, we do not have time to give you, of good things happening within the current system if people are prepared to be creative and a little brave. The system, though, does not give people permission to do that in a whole range of ways. People are rewarded for towing the line.

Your report is a chance to make a difference and to use the resources in a way that matters, that gives the sorts of things you are thinking about a life that continues way beyond the life of your Committee. We are not asking for an enhancement to DADHC's sector development but, effectively, a major shift with new people and clear leadership from government to do what we know can be done but for a whole range of institutional barriers, and our history to some extent, we do not do.

(The witnesses withdrew)

(Luncheon adjournment)