REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO RESIDENTIAL AND SUPPORT SERVICES FOR PEOPLE WITH DISABILITY

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At Sydney on Wednesday 17 April 2002

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The Committee met at 9.30 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

ROBERT WILLIAM FITZGERALD, Community Services Commissioner, 128 Chalmers Street, Surry Hills, sworn and examined, and

ANITA TANG, Manager, Policy and Community Education Unit, Community Services Commission, 128 Chalmers Street, Surry Hills, affirmed and examined:

Mr FITZGERALD: Currently I am the Commissioner for Community Services and as such head of the Community Services Commission, and I am appearing as representative of that body. I have received a summons, and I am conversant with the terms of reference for this inquiry.

Ms TANG: I am the manager of the policy and community education unit at the Community Services Commission. I am appearing in that capacity. I have received a summons, and I am conversant with the terms of reference.

ACTING-CHAIR (The Hon. Doug Moppett): You are aware that if at any stage there is something you want to say which you feel should be dealt with confidentially you only have to make us aware of that and we will take the necessary steps. At this stage we do not have a formal submission to this particular part of the inquiry. We have prepared some questions which basically will come to the heart of it. Unless you want to make some introductory remarks, we will proceed to the questions.

Mr FITZGERALD: I should like to make a couple of brief comments before we will go to the questions. First, I acknowledge the work of the Committee and the significant impact that it has already had in relation to the disability area and in particular to the well-considered and helpful recommendations that the Committee has already made. Fundamentally, we believe that many of those recommendations address the issues and, if implemented, would significantly improve the current system. So we start from that base. There is a foundation upon which a quality disability service system can be built. A number of the initiatives since this Committee's commencement make that now possible. The incorporation of the disability services operated by government moving from DOCS to the amalgamated department of disability, ageing and home care [DADAHC] now makes that more possible than it was previously, when there were extreme tensions between the two previous departments.

Secondly, the introduction of the Service Access System, which we will talk about in some depth, is also a positive step which now gives a way for some people to access the system in a way that was not previously possible. Thirdly—and we have mentioned this before—the increased resourcing that took place a couple of years ago still has made a significant difference at least in providing some resources to be able to implement change. Two years ago we could not have said that. So I think they are important. As we go through the questions it will become obvious, however, that notwithstanding those positive measures there are not only substantial weaknesses but also much unfinished business. If this was a goldmine, I suspect that what we have done is put in place some of the structures but there is little outcome for it and nobody would have made any money yet. So I think we are still very much in the earliest stages of trying to construct a well-founded system.

It is also clear that there are new issues that will impact on the disability service system that perhaps were not concentrated on in this inquiry to date. The first one of those is clearly the very large number of people who are inappropriately placed in aged care facilities. In a report we released recently, or comments we made in relation to that, just in relation to people under the age of 50, there are more than 460 people with disabilities in aged care facilities. That figure rises dramatically to close to 1,000 under 60, yet the paradox or the contradiction is that we cannot get elderly people with disabilities into aged care services. That is an issue that goes across both Commonwealth and State initiatives. But if you look at that, it is an increasing number of people who should not be in nursing homes and an increasing inability to place people who should be into those same facilities. That will concentrate the minds of government and the sector in the coming years. That is a significant issue.

We will talk about unmet demand issues. Those issues continue to remain high, notwithstanding the various initiatives that have been put in place. I think the overwhelming issue continues to be the lack of flexibility in the system. It is true that there is a trade-off, which we will discuss. We need to improve the system and flexibility may be a short-term trade-off, but we must ensure that throughout the life cycle of individuals they can make different choices and have different options available to them. The system is not yet at the stage where it can consistently provide that. The last point I would make is that devolution is painfully slow. The figures that are available—and I am sure you will deal with the department on those—still indicate that devolution is moving at a pace that cannot be in any way regarded as acceptable. So we will deal with those in detail.

I go back to where I started. The recommendations that your Committee has already made provide a good basis. If they were implemented, we would have improvement, and we will make some further suggestions in the oral presentations we will make. We acknowledge there have been some improvements. The foundations looked stronger than they were two years ago yet the business is far from a completed task. Indeed, we are still in our infancy in trying to develop a quality disability service system in this State.

ACTING-CHAIR: That strikes a very good keynote to examine some of the specific points. I feel almost apologetic about asking you again about the group homes project, which is right at the top of our list in question 1. I think we are pursuing that not just with political intent; it is important for us to round off our report with evidence of where that project stands and then the other key pillars of our investigation, that is, unmet need, what is happening in respite and the subject of devolution, which you have touched on. I invite you to expand on question 1 as set out.

Mr FITZGERALD: Yes I will, and I will do so in a couple of ways. I will deal with devolution first. I indicated in my opening comments that progress to date has been extraordinarily slow. At this stage we are 50 per cent of the way through the Government's commitment to devolve 400 people within a four-year period. At this stage we are nowhere near the 50 per cent mark in terms of the number of people who have in fact been moved from large institutions into alternative community accommodation. At the moment—and these are estimates only; you will obviously seek confirmation from the department—we believe that at the beginning of April 2002 possibly a maximum of between 50 and 60 people have moved. Undoubtedly there is work being done to move many more.

It is not appropriate for the commission to try to pinpoint that figure any further, but it is the case that 50 per cent of the way into the process we are nowhere near the 50 per cent mark in terms of people being devolved. More concerning to us is the lack of movement in relation to children and young people with disabilities, which was the Government's major priority and the most important commitment. There has been very little movement—almost no movement—of children and young people out of institutional care in the past two years. That remains a great concern. So in devolution terms I think the biggest concern we have had is its slowness.

To that extent, I think trade-offs will have to be made. The approach we understand that the Government took initially, the Ageing and Disability Department in particular, was to try to have devolution take place at the same time as increasing choice for consumers and increasing contestability in the marketplace. That is, we tried to do three things at once: devolve the service, increase choice and increase contestability between providers. It is clear now that that is stifling the ability to devolve in any way within the time we would regard as appropriate.

I think devolution will have to be reconstructed so that institutions are devolved perhaps either within the existing agencies or to other agencies but recognising that the choice may become more limited for the individuals in that process. We recognise that that is unsatisfactory in the long term. If a person moves from a large institution into a group home, it is imperative that the system allows flexibility beyond that point, such that in a few years time when a person makes the choice to know they can do so. It is equally true that the current emphasis on trying to meet and give maximum choice to individuals is in fact providing no choice. They are simply locked into those current services and the devolution process is undoubtedly being stalled.

We understand that the department of Ageing, Disability and Home Care is itself reconsidering its position, which I think is made possible by the fact that government services are now part of the same department. But it is a trade-off, and it is a trade-off that creates an inequity because people who are not in institutions but enter the system through the service access arrangement are treated absolutely individually. Their needs are met as an individual. Those people who come in through the devolution process will not quite have that same advantage in the first instance.

For the Committee, it is an important issue. In order to achieve devolution should we trade-off both contestability and a limited choice? I will just round off that comment because it may confuse people. There are two qualifications on what I have just said because what I have just said would not be acceptable to the whole of the disability sector. The first is that residents they are subject to devolution must have an opt-out provision, that is, if they do not wish to remain without provider, they should be able to find an alternative. That is very different from saying to a group of 40 residents, "Here are 67 providers, take a choice". But it is important that in devolution a person has the right to say, "I no longer wish to be with the Disability Service Directorate—the government provider—or with a particular private provider. I think that can be accommodated.

Secondly, the system must be able to respond to the needs and aspirations of people after the first move, so that we are not moving people simply from a large institution to a group home in which they forever become trapped. So there are two conditions. I fully appreciate that the commission's position on this would not be regarded as the most desirable outcome, but I think we have come to a point that the least desirable outcome is the current stalled devolution process—even though I will acknowledge that there has been considerable work done, and considerable work is taking place, around that devolution strategy. From our point of view it is certainly not progressing as well as it could. That is the trade-off that might have to be made.

Ms TANG: I would like to add some comments in the context of the slowness of the devolution. When you look at stage one, which is a commitment to devolve 400 people out of institutions, that only represents 15 per cent of all the people in institutions. If the progress is that slow now, the institutions that are not in stage one are the much larger ones and there would be much more difficulty in managing the process around those very large community-based facilities that are largely government-provided—those in the Hunter area and those in western Sydney—which house several hundred people. I also note that the Committee's previous recommendation was that 80 per cent of people be devolved by 2005. We are clearly nowhere near that. You can see where the current progress lies against that continuum.

Some other data that puts this into context is that, so far as interstate comparisons are concerned, New South Wales lags far behind the other States, in terms of the proportion of consumers who are in community-based accommodation. In New South Wales just over 60 per cent of accommodation consumers are in community-based services. The remainder are still in institutional services. That puts us behind most other States and certainly well below the national average, which is 71 per cent.

ACTING-CHAIR: I certainly do not want to take up the valuable time of my colleagues in talking to you, but I think in some ways you have hit so incisively on the issue that if we heard no more from you what you have already said would be illuminating. I think we have had in evidence from representatives of the department clear evidence of this problem that, yes, we are working terribly hard, whether it the respite care or meeting the unmet need, or this question of devolution. We are just held up because we are developing a brave new world which keeps changing, and so we can never move ahead. It is most frustrating. They say, "Oh no, we are not doing it that way because the end to which we had projected people would be going is now under question. We do not think the group homes are the idea any longer."

While this is being reviewed they stay there and I think the end result of that, in institutional care, is that people who had had reasonable expectations excited more than a decade ago, their whole lives are moving on. There is a phrase in this, when you think of the Richmond report—where they were, the recognition they had to go out of there and suddenly these people are now aged and decrepit in many cases.

Mr FITZGERALD: I think it has had profound effects. The institutionalisation regime in New South Wales is a system that has not treated its clients well, but it has the potential to treat people even more badly in the future, to use fairly simple language. My greatest fear is that devolution will be achieved in New South Wales by death. For many people the only way they can be devolved out of these services is in a coffin. That is not a sensational statement. The reality is that these people are ageing. At no stage in their lives will they have ever had the opportunity to live within alternative facilities. I think we at least owe them that.

The second thing I think of more dangerous concern for us is that as they age the temptation by Commonwealth and State governments will be to recategorise some of the institutions as nursing homes. It will be a cheaper option. That would be a profoundly distressing thing to occur, but as the populations within these facilities grow older, the temptation is there. We can already feel it and sense it. That would be a tragedy. These people deserve the right to have aged care, but it has to be of the quality that you and I also equally deserve and expect as a right. That means that some will live in larger facilities all their lives, be they nursing home hostels or what have you. I think there are those real dangers now if the devolution process does not speed up.

No-one is asking for an unrealistic timetable because 400 is the most modest target—as was indicated, 15 per cent. Not to achieve anywhere near that, for a State of this size and with this range of skills, I think is of concern. We share the Committee's concern to the point we have made is that these hard choices have to be made. I think the department has tried to do too much at the same time. Originally the department had no resources to do it. Then they in fact tried to everything all at once. I suppose the lesson over the last couple of years is that it cannot be done. Something has to be traded and I think that is what we have put on the table is clearly as we can. It is not an ideal outcome, but it is unacceptable outcome if the end result is a faster devolution of those institutions.

ACTING-CHAIR: I am sure that would lead into comments about respite care and unmet need.

The Hon. IAN WEST: Could I clarify a couple of those figures. No doubt your conclusions are correct but I am trying to understand the figures. You say that 400 represents 15 per cent only. Are the 1,000 people in nursing homes who are under 60 years of age included as part of the overall figure?

Ms TANG: No.

The Hon. IAN WEST: They are not part of that calculation of 15 per cent. Am I right in assuming that the 15 per cent, the 400, represents the easiest 400 to relocate?

Ms TANG: You might want to confirm this with the department, but stage one includes the priority around children first. So, it includes those institutions that house predominantly children and young people—they tend to be the smaller ones, coincidentally—but it also includes some of the smaller facilities.

The Hon. IAN WEST: Am I right in assuming that we have had difficulty in devolving the easiest 15 per cent.

Mr FITZGERALD: Yes. It is a mixture, because your need for the facilities you will have potentially both people with lower support needs—relatively, because they would not be in institutional care necessarily in if they have very low support needs—and people with higher support needs. Within the service you may have a range of clients or residents that present with very high support needs. It would not be right to say that we have only picked the easier ones to move. But it is true that, even where we have targeted a whole facility where there has been support for the devolution, where providers have been found, that has not yet happened. That is a problem. It is not yet at this stage where it is related to the complex needs of the client. It seems much more procedural. It will become more difficult as we move into some of the larger, more traditional, institutions that have a high percentage of very complex and high support needs. But, no, that would not be the reason for the slowness of the process to date. Not yet. The danger for us is that if it slows down much further they will just stay there.

The Hon. IAN WEST: Are you in a position to be able to answer the question that the the procedural issues that you will have spoken about do not include funding issues.

Mr FITZGERALD: Funding is always a difficulty, but we understand that that is not the immediate issue in relation to the devolution of these 400 people. It is in relation to meeting unmet need, both in the community in providing respite and providing other services. It is an issue in relation to providing additional supported accommodation for people in the community. We understand that the Government did budget sufficiently at the time to allow devolution to happen. DADAHC is the only body that can answer that. It may say that it is much more costly than it expected. I do not know the answer, but my feeling is that the issue is not resources in relation to the devolution of the 400.

The Hon. IAN WEST: As to the devolution of the 400, can you give some details about what you describe as "procedural difficulties".

Mr FITZGERALD: Only in broader terms. If a service is targeted for devolution—and the 400 have now been named—the approach until now has been to tell each individual client, his or her advocates or families within the service that they have a range of options. There is an eligibility list of 67 providers. The families are literally given the list and told, "Negotiate your way through this; who would you like to go to?" The process has become disempowering. That is one problem. The second issue—which I will come to in a moment—is the ability of service providers to take these people. Part of the issue that I shall refer to is service provider development. Service providers are frustrated because they put a huge amount of effort into submissions and then things do not happen.

The third issue relates to the services themselves. They are complex services. In and of themselves that is not a reason why we have had this slowness, but there are staff issues and all sorts of other issues. A number of things have come together to slow it down. Even the Government has found it difficult to devolve its own services over which it has much greater control. Even when you own and control it we are not seeing the devolution that we should. There are exceptions: there has been some movement, but not to the extent that we think is appropriate. For example, Greystanes is a service that was devolved recently.

ACTING-CHAIR: Interestingly, our staff related the anecdote that, with the opening of submissions for the child protection inquiry, someone rang the other day to ask, "Are you taking submissions on the closure of Mannix?" It is all out there.

Mr FITZGERALD: We understand that Mannix will be devolved within 12 months.

ACTING-CHAIR: What about group homes?

Mr FITZGERALD: I do not wish to go into much detail about group homes other than to say that we still do not know, or have full details about, the number of people who will eventually be moving under the group home proposals. To date very few people have moved. We believe the process, as you are well aware, is deeply flawed and should never be entered into again by government. The process was driven by a wrong motive, was implemented inappropriately and the results have been self-evident for sometime. Our concern is that now that a number of people have made a choice to move to alternative providers that should take place quickly. The process has been in place for a very long period of time. It is extremely important that, now decisions have been made, the department moves quickly to make those placements a reality.

If that does not happen, disillusionment will once again reign. The choices that were made a year ago will no longer be current and relevant and we will be in the same position as we are with devolution: raised expectations and little outcome. It is critical that the department treats with priority the transfer of people from government to non-government agencies now that decisions have been made, otherwise the damage will be exacerbated. It is clear that the process was ill-conceived, both in process and in terms of motive. That is the evidence we have seen. I do not think anyone in government today would want to go through that process again.

Let me be clear: That is not to say that people should not be able to move from a government to a non-government provider. That should be a constant choice. It is not to say that government should not have the right to decide that it no longer wishes to provide different sorts of services; it should have that right at all times. However, this process was flawed. In fairness, when the process started I think we ran into the same problems: We tried to achieve too many outcomes. One outcome we hoped for was that the services left with government would be provided differently and that we would see a different management arrangement. One of the initiatives was to see cluster management—in other words, a group home would have not a house manager but a cluster manager. That was meant to be a cost-saving model. It is a model that is used in the non-government area. However, that has not been achieved. So even those sorts of outcomes have not been achieved through the process. Nevertheless, a number of people—we simply do not have the exact numbers—have now made a choice, the department has agreed and the transfer should take place quickly.

ACTING-CHAIR: We took evidence not last Christmas but the Christmas before that very few, if any, people had moved. The department then responded saying, "That is because we now have a new range of super-duper options and it will all happen after Christmas." After yet another Christmas we are still wondering when anyone will be moved.

Mr FITZGERALD: I can only say that I think there will be some benefits from the proposal. I think there are some new models or options available to people. Some people clearly made their choice and exercised it. To that extent, it has been a learning experience and, for some, it will be a better outcome. However, I think the price has been paid, both resource wise—this has cost the Government much more than it ever anticipated; it was meant originally to be a cost-saving exercise but it has been anything but that—and in the way it has damaged clients. Nevertheless, the department is in a better position to mention that.

That brings me to a general point: I think two things are very important. First, one of the things that has been missing—it is critical—is that we have a service development framework. We would add that to your recommendations. It is very clear that in all of the processes—the devolution process, the group home transfer and other processes—we have not yet mapped out a service delivery system. We are moving people from X to Y without knowing what Y should be. One of the most important issues for the department is to develop a very strong service development framework—that is, mapping the service delivery system and then ensuring that the service deliverers within that system have the capacity to deliver. It is pretty fundamental.

That is still not there at the moment: we do not have a well-constructed or well-designed service delivery system. We are still dealing with a lack of viability and we still do not really know which providers are capable of delivering services. We have not yet identified, even now in 2002, what will be the role of the government provider. It is not possible for anyone to tell you at this moment what business the Government wishes to be in in terms of service delivery. It is not a matter of saying what it should be in, but we hope certainly within the next short while that the Government will determine what business it wishes to be in. Once that is clear we can map a service delivery framework for both government and non-government provision. The point we would add to your recommendations is the need for a service delivery framework system.

Ms TANG: To elaborate on that, it is the flip side of our concerns about how the individual-driven proposals have held up the process. Everybody was told, "You can go out and negotiate with a service provider, develop an individual proposal about what you need and we will fund it". However, that was not matched on the other side by work going into service agencies to allow them to develop the expertise and the capacity to support people in different ways. We have a list of 67 providers and we know that some of them have no experience providing person-centred services and may have limited experience providing community-based services. But they are being asked to come up with proposals about how they would support people in a different setting. They are not getting the support, guidance and assistance to do that. Work needs to be done at both ends. At present the individual-driven approach means that it is a very ad hoc and piecemeal approach to devolution and developing services. It can be quite fragmented and non-strategic.

Mr FITZGERALD: The flow-on from that is the need for a clear accommodation policy that gives guidance to providers as to what is acceptable. To date there is no guidance for service providers. We have consistently asked the Minister to move to that position. The word "flexibility" is not policy. In my experience, flexibility is the complete opposite of good policy. The sector—both the service providers and the consumers—need guidance as to what will be acceptable, together with the support that is necessary as part of the service development. We need a very comprehensive accommodation policy. I understand that once you commit to anything there will be critics of it, but the absence creates problems.

Ms TANG: There are real risks associated with not having an accommodation policy, including the risk that service providers will develop proposals that are not acceptable. They will do the work and take families down that path only to have the proposal rejected. However, the bigger risk is that we could end up with services being developed without any open debate about whether that is an appropriate way to go. Almost by stealth you could end up with service models that somebody has approved but about which there has been no public or sector discussion regarding whether that is the way to go and whether it is the best way to provide accommodation support for people. It is a particular risk regarding certain groups of clients—people with challenging behaviour, children, young people and adults with very high medical support needs, or people with offending behaviour or contact with the criminal justice system—whom it would be very easy to house inappropriately. In the absence of a process of developing an accommodation policy, there is no scope for having that debate.

ACTING-CHAIR: You are inspiring us to so many diversions. We will turn to the service access system in a moment and its role in planning the development of a delivery strategy. Do you think there is a conflict in the department's role in developing and establishing it while monitoring its implementation and running? Is there a conflict in the department's role in the areas of developing and implementing the strategy and then monitoring the results? How do you think that could be resolved? It is a fundamental issue.

Mr FITZGERALD: Unquestionably DADAHC has many conflicts of interest internally. One of the most important issues is that it is now the provider of 60 per cent of residential care, or thereabouts, and it is supposed to monitor and review itself. That is a clear issue that the sector has raised. You are absolutely right: the service access system is the department's system, which it also monitors. So there are inherent conflicts. I cannot give you an answer has to how that can be improved because there is trade-off. Some have said that other bodies should look over the department activities. This has happened in the past. There has certainly been some move to make accreditation a part of the system—we agree with that—and for it to be dealt with by another body.

To be honest, I think at present we need the department simply to function—that is the most basic performance measure that can be applied to any government instrumentality. If it could function, we would probably live with the conflicts for the time being. In the long term, it is not a desirable outcome. If I seem to have moved my position in recent years it is only because that is the reality. Having said that, the department must, within its internal structures, ensure that monitoring and review can take place with a degree of robustness and transparency, and ultimately it will be audited for that. It is capable of establishing a regime within itself that can monitor its services and what it does. I am sure that the director-general of DADAHC will talk about how she believes that is going. There is work being done in that area. There can be—and need to be—some internal structures put in place to allow that to happen.

In the long term I think accreditation will be an essential feature of the disability service area and that accreditation will need to be done by an independent body, as occurs in the health area. I do now know whether that is appropriate now; I believe we could probably delay it for a short time. However, I think ultimately accreditation will be important and we will need to ensure that more robust monitoring and review takes place. However, that is not the universal view.

Ms TANG: I think those risks can be minimised even now in fairly simple ways. One issue is the openness of data and information from the department. People might derive a lot of comfort from being able to see for themselves the figures regarding how many people are getting through the SAS system, how many people have moved out of institutions and how many people have moved out of blocked respite under the 197 program. But that data is notoriously difficult to obtain, as some of you know from budget estimates. That would help to give a level of accountability and transparency, even if the department were still running, managing and monitoring it, because it would put the information out there. The alternative, as Robert suggested, is to have some open audit process on a regular basis. I think it would help if the department provided the data and could show that it was robust.

Mr FITZGERALD: There are things that could be done without creating new bodies at this point in time and without trying to deconstruct the department, which has only just been reconstructed. I think that would be an unfruitful venture.

The Hon. DOUG MOPPETT: We had the same thing with our inquiry on respite care. We all welcomed the extra provision but the answer came back, "Oh well, we have not done much about the centre-based ones because we have this new you-beaut idea about providing respite in other forms." So the beds are basically still blocked while we think about new ways. They are important issues but they continually seem to produce a state of inertia.

Mr FITZGERALD: We do not have enough detail on the current respite figures to advise you. The department would be able to do so. Considerable extra resources were committed by the Government. They should have led to an increase in the availability of respite beds. We do not know whether that is so or not. You would have to find that out. But it is true that centre-based respite remains a problem. The next part of the equation is that if they are blocked beds, which effectively means that they are permanent residents, you would have to move them to somewhere else. Therein lies the difficulty we have faced with all of the problems: the group home transfer, the devolution and so on. So there are still major hurdles in unblocking those beds. The other danger in that area is that the redefining of beds becomes an issue. You can unblock a respite bed by simply redefining it, and that occurs. So that area is a bit difficult for us to comment on.

The Hon. IAN WEST: Does that not go to the issue of the quality of the data that you get, therefore determining your ability to monitor that data?

Ms TANG: Absolutely.

Mr FITZGERALD: The Audit Office plays an extraordinarily important role in New South Wales in being able to be contracted to provide the audit. Obviously, it does the audit in relation to financial administration but the Audit Office has developed a real competency in terms of performance-based audits. We would think, at the minimum, that it should be required to provide audits on those sorts of data. We think that is very important. The Audit Office waxes and wanes in its commitment in that area but in recent years it has had a strong commitment to performance-based audits, targeted so that it is not trying to audit every figure. But we think that sort of approach is appropriate and would be a mechanism of achieving some safeguards—not the ultimate but a way forward.

Ms TANG: The blocked respite beds in the centre-based services comes back to that issue of service development because many of those people are actually identified under the 197 program and have funding attached to them. The problem is that they are in those blocked respite beds because their needs are so complex and challenging that they lost their community placement or the previous care situation broke down. Part of the problem is that even when they have money attached to move them out of the respite bed there are not service providers who are capable of meeting or willing to meet their needs.

Mr FITZGERALD: It is part of the same issue. I suppose we should talk about SAS in more detail. I will go to the bottom line on that. Our information is that only 1 per cent of people who have applied to SAS since its inception have received long-term support as a result of their application. We have a number of figures but basically about 75 per cent of the 1,965 applications have been assessed, although a majority are still awaiting recommendations to be what is called processed. A number have been determined. About 501 have been found to be eligible and those have actually gone through. The 80 per cent whose applications have been determined have been found to be eligible. So we have a fairly slow process between having your application found to be eligible and the delivery of a long-term service outcome. [Following their evidence the Community Services Commission provided the following statement: *Our comments about the SAS and the proportions of people who have applied, and been provided with support of various forms, is based on data provided to the Commission by DADHC in December 2001. This is the most recent data made available to us by the Department*.] That is the easiest way that I can put that.

We have had a number of complaints and issues in relation to the SAS system. We can briefly identify what they have been. I would say, however, the first thing is that the system itself is a worthwhile initiative. It does provide, for the first time ever, a reasonable gatekeeping mechanism for the Government but also a reasonable entry point for people that meet the at-risk requirements. But it has experienced difficulties and the fact that only 1 per cent of all those who have applied have a long-term outcome would indicate those difficulties. There is a whole lot being processed but at the end of the line that is the group. A much larger number have received short-term support. In fact, short-term support has saved the SAS system because what the department did was, because the system was not working quickly and effectively, provide lots of short-term support to people. That has bought considerable time. Had that not been provided I believe there would have been real anxiety and issues raised by the community. But the short-term support that has been put in place has effectively bought time. That is appropriate but not the best outcome.

Ms TANG: Some of the things we do not know are how long it takes from the time a person applies through SAS before they even get their interim support. What we do know is that it seems to take a long time before they get their permanent support, because of the tiered process that you have to go through. That is a critical issue. It is a crisis intake system and if the department cannot respond quickly even with interim support then it is arguably not meeting is fundamental objective. The other thing that the analysis of the data shows is that if 80 per cent of people are found to be eligible then it is not about the system being flooded by inappropriate applications, which is one of the essential counter arguments around why it is taking so long.

We have dealt with a number of matters around SAS in terms of complaints and reviews. These are not all formal complaints. Sometimes we get contacts or informal complaints about them. But the sorts of issues that are emerging from the communications we have had with people are around things like delays in determining eligibility status if someone is waiting to find out whether they are going to get in through the door or not. Issues arise about whether people are deemed eligible when they thought they met the criteria and they do not understand why when later they are told that they do not. There are a lot of issues around information provision and communication, particularly people waiting on the outcome of the application. They feel that they are not being regularly kept up to date about the status of the application, when they will hear, what they have to do in the meantime and so forth.

There are some issues around the way in which interim supports are provided. For people in crisis, interim support may save them from some worse situation but it is not necessarily meeting their needs in the way that they would like them to. Then there are delays in getting services even after the service support plan is approved. So you have been through the four stages of the process, you get an approved support plan and then you still have to wait for that service to be purchased for you. We have had some information about withdrawal of interim support before the permanent supports are provided to people and they are left in a gap. They are the gamut of issues that we are getting through our contacts.

Mr FITZGERALD: There needs to be a refining of the SAS system which is informed by the past practice. But at the end of the day it will need to be a system that is more timely in its outcomes. Again, I think that the department, under the new director-general, is working on that at present and no doubt the department will respond better than we can on that. It is a bit like my goldmine analogy: it is still yet to produce a steady flow through it.

The Hon. DOUG MOPPETT: At one stage we entertain the fond aspiration that there was a survey being undertaken within each region which was going to be aggregated to project what future demand would be rather than all the time reacting to applications which had an emergency aspect about them. But that has disappeared from our screen. One would love to think that a service application system would be a way in which people entered in a way to procure the services but behind that would be an awareness by the department so that it could say that it was above or below what it expected: We know there are people who will appear in 2005 and there will be another lot in 2006 and we are already for them.

Mr FITZGERALD: Our strong view is that that is what is needed in order to develop a service delivery framework. But then you need to predict demand. My view is that the disability area is predictable. We basically do know with some surety the number of people with disabilities coming through the system. That is largely because we know what is coming through the education system, which has verifiable data. Added to that are people who acquire disabilities later on or whose disabilities degenerate. But it is not an unpredictable system once you have your baseline data in place. So we would think that you can predict future demand. It is also a system through which you can moderate demand or planned demand. By increasing respite you buy considerable time.

There is no question that the vast majority of families one speaks to say that if they could have more respite, more access to holidays and more home help they would be prepared to maintain their son or daughter in the family home. The second thing that worries them is about the unpredictability of their own death and what would happen to their children. If we could give them greater assurance and provide more appropriate respite we could manage demand. We in New South Wales have never been able to manage demand because we have never known what it is and we have not had the mechanisms in place to adequately deal with it. I am not sure what detailed work DADAHC is doing on that planning.

Ms TANG: There are different components that you have to have to make the disability service system work. Planning at that global level is definitely one of the things that is needed. Even if the SAS system worked well, as one day we hope it will, it is only a crisis intake system. It is only one very small part of what is needed.

Mr FITZGERALD: For example, it does not pick up—and it is not designed to—any movement. If you are already in an accommodation service you cannot access it. If you are in a nursing home inappropriately placed you are not able to access it. So it is only a system that picks up people in genuine risk or in crisis. So it is not a general demand-driven system, nor is it designed that way.

The Hon. DOUG MOPPETT: Are you aware of any outcomes that have arisen from the regional planning that was undertaken?

Mr FITZGERALD: No, I am not.

Ms TANG: No.

The Hon. DOUG MOPPETT: A black hole?

Mr FITZGERALD: There may be work being done on that but we are not aware of it. It is also a system that absolutely lends itself to regional planning and regional service delivery systems. Of all the human service delivery areas this one absolutely lends itself to a regional-based structure. I believe that the department also accepts that position. Getting there is another issue, but it absolutely is a regional-based system model.

Ms TANG: There is no reason why that planning should not happen. We live in an age of very sophisticated data collection and the information is there to be used. Other States are able to do it. For example, Victoria has developed a regional allocation formula to look at equity issues based on ABS stats and the amount of money that they currently put into disability services in each region. It has been able to use that to decide where the growth money should go to improve the equity across regions. That will not necessarily meet unmet demand but at least they are using the stats that are available to do some of that planning around how to allocate growth.

The Hon. DOUG MOPPETT: Similar to the resource allocation that Health now uses. You get a formula—

Ms TANG: Yes.

Mr FITZGERALD: It will work in disability more than it does in some other areas.

The Hon. DOUG MOPPETT: We have not touched on day programs, which are also important in supporting people in their existing circumstances; and advocacy, which we have touched on in our inquiries.

Mr FITZGERALD: We would like to touch briefly on a couple of things. In allied health services a major issue is specialist services. The Department of Ageing, Disability and Home Care has had a review of therapeutic specialist services on its books for a number of years. To date there is no outcome at all. To date we are no better or clearer in understanding how clients in non-government or government services access therapeutic and specialist services. It was a major issue of concern to consumers and their advocates in the group home transfer. It has been a major issue of concern in devolution and it remains a major issue of concern when you look at our reports in relation to nutrition, mealtime practices and so on.

It is extremely concerning that such an important and fundamental issue is still not, in anyway, being resolved. We as a State lag well behind other States in trying to address that issue. But critical to the disability service system is an ability to access specialist services, particularly dieticians and speech pathologists and occupational health workers. If you are not able to provide that access, you will have the incidents over and over again. In that report it was clear that not only assessment was inadequate but accessing specialist services was inadequate. It is no good knowing that a person has a feeding difficulty and not being able to access both dieticians and speech pathologists for six months or 12 months.

That system has not improved in the last three years. The department has failed absolutely to advance this issue. We regard this as a serious issue that needs to be pursued, and we would certainly say to the Committee that it is an issue that needs to be pursued. I have no doubt that the department understands the seriousness of the issue, but I think it is a serious problem and we have had no advancement in that area. It is quite a discrete area. We know exactly what we are talking about, we have some idea of the demand, and we know what is required.

The Hon. DOUG MOPPETT: In our early intervention inquiry we touched on this problem that services are being delivered by DADAHC, that therapy services only reach a certain point and suddenly they need to be accessed from New South Wales Health, which has a completely different set of criteria, so those people go down through the grading.

Mr FITZGERALD: If we are reliant simply on generic services provided by New South Wales Health, it will fail. This is a complete fiction and nonsense. This notion that we can so resource New South Wales Health to provide those resources as an answer is a nonsense. The problem is exacerbated by the fact that New South Wales Health operates on the basis of areas that allocate their resources differentially, with little regard to the policies of central office anyway. When you come to issues regarding people with mental health or with disabilities—as you will see in your inquiry when you come to the issue of child protection—those people always fall through the gap.

It is not up to us to comment on the Health Department, but we are saying that disability clients require a different form of entry. We are not talking about general medical practice, and we are not talking about general issues, but where we have significant health-related issues caused by or related to the disability, I think generic services will always be difficult for those people to access. So I think we need to have a different model for that. But, again, that is an issue that we think solely rests with the department, in conjunction with other departments.

Advocacy I do not think we will talk long on. Firstly, I want to acknowledge the Minister and the department's abandoning of its expression of interest process launched last year. Again, it was ill-conceived. We are pleased that the Minister and the department acknowledge that a better way forward was needed. The department has put in train, in consultation with the sector, a new way of addressing the advocacy framework. We welcome that. The issue for us is that it is a long-term strategy, and it will be important that the department continues to be committed to actually developing an advocacy framework. Our difficulty with the department has been that it is constantly committed, but shortly thereafter the commitment wanes.

We welcome the change. The process they have put in place seems to be appropriate, there is greater consultation with the sector, and will they are going to fund agencies for three years from the next financial year, and that is a welcome step. However, adequacy of access to advocates remains an issue. It is still true that the vast majority of people with disabilities, even in residential services, do not have advocates. Nevertheless, there is now a process put in place by the department to look at advocacy. I must say it is a significant improvement on what was presented 12 months ago, or less.

Ms TANG: There are three other areas that we would like to bring to your attention. They relate to other parts of the system that need further work. Day programs, we would agree, is an area that needs a lot more attention. It is a critical part of the system. If people have access to day programs, that can help sustain an at-home arrangement. The problem with the day sector program at the moment is that there is no viable ongoing funding of it. Two ends of the spectrum need to be picked up. One is adults who need a day program who left school prior to the establishment of post-school options. Then there are those school leavers every year who will be a cohort of young people with disabilities leaving school who need some sort of day program option. Any program must be able to address both ends of the spectrum.

The other two areas are attendant care and personal assistance care for people with disabilities, and services for people with brain injury. In both areas there is a critical unmet need. The greater the unmet need, the more vulnerable those people are. Those lucky enough to get access to a service become dependent on it, and are reluctant to raise issues or make complaints if they are unhappy with the service or if it is unsatisfactory, and they have a lack of choice about changing provider if the service is not satisfactory. This is particularly so with personal assistant care, because we are talking about fundamental support for people—being able to do things like get out of bed, go to the toilet and have a shower. That is a critical need of these people that should be addressed.

CHAIR: If we could move on to funding arrangements for the non-government sector and the continuing role of government in direct service provision.

Mr FITZGERALD: If I could make just a couple of comments. I have already made one comment previously. The Government must determine the business in which it wishes to be in relation to disability services. The outstanding issue for us is that the Government has yet to decide the areas of disability services that it wishes to be providing. Our view is that the government will always be a provider of disability services in New South Wales. There are certain groups of clients which I think will naturally fall to the government in its role as a provider of last resort. They may well be people with forensic behaviours—sexual offenders and so on. It may be for those who have exceptionally high challenging behaviours, not necessarily at the forensic level but differently. It may well be people with extremely high medical support needs, and there may be others.

Our issue is that the Government must at some stage answer that question. The answer more likely to be given is: We are in the provision of services that we currently provide. That is not an answer. It is an obfuscation. It is just a nonsense. There must be a clear decision. Of course, making that decision will have its critics, but it is utterly unfair to the Government's own departments and unfair to the non-government providers to operate in an environment where the major provider does not have a clear understanding of its future. Where is it going? I understand there are all sorts of complications, but it seems to me that we have reached a point where that is an extremely important issue. It will be a provider, but a provider of what remains the unresolved question for us.

CHAIR: Do you have any opinion about what is more appropriate, other than being a provider of last resort and perhaps taking the most difficult cases?

Mr FITZGERALD: Provider of last resort, by its very nature, means that it will take the most difficult and complex cases. I think government's role is that. In a sense, it is no different from the role of government generally. Where there is market failure, the role of government is to step in. Even the most economic hardliner accepts that. It is a bit the same in community services. Where the market, made up of non-government providers and others, is incapable of meeting the demand, the government has an absolutely fundamental role. The difficulty that I have—and I think we have not done enough work on it, and we would like to see the Government put forward a way to have this debate—is whether it should exclusively be a provider of those sorts of services or whether there should be a mix of providers. There are countervailing views on that.

Clearly, from a work force point of view, many would want a mixed environment of providing services for low support need clients as well as high support need clients. There are arguments that a service that deals only with the most critical edge may lose a breadth of knowledge and understanding and lose the context within which other people exist. There are all sorts of issues. We are not yet in a position to say that this is what we think. What we are sure of is that the Government needs to enter into a process by which that decision can be reached. It is a hard decision. It is not an easy decision. But I think the current environment is very difficult for government workers, it is extremely difficult for a planning department, and it makes it almost impossible for non-government agencies to understand their future. So it needs to be resolved.

CHAIR: There are difficulties with various models that you could talk about. If you say, for instance, we want them to continue on as a competitor with the non-government sector, the difficulty with that is—and it is equally true of some non-government service providers—we want a competitive atmosphere, but having developed all these resources you miss out on the tender. You have people at Kempsey and Narrabri saying: We missed that tender, so what do we do? It is rather artificial. I have a personal involvement with a constituent and a long-awaited determination of the SACS award, which sort of rejigged the competitive edge that the non-government sector had in some of these things.

Mr FITZGERALD: I think the issue of government competing with the non-government sector is a broad issue which the community service sector has had real concerns about for some time. I think it is exacerbated in the disability area by the fact there is no clear understanding of what the government provider is about. Nor is there a service delivery framework. Those problems become much worse when there is no context or framework for future operating. I think we need to work through what is the appropriate role of government and non-government providers in terms of contestability or competition. That needs to be worked through in the human services area. My concern is that that itself is not the issue at the moment. It is an issue, but the broader issue is that even if you accept contestability between government and non-government providers as an appropriate way forward, it has to be within some sort of framework, and we do not have that.

The Hon. IAN WEST: To what issues does that framework go—quality?

Mr FITZGERALD: The framework is: What is the service delivery model? That is, what is the nature of the service deliverers, the providers you want to meet the demand that we are talking about? What are the services that you actually want delivered? That goes beyond just accommodation services. In a sense, who is in the best position to provide those services? I take up your point about quality. You should only be deemed to be a provider capable of delivering those services if you meet the quality standards, but that is another issue.

The Hon. IAN WEST: But who determines that, how it is determined, and whether it is done by some regulatory framework or through competition in the marketplace or whatever is a question.

Mr FITZGERALD: Yes. I go back. The Department of Ageing and Disability and Home Care must be the standard setter. It is in fact the funder. It is the body that licenses—using that word broadly—the services or deems eligible for delivery of services, so it needs a very rigorous framework by which quality standards can be set and monitored. I think that is critical. Eventually, the disability area will move to accreditation. You may then look at the health model and say: Who is the best person to accredit? But right at the moment, you are absolutely right. That is one of the issues that we come to with the non-government sector. The current range of providers are variable in their quality. The department needs to have a serious look at how it determines which providers are eligible to provide different sorts of services for different clients. That is an issue. Again, the Director-General would have some comments on that.

CHAIR: That brings us to No. 5. One of the problems behind the previous question is that, in having predetermined service models, when you are negotiating with those people it has that awkward flavour of: This client wants three of No. 2, five of No. 6 and one of No. 9, and that equals so many thousand dollars you are going to pay us. It is all terribly compartmentalised. We have had evidence from various carers that they would prefer a much more flexible determination of funding so that they could then negotiate the services that they felt it best to provide.

Mr FITZGERALD: I think we need to look at this in a couple of ways. Firstly, I go back. Where the government is the funder of a service or a purchaser of services, a precondition from my point of view is that it now needs to do so at full cost recovery. What we have at the moment is a hybrid model of funding, and it affects flexibility. We have a hybrid made up of three parts. The first is individualised packages, so that a package of money is allocated and it sits with you. So Doug Moppett receives $70,000 per annum, and it can be spent only on Doug Moppett. We then have another form of model where the Government says it will fund this agency to deliver services but the agency must contribute something to it. That contribution is unknown, but we have agencies that might be contributing 10 per cent, 20 per cent, 30 per cent, 40 per cent, 50 per cent of the costs from their alternative funds.

We then have a preferred model where the Government says it will purchase this range of service but contracts are awarded on full cost-recovery basis with components for specialist services.

The model does not work. We now have gross inequities in the funding of services to agencies and this impacts on flexibility. We are moving to—and this is a move within the past six months—the Government now allowing money to be paid to an agency. That money is based on an assessment of the individuals but that money can be used across those four. Let me use an example. Instead of saying $70,000 goes with Doug, $70,000 goes with Ian and $70,000 goes with Jan or whatever it might be, and you can only use it on those people, we understand the Government is now moving to saying we will have a house and three of you will live happily together and we will allow you to use the $210,000 flexibly. Perhaps that is a better model.

The funding is based on the individual needs but it can then be used in a more block way. We believe by that approach you can get more flexibility into the system. Before, they were individual packages. In a sense it was meant to deliver maximum flexibility to the individual but in reality it was not doing that. It was constraining flexibility. Having said that, many parents of people with disabilities would like the notion of getting the $70,000 to use as they choose. From a consumer rights point of view that would be an ideal system, and for some it works. Our experience in the past two or three years is the system-wide approach has no chance of working. Again, that is a difficult trade-off to make. It does not mean that we never have individualised packages. That would be quite inappropriate. Many of the SAS applications, their interim funding, are exactly that. They do give great flexibility.

Many consumers wish to join together and form their own consumer-based groups, where they would like the money and use it however they choose fit. I could not oppose that, but if we are trying to look at a system we have to be a bit more practical at the other end and make sure that if a provider has sufficient moneys on a full cost-recovery basis to meet the needs of its clients, then he can use that money across a group to achieve flexibility. That is quite hard but we see movement in the department in the past few months that recognises that. Again, the department would have to indicate how that is happening, but we think that is something we have learned in the past few years. It is a hard issue. I bite my tongue when I say it, because in an ideal world Anita should be able to choose how she will meet her own needs or those of her son or daughter, but in a system-wide approach it is extraordinarily difficult to achieve.

Ms TANG: On some of the other elements of your question, one of the missing links in the system being able to meet individual needs in a flexible way, apart from the funding, is that there is no mechanism for people to indicate that they want to change the way the service is provided or who their provider is and to move within the system, outside of the new initiatives. If you have been living in a particular place and receiving a particular service for a certain number of years and you are now ready to do something different, there is no easy way for you to work your way through the system. People get locked into whatever they have now and that has contributed to some of the delays around developing services now, because people feel this is their only opportunity to shape something to meet their needs. It is now or never. It would be really good to see some mechanism for managing individual changes over time so that people's needs can be met within the system.

Mr FITZGERALD: At the moment that depends on the individual agency. You will see that some agencies use this collective money in an extraordinarily flexible way. Other agencies simply have not shifted at all—everyone is still in the group homes that they started with. The other point we make, and we have made before, about service development is that we have to be encouraging and requiring services to achieve what Anita is saying, to recognise when residents want to change, and there has to be a process by which that can be accommodated within the service itself or, alternatively, for the person or people to exit the service. We are a long way short of achieving that at this stage. Part of that at the moment is that we do not have good focus on innovation. In the disability area there are no demonstration models. We do not celebrate innovation in any creative way at all.

There are no research grants to look at flexibility models, and the other problem is that because the government provider is such a significant player it is always looking for a cost-effective outcome. In and of itself I can understand that, but it can stifle innovation as well. Having said that, there are many examples where there is innovation but as a system we do not seek and celebrate innovation in a way that you might see in other sectors. That is part of the sector development or industry development approach that we talked about earlier that needs to be brought into it. We do have to really push providers to allow for that flexibility and within that flexibility will come innovation and new models. But the funding has to allow that to occur as well. Again, I think there has been movement in the past 12 months to recognise that the purist view of funding is probably not achieving the outcomes we would like.

The Hon. IAN WEST: What movements are you aware of that have taken place in regard to some delineation between advocacy and provider so that the client does not become, for lack of a better word, a captive of the vision of the provider?

Mr FITZGERALD: Critical to it is our view that all people within disability services who are unable to advocate for themselves should have an independent advocate. Ideally we need to get to that point. I have used the word "trade-off" many times this morning, but there are trade-offs. By not having individual packaging and by having people within a service provider, and the flexibility occurs largely within that same provider, we do end up with this term that you have often heard, "client capture". There is no doubt at all that people with disabilities are at great risk of client capture. The move to individualised packaging, greater contestability, greater choice, was a good move to overcome that. If we are not able to achieve that for the reasons we have talked about, then advocates will be critical. So too will the role of the department in providing the facility for people to say they are not happy with the service, that they will not let me change. What will you do to help me? There is a role for government as well. It is difficult if it is also the provider. As I said, the SAS system does not allow that.

What is another mechanism that achieves that for a client? I think that is not yet in place. Theoretically a person should be able to require a service provider to allow them to change their circumstances and if they are not happy, to exit with ease. "With ease" is the issue. Everyone will say they can exit but there is nothing easy about exiting and finding alternatives, and the system is not designed for that. That is critical. Your point about individual advocacy is going to be very important. Otherwise we will be sitting here inquiring about client capture. That is the problem. So, again, it is putting the safeguards in place.

The Hon. DOUG MOPPETT: I think we have made some comments on medium and long-term planning and the need for the assessment, not only through the service access system but much broader planning. If there is anything you want to add, please do so. Otherwise, we need to deal with consultation and there is nothing we look forward to more than you addressing the short, succinct but nevertheless challenging question contained in question No. 8. I will leave it to you to round off through those.

Mr FITZGERALD: I want to be very brief about the community in consultation process. The Government has in place a Disability Council. We believe the Disability Council, effectively used, is a good means by which the Minister can be informed of disability issues broadly. We see, however, a need within the department to have in place strategically focused or desired consultation processes. For example, I do not believe the department needs another broad-based advisory body. My experience of the outcomes of those is that they can be quite limited. Because DADAHC relies on the sector to deliver a large part of the services and because of the conflicts we have talked about before, it is extraordinarily important that consultation and formal mechanisms come into place to guide it. If we are talking about an industry development arrangement, it may well be appropriate to have a targeted working party established with sector representatives for a period of time and with limited terms of reference to work together to look at what that means.

If we are talking about an alternative delivery system, it is extremely important that there be active consultation. Active consultation means also transparency and access to full information. There has to be a culture that values consultation—and by consultation here I mean real engagement, and real engagement requires transparency. The department has not been good at providing information, largely because it did not have much, but it has not been good at providing information on a consistent basis. My view about consultation is that the consultation needs to be strategic, it needs to be about very clear and clearly defined issues and there needs to be a real level of trust between the participants, and that means access to good quality information that the department has or can obtain. So, we are not recommending the establishment of any more advisory bodies. I am sure the Government will be pleased about that.

We are not recommending the establishment of any external advisory bodies or watchdogs, but there has to be a culture within the department that welcomes engagement and it has to be very strategic. They are all the comments I have on that issue. We would like to see an outcome of the inquiry. We have made a number of references this morning to some of those, and I might ask Anita to be specific about some of those. We want a service delivery system that is capable of meeting the changing needs and aspirations of people with disabilities. That is not a motherhood statement; that is a statement of their right, the right to receive services that meet their needs and changing aspirations. We want to see out of this inquiry an absolute commitment by the department to developing a service delivery framework to which I have referred, and a very clear and absolute commitment to a regional planning and regional delivery system of care.

We want a system that can respond to their changing needs throughout their life cycle. We have talked about that in a number of ways. If somebody wants to move, how do they achieve that? If they move into a group home following devolution, how do they move out of that at a later date? How do they move out of all of those into aged care facilities? How do they move from an aged care facility, if they are not meant to be there, into some other form of accommodation and then back into aged care when they need it later in life. The system needs to be flexible. Many of your previous recommendations help get us there. Some of the comments we have made today move us a little bit further forward.

Ms TANG: A strategic framework for the service delivery system should be developed in consultation, and this touches on that last question. We need a framework that is out there, documented, that has been developed in agreement with people so that everyone knows where we are going and we all agree that is where we are going. It should address many of the issues we have talked about today and that you have asked about, such as the role of government and how you get flexibility as well as innovation and reasonable progress on some key initiatives. In addition to what Robert has mentioned, there has to be infrastructure for service development and that has to include workforce development. We have not talked a lot about that today but the issue of competency levels of staff who provide these direct services will not go away. It comes up in all our work and there is a real issue about who should take responsibility for that.

Our view is that it is DADAHC's responsibility, not necessarily to provide training but to enable that competency to be developed. The crisis intake and response has to work. We have a system in place that needs to be improved. We need a rigorous system for monitoring the quality of services. In that way we will get to see the monitoring framework that the department has been working on actually being implemented. We need planning at several levels. We talked about population-based planning, demand planning across the board using Australian Bureau of Statistics-type statistics, and regional planning. But we also require planning around what other service types are needed in each region to meet that need. Those are the other elements of the system that are missing at the moment.

The Hon. DOUG MOPPETT: We are deeply grateful to you both for a most illuminating session. We thank you sincerely for your preparation. There is no doubt about the fact that you were able to focus your experiences and express them succinctly and forcefully. I am sure that our final report will reflect some of the aspirations that you have enunciated to us today.

(The witnesses withdrew)

JOANNE FLORENCE RIDDLEY, Chief Executive Officer, Disability Enterprises, 104 Rawson Parade, Leura, affirmed and examined:

Ms RIDDLEY: I am appearing here as the Chief Executive Officer of Disability Enterprises and, therefore, as Chief Executive of Greystanes Children's Home, which is part of that organisation. I can confirm that I have received a summons and I have most certainly read the Committee's terms of reference.

The Hon. DOUG MOPPETT: If at any time you feel that what you would like to submit to the Committee is sensitive and you would like it to be dealt with in confidence, you have only to indicate that to us and we will take the necessary steps.

CHAIR: Before we start I place on the record that I am particularly grateful to Jo for coming. I asked her to give us her point of view about the running of children's services—someone who could give us a snapshot of the stage that those services have reached. I am grateful to her for attending today.

Ms RIDDLEY: I am glad to be here today.

The Hon. DOUG MOPPETT: Before we proceed to questions would you like to make some sort of generalised introductory comment?

Ms RIDDLEY: I suppose that the comment I would like to make in general is that dealing with the devolution of Greystanes Children's Home, which is my major experience that will be of use to you, I probably need you to understand that the people we deal with are profoundly disabled. We are dealing with the most profound level of the disability spectrum that there is. So some of the issues that arise for us may well be very different to the issues that arise for other organisations and parents that you may speak with. We also have a mixture of children and adults. The majority of our residents are children but about a quarter of them are adults. I suppose that the age of our residents ranges from five years to 33 years. We were given the opportunity to devolve. We were given a three-year process from 1 July 2000 to 30 June 2003. So we are more than halfway through that time frame.

The Hon. DOUG MOPPETT: Could you explain the processes that are going on there now?

Ms RIDDLEY: As I said earlier, we were announced for devolution towards the end of June 2000. That announcement was not greeted with cheer by the families, the staff or most of my directors. We spent at least six to eight months just preparing families, directors and staff for those changes. I am very proud of them. Basically, they have taken it on extremely well. They have seen the benefits. They still have fears and concerns, of course, but we are now able to move forward. We had a major planning meeting or an announcement meeting with the department and our families. From there we have undertaken individual meetings. That major family meeting was an extraordinarily emotional day.

We decided that that was not a good way to proceed into the future as the emotions of one family spilled over to another. So we then dealt with smaller groups of families whose children may live together, or individual families, to discuss their individual needs and what they wish. I am talking here a lot about discussing with families. As I prefaced these comments, that is because our residents have the most profound level of disability. Very few of them can speak for themselves or can become involved in that process. We most certainly are involving those who are able to do that as we go along, but the majority of people that we are dealing with are families rather than individuals with a disability.

CHAIR: Is the family involved in every case, or is it a matter of a family handing over responsibility and needing to bring in advocates?

Ms RIDDLEY: We have brought in advocates. Two of our families do not even live in Australia. We have kept them informed of the process and about what is happening to their child by mail and email. We have brought in advocates for those that we felt were insufficiently represented.

We have involved families as much as possible. Some families are far more prepared to be involved than others. In fact, one of the issues that we have had to deal with is that many families have said, "You have looked after them for so long, you just make all the decisions." It has been hard for us in some cases to get families involved. On other hand, other families have been heavily involved and they have been pleased to be involved.

We looked at the ages of those that we care for. We made the decision to start with those families who were the most positive about the process so there could be some successes on the board and so that those families who were not quite so positive could then see that it was a good process and that things could work very well for their child or their relative. We were very fortunate in that the very first family member who approached us was a former foster mother of one of our youngest residents. She expressed a wish to take her former foster child back into permanent foster care, with our support. The first of the residents who left Greystanes was actually returned and reunited with a former foster mother in our local area. We offer her high levels of support.

Those families who were very positive were generally the families of the older residents because they could see that the children's home was obviously not a suitable place for their adult son or daughter to be living. Those people—all but one—have moved into what would be termed group homes. One has returned to her family through the week and she goes to a permanent place in one of those group homes at the weekend, which is a shared care arrangement. As her family ages—which they will, of course—that shared care position becomes her permanent home. So they have a good feeling of security there for their daughter. I think her father is in his early sixties and her mother is in her early fifties. The mother, who has a back problem, does not believe that she will be able to care for her adult daughter for a long time, but they desperately wanted the opportunity to have her at home for a while, so we put in place a shared care arrangement. Six other adult residents have moved into a group home, and the young fellow who has returned to his foster mother has also left our service.

At the moment we are trialling with a young girl who has moved to live with an authorised carer and her family. Her birth family is well acquainted with the carer and her family but she is not living with her birth family. She is living with an authorised carer through our organisation. That trial arrangement was to be a three-month arrangement but it is now in its ninth month and we hope to have that finalised and formalised so that it becomes a permanent arrangement. It is working extraordinarily well at this time. We have several other young residents under 10 years of age who we are discussing with their families and who will return to their families and live with a parent or a grandparent with us providing in-home support and long-term respite support, case management, therapy assessments, those sorts of things, on a long-term basis.

I suppose the outcome for the majority of our residents is that their families want them to stay fairly permanently with us. Therefore, if we cannot arrange a shared care arrangement, which is the arrangement we see as most suitable for most of our youngsters, we are arranging what would be termed group homes for those people. We have two group homes occupied and two more have been purchased. One is finished with its modifications and the other is yet to start its modifications. We know we need another five houses. We are informed by the department that adequate financial arrangements have been made for those five houses to be purchased in the next financial year, which is our last financial year for devolution. So we are very hopeful of meeting our deadline of 30 June.

The Hon. DOUG MOPPETT: I do not think you were here when Mr Fitzgerald was giving his evidence. I would not be misquoting him by saying that he felt that, of the 400-place devolution announced by the Government, very few have been effected. It sounds as if you are having more success than some of the other nominated institutions. From the perspective of your own successes and difficulties, can you comment in the context of question 1: In your view what is needed to ensure the process works, what are the barriers to successful devolution, and has DADAHC been supporting the devolution process adequately?

Ms RIDDLEY: Obviously the thing we need to ensure the process works is commitment from the organisation as a whole. Without that commitment, it just will not work. That involves from the chairman and boards of directors down. Certainly, it is utterly essential that key staff members support the process, otherwise it is very difficult to make it work. Other things that are key to having it work are the family involvement and a good knowledge of the requirements and needs of those individuals who are being devolved. Fortunately, for many years we have been providing support to the people we will continue to care for, so we have a very good background knowledge of their physical, emotional and support needs for the planning process.

Time is quite important. I must confess that I was very frustrated in the first six to eight months. I felt that nothing had happened, but it was very important to our families that were not keen on the process to get used to that thought. We were taking them from full institutionalisation to complete devolution, from A to Z, and there is no way we could ask them to take that big step to Z immediately. We needed to go through a few phases and stages. So time was more important than I think I at first believed. Planning and time for planning are important. In terms of planning, we found it difficult to find suitable housing. We are in the Blue Mountains. Obviously, the Blue Mountains are on hillsides, and it is very difficult to find sufficient level land or sufficient housing that is appropriate.

We very quickly realised that we would need major modifications to any building we purchased to accommodate the people we support. That obviously requires expertise and money. It costs considerable sums of money to purchase and then modify for those people with extremely high support needs, both physical and intellectual disabilities at the furthest end of the scale. Co-operation with the department, co-operation with your local community and your local council, all those sorts of things need a constant push, never letting it stop, never losing the momentum. It is a constant push the whole time.

The Hon. DOUG MOPPETT: One of Mr Fitzgerald's observations was that it appeared that progress was being made in the smaller institutions, in particular—as you have mentioned—those that have embraced the concept. Gradually working around the perimeter, it appears as if we are still left with the largest number of people in the largest institutions, which are the least desirable of all, and very little progress has been made, not that they were nominated in the 400. I guess we are trying to draw on your experiences to be able to formulate our recommendations in relation to speeding up the whole process. If we have not got very far with the 400 and our recommendation was that the whole process should be completed by 2005 or within a reasonable time frame, then we are not making enough progress at present.

Ms RIDDLEY: Some of that could be encompassed in the next question about DADAHC support. Unfortunately there are very few guidelines from DADAHC. It is an organisational issue, not an individual person issue. Some of the personnel at DADAHC have been remarkably useful and helpful to us but as an organisation as a whole chaos comes to mind. There appears to be very little consistent planning or consistent policy and direction that comes out of the department. I think that if it were made more plain as to what the processes are, people would be more able to plan for their organisation. Some of the larger organisations are government-managed organisations anyway, and it seems to me that surely between two government departments they should be able to do something about it.

CHAIR: It might be harder.

Ms RIDDLEY: It might be harder. Sometimes it is harder. From talking to someone who works within the system, I know that their industrial relations problems are much more difficult than mine. There are some really big issues so maybe some consistent approach with a union, those sorts of things, could help. I understand that there are quite a few industrial relations issues involved in the devolution of the larger organisations.

The Hon. DOUG MOPPETT: One suggestion that came out this morning which I thought was extremely significant, was that progress is being impeded by the two perhaps subsidiary but nevertheless important objectives of developing new service delivery models and testing and evaluating them, and contestability in those services. In other words, we decided on devolution 10 years ago but now we have decided that in addition to that we also have to serve the objectives of investigating something other than group homes and also allow the private sector—there are some 67 eligible service providers—to make the choice, which does occasionally disempower rather than empower.

Ms RIDDLEY: Yes, and it certainly would be a confusing situation to be in as a parent or as a person with a disability to make that decision, particularly if you have been with a government organisation for very many years and that is what you know. You are unsure of other organisations and the non-government sector sometimes is not presented in very good light so they may have some fears about going to a non-government sector. You made a comment about the notion of looking at innovative models. I suppose this is where my thoughts about a bit of guidance from the department would have helped. Initially, we were continually told that there are no models and we should come up with innovative thoughts and ideas, and we tried to do that.

It is hard to get families to accept innovative ideas. They want something that is tested and true. We have tried some things, for instance, the young girl who is living with an authorised carer in a family home but cared for by people other than her family. We have looked at shared care arrangements. I suppose from the point of view of the major innovations for people with disabilities being able to live alone or in a much smaller setting than the four or five that generally goes with a group homes, with a drop in support and things like that, it is actually not suitable for the people we currently support.

Their level of disability is so profound that they need 24-hour support for all of their needs, just the basics of getting up, getting dressed, cleaning teeth, brushing hair, eating food. Those people we support at the moment are not in a position to do those things for themselves and all. It is an accomplishment if we can have someone hold a spoon, basically. We put aside those sorts of innovative ideas because they did not meet the needs of those people we care for, but I can see that if you were a large organisation with people who were mobile, had intellectual disability and could actually learn to care for themselves outside of an institution, it would take some time to trial those things. It would take some time for people with disabilities to take on that learning and to then get used to it, prove it can work, and decide it is what they want. It is a time-consuming process.

CHAIR: Arising out of the question asked by the Hon. Doug Moppett, when you said earlier that the announcement was in June 2000 and that basically staff and families were not happy. I think you said you had a very frustrating six or eight months. I wonder whether, so far as the role of DADAHC is concerned, if they had been absolutely on top of everything, if all the models had been in place, if all planning had been in place whether they're still would have been that long gap because it was still a matter of persuading people.

Ms RIDDLEY: It certainly was a matter of persuading families to accept that their children would no longer live at Greystanes children's home. I think they may have felt more comfortable if they had been told, "These are your choices. You can have something like this or you can have something like that," or, "Please think about these sorts of issues".

CHAIR: Something they could go and look at.

Ms RIDDLEY: Yes. We have been providing that ourselves. We started with those families who were very keen. They were basically the families of the older people and did not want their adults still living in a children's home. We have been able to show less positive families that he has worked for some people. Before the houses were occupied, we were able to take families to those two new homes and show them the type of accommodation. It probably would have been quite useful, had we had the opportunity, to show some examples. On the other hand, of course, within our own organisation we cannot invade the privacy of people who live there. You have to determine when and how often and who you take to someone else's home to show them an example of the way that person lives. I know that the department was in the process of making a video of our devolution. I do not know where that is up to at the moment. The Department started to make a video of our devolution to use as a tool for other families into the future.

CHAIR: I was going to ask you whether your positive experiences would provide a mechanism to speed up the process for other people further behind you?

Ms RIDDLEY: If that is possible we would be very willing to support that in order to help others. It certainly has been a positive process but we have also made mistakes that we have learned from. They are the sorts of things we would like to share with other organisations.

The Hon. DOUG MOPPETT: You speak with the authority of someone who, if I may say so, knows the trade, not only your own operations but the outlook of service providers. The Committee was hoping you might comment on some of the other, almost notorious, issues that we have picked up in our reports—the group homes project, the initial 41 homes that were going to be transferred by the expression of interest [EIO] process, the problem of unmet need for accommodation services, respite care—which we used to just talk about the lack of, but now referred to in terms of reform because, again, it has moved from centre-based to alternatives as yet sometimes not determined, devolution, and the very important service access system [SAS]. The Committee would be grateful for your comments, looking at it from the other side of the counter, so to speak.

Ms RIDDLEY: I need to let the Committee known that I have worked in the disability field for only 3½ years. You have credited me with far too much experience in your brief introduction. My experience has been with Disability Enterprises, but I like networking. I am quite a good networker and I talk to a lot of other people within the sector. My general management experience has shown me quite a lot of things that are happening within the sector. While it is only 3½ direct experience, I think I can comment on some of those issues. The group homes project erupted about the time that I started working with Greystanes, really. We knew that there were a lot of families were very distressed about that. It seemed to be split into two camps: those families who desperately wanted to get out of the group homes and those families who desperately did not want to change.

I think lack of communication and lack of information was the greatest concern that I heard about from various people about the group homes project. They felt they did not have sufficient information. They felt that decisions were made or directives given that they were not aware of. I have to say to you that I am not a fan of the expression of interest process at all. I believe that the disability sector can only operate if we worked together, all of us. An expression of interest process pits one organisation against another and, generally in an effort to drive down costs, corners are cut. Generally there is not enough time. It is very difficult to know exactly what is required of an expression of interest and there is usually only a couple of weeks to do its.

It is an enormous amount of work to put together a proper proposal, and to convince yourself as manager to convince your board to take on the risk of starting something, for instance, taking on a large number of unknown clients in one lump out of the group homes project. Overall I am not a fan of the expression of interest process. The expression of interest process to devolve large numbers of people out of government homes into non-government sector is a huge risk for the non-government sector and I do not think there was properly enough time and understanding of that process at that stage on the part of the non-government people going into it.

CHAIR: What process would you use, if the process has to be in place because changes occurring?

Ms RIDDLEY: I suppose an expression of interest process of a type, but then having the opportunity to speak to your expression of interest rather than having to completely charged on paper. Generally what is being judged is the budget. I am sorry if I have been a bit harsh, but I believe it is generally the budget that is judged. There is no opportunity to really explore the reasoning behind the type of service that an organisation is offering. Why have they thought that service would best meet the needs of those people who need the support? I think it needs to be a very public process so that not just one or two favoured organisations who are constantly given the opportunity to participate in a closed expression of interest process, or closed tendering process. It certainly needs to be a public process so that across the board a large number of organisations are able to participate. I believe the written expression of interest is most certainly too black and white, too cut and dried. It is one-dimensional.

I think an opportunity to discuss your expression with both the department and other stakeholders before you put it on paper, and the opportunity to talk to where after having submitted it would be some improvement. I always laugh at this notion of the unmet need. I do not think anyone even realises how much unmet need there is. One of the basic needs of this whole sector is really to do some research and find out what is needed. There are a lot of bits of research around the place, but they have never been collated, I understand. I am giving this from hearsay and discussions with colleagues, but every time someone talks about unmet need a new research project seems to start up, rather than starting to collate all of the existing research that is in place.

I believe the fact that the SAS system has been totally overwhelmed indicates that no-one was aware of what the volume of need actually was. That, I suppose, takes me to the SAS system which, unfortunately, is simply totally overwhelmed. The way the SAS system started probably represents something of the way the department runs. It was announced and forms were sent out before staff had been employed and trained to manage it. By the time staff were there on the job ready to assess and go through the forms they had thousands of them sitting there. So, it started behind the eight ball completely.

I have not worked through the SAS system a great deal, because we are dealing mostly with people with disabilities that we already are supporting. We are having some people come through the SAS system— very few—and generally the department rings us and asks if we can take these people, please, temporarily until some arrangement can be put in place for them. At the moment our organisation has put forward an application to provide crisis support to two individuals who I believe are going through the SAS system. Their SAS applications have been in for quite some time. Unless you are totally in crisis, nothing happens. Nothing appears to happen. It is purely the volume. I do not think it is a particular decision by the department to just ignore things until it is a crisis. It is a matter of volume and those with the greatest crisis are obviously the ones who need to be dealt with first.

From our experience, we have two adolescents in respect of whom we have put in applications for support funding. It has been weeks and weeks and they were already in crisis. They have now gone into even further crisis where one of the youngsters has actually physically attacked and injured his mother. The family is falling apart completely when eight weeks ago there was an opportunity for them to make a decision and put something in place so that those worse than crisis crises do not arise. I honestly believe that the SAS system was started before it was thought out correctly and before systems were in place to help it worked. It was announced and the forms sent out in the November-December period but it was much before the staff were on board to work.

CHAIR: It is an awful dilemma, is it not? Somehow or other the entire system needs to be doing that fast enough to get over the crisis so that everyone can operate it in a regular, understood and co-operative way. How does one get over that massive, hopefully short, system-wide crisis?

Ms RIDDLEY: It is a dilemma in that those people working in the area are working their backsides off, but the volume is overwhelming. No group of people could cope with that with their current numbers of staff.

The Hon. DOUG MOPPETT: I do not think it is my natural cynicism coming to the fore, but it seems that it has taken us from panic to organised panic. The Committee took evidence at one stage that was very heartening. We met a fellow who was commissioned to do research in one of the regions and we understood every other region was doing it. It was almost a demographic plan but it seems that the streams of such information run-in subterranean caverns, which no-one can discover. We would like to think, for example, that in the western region people would be aware that there are certain people I have for immediate attention and people they think might bob up in five years, others in 10 years, and people already on their books who are reaching a stage their lives when they are going to move into another form. As Jan said, the difficulty is that so much effort is put into dealing with today and tomorrow and five years down the track does not get any consideration.

Ms RIDDLEY: Yes, and next year and the year after, and five years down the track does not seem to get any. I think the notion of a type of systems such as the SAS system is excellent. My colleague who has worked in the industry for 20 years has asked constantly why there is no central register of people who are currently receiving support so that we can track their changes and plan for them in the future; and those people who are not currently receiving support but will need it. That is what we thought SAS was going to be and we were, like you, very heartened at the development of that. I do not believe the resources have been put behind it.

The Hon. DOUG MOPPETT: Another issue our next question is going to open up is that was there is this concentration on people who are in this crisis situation, families breaking up and clients whose behaviour or health demands absolutely immediate attention, we forget that there are is a great range of people with disabilities almost close to managing their lives relatively independently but unlike the support of days programs and a whole heap of little things that would so enrich their lives. We are forgetting that enrichment of lives or reaching minimum standards of disability services. Did that apply to any of your clients? Would they have benefited from what I might call ancillary services rather than the direct, that you had difficulty accessing in terms of their new package?

Ms RIDDLEY: We have found that it is very difficult to access externally those extra things that people need that we are providing. Our organisation has taken on a physiotherapist. There is no way that you can access local physiotherapists. The Blue Mountains is quite well served; we are not exactly a tiny rural community. So we have employed a physiotherapist full time to deal with our clients. We deal with the local hospital dietician and those sorts of things. We deal with the local DOCS speech therapist because she is the only person available to us in that area. We find, as an organisation, that we need to search out and locate specialist services for our clients on a regular basis. Sometimes it takes a lot of looking to find someone. When we have enough clients with a particular need and we certainly cannot run the services, we employ them—we make sure we take someone on.

CHAIR: What is your total number of clients?

Ms RIDDLEY: With respite, at any one time there would be up to 40. We are only a small organisation. We would care for 36 or 37 people full time or have a long-term investment in their support. People come in and out for respite, sometimes for longer periods while overcoming crises, while waiting for something more permanent or for a short respite before returning to their families.

CHAIR: I was thinking about multiplying this by thousands.

Ms RIDDLEY: Goodness, yes. Your comment about day programs is very valid and I would like to mention that also. My major comment about the department is that things are launched before there is planning or before the resources are in place. The Atlas program and the post-school options program are fabulous ideas, as is SAS. I think it was mistakenly considered that people would come to the post-school options program, spend a couple of years there, get all the skills they need and then go and get a job. There was no realisation that the financial and economic reality is that it is very difficult for a person with any disability to get a job. Companies and organisations will not take them on. It is a cost to an organisation—perhaps not a direct money cost but a time cost—to take on people with disabilities.

So the post-school options program expanded and expanded to bursting. It finished and Atlas started. But what is the difference between Atlas and post-school options? Very little description is made available to us. In this last round of Atlas families and organisations did not receive proper information about how it would work or start until November—it was due to start in January the following year. No proper assessments have been made of those people who left school at the end of last year. It is a crisis: put them into a program now and we will assess them at the end of six months. At least they are receiving a service, and those sorts of post-school services really do enrich the lives of adolescents with disabilities.

Our organisation has started a program. We have purchased a building that we are renovating and modifying and we are purchasing equipment. We believe the particular people we are providing the service to who left school at the end of last year need that service. If they are assessed as not needing the service we will have taken a bit of a risk: we have made the investment. The assessment process in July may say, "You only need three of those people; the other five do not need a service", and we cannot make that service viable with three people. Planning and putting resources behind something up front is made very difficult when the planning and resources are not matched by a government process.

Our planning and putting resources behind any program that we run is basically costed to the last cent—that is part of my job—and we ensure that we have the resources. We do a risk management assessment each time and ask, "What is our biggest risk here?" Generally our biggest risk is that the funding will be removed. We have offered services to people and employed, developed and trained staff, bought equipment and in the case of the Atlas program purchased a building with our company funds. It is very difficult for organisations to plan for themselves in order to assist and support people with disabilities when we are unsure of where those resources will come from in the future.

Post-school options was a fantastic program. We have two—we had three but through devolution we received funding for one—residents who left school before a post-school options program existed. There was no funding for those people for any day activity program after school. We fund that through our company. So two adults—men in their thirties—would sit at home watching television or whatever unless there was a program available to them. Through the devolution program, which is a strong benefit to us, we are able to put forward requests for a budget to cover that person's whole life—which includes their day options, not just their accommodation. There are many people who do not have any funding for any activity programs from breakfast until dinner. There are many adults like that. They are starting to do something about school leavers with the post-school options program and Atlas.

The Hon. DOUG MOPPETT: I inferred from your comments that, through devolution at Greystanes, you have accepted the principle that congregative living is inappropriate but you are continuing to provide services by managing residential and procuring other services for most of your former clients and you want to continue that operation. This question may seem uncouth but it is not intended to be. Have any of your clients nominated other service providers and said, "We now feel, if we have the option, that we would prefer to go to some other locality or procure the service from other people"?

Ms RIDDLEY: Certainly. Probably half a dozen families have said to us, "We would really love for you to continue to care for our son or daughter but unfortunately we want them closer to home." At this stage our organisation is not prepared to spread ourselves too thinly geographically, and we are working with those families to arrange other services to provide care and support. Other organisations will certainly provide care and support to our existing residents.

The Hon. DOUG MOPPETT: I assume the opposite applies also: if there are residents of the Hunter Valley whose carers have moved to the Blue Mountains, would you be happy to take on someone who wanted to locate to within your catchment area?

Ms RIDDLEY: Yes. At present we are very happy with the catchment area from Penrith to Lithgow and perhaps Bathurst. We would like to be within about an hour or an hour and a half drive of our existing building from the point of view of proper support—not just to support of our clients but of our staff as well, because they can become pretty isolated at times if they are on their own and feel unsupported. We are very happy with a particular geographic region while we are going through this devolution process. That is quite enough change for us to be taking on in one jump. Into the future, if we identify a need, if we are approached by a family or an organisation to provide a service and if it is viable for our organisation, we would do that outside our very close geographic location. But we are certainly assisting residents to move out of our geographic location and our service and helping others in the local area to move in.

CHAIR: May I ask an uncouth question as well? I suppose I am playing devil's advocate. We have adopted a principle of devolution and your organisation is working through it. If a critic said to you that a group home is really only a mini institution—

Ms RIDDLEY: Which it certainly can be.

CHAIR: What if a critic said if Greystanes, with all the best intentions in the world, is moving to a total of seven or eight group homes and is continuing to provide the majority of support services for those people, have you really devolved?

Ms RIDDLEY: Yes. I understand that thought.

CHAIR: Can you encapsulate the difference?

Ms RIDDLEY: The difference is opportunity, and if the opportunities for client services are not taken up the clients might just as well still be in an institution.

CHAIR: If you are good people running good programs and using your initiative and imagination, is the institution that bad?

Ms RIDDLEY: I would like to think that Greystanes is probably as good an institution as you can get. But you are still waking up every morning and having breakfast with 35 other people. One staff member may be feeding five people at a time. It is hard to give individual attention and focus on an individual when you are responsible for five people who must be on the school bus by 8.30 a.m. You have to get up five people, bath and dress them, feed them and prepare them. It is very hard to spend some conversation time.

CHAIR: Would that not apply also in a group home?

Ms RIDDLEY: Staff ratios are very different. We are negotiating with the department that we would not want more than four residents in any group home and we would have two staff members to four residents at all times—except overnight when there would be one staff member.

CHAIR: It is a much bigger investment in staff.

Ms RIDDLEY: It is a huge investment in staff. It is quality-of-life issue: not getting up in the morning and breakfasting with 35 other people and shovelling spoonfuls into mouth after mouth. I am not denigrating my staff: they do a remarkable job. However, if you have time constraints and people to feed, you will be really pushing that spoon. There are opportunities for an individual room of your own. There are very few single rooms at Greystanes children's home; they are nearly all four or more to a room. They allow for a bit more expression of personal interests. Some young men absolutely adore the Eastern Creek raceway and we could put a couple of them in a vehicle, take them there for few hours and bring them home again. If there is a better staff ration you can cater more completely to individual interests, needs and activities.

As to the notion of packing up a bus with 10 people and taking them on an outing—"Isn't it wonderful they're out of the institution"—if there are 10 people together in wheelchairs it is basically an institution on wheels. If you can take out one or two people it is not an institution on wheels. It is also better for the community to come terms with people in wheelchairs who have quite profound disabilities in their local community. We need acceptance from our local community. It is very confronting to have 10 or so people in wheelchairs who are making lots of funny noises roll up to the local McDonald's. People feel embarrassed and they take their kids home. It is much better to have a sufficient staff ratio for one or two people so that they can be integrated into the community in a manner that is much more acceptable to the local community. That means our local community is lacking in some understanding, but it will never gain that understanding if it is constantly confronted with 10 or 12 people being wheeled out of a big bus.

CHAIR: I knew it was an uncouth question but it is excellent to get your side on the record because we hear a variety of evidence.

Ms RIDDLEY: Staff will make the difference. We have made a heavy investment in training staff, philosophically as well as physically—how do you wash a person, help them with their meals and load them into a wheelchair-accessible vehicle? There is also the philosophical notion: this is an individual with needs of his or her own who likes friendships and emotional support as well as physical support. Any group home can easily become an institution if the staff still think in an institutional manner. That is why there is a very much increased cost associated with running group homes in the way that we are running them over and above the per capita cost of maintaining and supporting a person in an institution.

If those costs are not met then there is no point to deinstitutionalisation because they are then just isolated in a small institution. It is a much more cost-intensive process to give people with disabilities a life in the community. You could easily triple what it costs to run Greystanes Children's Home to provide really good quality care in the community for those people who currently live there. They would get great benefits from it but if that funding resource is not applied to devolution you are creating very small, very isolated institutions in the community. That is all you are doing.

The Hon. IAN WEST: Have you had examples of people who have been devolved, for want of a better word, and who have then decided they want to make another choice and have moved somewhere else? Has that move been easy?

Ms RIDDLEY: I have not had personal experience of that because we are still in the process of our initial devolution. I am trying to think of any other organisation that may have mentioned this to me. I do not have direct experience of that.

The Hon. IAN WEST: So no-one from Greystanes has made any more than one move?

Ms RIDDLEY: Not at this point of time. We are about to go into a 12 monthly review with two families to ensure that that is what they still want. I believe that one of those families will probably say to us, "We need more support and would like now to be talking about shared care rather than complete care here in the family home." It is an evolving process for the family in working out what they can and cannot cope with. It will depend on funding being made available for that person then to be cared for semi-permanently so that we can evolve from being at home with the family to shared care into a particular place, to more time in the particular place than with the family, to eventually permanently within the particular place. It is a sequence, an evolving process. I have not yet had the experience because I have not put the budget up yet for that one to see whether it would be accepted.

The Hon. IAN WEST: Are you saying that the choices will be primarily dictated by funding?

Ms RIDDLEY: It is unfortunate but I think that is correct. A service cannot be offered unless there is a resource to pay for the service. So, yes, funding is important.

The Hon. DOUG MOPPETT: I think that goes a long way to covering question 4 but we do not want to pass over anything that you might wish to comment on. On the limitations of existing models and how services could adapt to better meet the needs, what are the barriers. Would you care to comment more on that?

Ms RIDDLEY: Sitting for 2½ hours on a train gives you an opportunity to think and put a few things to paper. NGOs can adapt better for themselves and many of them are. As I was just talking about, we need to invest in staff training and retention strategies. Turnover of staff is a huge problem for service provision. Your staff is your greatest asset. That is all there is to it. It is about 90 per cent of your costs: 85 to 95 per cent of your total budget will go on staff. It is the staff that will deal on a daily basis with your client that make a difference to the client's life. Staff are just so vitally important. As a whole, we need to look at investing in staff training, staff retention and valuing staff. Hands-on staff in the disability sector are just about the worst paid people in the work force.

They can earn more money as a sandwich hand at the local cafe. The hourly rate that they receive is appalling. Most of their work is permanent part-time. If you are working 20 hours a week at $12 an hour you cannot keep body and soul together: you have to get another job as well. Two or three jobs per staff member is chronic within the disability sector. Therefore staff are tired before they turn up at work. Just trying to make ends meet they have two or three jobs. It is very difficult for that staff member then to provide a good, safe, quality service when they start the shift tired. Investment in staff is a huge thing that we have to do as a sector to provide better service.

CHAIR: The SACS award has not helped a great deal?

Ms RIDDLEY: Not everybody is on the SACS award. For instance, we are not. We get no extra money from the department for our wage increases. Not everybody in the sector is under the SACS award. I think the majority probably are.

CHAIR: What is the arrangement with your staff?

Ms RIDDLEY: Historically, Greystanes Children's Home was a special-purpose nursing home. So it started under a nursing home nurses award. We are moving towards the charitable, aged and community care award. We have got some people under that. At the moment we are developing an enterprise award to try to cover all our staff. We have had quite a few pay increases, the cost of which are absorbed by the organisation.

CHAIR: So you would get no benefit from the Government's contribution to meeting the cost of the SACS award?

Ms RIDDLEY: No. but even if we were under the SACS award our organisation would not get any benefit because we were originally funded by the Commonwealth. My understanding from speaking to colleagues is that anyone who was originally funded by the Commonwealth and moved to the State is not getting the benefit; it is only new organisations that had always been funded by the State, that have been set up by the State—

CHAIR: Because the two levels of government are having a fight as to who is responsible.

Ms RIDDLEY: That is right. Unfortunately, that is a thing that we live with daily. It is not just funding like that; it is responsibility for people with disabilities who are ageing. It is a football between family and community services at the Commonwealth and State levels. The other thing that NGOs could do better is viewing ourselves as a business, not as a charity any more. We need to look at ourselves as a business and run the business part of our organisations as a commercial business. If we do not we are not going to survive. We cannot continue to think in terms of government funding and charity. We really need to start streamlining ourselves and looking for business opportunities and dealing in a businesslike way, and if we cannot offer a service we should not take it on.

Too many organisations take it on because they think they should but then they find that they cannot provide it properly. We need to start doing that, firstly, to be fair to our boards and our existing clients, but also to ensure that government realises the true costs of providing a service. As a business we can choose not to provide that service, which is a very hard thing and I find it very difficult to say no. We need to be really clear about our focus or prime purpose. We need to be very clear with people who we take on for our services: what we will provide and what we are expecting of them. I find that families do not often feel that they have a role. We need to ensure that they understand what their role is—both the emotional family relationship role and also a financial role. We need to have a top-down commitment to quality and then put the resources behind it.

The same with the government: it needs to have a top-down commitment to quality and put the resources behind it. And we always need to be looking for opportunities outside government funding. It is not necessarily government or individuals within the government who make the decision as to how Treasury will spend its money; it is society as a whole. Society will eventually say, "No, we are spending enough on people with disabilities. We want other things now." We have to be aware that there is a limit to funding and we are past just depending on government funding.

CHAIR: So what do you depend on? Do you get much charitable support, donations, bequests?

Ms RIDDLEY: It is very difficult to raise charitable money at the moment. We are moving towards trying to develop services that our company can provide to other non-government organisations and charge a fee, basically.

CHAIR: What sort of services?

Ms RIDDLEY: Consulting in business management, helping people develop plans for devolution, training. We are developing very good skills in training staff to work with people with disabilities. There is planning for writing policies and procedures, writing policies and procedures. We have huge expertise in medical issues for people with disabilities, hiring out some of that expertise. As with everybody, the needs of people with disabilities change. So organisations that have not been dealing with people with medical issues, as the needs of their client base change, suddenly find that they have medical and ageing issues. It is difficult to source ad hoc health and care there so we are looking at providing that sort of ad hoc help and care to other organisations in our local area.

CHAIR: I guess the best and brightest can make an income out of doing that but the people who are not currently the best and brightest can only shell out.

Ms RIDDLEY: And that will be a problem for them. I suppose our organisation has looked at risk management. The risk is that if we fall back only on government money we will not survive. So we have had to look at what we can do and try to be in there early and first so that we are the ones who get the opportunity.

The Hon. DOUG MOPPETT: We have touched on a number of things in question 5. You have talked about the type of support that non-government service providers need from government. You may care to be specific on that and what role DADAHC should have. I think we have talked about medium and longer-term planning and the absence thereof. Could you deal with the consultation process when these innovations come in? We would like you to take as much time as you need to tell us what you would like to see come out of this inquiry.

Ms RIDDLEY: The Government—and we are talking here about Department of Ageing, Disability and Home Care—planning and communication process could help organisations provide the services. A bit more consistency with the people you are dealing with would help. I am sure you are as aware as anybody of the musical chairs at management level of DADAHC. It is very difficult when you have developed a relationship with a particular manager, you have been dealing with an issue, you have developed their understanding of your issue and why you are talking to them about a particular issue and then you ring them the next week to talk to them and there is somebody else in that seat now so you have to start all over again. So lack of consistency of staffing is a difficulty. The things that the Government could provide to the sector as a whole would be perhaps more clear guidance and policy.

There is very little written policy. We specialise in children. The children's policy was being awaited when I arrived 3½ years ago and it is still being awaited. There is no children's policy available to us. We certainly do not want a department to tell us how to run our organisation. And I do not even necessarily want it to prescribe the models that we should be using for care, support or whatever type of service we offer. But it should provide guidelines as to what is available through funding. For example, when we were first devolving the term "whatever it takes" kept coming out. "What are we able to offer the families?" "Absolutely anything. Whatever it takes is what we will offer." In reality, we are down to four-bedroom group homes because that is what the funding will cover. We would much rather have been told up front, "Let's try to put as much innovation and individuality into what we are doing but we are really talking about money that will mean you will have two think about three or four people together." In fact four or five I think we are talking now.

The rhetoric and the philosophy are not backed up by the dollars. It is much better if we have the honesty up front so that we do not mislead families. That sort of guidance would help organisations. Regular and honest communication, some of it written, would be good. Most of it is on the telephone and it is very hard to say to the next person who steps into the shoes of your previous correspondent that so and so told me this and then you are told that it is not policy and you cannot have it. Something in writing would be useful occasionally. Another thing is understanding of our timeframes. With our service development plans that go to the department—we are as guilty of this as anybody—it takes us a long-time sometimes and we are late and slow in getting service development plans in, as are all organisations. But from the time a service development plan is approved there is about a 16-week lag for an accommodation service for people that we support.

Firstly, we have to just buy a vehicle and have it modified. It takes about 16 weeks so you cannot just get your approval one day and the next week you can open the service. We have quite long time lags. With advertising, recruiting and training staff it takes quite a while to get those things in place. We have taken a position that we will not put the staff into the service without adequate training. Sometimes that is up to three weeks of full-time training before we will put them into the service. So there is a long time lag between getting our approval and actually opening the service. More communication between the department and service providers and a better understanding of that time lag would be helpful.

These are very simple things, like saying, "We have not approved your whole service development plan, but we realise you will have to have a vehicle that is wheelchair accessible, so we will approve the order of that vehicle now and then go through the process of approving the rest of it as we go along." If you cannot order the vehicle until you get the service development plan approved, you are delayed for about 16 weeks. On many occasions we have bitten the bullet and ordered the vehicles, but if the approval of the service development plan is slow—which it frequently is—we are stuck with paying for that vehicle and being reimbursed by the Government later. We take that risk. We order it to make sure we have the vehicles available on time. For people with the level of disability that we support, very specialist hoisting equipment and so on is needed. It comes from Sweden, and it has to be ordered a long time in advance. So we order that equipment and take the risk.

Other things that the Government could help non-government organisations with is streamlining approval processes. Basically, they go through about seven or eight levels, and then have to go to the Minister's office. You can never find out where it is in the process. Getting feedback is difficult. I am sure people in the department would be delighted to have their approval process streamlined. But getting those sorts of things through the level of approval takes forever. And if someone is on three weeks holidays, the application sits on their desks until they come back, before going on to the next level. It is a very cumbersome process.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Would not that be tracked by a service access system? It is not a person system, but it is a service being tracked. In the end, that service will have to match with some of the people on that database, will it not?

Ms RIDDLEY: The service access system truly is only working with people in crisis. It is not providing any other planning service for people with disabilities.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Have there been outputs of it? Has there been any collated data?

The Hon. DOUG MOPPETT: I think at this stage we should resist the temptation to join in interlocution. In view of the time, I think we should ask you to address the Committee with your concluding remarks. If there is anything left over that you would like to submit, we would like to hear from you.

Ms RIDDLEY: I may send something in writing. What we would like to see come from this inquiry of the standing committee would be an acknowledgement that the whole disability area requires long-term planning. It does not benefit from ad hoc responses to either political pressures or advocacy group pressures. For the service to be delivered well, the community as a whole needs to understand the true costs and decide whether that is what we are prepared to pay, because this requires a very large financial commitment on the part of the State and therefore the people of the State. We would like an acknowledgement that perhaps we need to start from scratch and not keep putting the bandaids on. We need really good long-term planning.

If things arise that happen to be noisy and peripheral, we would like the Government to have the courage to say, "No, we're not going to deal with that," rather than moving resources to deal with the noisy things, leaving long-term basic needs not taken care of. I would hope also that there is an acknowledgement that there are some extraordinarily good people in this field in both the government and non-government sector but that processes and departmental structures in some cases get in the way of good people doing a good job. There is probably not much more than I want to say. We have had a few crises at work, and until I was coming down in that train today I had not realised how much I had to say to the Committee. So I might put something in writing and send that to you.

The Hon. DOUG MOPPETT: That would be good. Nevertheless, your comments about planning are profound. We recognise that. But you would appreciate they join with great resonance other evidence we have had. If nothing else came out of it, you could be very proud of the fact that we have in some small way instigated long-term planning that was not only available to the department but was publicly known as well.

The Hon. IAN WEST: In your written submissions, could you include some information about staffing in June 2000 and staffing now, and what the turnover has been?

Ms RIDDLEY: When I first went to the Greystanes Children's Home, which was at the end of January 1999, we had 55 staff. By June 2000 would probably had about 65 staff. Last week I paid 95 staff. That is only with two group homes opened.

CHAIR: Is that a full-time equivalent?

Ms RIDDLEY: No, that is not a full-time equivalent. I can do some of those full-time equivalent calculations for you.

The Hon. IAN WEST: I am thinking about people who were there in June 2000 and how many of those are still there now.

Ms RIDDLEY: I can provide some of that information for you.

CHAIR: There may be other things that you might like to say, and if there are we would be delighted to receive that. If you look at your notes and think that you ran out of time and did not get a chance to develop a point, you could provide that further information to the Committee. I return to my original statement about how grateful we are that you came and talked to us. We wanted you to talk to us because we thought here is a case study, here is a discreet example on which we can actually do a bit of measurement of this example of devolution. This is right in the middle of Government announcements. This gives us the chance to test some of what we are told in theory. If there are more examples of you being able to say this is what has happened at Greystanes, we would appreciate that.

Ms RIDDLEY: I would be delighted to do that. Do you have a timeframe by which you would require something like that?

CHAIR: Perhaps the third week of May. We are trying to finish the report by early June.

Ms RIDDLEY: April is utterly impossible but early May enables me to start on something like that.

The Hon. DOUG MOPPETT: Ms Riddley, our thanks, no matter how profuse, are beside what is owed to you by the people in the disability sector for your courage in coming forward and putting it on the line.

Ms RIDDLEY: Thank you.

(The witness withdrew)

ALAN JOHN KIRKLAND, Director, Council of Social Service of New South Wales, 66 Albion Street, Surry Hills, and

CHRISTINE ANN REGAN, Policy Officer, Council of the Social Service of New South Wales, 66 Albion Street, Surry Hills, affirmed and examined:

The Hon. DOUG MOPPETT: Did you each receive the summons to appear before the Committee?

ALL WITNESSES: Yes.

The Hon. DOUG MOPPETT: Are you conversant with the terms of reference for this inquiry?

ALL WITNESSES: Yes.

The Hon. DOUG MOPPETT: In what capacity are you appearing before the Committee?

Ms REGAN: As senior policy officer at the Council of Social Service of New South Wales [NCOSS], in the areas of older people, people with disabilities and community care.

Mr KIRKLAND: I appear before the Committee as Director of NCOSS.

The Hon. DOUG MOPPETT: If at any stage you feel that evidence you believe may be of value to the Committee should be confidential, you have only to so signify and we will take appropriate measures to ensure that it is confidential to the Committee. Would you like to make an introductory statement before we move to the questions?

Mr KIRKLAND: I would refer members of the Committee to our pre-budget submission for the upcoming State budget. That submission did address in some detail some issues regarding unmet demand. We have brought sufficient copies for members of the Committee. We will be referring to some parts of that submission and I merely refer the Committee to the more detailed work that is in it.

The Hon. DOUG MOPPETT: That is a great starting point. There are five heads of areas in which we have had some concerns with this inquiry. I am sure you have followed that up through our reports and so on. They are the notorious group homes project, the transfer of auspice, unmet need, respite care and attendant reform, but of course the devolution of residential centres and the recently introduced service access systems. Those are all matters of vital interest to us. We would like your comments on where you think all of those items are up to.

Ms REGAN: On the group homes project, as we predicted, we think the vast majority of people who are captured by the initial phase—which is the only phase that we are now talking about, the group homes project—have elected to stay in government-provided services. However, NCOSS believes there have been very few movements up until now. It is very difficult to get from the department exactly how many people have moved to a new form of accommodation, but we believe it to be 10 or less. That is an amazing target given that there were absolute guarantees of movements after the announcement in May 1999 that the 217 people would be moved by the end of December 1999. We knew that that was totally unachievable. It did not provide for the dignity of access and understanding of the people involved in that move.

However, we would be concerned that for those people who did nominate that they would like a change of circumstances the rollout has been very slow. There has been a group of disability peaks and other interest organisations who have been meeting with the department. The department has been discussing with us the progress of the group homes transfer. Those meetings have been spasmodic at best. They began quite well; there was quite good reporting. The last few meetings have been postponed. After the very last meeting—which, unfortunately, we were not allowed to attend—delegates reported back to us of their frustrations in trying to get information from the department. There seems to have been a gentle closing of information on that front. That is disappointing because people have taken an active interest in the group homes project in an advocacy role for the people and families most affected by that. That is probably as far as we would want to go on the group homes project at this point.

The next point was the provision of permanent accommodation to address unmet need. We welcome new money in the past couple of years and congratulate the Committee on some of the work it has been doing and the reports it has been providing, because we are sure that has triggered a much more generous Government response. However, as you have heard from the previous speaker and no doubt other speakers today, there remains a huge unmet need in disability accommodation. We are not just talking about crisis, we are talking about medium and longer-term planned accommodation; certainties for families as well as certainty for people with disabilities. The money that has come into the system is very welcome. The rollout of that money, as demonstrated probably by the group home project, has been unbelievably slow. That might be because the department has been coping with many internal changes and also with systems that have unrealistic timeframes in the first instance that have been adhered to at almost all costs from within the department but then failed, and then there was damage control. Had that time been planned from the beginning, possibly better outcomes could have been achieved within a more reasonable predicted time frame.

Under permanent accommodation to address unmet need, again referring to previous submissions that NCOSS has put before this Committee, we say there is a desperate need for planned life stages of accommodation for people with disabilities—not waiting until the families are very old or in crisis, not waiting until other crises occur or there is a serious or unexpected deterioration in health conditions, basically looking at a person and seeing what their likely life stages will be and what sorts of support those people are likely to need. That is knowing that every person with a disability does not need the same degree of support, nor does every person with a disability need support. It would be up to those people to nominate to what degree they need support and how that might be provided. When that is only left to crisis, that leads to a very high cost, less responsive option and problems with compatibility and placement.

At this point we refer to Mr West's comments on what are the opportunities for people after a first placement to then move on to other alternative placements. NCOSS is constantly concerned about the inability of a person once placed after some kind of dramatic life circumstance to then find a more appropriate accommodation option. Just like you and I, we might move out of home, which is a life transition, and go into a shared house and find that does not work. We decide to find someone we love and live with them, and that works or it does not work, and we may move on to living alone. People with disabilities have the same changes and needs to settle after a life transition. Often, once a person has reached a crisis and been settled after that crisis, they are considered to be no longer part of the process—that is a done deal. There is very little opportunity for that person to then find a more appropriate service provision within a guaranteed period, unless they re-enter under crisis, of course.

Again, we probably refer you to our prebudget submission, which also talks about accommodation unmet need and our previous comments on policy to support that unmet need that we put before the Committee. On the issue of respite reform, Alan and I have decided that probably we are not the experts in respite reform and would prefer to put no comment before the Committee. But, we would suggest perhaps that the Committee could ask some probing questions of any government representative you seek to provide evidence on the issue of respite reform and any plans to meet continued unmet needs in permanent and long-term accommodation.

CHAIR: Do you have in mind factual sorts of questions about how many extra places have been made available, or do you have in mind more systemic questions?

Ms REGAN: Probably more systemic questions, but you will notice in our prebudget submission we have put a target for respite, and that is dependent on funding for next year. This year's prebudget submission looks different from our previous prebudget submissions—and this Committee has now seen three—in that this year we reduce the number of recommendations we made in order to be much more strategic about what we hope the Government might provide at the base option in one year's funding, rather than providing a shopping list of anything that can be picked from. That was a decision that Alan brought with him under the new arrangement. We hope that will improve our contributions to policy development as well as be much more strategic.

CHAIR: So you probably want to put on the record that you made a recommendation for an additional 400 flexible respite packages?

Ms REGAN: In one year. You might note the comments that precede that, about the flowing on and the development of respite places. Regarding devolution of large residential centres, we continue to concur with the view of the Community Services Commission that the devolution could be accelerated and that the target of 400 places for the year 2004 is unlikely to be met. Again, that would be for the Committee to put that question to a government representative, who might provide more answers on that. But there is a lack of confidence within the disability sector that the first 400 places will be completed by 2004, remembering that depending on what day it is and how you count, there could be between 2,000 and 2,300 people waiting for devolution which is supposed to be completed by 2010.

So there is real concern that if that target is met, only 400 people will have moved by the mid term of that plan. We believe there should be an overall plan to require completion of devolution by 2010. We know there is a plan for phase one, which is about the 400 people at 2004. We have heard Margaret Alison say that one of her priorities will be the development of phase two of the plan which, hopefully, will see the completion of devolution by 2010. We have yet to see that plan and we are looking for results in order to maintain community confidence in the devolution process.

CHAIR: It has been recently brought to my attention that families and advocates and others associated with people living at Stockton have, in a sense, renewed their opposition to devolution. I wonder whether you have any comment to make on, firstly, the way the long time frame has an impact on the reaction of residents and families?

Ms REGAN: The NCOSS position continues to be whether or not that is an informed choice. What NCOSS would continue to support are the opportunities to access informed choices from a range of service provisions for a person with a disability. So, you do not categorise a person because of the diagnosis or condition; you investigate and assess the person according to the level of functioning, their needs, their interests and their values, and what opportunities they might choose. We would say that people who continued to choose large residential institutions—

CHAIR: Stockton is the biggest of them all—

Ms REGAN: Might not have any certainty or confidence in a community-provided system, and they also possibly have no good experience of any successes within that system. Personally, in my non-NCOSS role I come into contact in my local area with community service providers and some government providers at the local level, where there has been huge success in providing to people who have come out of long-term institutionalisation. The people often blossom, they find their own skills, they need less support sometimes, but certainly their quality of life is incomparably better than it was in the institutional setting. I am very concerned for the parents of Stockton who feel that their safety and protection cannot be maintained in a less restrictive environment.

Mr KIRKLAND: As the process rolls on, if it does roll on, that will give people confidence in the outcome of devolution and we are bound to see people's views change during that long-term process. The more success we see the more likely people will understand what it really means.

CHAIR: The service access system?

Ms REGAN: We support the comments of the previous speaker. Again, I cannot stress this enough, generally the disability sector seems to think that the service access system is a really good idea. The implementation of the service access system has been less than wonderful. There are huge problems. We would say that there is gigantic demand. It was unanticipated by the now DADAHC but certainly it was predicted by the disability sector and predicted to this Committee at our first hearing. There is no opportunity for families to register their future needs in the absence of any general intake system. Again, NCOSS has been saying that it is really good that there is a service access system that can respond to crisis. It is absolutely essential, a good way to go, a good first start, but there is no way for families to register an ongoing need or a future need in order to build up confidence and certainty in knowing there will be support as the time comes. We are also finding the service access system applications inflated by people who are using it for future needs, and NCOSS would believe legitimately so.

CHAIR: Do you know whether the system is proving able to work out whether some of the applications are those people who are terrified for the future? Is the system proving itself capable of distinguishing that?

Ms REGAN: I do not feel that we would be expert in answering that, but reports to us are that where the SAS system has delivered options, those options have been acceptable because the process is a good one. The bureaucratic handling of approvals is disruptive for families and is extended and, NCOSS would argue, unnecessary. I know it has to pass through the hands of several bureaucrats. Why that happens we are not sure. One other thing is, we also have reports of varying definitions of crisis, depending on how you enter the system, when you enter the system and who helps you enter it. That should not be a consideration under the service access system that responds to crisis. Either you are in crisis or you are not, according to their own definitions.

Also, the service access system has been seen as a panacea of all problems. So, we are finding that people coming out of contact with the criminal justice system are seeing the service access system as the way into a support system, and people with chronic health problems, for example, and mental health problems as well. To its credit, the department is starting to filter where people are entering the system, however, in the absence of a general intake system, where do they go? What happens next for them? If there is not an overall disability plan for the development of services and infrastructure and responses for people with disability in whatever way they enter the system, how can these things happen unless there are designated programs for every single life circumstance.

Again, we draw you to our first and second submissions to this inquiry. Both talked about what we called a disability policy framework and what we have reframed in our prebudget submission as a disability policy plan, so that we do not get mixed up with all the framework language all over the place. As you will appreciate, some kind of sequential development through the life stages for a person with a disability can engender some certainty and some joint participation responsibility for the person with a disability and their families in a support system as they enter it.

We support a streamlining of the approval process. We also support government undertakings as part of the service access system—in other words, not only are service providers within the service access system required to meet specific time frames; it would be good within an overall service access system that manages the perceptions of its clients for a government or a department to say, "We will provide you with an approval within X amount of time", rather than just have rolling uncertainty about certain cases. The other thing that we would be concerned about is the interim funding under the service access system. As we have told you before, we applaud the short-term funding that can get people out of absolute abject crisis. But that has been used as a stop gap in trying to get people onto more permanent plans. We think that it really needs to be allocated for its original purpose, which is to deal with immediate crises as they present.

CHAIR: You have really covered the field in the first question. You may find that you have already partly answered some of the other questions. You can always get back to us in writing if you want to draw things to our attention

Ms REGAN: Thank you for the opportunity to talk about two new projects which we have not previously spoken about with this Committee, but to which we alluded in our previous appearance before the Committee. The first one I will talk about is the issue of younger people in nursing homes. I have before me Commonwealth evidence that there are 1,800 people, who are younger than 65 but over 50, who live in residential aged care in New South Wales. I have evidence from Senator Chris Evans' office that states that more than 450 people who are younger than 50—between 18 and 50—live in residential aged care. I might take a moment to tell you what a day in the life of a younger person with a disability might be like in a residential aged care facility.

The beds in residential aged care facilities are planned, through business plans, to turn over at between six months and two years. So that means that you might be a younger person with a disability, who is not unhealthy but needing intensive nursing care, and you might live for 20 or 30 years—we do not know how long—in a residential aged care facility. All the people with whom you make personal or close relationships die on a regular basis. Also, the residential aged care facilities are required to provide maintenance and support for the people who live there. You are familiar with the provisions of the Disability Services Act, which actually state that a person with a disability should be entitled to development to their optimum potential and to also be given the same life opportunities as people without disabilities of the same age, regardless of their disability. That cannot be provided in a residential aged care facility.

What I would like to report to you today is that a group of concerned advocacy and other organisations have been meeting now for two years to develop some solutions to the problem. Our bottom line is that we do not believe people under 65 with disabilities should live in residential aged care facilities. That is our bottom line. We are most concerned, however, at the number of people with disabilities who are under 50 and who are in residential aged care.

CHAIR: Can you tell us who they are? We have had evidence about people with multiple sclerosis and people with certain kinds of profound physical disabilities. Is it possible to divide those 450 people into categories?

Ms REGAN: No. Probably the evidence that has been provided to you would be the evidence that we would know. What we do know about those people is the level of support that each one receives.

CHAIR: Would you be including acquired brain damage?

Ms REGAN: Yes, we do.

CHAIR: Presumably quite a lot of them would be in that category—people who have been involved in motor accidents, et cetera?

Ms REGAN: That is right. The four people that we are talking about are people with intellectual disabilities who entered, possibly with a family member, and for whom there was no other care option. The Commonwealth provided money some years ago under the 325 program to release people with intellectual disabilities from residential aged care back into alternative, more appropriate accommodation. So the Commonwealth believes that that job is done. However, that was 10 years ago. In the intervening decade the numbers of people with deteriorating neurological conditions, with severe physical conditions and also with acquired brain injury, have absolutely sky-rocketed. The support options for those people are limited at best. It is very important to remember—and you have heard from the Brain Injury Association—that a very small percentage of people with acquired brain injury are compensable, unlike popular conceptions where people think that, if you have a brain injury, you have actually received compensation. That is actually not the case.

So what we need, as a group of concerned people and organisations, is some kind of way through the Commonwealth-State nexus, as well as devising appropriate support options. We know that, in New South Wales, more than 456 people with the same degree of need as those people who live in nursing homes and hostels do not live in nursing homes and hostels. How are they supported? What we need to do is extend those kinds of options to the people who are now inappropriately in nursing homes and with no future option. It is important also to know that the service access system will not respond to people who live in nursing homes because they are not considered in crisis. Where are we up to? We are about to write an issues paper that sets out philosophically, emotionally and strategically the issue that I have described to you.

We have been working for two years and we cannot come up with the solutions, unless there is goodwill to solve the Commonwealth-State nexus on this issue. It is impossible for community people to go further because we continue to hit a brick wall. What we are looking for now is government partnerships at all levels in order to find some solution to this and to find appropriate care options for people who are now in residential aged care.

CHAIR: You referred to the Commonwealth-State issue. From the State's point of view, if someone is in a nursing home, it is the Commonwealth's responsibility?

Ms REGAN: The Commonwealth has actually said that, once you are a person with a disability, it is likely that you should always be treated as a person with a disability, therefore, the State has the major responsibility. We know that the mix of people with disabilities in residential aged care facilities can be uncomfortable and discordant. That is another issue that I will talk about in our next project. Basically, the services are not there. But again, it is a question of who is going to pay for the supports that need to be provided to these people. If they are already in the system, does that system retain responsibility for continuing to pay? If they are not in the system, or they are new, how do we find resources to meet their needs? That is clearly a Commonwealth-State issue. We want to know the admissions policy too, as we put the supports in place. That is the issue involving younger people in nursing homes.

The other issue that NCOSS has been vigorously working on, especially since late last year, is the industry group on people with disabilities—people with long-standing disabilities who are ageing. What do we do with people with disabilities who are now reaching retirement? We have no answers and we know that there is no planned service option at this point. We know that the department has a position called transition planner. We are not exactly sure where that was going. We experienced some frustration in trying to find out what the plan for that position would be, although we believe that the work of that worker is probably excellent. We decided to do something as an industry group. You will see that the three partners are the Australian Council for Rehabilitation of the Disabled, the Aged and Community Services Association and NCOSS.

Our issues paper sets out philosophically, strategically and environmentally the types of people that we are talking about and the numbers we are talking about. This is an emerging group. So people with disabilities are reaching the retirement stage of their lives for the first time in humankind in any numbers. What do we offer them? How do we go forward with service provision? It is also quite evident from our research that people with disabilities probably reach retirement age at a much earlier chronological age than people without disabilities. So again, how do we respond? How do they get access to aged care services that you and I would expect to access depending on our need? Are they the most appropriate services?

Are there other service options, or is there a mix of service responses that should be developed? Our issues paper is by no means definitive but it clearly canvasses the issues. We know that there are some good innovative responses happening but they are isolated and small. We want to find out what the success of those projects are in order to develop a final report that we can put before Government, hopefully, towards the end of this year which will describe not only preferred and leading practice models but also opportunities for training and opportunities for program responses.

Motion by the Hon. Dr Arthur Chesterfield-Evans agreed to:

That the documents be tabled.

Ms REGAN: We have already done a first response to our survey. The survey has only gone to service providers, and that was very deliberate.

CHAIR: That is the survey in the back of the document?

Ms REGAN: That is right. What has been copied is our first cut response summary. What we are finding is that there is a lack of dollars to respond to this. We knew that because it is an emerging population anyway and there are no programs that will deliberately respond. Mixed and collaborative efforts are the best way to resolve these issues. A deliberate joining and interface of Commonwealth-State programs also looks like providing the best options for people with disabilities as they grow older. What we would like to tell you, however, is that we think our consultation process is incomplete. So we are now negotiating with the department to run two workshops, one of which will again be with service providers only.

After we get the results of that we hope to run one with consumer agencies that will comment not only on our original documents but also on the responses of service providers so that we get, as our last comments, the comments of the people who are most likely to use and benefit from the services so that we can get our philosophy and service responses right. I tabled those documents to let you know that this work is being done by the community. We hope that there would be a partnership with and support from the department in the work that we are doing. One thing that we are finding, though, is that neither of these projects, up to this point, has received any government funding. Without designated research, as identified in some of our findings, we cannot go forward. So that will also be a good opportunity for the Committee to suggest some research and some further development of these issues.

CHAIR: Are any departmental people involved in your working groups, your consultations or your preparation of any of these things?

Ms REGAN: Not at this stage. So those are the two exciting issues that we are putting before the Committee.

CHAIR: Well done. They are certainly ones that have been mentioned to us, on and off, since we started this inquiry. They have probably been mentioned more in the tone of, "We do not know what to do. We can all feel this problem growing, but no-one is looking at it." So it is good that someone is looking at it.

Ms REGAN: We are now.

Mr KIRKLAND: I move on to the third question. I comment on the issue of day programs and, in particular, the ATLAS program. The Committee would be aware that the Adult Training, Learning and Support program [ATLAS] replaced the post-school options program. The intention was that ATLAS would be a two-year program. I guess that the department has not reached the point where it can really work out what happens to people when they exit that program. There was a review of day programs last year but that has not been released. It is important that that is released soon so that the options that come out of that can be debated. I guess the department really needs to engage community sector organisations in talking about how the ATLAS program develops from here. One of the issues that we put forward is that some of the premises of the ATLAS program may not be well-founded.

The premise that, after two years, post-school, all participants will move into the open labour market or into some form of employment may be unrealistic. While it might be desirable for people to exit that immediate post-school program, they may need to exit into something other than full-time employment, given their particular disability and the realities of the labour market. We think it is pretty important in terms of certainty for clients and their families that the department engages community sector organisations in talking about what happens to that program fairly quickly. Undoubtedly, that will require additional funding as well.

We would also touch on disability advocacy services. We note that the additional $1 million that the department had announced for individual advocacy has been allocated—that was announced last Friday. Obviously we are very pleased that the department backed away from its plans to use the competitive tendering process in relation to the overall disability advocacy program and, instead, is engaged in a process over several years of talking to the community sector about the future of that program, disability advocacy and information services. We are currently talking to the department about how those discussions will happen. We urge the Committee to recommend that the department continue that process of talking to community sector organisations about the future of the program and about the future processes for allocating resources.

As for the role of the government and non-government sectors, there are many strengths that non-government organisations bring as service providers. In particular, they allow for decisions about individual people and their services to be made closer to the ground and closer to the client, which tends to mean better quality decisions. It means better responsiveness, more flexibility, quicker responses and greater capacity for innovation. The other things that non-government providers bring are greater opportunities for community participation and participation of clients' families and other community members in the management of services and in decisions. A particular strength is around cultural appropriateness, particularly for Aboriginal and Torres Strait Islander communities and for some non-English speaking background communities where there may be a history of poor trust of government agencies.

Non-government organisations can get around some of those trust barriers as well as providing opportunities for particular communities to have a strong say in how services are developed and managed, which is important in terms of developing culturally appropriate services. Having said that, and supporting generally a strong role for non-government providers, we will continue to argue that government still has a role as a provider of last resort. It is absolutely crucial that there are government services to meet the needs of people who, for whatever reason, are unable to find a place in a non-government service system. It is absolutely crucial that government continues to provide that safety net. What that safety net is and how big it is will change over time but we cannot see that need disappearing in the near future.

One flow-on from an increased role for non-government service providers is that, perhaps in contrast to the views of the previous witness, the Government needs to acknowledge the full costs of service delivery and to fund the full cost of service delivery. Essentially, non-government providers are delivering essential community services which are necessary in order to have an equitable society. That means that those services should be seen as other core services and should be funded to their full core costs. That includes the operating costs of organisations that are necessary in order to have a service infrastructure. That has been acknowledged in some ways by the Government's decision to provide additional funding to meet the costs of the new SACs award. While many organisations have received increased funding as a result of that decision, the rest of their funding base in some types of organisations and services is still provided on the basis that the Government merely makes a contribution to the cost of services, rather than funding the full costs.

We think there is a contradiction at the moment in that we are told that government agencies have moved to a purchasing model of services as opposed to the traditional funding model. Our argument will be that the logical extension of a purchasing model is that you pay for what you buy. That is not the case, so we see a logical contradiction between the Government saying that it is purchasing services but not contributing the full costs of those services. Therefore, we would argue that as part of articulating its approach the Government needs to recognise the full costs of delivering all types of services, particularly disability accommodation support services, which are very high-cost services compared to many other types of community services.

CHAIR: Can I just clarify one comment you made? I think you said you see a continuing role for government as a provider of last resort.

Mr KIRKLAND: Yes.

CHAIR: Sometimes that language is used to suggest a residual role. For instance, it was sometimes used during the debate about the group homes project to suggest that maybe people with a lower level of need might be more appropriately cared for in the non-government sector but that government had to be there as a safety net. Is that what you mean, or do you mean that you are fairly relaxed about the mix as long as the Government stays in it?

Mr KIRKLAND: It is probably slightly different. The Government should be actively seeking to encourage non-government providers to play a role for people with all levels of need. We should not see the Government as being the provider for people with extremely high needs. Government should be seeking to develop high-quality services in the non-government sector for people across that spectrum of need and across different types of disability. Having said that, the process of funding non-government organisations is a process of negotiation. In order for the full range of services to be delivered, there needs to be a full range of providers that are willing to take on those services. We must recognise that there will be occasions when it is not possible to meet all those needs through the non-government sector so government needs to be prepared to step in and provide services for people whose needs cannot be met by the existing mix of services at any point in time. But we should not be designating that role at the outset for particular types of people or for particular types of needs.

CHAIR: So you are fairly relaxed about where the boundaries happen to fall. It is a matter of looking after the needs in both government and non-government providers.

Mr KIRKLAND: Yes.

Ms REGAN: Just in support of those comments, the response of NCOSS to the reconfiguring of the new super department was that we think there was a recognised lack of expertise in only a purchasing arm within ADD. Now that there is a provision arm as well, we hope that the expertise of being able to purchase and understand the services that are being purchased will improve. Therefore, the way in which services are purchased from the non-government sector will be informed by the fact that government is providing those services and understanding what it takes to provide those services. Therefore we were supportive of having two provider arms and one purchasing arm under the new department of ageing, disability and home care.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Can I just clarify that? It always seems to me that if you have a gap between what somebody wants and someone else purchasing it, presumably because of their expertise in negotiation or whatever, you still have a step in which the person who is buying a service does not know what he is buying, fundamentally. That makes it difficult, whatever negotiating skills they have in terms of bringing the price down, if they do not know what they are buying. You are saying that you approve of the model where the buyer is not the person specifying. Is that not a bit of a worry?

Mr KIRKLAND: That is not what we said. What we said is that we see a logical contradiction in the Government on one hand saying that it is purchasing services and on the other hand saying that it will not pay the full costs of those services.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I took that previous point which basically means we are saying we are bullies so we will get a discount. You have to meet 15 per cent of the cost and we will buy it at 85 per cent of the cost or whatever percentage is thought to be fair. In a sense, it is a partial subsidy if you look at it in terms of a service provision.

Mr KIRKLAND: It is often described as a contribution rather than a grant or a full purchase of services. It is often described as a contribution to the cost although we are supposedly operating within a purchasing framework. I guess the argument would be that historically organisations have managed to meet other costs through fundraising and other sources of income. However, I support the comments of the previous witness to the effect that those sources of income are drying up and it is becoming increasingly difficult to maintain those streams of income from fundraising.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The charitable sector cannot cope. I gather what you are saying in terms of the difference between purchases and specifying, if you want to call it that, was that that was when ADD or PADP was buying things.

Ms REGAN: That is right.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: And the person buying it may not understand what he is buying.

Ms REGAN: Exactly. That is why NCOSS has said from the beginning that we do not believe that competition and pure market principles applied to human services deliver the best outcomes for the clients, and we continue not to believe that.

CHAIR: Predetermined models, innovation and flexibility.

Mr KIRKLAND: Service outputs specified in funding agreements are often quite rigidly defined and do not facilitate flexibility and innovation in service delivery. While we understand the move to outputs and outcome-based funding and the need to measure outputs and outcomes, there are different ways of doing that. You do not need to specify the outputs up front but you can specify a suite of possible outputs against which an organisation will report, depending on the responses that are appropriate to the clients they are dealing with at a point in time. So rather than specifying the particular numbers of particular types of outputs at the beginning of a funding period, it is possible to identify a range of outputs and measures for the program. The outputs against which, within that suite, a particular organisation will report can then be based on client need, which would allow greater flexibility. We would encourage the department to move towards a more flexible approach to specifying outputs in funding agreements and that would facilitate more flexible responses. The other issue in response to that question, which I think has come up here before, is the mix between individual packages and a funded service infrastructure.

CHAIR: The Community Services Commissioner said quite a lot about that this morning.

Mr KIRKLAND: NCOSS has spoken about it before. Briefly, there needs to be a mix. Packages are probably most appropriate for people with high needs and high costs. But in order to have a good system you also need to have a service infrastructure. So to go entirely down the route of packages would be counterproductive. There needs to be a strong role within the overall system for funding the service infrastructure. We continue to say that packages are probably more appropriate for people with very high needs.

CHAIR: So you do not agree with those people who argue that the only real way to get innovation and flexibility is via individual packages.

Mr KIRKLAND: No, we do not.

CHAIR: Do you see them as almost acting like a ginger group or do you see them as meeting the needs of some families?

Ms REGAN: Perhaps we should specify what we mean by individual packages. In one of our submissions to both the reform of the Disability Services Act and also here we described how a package is considered by some government authorities—the difference between Commonwealth and State—and how the services view the difference between packages. A package might be an amount of money that is allocated for a specified individual. That money goes to a third party to manage the expenditure of that according to the needs of the person or the service plan, however that was organised. A package might also be an allocated amount of money that does not have a specified client at the point of allocation, and that is handed to a service provider who then finds the clients, because the demand is known. This is the sort of thing that happens in ATLAS or post-school options. That money then attaches to the identified client but when that client goes they may or may not use that package in another service. So it depends on the circumstances. Then there is the infrastructure so that some services are provided with input funding to be able to provide many outputs.

We absolutely support the disability sector in its quest for increased disability packages because they clearly meet the needs in a much more effective and efficient way. But our absolute premise would be also paying attention to disability service infrastructure, simply because packages are very high cost. They also identify a specified number of people. We also find that the added value that a receptive disability service infrastructure can provide would be to groups of people at the medium to lower end of the disability spectrum who might miss out entirely on packages. That is the kind of mix that Alan was trying to describe to you.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You are you assuming that everyone would not have a package and, therefore, you have to have some infrastructure, is that so? If everyone had a package then infrastructure that could not get clients to put their package into using that infrastructure surely would justifiably go out of business? Have you have a day-care facility or a home that no-one wanted to go into or stay in, surely that is a way of saying that, obviously, this is not much good. Admittedly, it might need to have a critical mass in an area where, if it did not have a certain number of people, it would go broke and the people who wanted to use it would miss out. I think you could justify maintaining infrastructure in that situation. But, on the other hand, if it is not able to sell services when there are enough people with packages, surely it should be allowed to wither.

Ms REGAN: If we were in a market where there was absolute informed choice, that would be a reasonable operating procedure. Given that we do not have that, that people are actually channelled to services, and also in many cases we do not have critical mass either geographically or by service type or degree of need or support, the difficulty is that we do not have informed choice whereby I, as a consumer, can choose to go to you Arthur or you Jan, and I pick the best. Now you go to the one that has the place open for you. Perhaps as the system develops we might then review the way in which we would present that. Certainly, for the foreseeable future, there remains serious unmet need within the disability sector and we will continue to pressure the government to put designated investment into disability services. We need that investment in disability infrastructure, as well as packages that respond to people.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Certainly, but a lot of people have said, "We say we want apples. They say that there are no apples, have oranges or nothing." Obviously the danger is if you maintain infrastructure with critical masses and involving critical amounts of money, you will get the situation where you will never have any apples, you will only ever have oranges.

Ms REGAN: That goes to devolution and also goes to service monitoring, which we have reported on to this Committee in the past, where there is an absolute government responsibility to ensure that services are meeting people's needs—not just the needs that might be suggested to people, but the needs that people themselves suggest. That is the critical difference. Also, there needs to be a certain standard of service and a certain responsiveness from the service viewpoint. In the past we have made comments on the monitoring of services.

CHAIR: I think you have probably answer to the most of the next question, on the need for medium-term and long-term planning. It was certainly implicit in your answer to the first question about each of the different aspects of disability services. You probably have more to say to wrap it up.

Ms REGAN: Probably we could leave it there, but the second part of that question is something we would be keen to remind the Committee that we have been saying from the outset of this Committee's inquiry that there is an absolute need and it is absolutely essential that the government has a disability policy plan that will bring it all together. The Hon. Dr Arthur Chesterfield-Evans's comments were spot on. While all the service provision is compartmentalised we will never get a flow, choice or responsiveness that packages can provide, should they be provided en masse. If we can have a plan that reduces the boundaries and limitations between funding, we could certainly move forward. NCOSS believes that in disability policy plan would go some way to creating that kind of situation.

We believe that the changes to the government's planning process, whereby it is now planning for all the needs of older people and of people with disabilities, rather than by program, is a step in the right direction. The implementation of some of that planning, however, has been problematic and we might talk about that very quickly in answer to question 7. The idea of deciding to plan for disability, rather than planning for HACC or for accommodation gives an opportunity to create that transition-in-life planning that is a critical and that the Committee has heard so much about.

CHAIR: What do you have to say about DADIC and its community and consultation processes?

Mr KIRKLAND: We are properly prepared to say that they varied quite a bit, according to the issue and the timing. Probably it is a priority with the new department and new management to actually developed some consistent approaches that are clearly articulated to clients, parents and to service providers. We have certainly argued to the Government at a whole-of-government level in relation to the proposed compact, that it is absolutely crucial that the Government commit to and articulate processes for community participation in identifying community needs and in identifying priorities for resource allocation.

Ms REGAN: In support of those comments, part of that original planning process, which was a change from the before when it was program planning to population planning, is how do we now consult with whole populations that do not actually identify hours a population of people? They may be a group of disparate people who have different needs, the same as you and me. One of the answers to that, and there was some concern in the community that this was not the most complete answer that could have been devised, was to develop regional advisory groups in each of the planning areas. There was one regional advisory group for older people and one for people with disabilities in every planning area.

Those regional advisory groups were supposed to advise the regional planner, and there was one regional planner in each area, on consultation processes and what has been left out. Over three-year period they were to build up a bank of reasonable consultation so that, at the end of the three-year period, there would be a reasonable identification of need. NCOSS has a copy of a letter, which I will not table, written to a member of a regional advisory group in recent times, I think in the last couple of months. It says, "Your services are no longer required". It was predicted at the time of the regional advisory groups that their functions were not well understood or articulated. Probably it was fair to say that NCOSS received some reports that even the members of those regional advisory groups were unclear about what they were doing.

They were not there is a filtering process; they were only to oversee the process of consultation and planning, not the content of the planning. However, NCOSS was concerned that they could be used as a ready filter in the region. There were not enough people with enough expertise and enough representation at any one point to do that filtering process. Obviously, the department has made a decision that the regional advisory groups are now no longer necessary. NCOSS would be keen to see what sort of commitment to ongoing consultation they would put in its place to make sure that the service providers, the families and the people with disabilities at the top almost asked their needs; and the types of needs that they want to move forward with, rather than becoming too scientific.

The disability minimum data set collections will give us much better information in future years, but in the interim period we will be relying on the expertise of local people. When we get the good scientific information, we absolutely need to filter that with the expertise of local people. That is where we are now. We are concerned about the lack of any designated regular consultation process in the absence of regional advisory groups.

CHAIR: Your feeling is that they have essentially been dispensed with. At the moment we have a vacuum and we do not know what might go in its place. That is certainly something the Committee can ask the department.

Ms REGAN: Certainly under the Ageing and Disability Department [ADD] we presented evidence to the Committee to say that we felt that consultation on new policy initiatives had dried up. We hope that will not be the case under the Department of Ageing, Disability and Home Care and we believe that we have cause for hope, in that we feel that the new management of DADAHC have gone some way to engender collaboration with the community. Again, however, the new management is very new, and we need to see some results. However, we believe that there could be a change in opening up proper consultation for the new policy initiatives. The consultation that we believed we had before was: This is what we are going to do. You can be in it or not. We were not the only ones telling you that at the time.

CHAIR: The last question—one we ask every witness who appears before this inquiry—is: What would NCOSS like to see come out of this inquiry?

Mr KIRKLAND: I would just reinforce the comments about the need for a disability policy plan or framework. There is a disability policy framework at the moment but it is more of a government statement of agencies approach to disability services. It is not actually an approach to the service system from the perspective of a consumer. That is the sort of approach that we would advocate, an approach that articulates the paths through the system, not just at point of crisis but at various life stages for people with disabilities and for their families to provide greater certainty and confidence in the system. We believe that would save resources, particularly in relation to the way the service access system is operating. We think the fact that there is only an intake system for people in crisis is costing more because a whole range of other people are seeking to go through that system because it is the only intake system.

We need a disability policy plan. We also need as part of that a general intake system that is not just based on crisis but is available to people at various life stages. I ask people to register future need, as we said before. Ageing parents in particular can have some sort of certainty about the level of service that their adult child can receive at this stage when the child needs it. The other thing we would want to see, and this goes back to what we were talking about, is a better approach to implementation. I am sure the issue of difficulty in roll-outs of new funding and new initiatives has been discussed at some length. We think that one of the reasons for that is that major initiatives are often announced with an unrealistic time frame, without their having been any dialogue with the non-government sector before that announcement.

That has meant that in reality the department then becomes engaged in a process of consultation. That has not always led to a situation that there is full support for an initiative or for a particular approach. That has then held up implementation; reforms are not fully implemented; money is not fully expended. What could in fact be well-supported initiatives simply are not implemented fully. That could be overcome by a strong, well-articulated approach to engage in non-government organisations in the development of initiatives. There are certainly other precedents in government where that has been the case, were a proposal has been developed before there is a budget commitment from the Government. It has meant that when the money has come through, sometimes a year or two down the track, it is clear that there is broad support for the initiative and that implementation can roll out much quicker.

CHAIR: You are confident that with all the people with an interest in disability services it is possible to reach those sorts of agreements? It is not an impossible task?

Mr KIRKLAND: I think consensus may not always be possible but, certainly, before an initiative can be implemented it is necessary to ascertain whether it has broad support from the people who need to participate in it. I think that having those discussions early on can produce that broad, if not universal, support. It can also identify possible problems with the proposed approach that might not be identified if all of the players are not engaged in the process.

Ms REGAN: A good example of that is the child disability policy framework which has never been finally ratified. It had good community processes that took time to develop and it is generally supported by the community, even though it has not been released. That is a case in point

Mr KIRKLAND: The other thing we would like to see come out of this inquiry would be a commitment to move towards funding the costs of providing disability services, for the reasons outlined earlier, as well as a commitment that planning for the needs of people with disabilities is not the sole responsibility of the Department of Ageing, Disability and Home Care; that all agencies, particularly service agencies, need to be incorporating the needs of people with disabilities into their planning. That includes the predictable agencies, such as the Department of Health, and the Department Community Services as well as agencies such as the Department Of Transport. Decisions they make can have an enormous impact on the level of need for services. Unless all of those agencies take on responsibility for planning for the needs of people with disabilities, I guess DADAHC will always be playing catch-up.

Ms REGAN: Continued investment.

Mr KIRKLAND: Absolutely.

CHAIR: It seems to be implicit in what you have said.

Mr KIRKLAND: Certainly. We recognise that the large amounts of additional funding that have gone into disability services in the past few years are catch-up funds for the number of years when there was relatively no growth in funding. While that additional funding is certainly welcome, it will not solve the problems. It must be part of an ongoing plan of increasing investment in disability services.

CHAIR: That is a small ask. Thank you not only for your efforts today and the new material and ideas that you have put before the Committee but for being an important part of the inquiry since the beginning. It has been one of our longer inquiries—I am not sure that that has done any harm—and NCOSS has been of great assistance throughout.

(The witnesses withdrew)

(Luncheon adjournment)

FAYE AINSWORTH DRUETT, Acting Chair, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, 2000, affirmed and examined:

DONEL KEVIN BYRNE, Executive Officer, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, 2000, and

MEGAN LESLEY SWEENEY, Council Member, Disability Council of New South Wales, Level 21, 323 Castlereagh Street, Sydney, 2000, sworn and examined:

CHAIR: Did you each receive a summons to appear before the Committee and are you conversant with the inquiry's terms of reference?

ALL WITNESSES: Yes.

Mr BYRNE: Please be aware that although I am a public servant I have been briefed by my council because Leonie Manns, the retired Chair, is unable to be here today.

CHAIR: Yes, we knew that. We invited Leonie to appear before the Committee even though we knew that she was the former Chair because of her involvement with this inquiry, which has been going on for two and a half years. We wanted to do a bit of a retrospective. We will talk to you about where we are now and you might also want to speak from Leonie's perspective.

Mr BYRNE: Yes. We have not made a submission to this part of the inquiry.

CHAIR: That is fine. Do you wish to make some opening remarks before we turn to questions? The scope of question No. 1 is absolutely enormous and probably gives you a chance to say almost anything anyway.

Ms DRUETT: I would like to make a brief statement, first, to acknowledge the work that the past chairperson, Leonie Manns, has done for the inquiry. Secondly, I offer the Committee her apologies. She intended to appear today but she serves on the Mental Health Review Tribunal and could not be replaced and did not want to upset the scheduled hearings. As the Committee will be aware, Kevin is the executive officer of the Disability Council so the views that he gives are those of the council, which are slightly different from many people in the public service. We have briefed him. He is the link between the work that he, Leonie and the council have done and me as Acting Chair. It is very important that he is here and feels free to say what he needs to the Committee. If it is okay with the Committee we will have a free-flowing discussion as we each have different areas of expertise and different information and come to the council with a different range of skills and experience.

CHAIR: That is fine. We usually like to do it that way as we find we get much further if we are fairly informal and follow discussions wherever they lead rather than sticking to a rigid structure. We have asked all our witnesses about the five areas that the Committee has been considering in the past two and half years of the inquiry. We are obviously visiting them now because we will soon make a final report. You may have more things to say about one area than another, but these are the areas that we are particularly interested in. We want to know what progress, or otherwise, can be reported at this stage compared with when the inquiry began.

Mr BYRNE: At the beginning of last year the Disability Council became increasingly concerned about conflicting information that we were receiving from the community. We were concerned that there was no progress, poor progress, bad feedback, bad follow-up and so on from the department regarding the group homes project, in particular. Yet the Minister was hearing from the department that everything was going fine and that consumers and their families were happy. We were a little confused, as a council, as to how to proceed. We decided to talk to the community independently and arranged a number of consultations.

There were consultations in the Campbelltown area, the Newcastle area and a smaller consultation in the inner west of Sydney. At each consultation families and consumers—particularly in Newcastle—expressed deep concern about the lack of progress with the group homes project. Not only were the assessments found to be inappropriate—too shallow, if you like—but some expressions of concern by parents, consumers and so on appeared not to be taken seriously by the department. Some people, particularly in Newcastle, said that their concerns were different in the report back. On consumer felt that her words were being twisted by the departmental officer to mean something else.

We provided a full report on the consultations to Minister Lo Po', who, upon receiving the report, said, "This is totally different from what I have been hearing from the department; the department has been telling me that everything is progressing well and has given no indications of concerns in the community." The Minister then asked that the department provide a full report on the issue and things were put on hold while the report was being compiled. We have not heard any real details about how it has progressed since. We are aware anecdotally that there are concerns in the community. There are 197 places that need to move and have not moved in the group homes area particularly. That is a major concern.

CHAIR: Do you know whether any people have moved yet?

Mr BYRNE: We have not received any advice about that, but I must admit we have not particularly sought it. They may or may not; it is hard to get statistics from the department.

Ms DRUETT: I support Kevin's comments about the lack of information. There is a formal lack of information but we have certainly heard stories about what I would describe as the total disruption of people's lives in the past two or three years. It is extremely worrying. People with certain levels of disability who live in a group home model of service were told that they were going to move. They indicated that they did not want to move and two years later they have not moved, but they have been told that they will still have to move. For example, a young man who was on no medication looks like he will have to take anti-psychotic drugs because of behavioural difficulties. It is clear to the psychologist involved and a range of other people that this young man is extremely distressed. I hear this sort of story a lot.

Another woman has been charged with being a public nuisance—I am not sure of the legal terminology—because she is so distressed. For instance, she sits in the middle of a country town and rips up newspapers and shouts and screams abuse at people although she used to be integrated in that local community. People are very distressed. Our report to the Minister provided a view different from the departmental view. We took that role quite seriously because we are concerned about outcomes for people with disabilities and that the processes and planning put in place achieve positive outcomes. The council has heard some positive stories to date—I do not wish to say that there are no positive outcomes—but, from our perspective, the negatives outweigh the positives. That may be human nature: you often hear the negatives not the positives. But certainly our level of research would have revealed the positives as well.

Mr BYRNE: Leonie asked me to pass on that she has had individual conversations with officers within the department and they have been quite encouraging about the progress. Yet that does not seem to be translated when it comes down to things on the ground, things actually happening in group homes. It seems to bog down somewhere in the middle of the department.

CHAIR: As you would guess, we have had similar evidence from other witnesses.

Mr BYRNE: On the provision of permanent accommodation to address unmet need, there is still an enormous amount of unmet need out there. We hear anecdotal evidence again. There has never been any real mechanism put in place to identify that unmet need although it has been an issue talked about for quite some time.

CHAIR: We might come back to that when we get to the service access system. From your point of view has more permanent accommodation been made available over the period we are talking about?

Mr BYRNE: I have not any real evidence of it out there on the ground.

Ms SWEENEY: On each of those points, we have no clear documented or even verbal information direct from the department to say that any of these things have improved. Anecdotally, on each of the points council hears that things are as much of a struggle as they were when this inquiry began.

Mr BYRNE: We do here of individual success stories but they are very much the exception rather than the rule.

Ms SWEENEY: A story I heard just last week was a new, modern one, if you like, about the group homes issue. A young man was told that he was going to move at the beginning of the project. There were issues about the choice of service provider. People thought that they had a choice and they articulated the choice and they were then directed as to who was to be their provider. This is what happened to this young man. Just recently you would be aware that the SACS award has increased. This young man had his assessment to see what level of support he needed. Money was allocated to him and now the provider that he did not choose but he was allocated has reneged on the offer, saying that because of the SACS award increase they can no longer support him on the funding he has been allocated. So now that young man is again in limbo about what will happen in future. He is in a very disturbed emotional state because of that. That is a clear indication of one of the problems of the length of time of this whole project as well is the lack of insight, I suppose, about those particular issues.

CHAIR: It is a gloomy picture that you are painting.

Mr BYRNE: In a similar vein but outside the group homes project, an issue close to my heart is the support of people with physical disabilities in the community—attendant care, personal care and the like. I was at a meeting last Monday where the community came together. It was reported that there were 48 people who were approved for attendant care packages last October. They had been waiting years to receive those packages, and yet six months later there has been absolutely no progress. They have not received an hour of that support at this time. They are still enduring inappropriate care packages through whatever means—it could the family, restrictive home care practices or whatever. Another 60-odd people who applied for desperately needed augmentation of their care package had been advised that that would not be a problem.

Once again, some six months after there has been no progress on that either. There are a couple of hundred people on the attendant care program waiting list and there are service providers who are at the moment in dispute with the department and unable to negotiate an increase in funding, although they are suffering severe losses in the provision of their care. Not that I am supporting service providers in their cost structure, but it is a problem for the clients because they are refusing to take any new clients on board. The home care service is also tightening right up and it was reported that it will not provide even an extra half-hour if desperately needed because it just cannot afford it. So there is a real problem out there and the department apparently is refusing to negotiate. So something needs to happen.

CHAIR: Other than the point you just made about the providers, do we know the reasons for the groups you mentioned who had approvals as long ago as last October not yet receiving anything?

Mr BYRNE: By all accounts there just appears to be a blockage in the department with the ability to role that money out to the individual. There appears to be no other reason.

CHAIR: So the approval is there, the money is there but there is a bureaucratic delay. It is not a matter of buying properties or employing staff?

Mr BYRNE: Absolutely right. Anecdotally, people were discharged from spinal units and the like to regional areas, being told that their care package was arranged and available for them. They returned to the country area and found that there is absolutely no care package available for them. They are now residing in hospitals out at Dubbo, Wagga or wherever. It is just not on. It is a similar problem. It just seems to be a blockage within the department delivering the program that has already been agreed to.

The Hon. IAN WEST: What sort of hospitals?

Mr BYRNE: The public hospitals, private hospitals, whatever is available for them.

Ms SWEENEY: Some of these issues go across the various questions that you have provided for us. Some of these people are ending up in nursing homes. I am sure you will be aware of that.

CHAIR: NCOSS said quite a bit to us earlier about that issue.

Ms SWEENEY: One of the issues is the service access system, which is meant to pick up these types of arrangements for people. Because it is such a long process, where the person at the hospital says you just have to leave, or the family has been caring for the person and they can no longer care for them, the young person ends up in a nursing home. Once they are in a nursing home they are ineligible for the service access system immediately. That is an absolute crisis issue at the moment. It goes into the question of people ending up in nursing homes and more or less ceasing to exist on the books. That is a major area of concern for the council.

Ms DRUETT: The processes that are in place to deal with these things sometimes—certainly not all the time, I do not think council would agree—seem to provide very solid answers but even between the processes and the practices there are gaps of delays and families and people are caught up in what seems to be a whirlwind. Their lives are affected in major ways. SAS as a program was rolled out quite slowly. It took a while to get staff. We all understand that those processes take time, naturally, and staff needed to be trained. It seems from our information that the people that are getting any money out of SAS are those that are in absolute crisis, in a critical stage. Certainly we would support that those people get the assistance but it is not that the program as a whole is not meeting its outcomes if it is dealing only at a crisis level all the time. Some people are going into crisis because they did not get services they need when they needed them.

CHAIR: Some of our witnesses have said that they endorse the service access system and they think it is a good system with potential but that it was perhaps announced too early before the staff and the infrastructure were there, and also that it has been overloaded by becoming in effect the only access system by which people, including even people with disability, feel that they can access anything. So the people with the responsibility of basically making it work are simply overwhelmed. Would you endorse those comments?

Ms SWEENEY: I think so.

Ms DRUETT: I think so.

Mr BYRNE: I think so.

CHAIR: A good system in theory but not yet working in practice.

Mr BYRNE: I spoke to an individual at the meeting last Monday who received extra hours to support her through the service access system. She was in crisis at home. She now claims it was an overassessment. She has 80 hours of support a week and she has got people constantly tripping through her home and it is destroying her life and marriage, she claims.

CHAIR: What does she feels she now needs?

Mr BYRNE: Back off. She feels that whoever did the assessment just went overboard.

CHAIR: Went overboard in the first place or she had a short-term high need and the system has not coped with the fact that that need has since reduced?

Mr BYRNE: I do not think the need has reduced but the assessment, as she claims, was just too expansive. Maybe she complained to much and they just leapt in. She now finds it very difficult to negotiate back so she has some reasonable quality of life.

CHAIR: We could probably all introduce her to a few hundred people who would take some of her hours.

Mr BYRNE: I am sure.

Ms SWEENEY: I am sure she would be happy to give some way.

Ms DRUETT: It has been my experience that the information provided is different depending on who you are. In my other life I am a legal guardian of a woman with an intellectual disability. I asked what her SAS assessment had said because I had not been involved in it, which is not unusual for someone who is in an institution. They said that SAS does not cover people in institutions because their needs are being met. As her guardian I said that I could not agree with that or else why would there be a devolution program being rolled out. Those two things do not make sense. So I think there were different levels of information. As you said, a program that has a good basis now has negative feelings attached to it, which is a real pity. There is a lot of work to be done to turn that around so that people see that and trust that. We are hearing a lot about trusting the bureaucratic system, that the quality of your life depends on a range of services and supports. Once that trust has gone or is disturbed in some way it takes a long time to get that back.

CHAIR: You mentioned devolution briefly. Obviously, we should talk more about that. So far we have not mentioned respite and reform that has occurred in that area.

Ms SWEENEY: Again, we have no official knowledge from the department about what is happening, but anecdotally there has been no movement or very little movement in respite reform.

Mr BYRNE: That is part of the whole system of group homes, and if other things get blocked up the respite beds get blocked up as well because people are unable to move on.

CHAIR: We have heard about new, more flexible respite packages and so on. You are saying that as yet people have not been taken advantage of those, although they are still being rolled out.

Mr BYRNE: We have not got the figures.

Ms SWEENEY: We have not heard, and that in itself is an alarming thing. Apart from getting a clear picture from the department about where it is at in these things, the department is not very good at advertising what it is doing well. We have no idea really. We would love to be briefed on the number of people who have taken up such packages, or to be told stories about people moving, but it is as if no information is coming out of DADHC at all, whether that information is not that good, such as numbers still to be moved, or whether the information is very positive about changes that are occurring. As council, we find that really disturbing, because our role is to advise the Minister, and her department, for whatever reason, is very reluctant to share information.

Mr BYRNE: The information that is divulged is usually that the program has been approved, that say 197 places have been approved, but they do not talk about the actual rollout or the actual stuff on the ground.

CHAIR: As you are probably aware, we will be wrapping up the inquiry with these hearings**.** Our last hearing of that kind will be with the department, which will have the transcript of today's proceedings in front of it. We look forward to its comments on the various comments that have been made about the department today.

Ms DRUETT: Recently new director-general, Ms Allison, come to council to speak with us about a range of things that are on DADHC's agenda. This has been something that council has tried, not with just DADHC but with a number of portfolios, because our council is a cross-portfolio area. Although DADHC occupies a lot on our time and energy, we want not to be briefed about a new program but to be involved at the beginning of the planning process. We would like much more input into programs. We can probably point to some areas that, from our experience, may or may not work as well. Most directors-general that I have had contact with think, "We will go and brief the council." It is a very passive process. We have advised many directors-general that it is a much more active and interactive process, as we are the group that provides advice to government and we also see ourselves as having a role in being actively involved, as does the community. The community has a very important role in signalling the positives and the negatives to DADHC as well as other agencies.

CHAIR: So you would see it as briefing rather than consultation?

Ms DRUETT: Yes. I think we are absolutely consulted out, and the community is absolutely consulted out.

CHAIR: You are probably in a better position than some other witnesses we have had today to give the Committee advice on question two. For instance, you mentioned some matters related to allied health services, which we have not had much evidence about. We gave the examples of daily programs and advocacy support, but there are other areas that we did not talk about in those five points in question one.

Ms SWEENEY: One of the issues was young people in nursing homes. That needs to be addressed. The issues that we are talking about that are the hinge of those first five points are not just DADHC's business. It is whole of government business and whole of non-government business to ensure that communities in which people with disabilities live are accessible, welcoming and well supported. We feel that that cross-portfolio and whole-of-government involvement are crucial to achieve the desired outcomes. There are the foundations of disability policy frameworks and action plans, but all of this information needs to be put into that context so that things will happen for these people.

Mr BYRNE: The Department of Ageing Disability and Home Care, in co-operation with the Department of Health and others, developed a whole-of-government framework some years ago. That was adopted across government. All departments were required to develop action plans in accordance with section 9 of the Disability Services Act. It is a matter of implementing that to bring about a better community for people with disabilities, such as transport, housing, education, you name it. It is not just DADHC; all departments need to bring that into play. IF that were to happen properly and be enforced across the State, things would improve all the way across the line.

CHAIR: Do you have what I might call a good list and bad list of departments that you feel are really falling down in the implementation? Are there departments that you consider to be doing their job? I realise that the demands on different departments vary greatly. You mentioned health, transport and education.

Mr BYRNE: One of the better ones is the Police Department. Their action plan was terrific. They have gone through a review of that, and it is one of the better ones.

CHAIR: So their plan is good but their implementation is also good?

Mr BYRNE: Yes. It appears that things are improving remarkably in that area. They certainly needed to, too, but that is all right.

CHAIR: Is Health the most important area outside DADHC itself?

Mr BYRNE: Areas of Health are working well, and I think there are other areas that need to work well. Education is picking up its game quite a bit.

Ms SWEENEY: Education is certainly taking it seriously, which is a start.

Mr BYRNE: The Department of Transport could do a lot still.

CHAIR: Would you like to give us some specific examples? You do not have to do that now; you can always write to us if there are areas that you want to identify either where progress has been made or where you think there are really big holes.

Ms SWEENEY: One of the crucial ones is around housing. There is still a long way to go.

CHAIR: This is public housing?

Ms SWEENEY: Public housing, but I suppose it is also linked. Building is not my specialty, but there are issues with local councils and zoning of land, and with the private sector as well, to make sure there is a range of accessible housing, both public and private, that people can either buy or rent. That is still a major issue that has not been addressed.

Mr BYRNE: Indeed it is. As a person with physical disabilities and being involved in the community, it is extremely disappointing that many councils do not yet adopt a proactive approach and push for adaptable housing in their developments or the inclusion of full physical access in housing developments and so on. We constantly see developers bypassing access provisions, or providing minimal access provisions, thereby denying a whole stack of opportunities.

CHAIR: When you speak of developers bypassing access provisions, you mean that councils make a bit of an attempt but do not follow through enough, so that developers are able to get around the provisions?

Mr BYRNE: That is right. You are all aware, I am sure, of the SEPP 5 debate going on at the moment. Some of those developments are supposed to provide for people with disabilities as well as the aged, yet I see this type of accommodation at the bottom of very steep driveways or on very inaccessible terrain. You might be able to get into the unit, that you certainly would not be able to get around your environment. Unless you get a taxi you would not get off the property. Those sorts of things should be looked at. We need to do it properly or just don't do it. A lot more could be done.

I learned yesterday of an inquiry into the quality of buildings. I think submissions close next Friday. The Department of Ageing Disability and Home Care contacted me at council to see whether we were doing anything, and they are putting in a nil response. I thought that was a golden opportunity for somebody who is supposed to be a policy development unit for people with disabilities to put in a submission on housing quality, calling on the Department of Housing and others to provide proper accessible environments in housing and so on. But this lead agency is putting in a nil response. That sort of thing disappoints me.

Ms DRUETT: Megan mentioned disability framework policy. Whilst it has some problems, largely being a desk audit, it has some exciting opportunities. I was disappointed that the director-general, Ms Allison, said recently at council that she thought there were onerous compliance requirements imposed on departments regarding the writing of reports. I know that departments need to write best policy statements and that there are a range of provisions that departments must comply with, but people with disabilities have not even got to the paper audit stage. This is the first time we have got to the paper audit stage, except for when the DSA came in around transition planning.

The policy framework is that generic service provision would be provided by State government run portfolios. To be able to talk to the Department of Fair Trading is just as important for some people as wanting to talk to DADHC. This process has the potential to have really major outcomes in changing the way government provides services to people with disabilities. We are members of the community and we do not always have to go to DADHC, because all of our problems are not disability specialist service based. The issue seemed to be that compliance was too onerous. She also suggested maybe it needs to be done in other ways. There is certainly some truth in that.

But if the disability policy framework is taken seriously enough, that in itself will bring about changes for people with disabilities. I see it as part of DADHC's role as the lead agency in disability to provide disability specific services but also to look at mainstream generalist issues that are as important to people with disabilities as they are to other sectors of the community. It seems to me the unit that was working with other agency has been downgraded. It seems that that whole framework report is another report that has been put on the shelf. Council would view that very seriously if that did happen, because, as Kevin said, we can see something positive from the Police Service. In the discharge of our monitoring role we do not want to be always telling government what does not work. We want to be telling government where it is doing things well. The framework is one area in which I thought we could do that, but it seems that it will not achieve the outcomes for some basic bureaucratic reasons. I think that is a pity.

CHAIR: Are there any specific matters that you want to put to the Committee, such as particularly day programs and advocacy support? I am conscious of the time and so on.

Ms SWEENEY: The council felt very strongly that an issue within DADAHC itself is that it does not have enough hands-on experience with living with a disability. There is lots of theory and stuff like that but a lack of that lived experience. We thought that having a disability reference group or something like that—high-level, lots of participation with people with disabilities themselves and not just a tokenistic "we will give you a briefing" but actual participation around decision-making, what will happen, what will work and what will not work—is absolutely critical to try to overcome some of the issues. That was a unanimous response from council about something that should come about.

We also felt that advocacy funding was crucial and there is a lot of debate about that at the moment, and the department is embarking on another process around advocacy funding. We will have to wait and see how that pans out. Also, there are issues around compliance with the Disability Services Act. We felt there is a great level of disrespect among government and non-government providers of services towards the Disability Services Act. We felt that unless there was some type of compliance or even punitive measures within the Act for people who do not comply, that will continue. It is a disgrace to see the way some people are living in services that blatantly do not comply with the Disability Services Act.

Mr BYRNE: People bend over backwards to meet the requirements of the old Occupational Health and Safety Act.

Ms SWEENEY: Or fire regulations. People in large residentials bend over backwards to meet their obligations under the fire regulations yet they still thumb their noses at the Disability Services Act. The council felt strongly that there needs to be that compliance function within the legislation and even punitive measures to boards of directors and things like that to change these things around.

CHAIR: What else is on your wish list?

Ms SWEENEY: The issues regarding attendant care and home care. There are still enormous issues with both those things, the rolling out, not enough places, when places are allocated they are too slow to get on the ground—those types of things are there as well.

Mr BYRNE: The other is a culture change within the department. As I said earlier, individual officers have great ideas and they are progressing but it seems to be bogged down in the middle. There is a need for a commitment as a department to move things on, otherwise things are not going to improve.

Ms DRUETT: It seems to me as a person who lives in a rural area there seems to be very little understanding of the differences between the city and the country, which are real and tangible, and the differences between regions as well. Regional offices tend, on the whole, to be fairly small, whereas council believes that DADAHC needs to be a department made up of people throughout the State. Many policies are city-centric policies. They are made in the city and applied in the country. Recently there were some changes to allied health services, and people worked out they were spending most of the time in a car driving from A to B. People tend to come into those allied health positions fairly soon out of university or training and there is not a lot of professional support, so people are in local regional areas on their own. There is only one occupational therapist and there is not a lot of training and backup and they probably have the most complex job. You cannot overload programs in one country area as you do in the city, it just does not work. We feel there is a need for much more input by the rural sector into policies so they are not seen as city-centric, because there is a great deal of cynicism about—it might work there, but it does not work here.

Mr BYRNE: Another thing with day programs is that they need to be integrated, not centre based, getting people into community things rather than going out for a picnic in the Rotary bus.

Ms SWEENEY: Community tourism seems to be what a lot of day programs are now, rather than living life within the community. It is almost like let us bus around and look at the community.

We really need to see it move on from that. Some of the things around our individualisation of things and more flexibility, which we will get on to in funding options.

CHAIR: The next question deals with funding arrangements. It is really about the role of government and non-government in providing services.

Ms DRUETT: We would say there is a role for everybody in the provision of services but what must be at the core of that are the needs of persons with a disability. We do not have a preference for government or non-government. We see the greater the mixture the greater the benefit with the needs of person with the disability being met. Clearly, that has always been council's view. Sometimes I think we get the questions wrong. We ask the wrong questions and, thus, get the wrong answers. If we ask a question about should we have both, we will get an answer that says yes or no or maybe altogether. If we ask a question what best meets the needs of a person with a disability, for one person it may be one thing and for another it may be another thing and for another person it may be a mixture of both. From council's perspective if you ask the questions the right way you will get the answers. I do not know that typically that has been done.

Certainly a lot of what we have just spoken about in terms of fire regulations and how they are complied with, we really do not believe that any government would defund the service. If you look at the number of people who die in care, the number of people who are injured in care, if you look at a whole range of things both in government and non-government services, I do not believe that any service would be defunded. I do not believe there is a plan that if that happens what do we do. "Punitive" may be one word, but there are range of words,, but if people do not comply with the Disability Services Act some action must be taken. Boards of directors of organisations for government-run services are responsible for the money, but more importantly they are responsible for those people's lives, and it seems to us that that is undervalued. If there is a fire, fix that but if it is a person who may die we do not worry that much.

CHAIR: That question is there partly because our terms of reference are very specific and some people have a philosophical view about it. If that is not a worry to you, we can move on. In a sense the next one is a philosophical one, about the criticism of predetermined models and your attitude to the need or lack of need for greater flexibility for meeting individual needs, and the need for innovation.

Ms SWEENEY: And those barriers. One of the things we said straight up were the attitudes of the department, attitudes of the service providers, attitudes of the community and even the attitudes of families with disabilities themselves—trying to change attitudes where people do not think you have this disability so that it naturally means this service is for you. That is one of the major things that needs to happen in New South Wales. It has become part of the culture of New South Wales, those in government service providers and even in the community. To try to change that attitude into everyone's being individuals and finding the support that individual needs within the community will be different even if people have the same level of competence or disability.

For instance, people from a non-English-speaking background want to stay living with their families. So, how do we find the support they need, because that is not unusual. Whereas, the one size fits all, if you had this little disability, naturally the group home is for you, if you are going to have any service at all. Changing those attitudes around, someone's level of disability meaning something in their lives around what service they will get is a key, fundamental issue.

Ms DRUETT: That would work the same for the Aboriginal community. The disability seems very different in the Aboriginal community and we need to be sensitive to that and design services around that. Sending somebody off to a group home model is just alien and offensive.

Ms SWEENEY: And the issue about rural and remote as well.

Mr BYRNE: The Disability Council is just moving into a consultation phase with the Aboriginal and Torres Strait Islander community, and that is what we are finding. They look at disability totally differently to the western perception. That is fine, it works for them.

CHAIR: What you are saying is we have to look differently, for instance, moving more towards individual funding packages?

Ms SWEENEY: Absolutely.

CHAIR: Do you have a view on the mix of direct funding?

Ms SWEENEY: It is about flexibility of funding. That is the issue. It is not one fits all. It is about having many different funding mechanisms and the flexibility about funding mechanisms. One of our colleagues said if someone has funding support and they want to go on a holiday to Queensland for three months they cannot do it. They cannot take their funding with them and go off and have a holiday. Yet, I know quite a lot of people in the course of their lives who decide to go north and try it out. The way things are in New South Wales, service providers and the Government would think you were ridiculous even suggesting that.

CHAIR: Could you go for a week?

Ms SWEENEY: Not unless you went on an organised tour and paid extra money. It is not your money, it is the services money.

CHAIR: So, if you have a disability you cannot have a holiday?

Ms SWEENEY: No, not unless you pay for it out of your own money.

Mr BYRNE: Actually, it depends on your disability. With mine, I have what is called the allowance model of attendant care. I have actually gone overseas and travelled in America and Africa, and so on, and taken my care hours with me and been able to purchase care over there. Someone from another care package cannot go out of the State, and quite often they cannot go out of their branch, and get a similar service. There are those inequities.

Ms SWEENEY: And the issue too about our ageing and the way our funding is so inflexible is now having serious impacts on ageing people with disabilities. What happens when they want to retire? This funding comes from the Commonwealth and this is from the States. That means there is no staff where you live during the day so you have to go to the day program all day regardless of the fact that you are now 65.

CHAIR: Not really expecting to have a job next month.

Ms SWEENEY: You may want to go part time or only two or three days a week, but you cannot. It is that inflexibility of funding that is the major issue. One of the things may be individualised funding, but having a variety of funding available is the issue, and that funding being flexible enough to change as people's lives and needs change.

The Hon. IAN WEST: Have you done any work about those flexible funding concepts within the bigger egg, which obviously has a finite size? What you appear to be saying is that not many people would object or oppose the principle but, as I understand it, the problem is coming from the ability to work at the financial structure incorporated with the bureaucracy. Obviously the bureaucracy is having a difficulty with the dollar amount.

Ms SWEENEY: At the moment, though, there is evidence that they have quite a bit of money butt they cannot get it out.

Mr BYRNE: It is in silos.

Ms SWEENEY: DADAHC has received funding for devolution, it has received funding for the attendant care packages and the models are there but they cannot implement that.

The Hon. IAN WEST: So, you are saying it is not a dollar issue?

Ms SWEENEY: There is around unmet need. There are dollar issues absolutely attached to unmet need, but a lot of people have been identified within devolution and within attendant care and money has already been allocated to them that is not getting out as well.

Mr BYRNE: It comes back to what we said before about focusing on individual needs. A lot of money is program based and you need to sort of burst those walls and let the money float across the paddock, if you know what I mean, so it is meeting the needs of the people with disabilities.

Ms DRUETT: As an example of that, Kevin has his own attendant care. I get my personal care through home care. When I am at home—my partner lives away home during the week and comes home at the weekend—I have four visits a day. I used to run the home care branch; I was a home care service co-ordinator. I could quite easily take that money, give the opening back to the State and do my own thing. But there is no mechanism at home care to do that. I cannot get onto the attendant care program because of the waiting lists. If I had a personal crisis and I went into a nursing home I might be able to come back out under attendant care because I am under 55.

But I will not be under 55 for that much longer, so if that is going to happen I had better do it fast. That is what we are talking about. Kevin's needs and my needs are different. He has a greater level of disability and he needs different things. But we are both equally able to manage that part of our lives. Because I am in a program that cannot happen. But I can actually see that the saving of administrative hours means more hours to someone who does not have hours at the moment. So you are actually saving dollars and not needing to get any more from government. But you must change the way you do it.

Mr BYRNE: Just to give an indication of what that may mean, it would cost the service $26.50 to get me out of bed and over $40 to get Faye out of bed. I get 20 hours a week, so you are looking at a saving of $280, or thereabouts, each week that could be achieved by Faye being on attendant care. I do not know how many hours service Faye gets, but if we translate that across many people with disabilities who are currently on home care, you are looking at millions of dollars.

Ms DRUETT: That does not mean we are saying that everybody should do that.

Mr BYRNE: But a lot of people on home care could transfer.

The Hon. IAN WEST: We do not have time to go into all that. It would be an administrative nightmare.

Ms SWEENEY: But that represents flexibility of support. You referred to it as being an administrative nightmare. But what questions are we asking? Are we asking about how best to support people with disabilities and about doing something about the crisis in unmet need, or are we asking questions about industrial regulations and supporting the work force?

The Hon. IAN WEST: When you break the walls of the silo is it only the water in the silo that spreads or are you breaking into a much bigger reservoir of water than just the water in the silo?

Mr BYRNE: It might be premature to state that I still think there should be some investigation into the effect of breaking the walls of the silo. I do not think anybody has looked at that yet.

The Hon. IAN WEST: That was my question to you. Have you had a chance to assess the effects?

Mr BYRNE: We have not done that depth of work. Last year a working group looked at flexible options for living in the community. We have an position paper which will overarch a number of other things that our strategic plan will address. We are in the process of addressing that in the coming month or two.

CHAIR: You might not have done that before we finish our report. We are trying to finalise everything by mid-May.

Ms SWEENEY: This type of process must be collaborative. Even if council put the time, energy and resources into coming up with that, DADAHC, the Government and the non-government sector would not own it. They would say, "Thank you very much" and keep doing what they have always been doing.

CHAIR: Do we need more pilot programs? I know that some people have huge reservations about pilot programs and about what happens to them afterwards.

Ms SWEENEY: We have a culture in New South Wales of distrust of different service models, regardless of what they are—regardless of whether they are individualised, more regionalised or closer to the person. There is a real distrust for many different reasons. Unless we have some type of pilots, trials or something, we will never get past where we are on this issue.

CHAIR: Is the struggle to get a lowest common denominator across need forever overwhelming different sorts of struggles to get even more individualised, flexible or more appropriate services for people? Is it that sort of tension that leads to a mistrust of flexibility?

Mr BYRNE: I think that a lot of it comes from the service provider sector trying to protect what it already has.

CHAIR: Government and non-government?

Mr BYRNE: Yes. You talked earlier about industrial nightmares. It is that sort of environment. We have structures, we have these institutions, or we have these organisations. Our jobs must be protected rather than looking at the needs of people with disabilities and whether those jobs, those structures, those institutions are the best options for them. That is government and non-government. They tend to look at it the wrong way around. They are asking the wrong questions.

Ms SWEENEY: If it is an individualised type of arrangement the person will still need support. Just because the funding is different it does not mean that the person does not have support any more. So employment is not the issue. The person will still need employment. Staff will still be needed, support will still be needed and services must be provided and things like that. We are looking at it in those situations where people with disabilities get what they need. Their needs must be supported in a different way. There will still be plenty of employment about. Quite frankly, it is more an issue of power and control over people with disabilities. That is at the heart of the issue.

The Hon. DOUG MOPPETT: Let us look at alternative models. Earlier we heard evidence about models in British Colombia which went to the abstract end of the spectrum by saying, "We have assessed you. Here is $50,000 a year. Go and do what you like with it." In New South Wales and, in particular, in rural areas, you would have great difficulty in procuring such services if you were just given money. That is the ultimate flexibility, is it not?

Ms SWEENEY: Yes. That is why we must be collaborative in developing those structures. In New South Wales it is alien to everybody's thinking that that type of thing would happen. So it would take some time. However, if that was available, over a period you would clearly have built up the supports so that that could happen. Often in rural communities if the means is there they actually come to the party. Community networks and the grapevine are good and all sorts of stuff like that. For people with high support needs it is not uncommon in rural areas to have property owners who are nurses. So if people need assistance with personal care and they need nursing staff they are there. At the moment there is no mechanism for finding that locally.

The Hon. DOUG MOPPETT: At what point should that be offered? A person whom I have followed in this area for many years was clamouring at one stage for centre-based respite. I said, "How are you getting on with that?" She said, "I have given it away. I am now able to do much better by arranging for a neighbour, a friend or someone in Walgett to come out. I am given the money and I organise it. That is a hell of a lot better." That is what has happened in recent years. If somebody has been identified as being in need and services are offered—and this might not apply to everyone—one of the options that could be given would be for him to organise it himself.

Ms DRUETT: In a period of social change if I have not experienced something I might not be trustful of it. Some parents still say, "Institutions are what we want. We feel secure that way. We do not feel secure for our children in other ways." Over the past 10, 15 or 20 years some parents said, "My children can do a lot more with resources that are not attached to me or to an institution." It is about explaining and providing that. Certainly some new money went into centre-based respite care. They wanted bricks and mortar. The regional director said, "There is no way that I can get them to look at another model until the bricks and mortar are there." I was literally tearing out my hair and saying, "But the money can be spent better and more effectively and achieve better outcomes." He said, "The people who will use that service will never believe that until they have had centre-based respite care and they see that it does not work."

How do we communicate those changes to people? How do we build up trust with those people? Communicating that information is very difficult for people. Changing overnight is very difficult. We are going through different model types. Often what we do not have is what we want. When we get that we want something else. That is true not just of people with disabilities; it is true of all human beings. It is about an educative process. The word that Megan used that I would support is "collaboration". We must work collaboratively with each other so that all our differences are incorporated into whatever it is that comes out at the other end, otherwise we will continually be doing things like we are doing.

CHAIR: We have addressed some of the questions relating to communication and consultation processes. If you have prepared detailed notes you may be able to give to us in writing what we have not yet dealt with.

Mr BYRNE: When do you need that written information?

CHAIR: In two or three weeks.

Ms SWEENEY: Mr Moppett referred earlier to the fact that when most people get into service provision they are actually in absolute crisis. We have no preventative mechanisms. People are pushed and pushed despite the fact that they are telling everyone that they are not coping. They are pushed until they are over the edge. That is when something is done. If you say to someone, "We will give you the money but you have to do it yourself", that person does not have the capacity to do that. It is so overwhelming because they are kaput. For that model to work well we must get out of this mentality of crisis management. If people are given an opportunity to get support that they need when they are asking for it before a crisis hits, they will be connected to the community better, they will have a better capacity to manage their own affairs and think clearly about what would happen to and they will be able to be creative. We will prevent a crisis from occurring and we will also get some good outcomes for people in their communities.

The Hon. DOUG MOPPETT: But you would go to people in settled programs who have been through all that you have described. You could say to people in settled programs, "From now on you have two options—continue as you are or take the money."

Ms SWEENEY: The issue about taking the money is important but again we need the collaboration. People need expertise in order for these things to happen. Families and people with disabilities often need support to make it happen. DADAHC could definitely play a role in this. The other thing is that service providers have to think differently as well. There is a real need for service development, for initiative, for change and for those staff to be the facilitators of that change. They must walk people through it, live it with them and hold their hands until things start to occur.

CHAIR: Some of our witnesses sounded warnings and said that, if sufficient funding did not go into the programs, to service providers and all the rest of it, that end would wither and the range of choice for people who often obviously need a great deal of assistance in making choices and putting in appropriate services and support just will not be there. Some of our witnesses have said, "We think you need to be incredibly careful. If you have more flexibility or more individualised funding, however you define it, you must not throw away the other end of it otherwise you will end up in a great mess."

Mr BYRNE: That may or may not be true but you also look at some service providers who are doing very nicely, thank you. You wonder whether their administrative structures are actually reflective of the level of services they are providing as well.

CHAIR: When you say "doing very nicely" do you mean making nice profits or wasting money?

Mr BYRNE: Some of their executive staff are very well paid, and the level of service they provide is probably not as reflective.

CHAIR: So the senior people perhaps are well paid. Most people seem unanimous that the people at the lower levels are not well paid.

Ms SWEENEY: Absolutely.

Ms DRUETT: But, whatever we do, we need to be innovative and collaborative. We need lots of communication around what is happening so that some of the miscommunication does not occur and we can allow people the opportunity to take a chance, from Hon. Doug Moppett's example of centre based to "No, I want to do it myself". All this is happening. That question was, to me, what was the outcome that person sought, and the answer they probably got was a service type, not what they really wanted. The questions we ask are crucial. If we do that with a lot of difference, I think we will get better outcomes and better information for people to make those choices about what services or service types or programs that people want that are effective and using the tax dollar in the best way that it can be used.

CHAIR: What crucial areas have we not mentioned at all or what do we need to mention now?

Ms DRUETT: One thing that council talked a lot about when we were preparing for this was the issue of communication and collaboration, not at the level where we said, "Here is a briefing about what we have decided to do" but to get into DADAHC and other departments, although the DADAHC terms of reference are specific. Peak bodies have a huge range of skills and expertise that are different to each other if they are about different disability types. Certainly, council has a role but we also have a role to monitor. People often say that the Disability Council is there so no-one else is needed. Our role is to stand back from government as well as to interact with government because we have a monitoring role.

At the moment DADAHC is undertaking a strategic planning process. We hear that over the Internet; we have had no connection around that. Yet I would think that is a huge opportunity to engage the community yet I have not heard where that engagement may have started. Again, it is a bit like DADAHC is there and the community is here, and that is certainly not what we want. We want to see that expertise in the department, and we want to see it brought in externally in valued processes at a very high level so that they do impact the product, whatever that may be.

CHAIR: I think we have probably covered most things. As I said, if you feel that there is something we have not discussed properly you are very welcome to ring us or write to us.

Mr BYRNE: Certainly there are a couple of issues such as we talked about before about the good things and the experiences in other departments. We will certainly be documenting that, and there are other areas. The position paper we have developed on flexible options for living in the community, things like that, we will include in a package to you in the next couple of weeks.

CHAIR: Thank you. That would be terrific.

Ms SWEENEY: Just to give you a story that sums up our frustration around DADAHC is that we think they are very skilled and very good at policy, planning and assessment, and those things are really important. But when it comes to the delivery of what has been planned and policied and assessed, it falls down. Again there is community outcry. There is unrest. There are reports, there are inquiries. Then DADAHC or ADD in the past and DOCS before that—it is a common thread; this is historical—goes back and plans again and does another policy about why it could not do it and assesses everybody.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: And does not deliver again.

Ms SWEENEY: And it does not deliver.

CHAIR: Some people have shown us their transition plans from about 20 years ago.

Ms SWEENEY: It is a cyclic thing; the department keeps reinventing itself. It is in a state of flux so there is no memory horizon within the department from DOCS to ADD to DADAHC. Lots of people are in contracted positions; they are short term. You need to have organisational memory so that you do not keep reinventing back to the beginning. Of course, people with disability in their family have long memories because they live their lives knowing this. So you can see that it is collective unrest about those issues. The department often does not understand that because it does not have that bureaucratic memory or the memory horizon of the people who live it. They often say, "These angry people" and "It's not our fault".

To give you an example, ATLAS and day programs have been under review. I think ATLAS has been under review since it started, and post-school options before that. We have been involved on a reference group. The Disability Council is the only external member except for departmental people on that. Our representative came back last week and said, "We are having a review so the first thing we need to do is go back and re-assess everybody on the program." It is a prime example that the department is still doing what it has always done. That is not to say that it is not valuable; it is to say that you have to implement these things.

Ms DRUETT: A question I asked about ATLAS, which is about employment, was whether public sector employers were involved. I was told that the department is not looking at the public sector. I said, "Why not? If you are going to ask business to employ people with disabilities you would think there is some benefit in having the public sector model that." I was told, "Oh, we might do that next time around." To me, you do that first. You show that the public sector can provide employment and then you go and ask business. But this person looked at me stunned when I asked about the public sector. There are some metaphors around that that are negative around people with disabilities. We the public sector will not hire somebody but McDonald's or Coles can. I think there are some very bad metaphors about the value of people. It was such a shock to this person, who just looked like I had said something that never entered his mind. I was absolutely stunned.

(The witnesses withdrew)

(The Committee adjourned at 3.40 p.m.)