REPORT OF PROCEEDINGS BEFORE

GENERAL PURPOSE STANDING COMMITTEE No. 2

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

At Sydney on Tuesday 10 May 2005

The Committee met at 9.30 a.m.

PRESENT

The Hon. P. Forsythe (Chair)

The Hon. A. Catanzariti
The Hon. Dr A. Chesterfield-Evans
The Hon. J. Jenkins
The Hon. J. F. Ryan
The Hon. C. M. Robertson
The Hon. H. S. Tsang

CHAIR: Welcome to the first hearing of General Purpose Standing Committee No. 2, Inquiry into Changes to Post-school Programs for Young Adults with a Disability. Before we commence, I would like to make some comments about aspects of the Committee's inquiry. This inquiry has attracted strong community interest, in particular, from parents of young adults with a disability. The Committee has received 150 submissions to this inquiry. On behalf of the Committee, I would like to thank all of those individuals and organisations that have taken the time to make a submission to this inquiry.

Many of the submissions to the inquiry had been placed on the Committee's web site. The secretariat received several calls from parents and carers who indicated that, while they were happy for their submission to be published, they did not want their submission placed on the Committee's web site. In the interests of privacy, submissions from individuals, therefore, have not generally been placed on the web site. However, the Committee values the experiences of people with a disability, their families and carers and will place any submission on the web site it receives, if it receives a request to do so.

The Committee has planned various activities to obtain evidence about the changes to post-school programs. This is the first of two public hearings this week, the second of which will be held tomorrow. Next week the Committee will visit Tamworth, Armidale and Wagga Wagga to meet with people with disabilities, their parents and carers, and to visit organisations providing post-school programs. The Committee will also hold parent forums in Armidale and Wagga Wagga. Later, the Committee will hold discussion groups with people with a disability. Transcripts of our hearings and parent forums will be placed on the Committee web site, as will the report on the discussion groups.

Parliament House is an accessible building. A hearing loop is installed in the Jubilee Room and accessible toilets are located off the main lobby. Parking is available on request for people with mobility restrictions. The attendants are available to provide assistance during today's hearing. Mr John Jenkins will substitute for Reverend Dr Gordon Moyes for the duration of this inquiry. Reverend Dr Moyes has advised the Committee that he has withdrawn from participating in the inquiry due to his perception of a conflict with his role as superintendent of Wesley Mission, a large disability support provider, and the terms of reference for this inquiry.

The Committee has previously resolved to authorise the media to broadcast sound and video excerpts of its public hearings. Copies of the guidelines governing the broadcast of the proceedings are available from the table by the door. In accordance with the Legislative Council guidelines for the broadcast of proceedings, a member of the Committee and witnesses may be filmed or recorded. People in the public gallery should not be the primary focus of any filming or photographs. In reporting the proceedings of this Committee, the media must take responsibility for what they publish or what interpretation is placed on anything that is said before the Committee.

Witnesses, members and their staff are advised that any messages should be delivered through the attendants or the Committee clerks. I also advise that under the standing orders of the Legislative Council any documents presented to the Committee that have not yet been tabled in Parliament may not, except with the permission of the Committee, be disclosed or published by any member of the Committee or by any other person. The Committee prefers to conduct its hearings in public. However, the Committee may decide to hear certain evidence in private, if there is a need to do so. If such a case arises, I will ask the public and the media to leave the room for a short period.

GARY MOORE, Director and Chief Executive Officer, Council of Social Service of New South Wales [NCOSS], 66 Albion Street, Surry Hills, and

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

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

Mr MOORE: Yes.

Ms REGAN: Yes, I am.

CHAIR: If you should consider at any stage that certain evidence that you wish to give or documents that you wish to tender should be heard or seen only by the Committee, please indicate that fact and the Committee will consider your request. Do either of you wish to make a short opening statement?

Mr MOORE: We would like to jointly make a short opening statement, firstly, to say that NCOSS believes that the reforms introduced in this area had sound objectives but were very poorly designed and executed. We supported the need for reform today in school leaver programs to provide better integration and streamlining of a number of programs to provide improved services and develop a whole-of-life support to adults with disability. NCOSS supports the goal of employment and work for people with disability and, where that is not possible, dignified daytime participation in lifelong learning, personal development and community involvement.

Ms REGAN: The announced changes in July 2004 do not meet the anticipated goals. Instead, the Department of Ageing, Disability and Home Care [DADHC] announced reduced per capita funding but a slight increase to overall funding over four years—that changes from $50 million in 2004 to $54 million in 2008—but with nearly twice as many service users. The Adult Training, Learning and Support [ATLAS] program was to be replaced by two new programs—community participation and transition to work, thereby increasing the number of day programs. There has been a loss of individualised funding in favour of block grants to providers and there was an extensive tender process almost immediate, and not consulted with any sector.

The then Minister Tebbutt assured families that the two new programs would be substantially different from the existing ATLAS program but did not explain in what way. Minister Tebbutt further assured families that the reforms were not intended to result in a loss of hours or cuts to service, and they have done. NCOSS supports many of the goals of the two new programs but the reduced per capita funding will negate any proposed benefits to individuals with disability and their families. The loss of individualised funding has resulted in a loss of portability, a loss of flexibility and a loss of responsiveness to individual needs.

Mr MOORE: The process used to announce the reforms, then to amend the reforms, then to contain reactions to the reforms, in our view, has been very badly handled by the Government and the department. The DADHC projected outcomes for the new programs have not been supported by evidence, except reference to similar programs in other States. Last week NCOSS spoke to representatives in most other Australian States, only to find that they are watching developments in New South Wales before they proceed with their own reforms.

CHAIR: Thank you very much, and can I also thank you for the extensive submission that was received from NCOSS. Prior to the changes, we have seen a throughput of about 3 per cent, as you indicated, in the two new programs and yet, according to the department, it is based on an assumption that that throughput will increase to a very significant number of people going into the transition to work program. What sort of figure would you believe is realistic for what they will be able to achieve?

Ms REGAN: I would say that is very difficult to estimate, basically because originally, after the reform process was announced, people and families were assured that there would be substantial differences in the programs that were provided after the reforms and comparing that to ATLAS. You are quite right, DADHC has reported that there was a 3 per cent throughput under ATLAS and post-school options. Under the proposed reforms it looks like DADHC is anticipating a 60 per cent throughput—some directed to Commonwealth programs and some to transition to work. Of those who do not go directly into Commonwealth programs, half the remaining applicants would go into transition to work and half would go into community participation.

Without substantial changes to the provision of the programs, it is really difficult to estimate that in one or two years there could be a change from 3 per cent to 50 per cent. We would have seen that there should be incremental changes and one of the reasons why NCOSS was very supportive of participating in the prospect of reforms was because there needs to be improvements to ATLAS and to the new programs. So, I would hesitate to actually give you a figure amount, but I think there will be people appearing before the Committee who could give you that.

The Hon. TONY CATANZARITI: In your opening statement you made reference to the fact that programs do work elsewhere. Can you provide examples of that?

Ms REGAN: Under the ATLAS program there were some creative providers, who were actually having really good involvement of people with disabilities in prevocational and vocational programs as part of the former ATLAS program. There are other programs that are innovative under a range of funding options that do have some success in transiting people with disabilities from school into a work environment, but they are few, and they are usually innovative programs that have been initiated by specific providers. I think that you would get better information on the content of those programs and how those would operate from tomorrow, when you talk to your service providers.

The Hon. JOHN RYAN: Thank you for coming today, it is much appreciated. Can I ask you a couple of questions relating to amplifying or explaining some aspects of your submission? First of all, you have referred to a report by the Productivity Commission, which reported that New South Wales had the lowest number—4.2 per cent—of people with disabilities using community access services defined as learning and life skills development as a proportion of the estimated potential population of community access users, the national average being 7.3. That appeared to me to be a profoundly interesting paragraph of your submission but it really was not clear to me what you were getting at.

Ms REGAN: Many of the proposed changes were premised on anticipated reforms in other States. We were concerned not only that New South Wales had such a low proportion of existing participation, but also because under the reforms we would have lower per capita expenditure in that participation. It was very difficult to see how the reforms would operate to increase the number of people who would participate in community access programs. Mostly, the community access programs referred to in the Productivity Commission report relate to the community participation program that we would be talking about under the reform process. It was very interesting that, while New South Wales was watching what other States were doing, in our recent and ongoing discussions we found that all other States are now watching what is happening in New South Wales in order to change their own practices in the same and like programs in other States.

The Hon. JOHN RYAN: Is what you are saying regarding programs like post-school options, Atlas, transition to work and community participation that less people per capita in New South Wales are participating in those programs by comparison with other States?

Ms REGAN: Yes.

The Hon. JOHN RYAN: Do we have a way to go in funding? What is the reason for the difference in participation? Is it that programs are not available, or people just not interested in them?

Ms REGAN: It is interesting to note that the programs began in 1992. Before then, if you could not get into a business service—which is a new term for sheltered workshop—it was very unlikely you would receive any day supports. There are a very large number of people in New South Wales who are at home and supported by families. Those families have had one or two parents remaining at home to support that person, who has no day activities. Maybe those persons have had some recreation, and maybe they have had some respite, but it is likely we have a very large population of adults who do not receive any day supports or life-long learning or community participation programs. So the deliberate expenditure in New South Wales only began in 1992.

The Hon. JOHN RYAN: Further on in your submission you advance to flow-on effects of some of the reforms. One of the flow-on effects that you have reported is a relationship between how people will exit New South Wales programs and enter Commonwealth programs. I am not sure that would be well understood by all members of the Committee, so it might be helpful if you were to explain that in lay terms.

Ms REGAN: It is estimated that 20 per cent of school leavers who are supposed to go through the new programs could go directly into a Commonwealth program. That means there would be some assessment of whether or not they would be eligible to enter pre-vocational or vocational programs provided by the Commonwealth. The transition to work program will receive 50 per cent of those not going directly into Commonwealth programs; that is, school leavers with disabilities and others already on the program are supposed to go in for two years of pre-vocational training in order to prepare them for two outcomes: one, that they then go on to a Commonwealth work program; or, two, actually enter directly into employment.

We have asked questions of the department throughout the reform process, such as, "Has there been negotiation with those Commonwealth programs so that the entry criteria for those programs is the same as the exit criteria for transition to work?" That is so that a person who finishes, or graduates from, transition to work who might not find a job but needs to enter and employment program goes seamlessly through. Each time the department has come back and said, "We are entering or are about to start those negotiations." NCOSS is very concerned that the negotiations for a program of this magnitude, particularly one with such far-reaching effects, possibly should have been completed before the announcements were made about the changes.

The Hon. JOHN RYAN: What do you feel will happen to people who reach the end of the two-year transition to work program and are not eligible for Commonwealth programs?

Ms REGAN: Many families and service providers have contacted NCOSS expressing those fears. The expectation is that someone who leaves transition to work, having gone through a vocational program—which we assume will have quality, because you will notice in our submissions that we are supportive of most of the objects of both of the two new programs—will go on to the next thing. The next thing will either be employment—and there we also have concerns because in many cases that employment will be part time, and there could be a need for further supports during the day—or it could be to go into a Commonwealth program that might then lead them to ongoing employment. But, if neither of those happens, what then happens? The department changed its story last year.

Originally, nothing happened, so the people were then required to "manage". But now the story is that if people exit the transition to work program and have no other supports during the day, they can then enter the community participation program. The process for doing that is obscure. Having seen the draft guidelines over the past couple of days—they have not been released yet for either of the programs—it is still unclear how that transition will work. NCOSS is very concerned that, once the transition graduates enter the community participation program, which is at lesser funding and an ongoing program, they may not again get access to vocational or other opportunities that come through the Commonwealth to increase their skills. We are worried that there will be a loss of skills, a deterioration of health, and a loss of motivation perhaps to maintain the skills that they use during transition to work and then those opportunities dry up.

CHAIR: What has been the response of the Department of Ageing, Disability and Home Care [DADHC] on that particular issue?

Ms REGAN: I think DADHC thinks it is quite okay for a transition to work person who does not get access to anything else to come to community participation. DADHC reports it is expecting there will be transfers between community participation and transition to work. As John rightly said, we are concerned about what will happen to enable graduates to transition to work to maintain their skills. We are also concerned for those community participation people who leave school and are not ready for pre-vocational skills but might in a couple of years then become ready. How do they get access to transition to work?

You will note that in our submission we have suggested a scenario that says that there is an actual structural and financial disincentive for community participation people to enter the transition to work program. We are worried that transition to work graduates who then are parked in community participation will be treated like another community participation applicants and not get access again to transition to work at some appropriate time in the future. None of those program guidelines have been clearly developed yet, nor the system worked out, in our opinion.

The Hon. JOHN RYAN: As I understand it, essentially what has happened up until now is that the two programs largely have been integrated. If you were to go to most of the service providers you would have people who were learning skills that are relevant to work working together with people who were doing a longer-term program when it was understood that those people would never make it to work. The impact of that has been that the two programs have been funded at exactly the same rate. Is there a case to fund transition to work differently from community participation programs? And is there a case to separate the operation of the two programs?

Ms REGAN: I would refer to a statement made at a community meeting by a senior DADHC staff member on this issue. The senior DADHC staff member said, "We must fund transition to work on a per capita rate that is higher than community participation because those people are likely to work, and so the service providers will need better skills." I think that is an incredibly demeaning statement because those in community participation are as valuable as anyone who works or is in employment. Some of them have very complex needs. People need to have a minimum degree of skills and qualifications in order to provide the appropriate supports and opportunities for people with disabilities, whether or not they are entering work. That was the reason given for a lower amount for community participation and a higher amount for transition to work. NCOSS absolutely out of hand rejects that reason.

The Hon. JOHN RYAN: It is a bit hard to find material in the DADHC submission that justifies why it has come to the $13,500 cost, but the one paragraph that seems to be relevant I would like to read to you and seek your comment on. It is on page 17 of the DADHC submission, and says at 2.13:

> As the community participation program has a long-term focus on the development of life skills development and community participation, rather than the shorter-term intensive focus on transition to work, DADHC expected Atlas services to reconfigure their programs and costs to provide longer-term support. The base rate of $13,500 is seen to be reasonable as it's equivalent to many interstate programs.

There is a lot in those two statements to comment upon, but would you like to respond to that justification for $13,500?

Ms REGAN: It is absolutely true that in other States there are rates at $13,500 and there are rates at $9,000. In fact, in one State there is one rate at $1,000. But we have to be really clear that we are comparing like amounts of money. We are not comparing the skills, capabilities and needs of people who need those services at those rates. Previous research by NCOSS has shown that the differential rates in other States are comparing people with different needs and skills on different rates. In other words, in New South Wales we are looking at providing $13,500 per place for people who in other States would reasonably get $16,000, $18,000 or $20,000 per place.

However, if you look just at the dollar amounts and not attach that to the degree of need or the degree of intervention, that does not give you a picture of who your clients are and whom you are working with. For example, in Western Australia the lowest rate is $1000, and that $1000 is provided in a package and individualised for the support of the person with mild disabilities who needs a little extra support to access other services. So you would not then compare that person with a person in a community participation program who, like those in other Atlas programs, has at least moderate to severe disabilities and would require support in an ongoing way. Is that clear?

The Hon. CHRISTINE ROBERTSON: Could you give the Committee some idea how the other States have set criteria for the different gradings?

Ms REGAN: As I have said, they are looking to New South Wales for changes that they might introduce.

The Hon. CHRISTINE ROBERTSON: You gave the example of Western Australia.

Ms REGAN: My understanding is that Western Australia has about seven rates, and that those rates are pegged to the degree of need of the person receiving the package of care. The highest rate is $25,000.

The Hon. CHRISTINE ROBERTSON: Who does those assessments?

Ms REGAN: I understand that is part of the function of the Disability Services Council of Western Australia, but I am not certain of the actual process. I know it is very individualised and that the person and the family are able to designate what the priorities are for spending for those daytime activities.

The Hon. JON JENKINS: In your submission you mention that the Government had undertaken some research to try to classify and assess funding. You note also that that research has not yet been released. Do you have any research as to what the appropriate funding levels are?

Ms REGAN: No, we do not. We would be relying on both the industry and some of the advocacy organisations for information on those rates. We certainly know that, under the previous Atlas program rates, service providers were reporting to NCOSS that they were struggling to provide ongoing service at the higher levels. Those levels ranged from around $14,000 at the lower end to upwards of $21,000 at the higher end, depending on the person who was being supported. But, generally, they ran around $16,000 or $17,000. So the new rates are a significant decrease, even when services were saying in some cases they were struggling to provide opportunities and support at the higher levels.

The Hon. JON JENKINS: Are you saying that, at least on the evidence you have, a significant increase in funding is required?

Ms REGAN: The original level for entry to community participation under the changes announced in July last year was $9,000. Then there was a change to $13, 500, which is the amount we are now talking about. When the change was announced there was some expectation from the department that families would find comfort in the increase. Our experience from talking to families is that, instead of representing a 50 per cent cut, it now represents a 25 per cent cut, and continues to provide no comfort to families.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is not the key problem here a big explosion in demand with the Government capping the amounts?

Ms REGAN: I would say certainly the Government capping the amount, I do not think a huge explosion in demand because we know how many people with disabilities there are. We also know how many people with disabilities are coming through the school systems and those populations are known. What we would say though is that the day support programs of this nature only began in 1992 so deliberate expenditure began quite late in many people's lives. The population of people with disabilities is increasing, as we noted in our submission, but those figures come from DADHC's own references so these populations are known. I do not know if there is an explosion. I think these are known populations that have suffered from a lack of deliberate expenditure in any longer term or actual considered way.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Perhaps when I say "explosion" I mean—you are saying that it did not start until 1992, which presumably means that it was zero in 1991 and now it is considerable with kids coming through at the end of each school year.

Ms REGAN: Before then, as I said, we needed to either get access to a business service, a sheltered workshop, do your own arrangements, try to get into a Commonwealth program or go to a day activity centre. A significant number of young people with disabilities ended up in aged care day activity centres, and there are a few historical services that are still day activity centres of the old nature, which is often well-intended but large group activities in a large room.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But this is still a big increase in demand. I mean, you are talking 30 years here. Is this because more people with disabilities survived after the Second World War and then they want a decent life and now their parents are ageing? Are these three factors increasing the demand such that the Government, which thinks in terms of CPI increases for every budget line item, is on the wrong planet?

Ms REGAN: I cannot comment on whether or not the Government is on the wrong planet but I would say that the populations have been known but you are quite right. The population of people with disabilities is growing at a rate of 18 per cent for the same period when the general population will grow at 8 per cent. So there is an extended growth, an exponential growth. I think that results in people with disabilities having better access to care and health services so that people do not die, better medical treatment and better expectations of people with disabilities and their families, yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So in other words if it is increasing, if the people with disability needing help is increasing at more than twice the population rate, the Government is not really getting its head around that because I think the general population has not got its head around that.

Ms REGAN: That is exactly right. With deliberate expenditure then we can absolutely avoid or head off the bandaid very expensive contingency funding and programs that tend to happen at a crisis. With some deliberate expenditure we can provide opportunities for people to stay healthy, to contribute in their community, to possibly get jobs and to go into employment, which is what we want for most people with disabilities, as is their right, as we take for granted.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is there a lot of money to be saved by tailoring packages such that the people who do not need very much have a package that is more flexible but needs less total money, is the cost of administering that very high because someone has to meet very individual needs, or are the levels of aid so low that in fact whether you tailor a package or not there is absolutely—

Ms REGAN: NCOSS remains committed to individualised packages. At the existing levels, we would say that that is not reasonable, that money is very low, but in answer to your other point we have found where people have some degree of control and exercise decisions and choice over the way their money is spent then there is more confidence in being able to have their needs met and less likely to escalate to a crisis or anything goes situation that then clearly wears out after a while. Those are very high cost, very expensive options. In our opinion there are very few people in New South Wales who are at the very high end for day packages. Most people would fall into the middle and most people would benefit from being able to have some control over the type and choices that they make around the funding for their day programs. I might also say though that that system continues with post school options so people who are on the Post School Options Program can still exercise that choice and can make the best use of every dollar on their programs.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It was said that DOCS was a dysfunctional department, and we had an inquiry into it. People have said to me that DADHC is completely dysfunctional and does not deliver. Do you think that is a harsh criticism, or do you think it is true?

Mr MOORE: Certainly, people in our sector have suggested that DADHC at the moment is at the same point that DOCS was at in the late 1990s. In relation to this issue, we were certainly told off the record both by the Minister's office and by senior departmental staff last year that this decision was foisted on the department by Treasury. It was based around looking across the expenditures in the other States, in particular what Victoria was doing. That is where the $9,000 figure came from. The department had little option in terms of accepting it because the department was seen as a financial basket case.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think that DADHC is doing quite well with the resources it has?

Mr MOORE: I think there is some evidence in recent months that there are some improvements in some areas. However, the department still has a long way to go to retain or grow the confidence of the non-government sector and of families and carers. Unfortunately, there is still at times an approach to change and reform in dealing with significant issues which is wholly arrogant in its approach, is non-consultative and which does not simply deliver results at the end of the day. Having made those criticisms, NCOSS, along with ACROD and Ageing Community Services New South Wales, is engaged in discussions and attempts at negotiations across a range of DADHC programs at the moment. We are having some success in developing some better pathways to results; in other areas we are doing very poorly.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think that the Government would do better to transfer a bigger percentage of the pie to the non-government sector and less with the department?

Ms REGAN: There was an attempt at transferring some disability direct services in 2000-01. The reaction of the sector and in fact NCOSS's position at that time was that there will always be a need for government providers within the disability sector. However, it is true that many non-government providers can provide quality, flexible and responsive services, and possibly at a lower per place rate than within government. However, our research at that time showed that the people who were generally in government direct services were people with very high needs or higher needs than can possibly be supported in non-government services. So it would be difficult to say whether or not proportions should be just transferred out without some kind of review and planning process.

The Hon. JOHN RYAN: We referred earlier to some research. I want to refer you to some research that is in the DADHC submission to the Committee. Are you familiar with a review of day programs conducted in 2002 by Brian Elton and associates? Is that document public, and are you familiar with it?

Ms REGAN: To our knowledge it is not public. NCOSS has asked each year in its budget statements and response to the department when the day programs review would be released. We have been expecting it since 2001, and we have been assured in two years, in 2002 and 2003, that it would be released each year. We fully expected the results of that research to be part of the prospective reform process that we were supportive of before the ATLAS announcements.

The Hon. JOHN RYAN: I think this Committee has been waiting for that report occasionally, too. Would it interest you that apparently the result of that review of programs was that there were significant differences in the number of hours of support provided through day programs ranging from 12 hours to five days a week on both PSO and ATLAS services provided, 18 to 20 hours a week, where possible people received a service for 24 or more hours a week. This was usually the result of the person attending TAFE or unsupported workplace. In other words, I think the point being made is that there is a variety of hours. Is there anything in this reorganisation of programs that does anything to address that problem?

Ms REGAN: No.

The Hon. JOHN RYAN: One of the other issues was that the minimum cost for the day program was $9,667 in 2001 per person. There was a wide variation in funding levels ranging from $458 to $34,500 per year. Is there anything in the current arrangements that do anything to address inequities in funding?

Ms REGAN: I would find it very difficult to compare the ATLAS program or the two new programs to the day activity programs. The day activity programs were those programs that I referred to earlier, where they are historical. They were developed—in many ways they are one up from respite—and it depends on the quality of the provider about how the opportunities that the people who attend those programs can access, rather than any guidelines or any obligations on the provider as part of their funding package. Under ATLAS and under community participation and transition to work, there are obligations on the part of providers as part of their funding contracts to provide opportunities in lifelong learning. The problem here is that the funding is so restricted that those opportunities will necessarily be reduced, diminished or restricted as part of that funding contract and that is what we are reacting to. I would be interested in the outcomes of the day programs report because we were hoping that the reforms to adult daytime activities would be part of one reform process and we would have one process regardless of where you entered the system.

In other words, school leavers would be able to enter at the appropriate point; adults who became part of the program could enter at a particular point; adults who sustained a disability in adulthood and who needed this kind of support could enter at that appropriate time. At the moment if you are in a day activity or a day therapy program it is because you were there, or because there was one nearby and nothing else happening for some years before 1992. Then in 1992 post school options changed and if you were a school lever you could have access to that but if you are in adult and still unclear what you would do and where you would go, historically we were hoping that the reforms would start to streamline those and make them clearer for families and for people as part of a whole-of-life response. We believe that has not happened with the splitting of one of the existing programs.

The Hon. JOHN RYAN: One of the other dot points mentioned in the Elton report is that services lacked flexibility in responding to individual needs. Do any of these reforms address that concern?

Ms REGAN: In the change from individualised funding to block grants, we would be very concerned, as we have made the point fairly clearly, we hope, in our submission, that there will be a loss of individual responsiveness simply because in order to provide a degree or a quantity of service you will need to group people in two large groups with more common good activities. Despite the guidelines coming out and saying we need individualised packages, it is difficult to see how $13,500 per person will be able to deliver that for people with moderate needs, let alone people with high support needs.

The Hon. JOHN RYAN: Have you heard of a report prepared by Ernst and Young on an evaluation of post school options published in 1997?

Ms REGAN: We are not familiar with that report.

The Hon. JOHN RYAN: Is it likely that that has not been published either?

Ms REGAN: Sorry, I am not familiar with that.

The Hon. JOHN RYAN: Are you familiar with a piece of research done by ACROD in 2000 New South Wales services project issues paper?

Ms REGAN: We knew about the ACROD research, yes.

The Hon. JOHN RYAN: Finally, are you aware of who was doing the costing survey from Wollongong? Do you know who the academics were who were doing that research?

Ms REGAN: We did know at one time but we have not been in recent contact with them.

The Hon. CHRISTINE ROBERTSON: You have a section in your submission in relation to assessment methodology but not a lot of information on what you suggest to be the resolution to this except that it should be face to face and individual but still leave subjective places. I am just wondering if you know how much information there is available on assessment methodology.

Ms REGAN: In our opinion there are some good assessment methodologies. What we were reacting to was the fact that for community participation by our count there were five assessment processes that either an organisation or a person would have gone through to be determined about their eligibility for either transition to work or community participation if they were an existing ATLAS person. That created huge uncertainty, as you would expect, amongst families. It got to a point where families were wondering, "Will there be another assessment? " or, "What's going to happen next?"

The big issue there as well, aside from the actual methodology—and I am sure families will give you first-hand accounts of that this afternoon—is the fact that the assessment methodology applied, but there were no guidelines about what would happen next. Where a person or a family disagreed with the outcomes of the assessment methodology there was no recourse. Reports to us are that DADHC would say to families, "Yes, you can have a reassessment, but it will be in six months", which effectively meant after you began whatever program you had been streamed into. That was very disheartening for both providers and for families as well.

The Hon. CHRISTINE ROBERTSON: I have heard that we have these changes, and I am not saying whether this is right or wrong, but quite a few people hours were dropped back because of the 13,000. But as well as that per hour with many of the providers, the individual people were paying quite a lot more money per hour not necessarily for a different service. I think it was the Hon. Dr Arthur Chesterfield-Evans's question in relation to non-government providers and necessity for profit margins or even breaking even. Could you tell me what you know of this?

Ms REGAN: Reports to NCOSS on this issue are twofold. One, that in order to provide quality service many service providers have decided to reduce hours in order to maintain a standard of quality that would meet with the Disability Services Act. Reports have come to NCOSS that some hourly rates have gone up, while that has been discouraged by the department. But there have also been reports that some families have been so pushed to receive services that they are offering to purchase days from providers and you can spend anything between $80 and $140 a day if you want an extra day and that comes just out of the family's pocket. ACROD would be a better avenue to answer the question about the hourly rates. There has been set fee set by the department. It is basically industry standards.

The Hon. CHRISTINE ROBERTSON: The Commonwealth or the business services themselves have changed a lot of the criteria for entry into those and are expecting a much higher level of skill for individuals who can be there. Does this make a lot of difference to the day care or community-type program requirements?

Ms REGAN: Absolutely. But we are talking about people with disabilities. We would not be referring to day care because we would have been talking about a support of people in order to access community—

The Hon. CHRISTINE ROBERTSON: The language is not quite right.

Ms REGAN: It sometimes falls into a children's problem, which is not what you are suggesting, but that is something we would seek to avoid. The fact that this comes hard on the heels of changes to the business services entry criteria and productivity assessments just exacerbates the opportunities for people with disabilities to go into work. Before business services would accept people with disabilities, almost anyone who wanted to be in some kind of occupational work. Now there needs to be a particular outcome, a particular level of productivity, as you have quite rightly said, and that means it is more difficult to enter business services if that is what you chose to do. And business services are required to have a higher level of productivity and act more like businesses. There has been some discussion on whether or not it is reasonable for business services to act like commercial enterprises. That is another discussion. But that simply exacerbates the pressure on community participation and transition to work, and entry into any of those Commonwealth programs.

Mr MOORE: Could I re-emphasise the point that was made before in terms of the lack of discussion between the two levels of government in terms of the changes taking place at both levels before these changes were put into place.

The Hon. HENRY TSANG: How can the Commonwealth and the State providers reform the service so that there is a better service for the people with disability? They must be able to talk to each other and come up with a total service.

Ms REGAN: We believe they can. In reality it is very difficult for Commonwealth and State to negotiate on such programs. But where the guidelines for entry criteria into Commonwealth programs are very clear then it would make sense that the exit criteria for State programs that are supposed to stream people into Commonwealth programs should also then be identified and negotiated. The problem occurs where there is some grey area between entry criteria and exit criteria. But the point that Mr Moore was just absolutely emphasising was that very few, if any, negotiations occur at the time of the reforms and we would say if that could have been negotiated there could be some confidence of transition to work graduates actually then being able to enter the Commonwealth pre-vocation program or a Commonwealth employment program, or then directly on to a job. But that simply has not occurred.

The other point I will make there is that there was an expert reference group that DADHC consulted with in the years previous to the reform announcements and I believe that they made some good recommendations and strategies on how the Commonwealth and State might actually streamline their entry and exit criteria. But when the announcements came through the members of that expert reference group informed NCOSS that they had not been consulted or consulted any of the major changes, being the drop in funding, the change to block funding and the tender process. None of that had been discussed with the expert reference group.

CHAIR: Thank you for your participation and, as I said earlier, your extensive submission and the time you have given us. If there is anything else you believe that we need to be aware of arising out of questions, we are always happy to take further responses from people who have participated as witnesses.

(The witnesses withdrew)

ANDREW BUCHANAN, Consultant, sworn and examined, and

DOUGLAS DOUGALL HERD, Director of the office of the Disability Council of New South Wales, affirmed and examined:

CHAIR: In what capacity are you appearing before the Committee, that is are you appearing as an individual or as a representative of an organisation?

Mr BUCHANAN: As a representative of the Disability Council.

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

Mr BUCHANAN: Yes, I am.

CHAIR: In what capacity are you appearing before the Committee, that is are you appearing as an individual or as a representative of an organisation?

Mr HERD: A representative of the organisation.

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

Mr HERD: I am.

CHAIR: If you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee, please indicate the fact and the Committee will consider your request. Would either of you like to make a short opening statement?

Mr BUCHANAN: I would like to thank the Committee very much indeed for inviting the Disability Council to give verbal evidence to complement our written submission. Can I make it clear that it is not Mr Herd's or my intention to repeat what is in that submission, but basically to speak to the fundamentals and we do not intend to speak for service users or providers. As you know, we are not a non-government advocacy organisation trying to represent a community perspective. Others, of course, at the hearings are far better to present those points of view. We would also like to complement such perspectives with elements of the best advice that we are able to give to government because, primarily, that is our role as a disability council. At the outset we need to confirm that progressive development of the former arrangements was both very necessary and overdue. No stakeholder had its needs met wholly by the former arrangements, and it was in no-one's interests that the former arrangements be sustained.

We recognise, however, that grasping the reform nettle presented challenges to everyone involved, and that is obviously why we are here. Would the best interests of individuals with disability be met? Could the legitimate anxieties of the families be assuaged? Can stable and non-government services to be developed and sustained at the same time as enhancing the flexibility of a person's centered planning that might at best be served by an individualised funding model? What levels of funding would guarantee successful outcomes for individuals? How high a priority for investment by government would reform receive? What priority does success in these policy areas have with the public at large? And how do we define success? We do not underestimate the difficulty of the procession of reform. Although we believed that reform was necessary we acknowledge that it was never going to be easy–probably easy with a capital "E". There has been, and remains, potential for conflicting interests to collide. In our view, therefore, the overriding interest must always be to determine what is in the best interests of the individual with disability. I repeat, what is in the best interests of the individual with disability.

I say that because we believe and also because the Community Welfare Act, which created out Disability Council, places a duty on us to promote participation by individuals with disability. Throughout the process of reform everyone has indicated that one of its objectives was to achieve higher quality outcomes for people with disability and yet, somehow, we have managed to reach a position in which individuals with disability are not guaranteed that either of the reform programs will lead to the outcomes to which they are directed: transition to work or community participation. It seems to us that individual's anxieties have increased because neither objective looks as if it will be more easily achieved or more likely to be sustained. Families and the associates of people with disability may feel less confident that the family unit is supported and sustained as a result of the reform process at a time and in circumstances when life is already tough enough.

Service providers seeking to develop, improve and sustain higher quality services have expressed doubts that the new framework will make that easier to achieve. And while no-one contended that the initial funding formula was adequate, it may be that almost everyone still questions whether the latest figures constitute the necessary and adequate funding settlement. The Committee may hear more about that over the course of the next two days and, of course, in subsequent evidence. We had acknowledged that reform was necessary, but difficult. We must, however, make some additional observations. The difficult process would have been easier to manage and sustain if its policy and funding drivers were very clear from the outset, and we feel that there was a lack of clarity and purpose that proved to be very unhelpful. More could have been done in the lead-up to reform to explain its purpose, its objectives, and how the reform was to be conducted and what its outcomes might be. Change is always unsettling and the potential for this change is particularly unsettling for the individuals. At the heart of it, it seems to have been underestimated, perhaps by all concerned.

Given the existence of expert groups and interested parties convened by the department, not enough was done to bring those legitimate stakeholders on board at an early stage to benefit from their expertise and commitment. More attention needed to be given to managing and administering the changed process. Individuals and families needed to be better informed. The mechanisms for problem solving, complaints handling and appeals about the decisions ought to have been developed earlier in the process. And at a purely human level, which after all perhaps is the crux of it, the process could have been better handled. Too many ended up anxious, as I mentioned, because they were made to feel unsure about what was going on and what the results would be.

We are still not convinced that current arrangements will lead to those intended outcomes. We hope that some additional reassurance might be able to be given by the department. According to the figures we have seen, and as you heard earlier, it is clear that in New South Wales we all need to do more to improve participation by that target group both in employment and in the community. Life transitions such as that from school to adult life are hard enough for everyone. People with disability encounter additional barriers and difficulties that most people never experience. We need to accept that this is not a problem for, or the responsibility of, the State Government alone. So often I think it is very easy to blame State governments.

This difficult time of transition occurs at a problematic point of intersection, to use a bit of jargon. The State and Commonwealth must work better together to solve some fairly tricky problems that only jointly they can address. In conclusion, we recognise the need for reform, but we believe that the reform must fit the needs of individuals. We believe that the reform process should have started at a different point. The key question is not what kind of service we can build; the key question should be and must remain: What support is needed to bring about the results that we seek to achieve for each individual with disability? The process of reform could have been better handled.

We do not yet have a final package that is guaranteed to deliver the desired outcomes of effective transition to post-graduate participation in employment, education, training and/or the community. This debate must be about more than just money. We believe it must include discussion at funding levels, which appear to us still to be insufficient for the tasks ahead. We need to seek solutions together that encourage all stakeholders to commit to positive processes of change. The State and Commonwealth governments must work together more effectively—they must have a successful marriage. We need to restate our shared commitment to a common purpose—providing timely and best quality support—so that individuals with disability may achieve what they can to the best of their ability and so that may live those ordinary lives that most people take for granted.

CHAIR: In the lead-up to the reform process, what consultation took place with the Disability Council relating to the nature of these reforms?

Mr BUCHANAN: I think it is fair to say that we had preliminary discussions with the department. We are there simply to advise, which is what we did. Again, as we said in our written submission and from what I said this morning, naturally we would have liked to have had more detailed communication relating to the repercussions and all the outcomes.

The Hon. JOHN RYAN: I wish to seek more detail to that important question. These reforms were introduced around July 2004. Exactly what briefing did you get prior to that? Before these things were essentially ready for announcement was the Disability Council consulted at all?

Mr BUCHANAN: It was consulted in a very preliminary manner. Perhaps in hindsight it would have been preferable if it had been more detailed.

CHAIR: Mr Herd, can I confirm whether or not you wish to make an opening statement?

Mr HERD: No, the chairperson has done that.

The Hon. JOHN RYAN: Mr Buchanan, you mentioned at the outset of your verbal submission that reform was needed. What are the issues that need to be addressed by reform?

Mr BUCHANAN: In essence, one of the difficulties has been that it was not really meeting the requirements of those who were there. This is a dilemma, is it not, for all concerned and in particular for individuals. The needs of those with a disability were not being fully met. There was not a great deal of encouragement and there was not a great deal of flexibility. I think it was probably pertinent and timely for there to be an examination of those. From the Government's point of view, of course, at what level do you provide funding? The unmet need for some of these issues would never be met. So I think it was quite a mature approach to at least initiate some form of reform.

The Hon. JOHN RYAN: I am still having difficulty getting from you what are some of the issues that you thought needed reform? Perhaps I could give you some ideas. The department's submission to the Committee outlined some issues raised by a report prepared by Mr Brian Elton in 2002. He referred to the fact that some of the programs were merely concerned about filling in time and they were not addressing individual aspirations; services lacked flexibility; there were variations in the unit costs of each of the programs; there were significant differences in the number of hours of support given to each individual; large numbers of people did not have access to day programs at all; and so on. Are those the issues that you are referring to, or is there something else?

Mr BUCHANAN: Those are the issues that I was referring to. With respect, I did talk about flexibility and creativity. I am sorry that you are not clear, but I think that I covered some of those points.

The Hon. JOHN RYAN: Your organisation's submission refers to difficulties and states that the community participation program does not include people who get involved in post-secondary education. Could you explain to the Committee how that works? For example, are people who go to TAFE eliminated? Are only people who go to university excluded? Could it affect people who might do only a limited number of hours of post-secondary education?

Mr HERD: My understanding is that people who go to university are excluded. It is not clear exactly what happens to people who might end up in TAFE. Some people do; some people do not. Part of the need is to have that clarified for everybody so that they understand what option they can be presented with at the critical point in their life when they have to make a choice, which any of us has to make at a time that could determine all kinds of possibilities in the future. It seems a bit of a cliché to state that, by and large, you get only one shot at this. If you get it wrong it can govern decades of your life. So decisions are being made in difficult circumstances and at critical times, perhaps without the full breadth of experience that most people might take for granted. Does that answer all your questions?

The Hon. JOHN RYAN: I think what you are saying is that people who finish school may not be in the best position to decide whether that is the right time for them to do the transition to work. It might be better if they were in a community participation program for a while and that they changed at a later stage when they had more skills. Is that what you are saying?

Mr HERD: I was the least equipped person on the planet to know what I should do when I was 17 years old. Forgive me for personalising it in that way, but I think I am as typical as anybody else. It needs to be said from my personal experience—not to be too immodest about it—that I was at the top of the tree. If somebody equipped with the benefit of the best education that my home nation could provide, who had achieved heights of excellence that were very near the top of the list, and who had no external other barriers such as disability, found at the age of 17 or 18 that he was not quite sure what he wanted to do with himself, those difficulties and choices become much more complex and fraught with uncertainty the further away you move from that ideal type.

It is not unreasonable to imagine that people with disability and their families will find those choices very difficult because they have done it tough up to the point they get to when they are leaving school. We might also want to put this view: Some of the problem, in some senses, is coming to terms with dealing with success. I know that that sounds like an odd thing to say, but I think it is correct to say that we are going through something of a paradigm shift for people with disability. There is a growing expectation that people or children with a disability will benefit from the educational policies of a government committed to full integration at primary and secondary schools.

If more and more children with a disability go to those primary and secondary schools and they go through the full cycle of educational opportunity, which I think the evidence supports, we should recognise that that next stage needs to be supported as much as primary and secondary education because we are dealing with an increased number of people with disability and their families with expectations for the future that did not apply 20 and 30 years ago. In some senses that may suggest that, for a period, whilst this paradigm shift continues, we may need to invest a little more historically than we have done to get us over the hump of this change. So we can imagine in the future that people will be better prepared to be more autonomous and independent and, therefore, perhaps less reliant on services in the future.

CHAIR: In your submission you referred to the lower per capita amount that is to be provided under the current funding model. You suggested that that might result in some services "cutting corners". Is that an intuitive response, or do you have any facts to suggest that that will be the outcome of the new funding arrangements?

Mr HERD: I was not an employee of the council at the time—I was an employee of the department actually working on behalf of the council—so I cannot answer. However, my guess is that it was intuitive at the time. We are saying in our submission that we anticipate there will be a cutting of corners. The new system has operated only from 4 April. I think representatives from the Australian Council for Rehabilitation of the Disabled will probably tell you—should I be saying what they are probably going to tell you?—that people are finding it difficult to do the best quality job with the resources available to them. If I were a good service provider, which from time to time I have claimed to be, I would find ways to cut corners to deliver the best service possible, knowing that if I had more money I would deliver a better one.

The Hon. TONY CATANZARITI: Would the $5 million increase in overall funding this financial year be enough to meet the increase in demand without any reforms?

Mr BUCHANAN: It is very difficult for us to comment on that. Obviously the $5 million would be a huge advantage. I refer again to my earlier remarks about unmet need. How do we realistically suggest that any figure is going to be worthwhile? We are dealing with a very emotive subject. I refer to what Judy said about cutting corners. Obviously, what we are interested in is a quality service for those with a disability in this arena. I suppose if you want a clear-cut answer, no amount of money is sufficient, but certainly $5 million would help. I sense that there is a growing awareness within government that the cost of a disability is a real cost and perhaps it is one that really should be addressed by all concerned. Maybe we as community have not really communicated that message to government as a whole in the past.

The Hon. CHRISTINE ROBERTSON: You refer in your submission to key performance indicators. Do you know of anybody who has any work that means anything relating to key performance indicators for these programs?

Mr BUCHANAN: I think the simple answer from my perspective is no.

Mr HERD: No.

The Hon. CHRISTINE ROBERTSON: So if you needed to create such things you would need to go through a massive consultation process?

Mr BUCHANAN: And perhaps it is consultation that is long overdue from both perspectives. As we were suggesting both in our written submission and also in our opening statement, the area of communication is one that I think perhaps in hindsight we have all learned from. Had there been more discussion and communication the fear factor may well have been eliminated to a certain extent.

The Hon. CHRISTINE ROBERTSON: Developing things such as quality measures has the potential to create enormous fear in its own right, does it not, and not just from providers either?

Mr BUCHANAN: Yes.

The Hon. CHRISTINE ROBERTSON: You talked a bit about the program requiring change. What sorts of indicators are there, despite the ones to which the Hon. John Ryan referred from the department? Are there other indicators that change is required? Are there people missing out?

Mr HERD: There are two things, if I may. Forgive me for putting it this way.

The Hon. CHRISTINE ROBERTSON: I will.

Mr HERD: I do not think this is the same as rocket science. We are dealing with human beings and if we want to assess outcomes I kind of think, "Well, why don't we just ask them?" I have all kinds of theories that I can back this up with if anyone really wants to hear the theoretical platform upon which I am going to base my next statement, but I think you just begin with a conversation. You say to the people who receive the services, "How's it going? What do you think of them? What are you doing with yourself?" It is not difficult. If one of the objectives of one of the program is community participation you can do a pretty straightforward "How you spend your time" analysis and we will get a sense of whether or not those people who use the services, their families and their close associates—those on whose behalf the money is being spent—feel more or less able to participate in the community.

I do not think people with disability who receive any of the support through any of these services are any better or less well equipped than, dare I say, any member of the Committee to determine whether or not you feel you are communicating and participating to the best of your ability and as you wish. I absolutely accept that it is difficult to find objective measures for social participation and social outcomes but we are not counting tins of beans on the supermarket shelf; we are asking human beings how well their need to engage socially is being met. I think we can also ask questions in the other program—the clue is in its title: transition to work. There are workers, the process of getting from A to B and how well you are doing. We can number crunch on that: Do 5 per cent get through, do 10 per cent get through, do 90 per cent get through? We can look at the barriers that might make it more difficult for that to happen.

But we can again ask people how well equipped they or their family member may feel may feel they are to engage with the new world in which we find ourselves—which becomes an even newer world when Treasurer Costello gets on his feet this evening and makes his announcements about changes to disability support pension and perhaps tax arrangements that might encourage more people with disability to take the risk and make the transition from disability support pension to work. I guess one of the things that we would be hopeful of is in the conversation that needs to take place with service users and service providers and funders there is better dialogue going on between the State Government and the Commonwealth Government about how the framework can be constructed so that people can begin to make the choices that we can then assess. I am sorry if that lacks some of the rigour that one might expect but I really do think it is easier than we sometimes believe, and it begins with asking the questions of service users.

The Hon. CHRISTINE ROBERTSON: Do think it is possible to have some subjective and objective criteria to measure? You are describing subjective measures. It is sometimes easier to feed people with subjective measures. I am asking a question; I am not having a go.

Mr HERD: I concede that it is a messy business but part of it will go back to the quality of the assessment process that exists at the outset. I think one of the concerns we have expressed—and I think is shared by many—is that the assessments that are conducted are, in many instances, still firmly rooted in what we might call a medical model of disability geared toward quantifying and assessing functional capability, which may or may not be a useful tool. I, for instance, need to know the consequences of my own C5-6 quadriplegia and my functional capabilities but the fact that I am a C5-6 quadriplegic makes absolutely no difference whatsoever to the quality of the work that I do as Director of the Disability Council of New South Wales.

I think we need to get a more sophisticated set of instruments that can assess people's need for supportive services that engage them in other community participation or transition to work, or both. That is a different set of tools that I think is immediately apparent to us as being on evidence in the current assessment process, which—forgive me if I generalise here—looks like an assessment of eligibility for a program rather than an assessment of need for support. Those two things are legitimate and valid but they are not the same.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I am interested in the imbalance between demand and supply in this area and the fact that the Government tends to think in terms of consumer price index [CPI] increases for each line item in the budget in a stable situation. It seems to me that advances in medical technology that allowed people to survive occurred after the Second World War. Then parents either put their children in institutions or looked after them themselves. Now there is a movement that disabled people should have the right to a decent life and that they should be integrated in the community. So you have a lot of factors maturing and changing that would mean that the demand is increasing more greatly than the budget amounts. Could you comment on the factors that are causing this increase greater than the budget because it seems that the Treasury, at least, has not got its head around this at all?

Mr HERD: I agree with you absolutely. That will come as no great surprise. I mentioned a paradigm shift; it is such a cliché but I think it happens to be true for people with disability. The advances in medicine, science and our understanding of the position that people with disability occupy in a modern society are dramatically different, let us say, from my pre-war parents' understanding. Again, I can only illustrate it through this personal way of looking at things because it cuts through some of the rhetoric, if I may. My mother was devastated when I became a person with disability: She thought my life was over. I kind of thought, "Oh well, that's a bit of a bad incident; I better get on with my life". I think that is because I am 40 years younger than my mother and I was educated, brought up and have lived my life in a different set of contexts and experiences.

I think our service systems and our funding regimes generally have not caught up with or kept pace with the changing perceptions of what people with disability and their families want, need, expect and hope for for their lives. I think there are always touchy-feely reasons for doing it: we are living longer, we are living better and there are more of us. All of those things are good things and would it not be better for us all to be able to contribute more, participate more, blah, blah, blah? But there are some hard economic rationalist—if you want to use that terminology—reasons for doing this. It does not make economic sense to keep people with a disability economically inactive and getting them from the position of being passive in an economic sense, as they have been for most of human history, to being active requires some investment in the future.

But there are spin-offs and benefits that will come to us all if we invest a little bit more—we are not talking hundreds of thousands of dollars here; we are talking about maybe instead of spending $16,000 to $17,000 spending $20,000 to $22,000. If we spend that little bit more for a short period of time we will get outcomes that will produce hard benefits for us all in the future. More people will be likely to go to work and fewer people will be likely to depend upon other services in the future—and those include what we call respite. Socially active people are less likely to have health problems, less likely to have social problems and less likely to have problems of alienation and isolation, which can lead, tragically, to the development of other health problems not disassociated with mental ill health. You can be a nice touchy-feely liberal like me and want to achieve good things or you can be a really hard-nosed rationalist if you want. Both of us manage to succeed in getting some benefit out of a bit of adjustment here.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You have brought in a new component, which is the amount per person.

Mr HERD: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I am talking about the number of people with disabilities who are coming into the system perhaps because of their parents' ageing—people who have been looked after. The family support is literally dying out. How important is that in terms of overall support needs for the sector? While the post-school options is one part of that sector the Treasury presumably looks at the total budget of DADHC and says, "This is the amount going on disability support; it has to go up only a little more than the CPI". Is there good data to say why there are demand increases across the sector?

Mr HERD: The Australian Bureau of Statistics provides that data all the time that tells us that this is an inescapable problem. We have an ageing population; we have an increased number of people with a disability. The cohort simply gets larger. It will never get smaller again. We have gone through the door and we do not go back through it. Again, I can only illustrate it from my own example. Fifty years ago if I had had my accident my life expectancy would have been six weeks. When I had my accident the first question I asked my doctor—after the traditional "Will I ever walk again?"—was, "How long will I live?" The doctor said, "You've got a normal life expectancy". This meant that the system—our community and government—had on its hands for the first time ever a population of profoundly disabled people like me who were going to be there for 40 years, whereas previously an infection would have got me in six weeks.

Those kinds of stories are being repeated by people with disability of all types, shapes and forms, many of whom are either in service at the moment or want to get access to service. The problem is just a new one that we will all have to deal with. My understanding is that our Government is struggling with that problem, as are all governments. But some of it will take money to fix the problem. But I think I agree with your initial question: There is a fundamental demographic and modern social set of circumstances that mean what we are looking at now is not the same as what we were looking at even 20 years ago.

If I can say about my own experience of listening to the comments from that cohort of ageing parents that you talked about, the second most common view I heard expressed deeply and passionately almost universally from parents was a concern about what happens when they are not there to look after their son or daughter. There is an almost unbearable sense of responsibility on their part and uncertainty about not knowing what would happen when their son or daughter was left on their own, as they saw it. I think all of us have a responsibility to answer the questions and uncertainty that those parents have because it is unfair to leave any human being with that degree of uncertainty about a loved one.

The Hon. JOHN RYAN: Madam Chair, can I ask some questions to do with our terms of reference because, interesting as this is, it does not—

Mr HERD: Sorry.

CHAIR: One more question from Arthur.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The Minister seemed very perturbed in her answer in the House that the number of people coming through school had increased and the number of people on the program was obviously going to increase far more than the CPI. Perhaps that is why she is trying to put a lid on the amount, despite the increased number of participants. In other words, the jam is being spread thinner—if you want to put it that way. Is this again because of the de-institutionalisation paradigm—a big quantitative shift?

Mr HERD: If the Minister for Disability Services and the Minister for Education and Training, who were different people at the time, are successful in their policies, it must have consequences for other ministries and/or other bits of the portfolio. If you have a process of deinstitutionalisation, if you have a process of opening up integration into schools, you must necessarily have more people with disability integrated into the community and integrated into schools and at the point at which people transition from one bit of the system to another bit of the system, there will be more of them. That is why I mentioned earlier that partly it is a problem of success—and I have not heard anyone argue that we should reverse the policies of devolution or reverse the policies of integration into schools and, therefore, the problem is simply with us forever.

The Hon. JON JENKINS: Thank you for coming and for your submission. My initial impression, as others have said, is that these reforms are partly being driven by the Treasury and the want to cap funds. I admit some concern that it has been without proper research. I notice you mentioned before that if these programs do not work properly, people will have very little options; they return to disability pensions or, in the worst and distressing cases, we have heard about people being returned to full State care. In your opinion, with the hardline financial side of the equation, is it possible to estimate the financial gain to governments based on our current numbers and the current success that we have with people with disabilities back in the work force? Is it possible to estimate how much gain this will be to governments, taking into account the alternative, which is that people will end up under some sort of full-time State care.

Mr HERD: It is possible, but we have not done it.

The Hon. JON JENKINS: Has anybody done it and then put this as a case to the Government?

Mr HERD: A piece of economic modelling could be done that would show the cost benefit of different levels of funding.

The Hon. JON JENKINS: Would it be useful for the Government itself to undertake that?

Mr BUCHANAN: I think it would be a highly useful exercise to do. Again, in terms of your question and the earlier question, sometimes this whole thing is also being driven by attitude, and by attitude particularly from those with disability. It was probably very easy in yesteryear, for families, government and community, for those with a disability not to have a voice. It was much easier to categorise. This is not really a black-and-white issue and I would really hope that out of this inquiry and this Committee—obviously, I am not suggesting that you will, but we cannot see these things just purely in economic rationalist terms or in black-and-white issues. There are many more areas of grey and I think one of the dilemmas is, and one of the advantages is that the so-called disability sector is a far more emotionally mature and articulate sector than perhaps it was even two to five years ago. The issue that was referred to of ageing and disability, which I know is not being discussed here, but it is another area that will be a huge challenge for the community.

The Hon. JOHN RYAN: Can I ask a question about block funding because we have not discussed that as yet? In your submission on page 3 you state:

> Given that the funding model has moved from an individualised approach to one of a block grant nature, it could easily result in less flexible services—

you recommend that there be a capacity—

> For individual clients to withdraw from a service and for an appropriate level of funding to be reallocated to a new service should the client choose to transfer … We recommend that safeguards be put in place to ensure that service users can negotiate individualised support options when required.

Are you not really saying that it would be better not to have block funding and that individualised funding is, in fact, a preferable model to work from, than the Government's proposal of block funding?

Mr BUCHANAN: I think that is a perceptive analysis.

The Hon. JOHN RYAN: Do you see any reason why New South Wales will be one of the few States that will have a block funding arrangement when Victoria allows for individualised funding, Queensland allows for individualised funding, South Australia has a mix, the Australian

Capital Territory has funding on an individual basis, Western Australia has individualised funding and the Northern Territory is the only State or Territory to have block funding alone? Does that suggest that New South Wales is going against the trend or moving towards something different?

Mr HERD: It certainly suggests that it is not with the rest of the States and Territories, yes. Our position, I hope, should be clear. Empowering and giving choice to service users is probably a key mechanism for positive change, however that might be structured. NCOSS mentioned earlier that there is already a variation of funding model in operation for post-school ATLAS-related options, whatever they might be called, and in other bits of the service system funded in the same department there are individualised funding models being used to empower service users, and I think that is a strong tool that can be used.

The Hon. JOHN RYAN: You have advanced the case that there should be funding for people who are involved in post-school training of other sorts. Can I advance an argument to you, which I suspect will be the response from the Government—and I am speculating that this will be the case—that if a person goes to university or is successfully attending TAFE, they are effectively involved in another program which does the same thing that either community participation or transition to work does: therefore, there is no need for particular funding for them because, in a sense, they are just the same as someone who has gone on to work; they do not need that additional support. Would you care to respond to an argument that might run along those lines, given that we will not have the chance to get to that, if there is an argument of that nature advanced?

Mr HERD: I said earlier that I think we should all recognise just how difficult this life transition is for everybody and that all legitimate contributors to making that transition a successful one should make a contribution. I think there is an argument to be made for the State Government that has assisted people up to the age of school leaving to continue to make a contribution where ever that person may be transitioned into. However, I think it has to be said that there comes a point—and this is part of our concern about some of the conflicting interests here—that the notion of transition can cease to apply to the circumstances of an individual.

Transition has to come to an end. You have to move on somewhere and I think it is legitimate to argue that at some point after having made a contribution to the period of transition, however long it might be—two years, three years, one year—the State Government is understood to have a legitimate right to stay out of the life of the person with a disability because there are others who should be providing that support. That is why we made the point in our submission, and in our verbal submission, that there needs to be much, much better dialogue between the Commonwealth Government and the State Government because it is transparently clear to everybody that part of the problem is that we have two systems that do not talk to one another as well as they ought to.

CHAIR: I will stop questioning at this point because we do need to adjourn. I thank you for your contributions. If any members have questions arising out of things that might have been said today and submit them in writing, would you be prepared to respond to them?

Mr HERD: Absolutely.

Mr BUCHANAN: I would be delighted to.

CHAIR: Indeed, if you feel there is anything else that you wish to add, we are willing to receive further submissions from you.

(The witnesses withdrew)

(Short adjournment)

DEBBIE MATTHEWS, Secretary, 34 Ambon Road, Holsworthy, sworn and examined, and

JAMES GEORGE MURPHY, Draftsman, 4 Robert Street, Holroyd, affirmed and examined:

CHAIR: Ms Matthews, in what capacity are you appearing before the Committee—that is, as an individual or as a representative of an organisation?

Ms MATTHEWS: As a parent to Leanne Matthews.

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

Ms MATTHEWS: Yes.

CHAIR: If you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee, please indicate that fact and the Committee will consider your request. Will you wish to make a short opening statement?

Ms MATTHEWS: Yes.

CHAIR: Mr Murphy, in what capacity are you appearing before the Committee, that is, as an individual or as a representative of an organisation?

Mr MURPHY: As an individual and concerned parent.

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

Mr MURPHY: Yes.

CHAIR: If you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee, please indicate that fact and the Committee will consider your request. Will you also wish to make a short opening statement?

Mr MURPHY: Yes.

CHAIR: I will ask Ms Matthews to make her statement first.

Ms MATTHEWS: Thank you for inviting me here today. I want to start by telling you a little bit about my daughter Leanne. Leanne is 21 years old and has Down syndrome. She loves music, dancing, movies, bowling, indoor cricket and gym. She would never miss an episode of *Home and Away* even if her life depended on it, and never misses an opportunity to buy stationery. I often refer to her as the "Stationery Queen". You may wonder why I am telling you this. One thing that has truly upset me throughout this ordeal is the term that the Government keeps using to describe my daughter—"block funding". Leanne is an individual and a very valuable member of our society, and should be funded and termed as such.

The funding cuts now have me questioning myself as a mother, something I have never done before. I worry what will happen should I not be able to afford to keep Leanne at her centre five days. I am self-funding too at the moment. I consider myself to be a great mum. I try my hardest to provide for my daughter and myself, and now have self-doubt. It has been extremely stressful and is starting to show in my work and within myself. I ask you as a Committee to take on board the comments you will hear from parents and service providers during this inquiry. I have read all submissions published, and not one is positive. Surely the Government needs to ask parents, carers and more importantly the young adults that these changes affect what they need and how the reduction in days demeans their position in our society as they will not learn all they need to be safe.

These young, special people were sent to us for very special reasons, and as parents we know the joy, the tears and the elation they bring to our lives. I will do whatever is necessary to ensure Leanne suffers no loss of hours at her program, as I have with other fights for her rights and entitlements. No government department should ever be able to take these rights from her simply because she is unable to voice her needs.

CHAIR: Mr Murphy?

Mr MURPHY: My son Daniel is 24 years old. He is profoundly disabled, both physically and mentally. We have provided for him for the past 24 years. He has been to Holroyd special school for nearly 16 years, and then 4 years at Flintwood. In both instances he has had a five-day service, which he absolutely loves. He has quite often been known to throw tantrums when he has been picked up from the day service or when he was brought home from Holroyd special school, because he just loved his time there. He has now been cut down from five days a week to five days a fortnight, which we feel is unfair on Daniel.

We have a daughter that we are trying to put through the Blue Mountains hospitality school, and that is costing us quite a lot of money, and we cannot afford at this stage to fund Daniel for the extra days. The handling of the matter by the Government has not been very good. We have written numerous letters and not received a reply from Mr Della Bosca. It was only after emailing him night after night for three nights that we eventually got Adam Cox to reply, and basically Adam's reply was to ring Tessa Wells. I had been ringing her nearly every fortnight to find out different things that are going on. She knows Daniel; she used to work at a respite centre that Daniel used to go to. She was very upset by all the funding cuts and what is happening to Daniel.

They just kept saying to wait for the $1.4 million pool of money. The papers for that did not come to our service provider until I think 11 April, and we had to have our submission in by 29 April, which left 18 days to get reports from psychologists, neurologists and occupational therapists and various other people. We still have not seen a neurologist. The soonest we could get to see a neurologist was on 7 July. I think it is just unfair, especially for those who left school last year and started on 7 February, that they were not able to gain access to this extra funding until now, let alone for my son, who started on 4 April. We made the biggest decision of our lives on 3 April: to leave Daniel in respite care. It has affected our life greatly. We are just waiting in hope that we will get the funding and we can have our son home.

The Hon. JOHN RYAN: First of all—and I know all members of the Committee join me in this—we thank you for the courage that you are showing today to reveal essentially very personal things about your family situation. We wish you were not in this position, but we thank you for doing it. We enormously admire you for the challenges that you face, particularly in giving evidence. Could you tell us, Mr Murphy, what was the service that Daniel was in, and how many hours did Daniel have before these changes were introduced, and how many hours was he getting just prior to your decision to leave him in respite care?

Mr MURPHY: He was getting five days a week, and basically he would be there from eight o'clock in the morning until four o'clock in the afternoon. So we were most likely getting a lot more hours than a lot of others, and that got reduced down to three days one week and two days the following week on a rotational basis.

The Hon. JOHN RYAN: What were you going to do on the alternate days when Daniel was not in the service?

Mr MURPHY: Both my mother and my mother-in-law offered to look after Daniel but they are both nearly 80 years old and for them to look after a 24-year-old who is still in nappies and needs to be changed at least twice in the time we would be away, we just thought we would be sending our mothers to an early grave.

The Hon. JOHN RYAN: And the additional funding which is for people with high support needs, has it yet been determined as to whether Daniel will be one of those people funded for high support needs?

Mr MURPHY: Apparently they are meeting this week. Our submission was put in on the 29th and apparently they are meeting this week and hopefully we will find out—

The Hon. JOHN RYAN: The level of funding is reasonably modest—it is $1.5 million to be spread over a considerable number of people. Has your service provider indicated to you that even if he is successful as to whether or not they will be able to restore all of the days that Daniel used to previously be part of the program?

Mr MURPHY: I think we would have to give the amount to make up the old amount for Daniel to receive the same amount that he was getting.

The Hon. JOHN RYAN: Do you know what the difference was?

Mr MURPHY: Basically, $6,500.

The Hon. JOHN RYAN: Ms Matthews, you took a decision, if I remember rightly, to fund some of the program yourself. Is that because your daughter Leanne's hours were cut at this service?

Ms MATTHEWS: Leanne's hours were cut down from 30 hours a week to 18 so I have taken the decision—I have gone to the bank and borrowed $3,500, which blows out to $4,600 with the interest rate. I have since learned in the past few weeks that that $3,500 that I thought was the shortfall between the $17,000 and the $13,500 currently will only buy me 14 weeks of extra time and then I will have to start paying out $500 a fortnight.

The Hon. JOHN RYAN: So notwithstanding the fact that you have taken a loan you still face a shortfall.

Ms MATTHEWS: Yes.

The Hon. JOHN RYAN: The Government might put to us that one of the difficulties—you recall that the Minister made a statement on numerous occasions where she said that there was no expectation on the part of the Government that these changes would result in cuts to individual's hours.

Ms MATTHEWS: Yes.

The Hon. JOHN RYAN: Do you have any idea as to why this has happened in your case? One option is that the service provider is trying it on, that they have decided to use the changes in order to fund things differently and cut your hours, and the Government then becomes a convenient scapegoat for them to use as an excuse. Do you think there is any credibility to that sort of argument?

Ms MATTHEWS: The service user cutting hours was suggested to me by two senior managers of DADHC. I had them ring me one Friday night at 8.15 requesting to come and visit me because I had made a complaint to the director-general. They told me that the Junction where Leanne goes was cutting things back, which was resulting in dropping Leanne's hours. I have spoken with the Junction and I believe they are trying to provide the best quality service they can. I just do not understand how someone can say, "We will take money of you", and still expect the same service. It is just not possible. One other service provider I went to, when we had the chance to change service providers, informed me that DADHC was pushing them to have a 8:1 ratio instead of 4:1. They refused so they have had to reduce hours at their service as well.

The Hon. JOHN RYAN: So an 8:1 ratio refers to the number of staff looking after the number of clients.

Ms MATTHEWS: Eight clients to one staff member.

The Hon. JOHN RYAN: Mr Murphy, would you care to comment in terms of whether you think the service provider or the Government is to blame for the cut in hours?

Mr MURPHY: I think the Government myself. I would not be happy if Flintwood cut the quality of service that Daniel gets. I know that when I spoke to Adam Cox—I rang him on the Monday after we left Daniel in respite—he suggested that the cut was only one-third of the money and how could the service provider only give Daniel half the time. I said to him that I was not the smartest person in the world but I thought that they would understand. They still had the same rent to pay, all the overheads are a telling factor in that. So I could understand it myself. When our service provider spoke to us about it and then Adam Cox seemed very au fait about it, it just was not right that he should be getting only a one-third cut, not cut in half.

The Hon. JOHN RYAN: Your son has been placed in a respite facility. Have you been able to visit your son while he is there?

Mr MURPHY: We have chosen not to visit him at the respite centre. I go to Flintwood in the morning before I go to work. All that Daniel would understand if we were to go to the respite centre, he would think that we are there to pick him up and take him home. So we have decided not to visit him there. I have been up there and dropped of clothing and nappies and that stuff to them, but I have always just been at the door. They have always invited me in, I will give them that, and they have offered but I think that for Daniel's sake it is better to leave it with the way we have got it at present and just see him on the days that he is at Flintwood.

The Hon. JOHN RYAN: Do you have any idea of the impact that leaving him at a respite facility has had on other families who use the respite facility?

Mr MURPHY: That I would not know, unfortunately.

The Hon. JOHN RYAN: You would expect those that less people would be—

Mr MURPHY: That less people would be able to, yes, unfortunately, yes.

The Hon. JOHN RYAN: And I imagine that the cost of keeping him at the respite facility would be much greater than—

Mr MURPHY: We would most likely spend more than the $6,500 that I require to have Daniel back in full-time care, yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Mr Murphy, what problems did you experience with the ATLAS program, if any?

Mr MURPHY: None.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: None at all?

Mr MURPHY: No. We could not understand why they wanted to change it, basically. As far as I am concerned, the new system has not changed. The only thing that has changed is the hours. Daniel is receiving half the time. It is still the same program.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In essence you put him in respite because you could not afford to pay the difference to keep the same hours.

Mr MURPHY: That is right.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: And the cost of him being in respite full time now is immensely greater than the $6,000 you wanted to fund that decrease in hours.

Mr MURPHY: Yes. I would think it would be. I do not know exactly how much it costs per week but Daniel has been in there for five weeks now. I know that some group homes can cost up to $300,000 per year.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Per person.

Mr MURPHY: Per person, so if you divide that by 12 basically to get a month's worth, it is a lot more than $6,500 that we require to keep Daniel at Flintwood five days a week.

CHAIR: When your son was accessing the program five days a week what was the staff ratio of the group he was part of? How many participants to the staff member?

Mr MURPHY: I am not totally sure of that. Jackie from Flintwood is here.

CHAIR: Perhaps you could take that on notice and let us know.

Mr MURPHY: Yes.

CHAIR: Prior to the announcement of the changes had there been any consultation with you as parents or the service—

Ms MATTHEWS: No.

Mr MURPHY: None at all. The first thing we heard was went Flintwood invited all the parents in for a group meeting.

Ms MATTHEWS: The same thing at the Junction.

CHAIR: What was the message you were given at that group meeting?

Mr MURPHY: We will just have to try to fight this because nobody really knew what the cuts were going to be, I do not think at that stage, and we have been on the committee at Flintwood to try to fight the cuts.

The Hon. CHRISTINE ROBERTSON: I understand that the ATLAS program finished at some stage, lasted for a certain period of time, is this correct?

Ms MATTHEWS: It was apparently a two-year program. This was never explained to me when Leanne was at school and having her assessment interview. The person assessing Leanne said she would be ATLAS funded but never said there was a cut off. I always believed that it was ongoing funding.

The Hon. CHRISTINE ROBERTSON: Did you understand that it was—

Mr MURPHY: Yes, we did understand that it was only a two-year time but there has never been a problem. Daniel has been funded—

The Hon. CHRISTINE ROBERTSON: It has continued on, has it not?

Mr MURPHY: Yes. There has never been a problem getting funding so Daniel has been under the ATLAS scheme for four years.

The Hon. CHRISTINE ROBERTSON: So some people were able to obtain continuing; others were not apparently, I understood.

Mr MURPHY: I am not too sure on that.

The Hon. CHRISTINE ROBERTSON: So I understand the crossness about the hours cutting and everything. Would the certainty of the community participation program be a bonus?

Ms MATTHEWS: I have not—

The Hon. CHRISTINE ROBERTSON: I realise—I will go back to that. To know that it would be possible to be ongoing, would that be a benefit?

Ms MATTHEWS: It would be if it was kept at a rate where—my daughter is having five days service to learn. Yes, it would probably be great but two days a week, she would be sitting at home with me because I would have to give up working and go onto a carer's pension.

The Hon. CHRISTINE ROBERTSON: I also understand your frustration because obviously you have had very good service from providers for some period of time. But both of you have had fairly extraordinary per hour increases to your service provision.

Ms MATTHEWS: Decreases.

The Hon. CHRISTINE ROBERTSON: Costs, sorry. I did not finish my sentence—quite high increased costs per hour. The funding has been reduced by 20 per cent and one of you has lost 60 per cent of your hours and one of you has lost 50 per cent of your hours. That is a phenomenal amount of time. I realise that there were other considerations in the new program they were to deliver although they do not have the measures together to do that. But it was not good timing, was it?

Ms MATTHEWS: No. There was no consultation with anybody. It just seemed like it was a decision made and implemented straightaway.

The Hon. CHRISTINE ROBERTSON: But both of them came together, the increase in the hours and then you went and borrowed the money and then discovered it was not enough because the hours had increased not just by 20 per cent.

Ms MATTHEWS: Yes. I get charged at a rate of $125 a day for our centre.

The Hon. JOHN RYAN: Ms Matthews, there might be some—we should address this while we have the opportunity of you being here—who would say that you are in fact doing something which parents should do, make a contribution towards something that their kids are involved in, and that you are in fact doing something, a reasonable expectation that you would make a contribution towards your daughter's program so that you can go off and have the economic benefit of going to work. Do you accept that argument or do you think there are—

Ms MATTHEWS: I accept that I am responsible for my child. I also pay a per day fee. If the funding was normal anyway I pay a per day fee. Leanne is unable to self transport so she has a taxi transport going to her centre and to home again. Even though she receives taxi subsidy vouchers, I still pay $100 a fortnight for taxis. She still requires day care in the morning but because she is over the age of 21 fee relief has stopped so I still pay $140 a fortnight for day care. I guess I am just asking for a little bit of help. If it was to increase to $20 or $30 day I would still pay it because I see what she is learning. I see that young woman she has become and I do not want to lose that. I do not want her to go back and just be able to sit in front of a television.

The Hon. JOHN RYAN: That brings me to another important question. What happens at ATLAS for your kids? What goes on and what benefit do those programs make to your son and your daughter? One way we can get this information is to ask you.

Ms MATTHEWS: Leanne loves going, I think, like Daniel, as Mr Murphy said about Daniel. She has a social outlet. When she gets home there are four or five phone calls a night from friends that she has been to the centre with all day and she sits on the phone and talks to them all day. She went out on Saturday night with a friend from the centre and his family. It is more important, the social outlet. She would have no-one because, as much as we hate to say it, she is not normal as they say in society and society looks down upon her, even though they probably should not. But she has learned things—she can now write her name, she can now write her address, she knows how to use a phone—just the little things that you and I take for granted that we can do every day she has had to learn and continual reinforcement not only at the centre she attends but with me at home. The simple thing of going into a shop saying, "You have too wait for your change to see if there is any change" and things like that. She has grown into a young woman and I will do whatever it takes. It does not bother me.

The Hon. JOHN RYAN: Mr Murphy, would you care to comment?

Mr MURPHY: Yes, I agree, it is more the social aspect of it for Daniel. Daniel knows or has only about 12 words that he speaks. He communicates by gestures and stuff like that. People who know him can basically communicate with him but it is a social life for him. If he does not get the extra days he would just go crazy at home. The one-off that the Government did make to us was the days that he was not at Flintwood they would leave him at the respite centre that he is at, at present. We basically declined that offer because it is just a babysitting service, unfortunately, even though he is there at present. But he is there only because we cannot afford to have him at home we want to have in the home, but we need five days a week care for him, and quality care.

Ms MATTHEWS: If I can just add to that, when DADHC came to see me they offered me the three days that Leanne is at the Junction, they offered me a two-day recreational program, which I also declined. I can take her bowling and to the movies. I do not need someone else to babysit her and to do that. I need her learning five days a week.

The Hon. JON JENKINS: Thank you for coming, and thank you for your submission. Would I be right in saying to both of you that if this funding cut continues there are only two alternatives, either you have to cease full-time work or you have to put your children in full-time care?

Mr MURPHY: For me, yes.

The Hon. JON JENKINS: It is a reasonable assessment for both of you?

Ms MATTHEWS: Yes.

CHAIR: I thank you for giving us your time and sharing your story with us. I do not imagine there will be any more questions to you, but thank you. If there is anything else you feel that you wish us to know we are always happy to take some supplementary material from our witnesses. Thank you for being with us today.

(The witnesses withdrew)

GREGORY RICKETSON, Film Producer, affirmed and examined, and

LYNN GOULD, Teacher, sworn and examined:

CHAIR: In what capacity are you appearing before the Committee, that is are you appearing as an individual or representing an organisation?

Mr RICKETSON: As an individual parent.

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

Mr RICKETSON: Yes, I am.

CHAIR: If you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee please indicate the fact and the Committee will consider your request. Would you wish to make an opening statement?

Mr RICKETSON: Yes, please.

CHAIR: In what capacity are you appearing before the Committee, that is are you appearing as an individual or a representative of an organisation?

Ms GOULD: As an individual.

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

Ms GOULD: Yes, I am.

CHAIR: If you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee please indicate that fact and the Committee will consider your request. Do you wish to make an opening statement?

Ms GOULD: Yes, please.

CHAIR: Mr Ricketson, if you would like to proceed?

Mr RICKETSON: Thank you for having me here today. It is not easy. I am here for my daughter, Tess, and I am here for the thousands of young kids and their families and carers and supporters and what have you. I will be very, very brief. I have also taken the opportunity over the last week to read pretty well every single submission, and there is absolutely only one conclusion. There is nothing positive. It is all negative. It is heartbreaking. It is dismaying. It is demeaning to the children, their families and their carers. It is a disgrace. In my submission I suppose I followed two major lines, one was that Tess' mother and I are divorced and have been for quite sometime. It has been very, very difficult. She has just left school at the end of last year. She has just entered this program.

One of the things that we had always anticipated post schooling was that the arrangement that we had planned on right through the 1990s that used to be available through the PSO program and the ATLAS program as portable funding that it was going to be possible for us both to share in the support of Tess: Let Tess have a rest from her mum, let mum have a rest from Tess and for us both to have a relationship with our daughter. Under that block funding arrangement all that has gone out of the window. She is going to be stuck in exactly wherever the service provider is. The opportunity of her maybe spending a day or two in my house attending a particular service provider for a day or two has gone out of the window. Various options were open for my ex-wife to, perhaps, move away from her current living situation closer to where her immediate family support networks are. That is unlikely to be able to happen now.

There could well be circumstances in the not too distant future where her own mother, who has provided a huge amount of support for Tess over the years, is becoming elderly and it may well be that it will be time for my ex-wife to give a lot of care to her mother in turn, and quite correctly so, but returning exactly what her mother is bound to do for Tess. Having read pretty well all the submissions I find it really dismaying and really quite alarming that I have not found one comment, not one comment, either through any of the submissions—and I combed for four hours yesterday every word of that department web site—there is no guideline, there is no anything, there does not seem to be any mechanism whatsoever that addresses issues of separated or divorced families where there are two parents who are, in fact, dedicated and wanted to look after their child.

A child she is, and a child she will remain. We have known this all her life. We are going to have responsibilities for her all her life. I think my submission is quite clear and I will stand by that, but I will bring just one particular aspect up to date. I made the point in the submission that kids with disabilities, particularly with intellectual disabilities, can go up and down, up and down, up and down in terms of their particular abilities in any particular month or three months or six months or whatever. Tess, in the last nine months, has become extremely disturbed and emotionally distressed, and has gone backwards in many, many ways. It is probably to do with certain factors. She has been at a very dedicated school for seven years, a large group of friends and a structure, which she needs. The stress of moving off into new areas is something that every child faces, but it affects children with disabilities very, very strongly. A similar thing happened when she was moving from her special primary school. The gregarious, wonderful, social Tess of 12 months ago became less and less herself, more and more withdrawn, more and more stressed to a point where she has been under some pretty heavy-duty medication and visits with psychiatrist for the last several months.

She was meant to start the transition to work program in February, but to date she has been able to attend about eight of the 12 weeks. That opens up a very, very important question as to the assessment mechanism. If she had been assessed in any particular month over the last nine months the assessment in any month would be different from the one that she would have had. She has missed this time. It will not be unusual for kids in these programs to miss time because of either physical or medical illness, or mental illness. It is not an uncommon thing with the type of kids we are talking about. What happens? What happens in that case? What happens if a child with a physical disability misses six or seven months due to the necessity of surgery and rehabilitation after that? Does it get added on to the program or does the two half-year deadline still stand? None of those questions are answered in any of the guidelines at all. There is a paucity of any information whatsoever on the web site available through the department.

I will sum it up by saying that these circumstances for young children, or young adults, are always going to change progressively. They are tragic. The kids are the most wonderful, wonderful people. You will hear that from every single adult that appears here today. They are members of our society and we seem to be just dumping them. I just think these new policies—they are not reforms—I can see lots of good things about the new policies, provided there is funding that is sufficient, as has been said earlier, to actually achieve the rhetorical outcomes. I just think it is heartless and I am pretty ashamed of my society now.

Ms GOULD: I also would like to thank you for inviting us and providing us with an opportunity to express our grave concerns with regard to the changes in the ATLAS program. I have a beautiful son, Nathan, who is currently in the ATLAS program in the transition to work. He has thoroughly enjoyed his program. He has found it stimulating and it has been appropriate to his needs, thanks to the quality service provided by Flintwood Disability Services. He has continued to progress with this good, consistent, individualised program. Many families who have children with disabilities are emotionally and physically exhausted, and they are really only just keeping their heads above water. They are able to stay afloat when their child is catered for appropriately in a stimulating environment five days a week.

Cuts to individuals in the Adult Training, Learning and Support Program [ATLAS] have had a devastating effect on young adults as well as their families, including ours. Our young adults have the right to reach their full potential just as any other individual has that right. If they are able to attend quality programs throughout the week they will be able to reach their full potential. Cuts to the funding have seen many of these young people reduced to attending their programs only a couple of days per week instead of five days per week. The repercussions of providing an inadequate level of funding to our young adults have been outlined in practically every submission that I have read—problems such as increased stress levels, emotional health, dropping self-esteem and boredom, to name just a few.

Drastic consequences then flow on to the immediate family and they continue to flow into the community. If money was the leading factor in the decision to cut funding to our young adults the Government has not really considered the ongoing ramifications. It is really false economy. Many families will go under and be unable to care for the young adults, leaving them in State care, which costs tens of thousands of dollars more per annum. Others already in care will have reduced access to day placements and their group homes will have to be staffed and funded accordingly. Many working parents will have to reduce their hours or even resign, costing the Government tax dollars. Of course, this becomes a huge financial burden for the family, including ours, trying to care for siblings' needs as well as those of the child with a disability.

The need for respite places will increase and many families will disintegrate under the pressure requiring further government support. The structure of the program as it is, is too rigid to accommodate the needs of individuals. If there had been adequate consultation with parents in developing the structure there would have been greater flexibility and certainly a change in the time frame given to the transition-to-work program. I also find it amazing that there is a discrepancy in funding between the Post School Options [PSO] Program and ATLAS. They are young adults with similar disabilities and needs. The current ATLAS funding should be increased, at least to the level of the PSO funding. People with disabilities have the right to access services and to be treated with respect and dignity.

The rights of our young adults have been seriously impaired with the introduction of block funding, something to which Greg referred earlier. Individualised programs require individualised funding. Should people require a change of service, or to be flexible with their service provider, or they need to be able to move for whatever reason, their funding should be portable. That is another serious problem that really needs to be addressed immediately. The new ATLAS program seems to have been rushed in with a, "Plan as we go" feel about it. Many decisions have been made without adequate consultation with young adults and their families, as well as service providers. Many times the Government has placed unrealistic time frames on service providers to provide copious amounts of information to them. The communication between parents and the Department of Ageing, Disability and Home Care has been less than impressive, with very many standard type answers that have just been churned out repeatedly to us. The Government really needs to listen carefully to the issues raised by parents and by those who know what a devastating effect this has had on young adults and their families. It really needs to be rectified.

The Hon. CHRISTINE ROBERTSON: I wish to ask a question relating to your submission. What was your experience with the assessment process? What did you have to do in relation to that process? You said in your submission that you are not happy.

Ms GOULD: Basically, I ticked a few boxes and stated what were my son's abilities, rather than what were his disabilities. I was very surprised to find that he was given the transition-to-work program. It has been rather fortuitous because he has been able to continue his program until next year, which is when he will be having cuts to his program. He is legally blind and has cerebral palsy—he can work but he is quite debilitated—and he is intellectually delayed. I could not see how he could manage to do the transition-to-work program within a two-year time frame. People have provided him with an opportunity to work at Woolworths, fully supervised and obviously in a very structured environment, and he loves it. He is so proud. But I cannot see that happening in a two-year time frame.

The Hon. CHRISTINE ROBERTSON: So the assessment was based on objectives set out by you on a piece of paper?

Ms GOULD: No, we were asked questions and we basically answered them. We ticked boxes to establish where he fitted in. Of course, boxes are very inflexible as well, are they not?

The Hon. CHRISTINE ROBERTSON: Yes. There was no other component to the assessment?

Ms GOULD: I would assume that the teachers and the school conducted an assessment. The school was very surprised that he was put into that category and it mentioned that to other people. I actually rang and questioned the categorising as well. Nothing has been done.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think the assessment program that was used to put him into this relatively advanced program was a valid assessment tool?

Ms GOULD: I think at that time I was so stressed out with wanting to know what was going to happen to him after school I did not take as much notice. I probably would have liked more input into that assessment process. I did what I thought and what everybody was handed. With hindsight I feel that we definitely needed far more consultation with family, parents and the school.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You said that you ticked the boxes and that the school was surprised at the outcome?

Ms GOULD: The school was also involved.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The school was surprised that he was put in that program. Does that mean the school did not think he was able to be involved in that program?

Ms GOULD: I think the school had doubts as to whether he would be able to do the transition to work within a two-year time frame. That is what the transition to work is within that two-year time frame. The school was surprised that Nathan was placed in that position.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: How did he go at Woolworths?

Ms GOULD: Fully supervised he enjoys his work. He picks up fruit and puts it in a box. The last time was a bit of a challenge—he was actually packing chocolates. I was proud of the fact that he did not eat them. Apparently, he did very well but he does get a lot of guidance with that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is that likely to succeed within a two-year time frame?

Ms GOULD: No, I would say not. The staff ratio would have to be nearly one to one for Nathan to succeed in that sort of environment.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In that sense would you say that his assessment has not been correct?

Ms GOULD: I would absolutely say that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you then support the comments by People With Disability that the assessment should be more transparent and more appealable?

Ms GOULD: Yes, definitely.

The Hon. JOHN RYAN: How many days a week does Nathan participate in the transition-to-work program?

Ms GOULD: Currently, five.

The Hon. JOHN RYAN: Is that the same as what he had previously?

Ms GOULD: Yes. The funding cuts to his program will start next year when I assume he will go back to community participation.

The Hon. JOHN RYAN: So because his funding is the same this year as it was last year there have been no cuts to the program? Is there a visible difference to the program he is doing this year compared to the program that he did last year?

Ms GOULD: The visible difference is that he is really missing some of his friends who have already had cuts to their programs. Obviously there are changes going on. People are trying to maintain a steady program and stability for the children. I think he has been a little more unsettled, but his program is still continuing.

The Hon. JOHN RYAN: When I refer to the program I am referring to its content. Is the program that he completed this year significantly different from the program that he completed under ATLAS? One of the things the Government is saying is that the transition-to-work programs are now specialised for that purpose. They are no longer integrated with the sorts of people who are involved in community participation programs. As a result of the program being specially designed for transition to work, they are more intensive and they are tailored to get an individual to work. Have you noticed any significant difference in the services office by your service provider and is there any difference in the program content?

Ms GOULD: They have tried to include as many opportunities for work environment. I would say that it has not changed all that much, purely and simply because that was what he was doing beforehand as well. They were trying to provide opportunities for him. They are also trying to provide opportunities where people would have them as well. When you have children with cerebral palsy and visual impairment some places will not have them come in because of occupational health and safety issues.

The Hon. JOHN RYAN: Is your son considered to have high support needs?

Ms GOULD: No, he does not have high support needs.

The Hon. JOHN RYAN: Under the current arrangements how long does he have to make the transition to work?

Ms GOULD: Until the end of this year.

The Hon. JOHN RYAN: Why is it only one year?

Ms GOULD: Because he started last year. It is a two-year program.

The Hon. JOHN RYAN: So at the end of this year you have to make a decision as to whether either he has a job or he will be in community participation, I take it?

Ms GOULD: He would have to be in community participation. I cannot see how he would be able to obtain a job because of the way he is.

The Hon. JOHN RYAN: So the current level of funding is about $14,000 or $15,000?

Ms GOULD: It is about that.

The Hon. JOHN RYAN: Would he then be under a lesser amount of funding? Have you any idea whether that would make a significant difference to the number of hours?

Ms GOULD: Absolutely, yes. All the other children are being cut to five days a fortnight, possibly three days a week maximum, which has drastic consequences on our family.

The Hon. JOHN RYAN: Mr Ricketson, you said earlier that your daughter is now involved in community participation. How many days a week, or how many hours a week does that involve?

Mr RICKETSON: Could I correct that statement? She was allocated eventually into transition to work.

The Hon. JOHN RYAN: So she is doing the transition-to-work program?

Mr RICKETSON: That is correct.

The Hon. JOHN RYAN: For how many hours a week is she involved?

Mr RICKETSON: She is attending four days a week. That is about seven to eight hours a day.

The Hon. JOHN RYAN: One of the issues you raised related to portability. If she were involved in the transition-to-work training program it would be a bit hard to deliver that in two different places. Do you understand that there would be a need for continuity in a program of that nature?

Mr RICKETSON: I wish to comment on your earlier question. Where Tess is currently attending each day the people who are streamed as transition to work and community participation essentially are doing exactly the same program. At this point there is no evidence of much more intensive activity, streaming, or whatever. The other point I wish to make, just going back to the assessment mechanism, is that four of the assessments out of Tess' school class of nine who left school last year were quite contrary to what parents and/or the school would have anticipated. The next point to make is that Tess is in the transition-to-work stream largely because my former wife and her mother have extremely loud voices and they won the day after many months of lobbying and what have you.

Tess is an unusual child in the sense that at any time she is sociable, she can carry out functions under supervision extremely well, and there is a high probability or chance that Tess at some stage—not necessarily within the two-year time frame but at some stage—will be able to take on fully supervised and good quality work. But it will not be this year and it will not be next year. I can certainly see the possibility—I think even the teachers at the school and maybe the service provider can see the possibility—that over a period once her level of attention improves and some of those skills are developed she will be able to enter the work force. So where does she sit? I referred in my paper to the huge grey area here.

You cannot just categorise these kids as to whether they can or you cannot work, whether they might be able to work in the future, or whether they are absolutely unlikely to. This goes against even the department's own papers. At the end of its submission it refers to the trends overseas. There are a couple of memorable quotes in those documents. There is the state of policies in Canada, America, Europe and the United Kingdom. Every one of those recent government policy papers has indicated that the worst possible thing to do with young adults in transition is to firmly and categorically place them into "can work" and "cannot work" categories. That is my point.

Tess, like so many young adults, is sitting right in the middle of what might be two very comfortable policy options. As the people from the Disability Council indicated earlier, what is appropriate for a particular period of time for an individual? It may well be that community participation is the best approach and then after some development or further development of skills they should move into other programs. Sometimes there will be regression. Sometimes they might need to go back to community programs that are less intensive. Even the department policy documents state that it is imperative that there be movement between these areas. I cannot see how under the funding mechanism this could happen. I do not see the mechanisms.

The Hon. JON JENKINS: I have a couple of questions. You mentioned in your submission that the majority of parents of these children are divorced. I suppose that is understandable because of the extra stress that is put on the relationship. Can you elucidate a little more about the special problems for the child or the adult under care who comes from a divorced or separated family?

Mr RICKETSON: I would love to answer that. I think they are very simple questions. It is difficult enough in divorced households and whatever to try to set up a harmonious situation where children of divorced households can move freely between households. There are cost factors and difficulties about where different parents need to work, live or whatever. There are a lot of geographical factors, even for families without children and young adults with disabilities. Tess lives in a suburb that is very, very close to her school. That is understandable. I have to live in the city, which is close to my work and my activity. So there is quite a geographical separation. It is essentially a three-hour or three-and-a-half-hour round trip if I pick her up by train. She is not able to organise her own travel—it is unsafe for her and she is just not up to that capability at this particular point. It is not always possible for me to drive either to pick her up or to drop her home. It is the same thing with her mother. Her mother has been attempting over the past several years to do part-time work in the afternoons, which also includes Friday afternoons. It is very difficult to get over the geographical divide. That is just one issue.

The second issue is like that for any child whatsoever. Parents need to maintain contact with their children so that they have a proper, healthy parental-child relationship. We had always considered that once Tess had been unlocked from being in her particular special school from 9.00 a.m. to 3.30 in the afternoon, five days a week, the types of programs that it was possible to purchase through the PSO—and, lesser so but you could still do it, through ATLAS—would have allowed a genuine sharing of time. It would be good for Tess—primarily, it would be fantastic for Tess—it would be good for her mother and it would be good for her siblings.

The Hon. JON JENKINS: I noticed that both of you commented on the lack of flexibility to move to different providers. Would you like to expand on that a little because all the people who have spoken to the Committee have said that there is a lack of flexibility and highly structured, one-or-other relationships? What is the effect for each of your children?

Ms GOULD: I think our children have a right to choose as well. If they choose to go to a particular place then they should have the right to go there. What happens if something does not quite work out? There might be a clash with another person or we might find something more appropriate. You should have the flexibility to be able to attend that program. For instance, the Minister at our church has a disabled son. Ministers move frequently. What will happen to that child? People need to be able to be flexible with their families. They should not have to stay in one particular spot because that is where the money is going to one particular service provider.

Mr RICKETSON: I back up that comment by saying that the very thrust of my submission goes to the heart of flexibility, in the sense that here we have another branch of society looking at perhaps different approaches in the Family Court about shared custody and what have you to try to overcome some of the immense difficulties that there are and the ever-increasing level of separation and divorce. The official statistics are above 30 per cent. My understanding, to go back to your earlier point, is that the separation and divorce rates amongst parents of kids with disabilities and whatever is more than 60 per cent, or almost two-thirds. So a program that, by definition, is block funded and locked into one particular service provider in a particular geographical location defies something that is very common in society, where you have different people in an extended family network who might not necessarily be able to be absolutely confined to exactly where those providers are.

So to be able to split some of the activities between different providers that also offer different types of stimulation and different types of activities adds to the stimulation for the child, which is what everybody's intention is. But it can also address some of the issues that are there as regards parenting and where people's different support networks are. The flexibility is vital. Once again, I refer to the last three pages of the department's submission, where it indicates what the latest best practice policy is in Europe and North America. Once again, it is about flexibility. Everybody is emphasising it; I do not understand why a child such as Tess is not given the opportunity to play a part in determining where she undergoes these activities and what types of activities they are. That has been denied to her.

CHAIR: Thank you both for giving us your time today and for sharing with us the difficulties that you are facing. We genuinely appreciate the fact that you, as parents, and so many other parents have written to the Committee. It certainly enlightens us about what you are experiencing. If any other issues arise as a consequence of your answers or the issues that have arisen today, we would be more than happy to accept any further submissions from you as witnesses.

Mr RICKETSON: Thank you.

Ms GOULD: Thank you.

(The witnesses withdrew)

HEIDI FORREST, President, People With Disability Australia, PO Box 666, Strawberry Hills 2012; and

THERESE PAULA SANDS, Senior Policy Officer, People With Disability Australia, PO Box 666, Strawberry Hills 2012, affirmed and examined:

CHAIR: Thank you, Ms Forrest and Ms Sands, for your submission on behalf of People With Disability. Ms Forrest, in what capacity are you appearing before the Committee? Are you appearing as an individual or as the representative of an organisation?

Ms FORREST: I am appearing as the President of People With Disability Australia. I have a disability and I am the parent of a child with a disability.

CHAIR: Ms Sands, in what capacity are you appearing before the Committee? Are you appearing as an individual or as the representative of an organisation?

Ms SANDS: I am appearing as the Senior Policy Officer for People With Disability Australia.

CHAIR: Thank you. Are you each conversant with the terms of reference of this inquiry?

Ms FORREST: Yes.

Ms SANDS: Yes, I am.

CHAIR: If either of you should consider at any stage that certain evidence you wish to give or documents you may wish to tender should be heard or seen only by the Committee, please indicate the fact and the Committee will consider your request. Ms Forrest, do you wish to make an opening statement?

Ms FORREST: Yes, thank you.

CHAIR: You may proceed.

Ms FORREST: First of all, I would like to thank you all for the opportunity to appear before you today. As you are aware, I am representing People With Disability [PWD], which is a national disability advocacy organisation that is 100 per cent governed by people with disability and has a cross-disability focus. PWD, along with many other advocacy organisations, individuals and families, supports reform of the spectrum of all day programs, including post-school programs, for people with disability. PWD made a significant commitment to the ATLAS review and reform process of the Department of Ageing, Disability and Home Care [DADHC] that was conducted in 2003. We had three senior staff members on the three working groups that were established as part of the reform process and we supported the principles of the reform. These included looking at meaningful and flexible whole-of-life transitions and pathways, lifelong learning and meaningful participation in community life by people with disability, and service delivery based on person-centred planning that focuses on individual goals, needs and interests.

Along with many others, we were shocked and taken by surprise by the changes that were announced in July last year. Despite the former Minister's statement that changes were based on a number of factors, including advice from the 2003 working groups, at no stage were any of the changes recommended by these working groups, nor did the Department of Ageing, Disability and Home Care inform any working group of these proposals or seek working group advice in relation to them. We completely disassociated ourselves from these changes and, as we said publicly in a press release in July 2004, we are confident that if these changes had been presented to the working groups they would have been universally rejected.

We believe that these changes are being driven by principles of expenditure reduction and are based on shifting costs to other State and Commonwealth jurisdictions. There is no evidence base for these changes. The changes fail to take account of the reports from the reviews of the pilot programs and the studies that have been undertaken within Australia and internationally. Despite the policy framework of the new programs using language such as "person-centred planning" and "meaningful life transitions" and "maximising individual potential", the changes will not achieve this. The changes are not driven by the Disability Services Act and its focus on people with disability achieving their maximum potential as members of the community and the development of innovation in service delivery.

Our submission highlights the negative impact of this on people with disability and their families. In summary, we argue that the changes to post-school programs will not be successful in fulfilling the objectives of the Disability Services Act. At a minimum, we argue that essential components of the programs need to be considered. We need to restore individual, flexible and portable funding; increase funding to ensure that services can comply with the Disability Services Act; restore eligibility for individuals entering higher education; end the assumption that people with disability can be streamed from the outset into work capable and work incapable; and end the two-year time limit for the Transition to Work Program that ignores individual skill development processes and the structural barriers of employment. We need to provide mixed service options or blended programs based on structural linkages between State and Commonwealth jurisdictions. Thank you.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You have talked in your submission about the need for an appeal mechanism. How would you envisage that working?

Ms SANDS: We have not necessarily looked at that in terms of specifics of how it would work. What we would be looking at, though, is an appeals mechanism that would enable individuals affected by decision making to be able to have a clear, transparent process where they can actually take an appeal and know what the process is beforehand. Part of our concern has been that there seems to have been a great deal of confusion within advocacy organisations, service providers and individuals affected by the changes and their families about, if you can make an appeal, how you make an appeal, when you make an appeal, what will happen to it.

There does not seem to be any written material about it, and we have had a number of concerned individuals who have constantly called PWD since the changes have been announced saying they have been told they cannot make an appeal or there is no appeals process. They have no recourse or it will be taken but they do not hear anything back. While that is all anecdotal, there is enough to suggest that there is a great deal of confusion. So an appeals process needs to be transparent and clearly articulated, written and conveyed to people so they know exactly what they need to do and what will happen to an appeal.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Would you envisage an appeal to a paternalistic government assessor, who says, "If you have this program, you have this money; if you have that program, you will have that amount to money and these features", and do you match up to criteria? Then you make submissions looking for consensus in a medical case discussion or are you looking for a mental health tribunal, where you have an adversarial system or an Administrative Decisions Tribunal mechanism? What sort of system would you eventually say that there could be an individual assessment because, presumably, this is the same sort of appeals mechanism you would have in terms of what package you were getting for an individually tailored plan, would it not? This would be the same sort of appeal.

Ms SANDS: Yes, they could well be similar to that. As I say, I cannot give you a position from People With Disability Australia because we have not sat down and said, "What will we have as a model around complaints and appeals?" So I cannot give you that position. Basically our submission has addressed the changes and what the consequences of those changes have been, but certainly we would probably want to look at, maybe, an independent process, which was not confined within a departmental process. That maybe one feature of it, but just the clarity and transparency of it and the information actually provided to people so they know what that is. There may well be consultation around how that might work best and what some of the issues are. To date there has been none of that kind of discussion. I do not know whether you would like to add something, Heidi?

Ms FORREST: Our organisation fully advocates the social model of disability so, therefore, any appeal would need to be based on the strengths of the individual and would need to incorporate information from generic services like schools that the person accesses so that we can understand their ability to fully integrate into the community and transition successfully. Because it is more than just the medical knowledge of the person; it is about how they can cope in the mainstream and how they can cope in the generic structure. It might be that within certain services, because they understand where they are coming from, they can handle it better, so, therefore, that appeal needs to be more inclusive of more things than just maybe medical.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Sure, but if there was a functional assessment, at one level a bean counter might say: Of the people who went into the transition to work program a certain percentage succeeded. That is the overall big picture, but in terms of assessing each individual, what is the chance of this individual succeeding and what changes of function will they get, you would need an individual assessment?

Ms FORREST: You would.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Obviously, that is going to be controversial in terms of how many resources and how much of each person's time is put into that.

Ms FORREST: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: That would suggest the need for an advocacy and adjudication procedure?

Ms FORREST: Yes, it does need to incorporate that, but, for example, I am also a student at Newcastle university and one of my friends at the university has pretty severe cerebral palsy and she just had a funding cut and was told that she had to go onto a day program, which is learning how to do literacy-type stuff. Yet she had been invited to begin the honours program at Newcastle university, so if the assessment program was not flexible, her needs would not be supported.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: That suggests that the tick box or however she was assessed is something like a bad joke in her case, does it not?

Ms SANDS: That is right.

The Hon. CHRISTINE ROBERTSON: The assessment process is still a mystery to me from this inquiry.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I do not want to answer what the assessment process is. Perhaps you should ask the witnesses?

The Hon. CHRISTINE ROBERTSON: I tried. Do you people actually really understand the assessment process and who is currently involved in the assessment process?

Ms SANDS: Our understanding of the assessment process is that it is based on a transition teacher at school filling out nine questions around functional capacity in a number of areas—domestic functioning, social skills, a behavioural element and there is also another component, which, I understand, is around behaviour. Once the transition teacher fills that in, it goes back to DADHC, which then sends them to Wollongong, to the Centre for Health Service, to be assessed. So while the transition teacher who may know the individual fills out the assessment, one problem we have is that it is only based on incapacity or what a person can do functionally. The other thing is that the assessment then goes back and while it may seem independent, as Heidi's point illustrates, it can be very easy to look at very high levels of functional support and equate that with an inability to be able to achieve work or an educational outcome, and that is a false assumption because it does not equate in that way. People with very high support needs can successfully be employed or attain high levels of educational outcomes.

As we have stated in our submission, we find it very problematic that the assessment is a functional-based assessment only and does not look at an individual's current situation around what their choices might be, what their life ambitions are or where they would like to see themselves going—one just based on individual preference. The second thing would be that that functional assessment is not based on any structural analysis of the barriers of, particularly, people with disability obtaining employment or education. It is based on whether their functional capacities will enable a person to get to work within two years. We just believe that is incredibly problematic, philosophically as well as practically.

CHAIR: Did the 2003 working groups address the issue of an assessment tool?

Ms SANDS: Yes, one of those working groups was on the assessment framework, so it was solely looking at that issue. With those working groups, though, they met at various times but probably they were only about two to three meetings into a review process and looking at those issues but, yes, there was one that was looking at the assessment framework.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is this not the one that had the acronym SNAP, that they could give very quick assessments that were very accurate with a tick box system?

Ms SANDS: Yes, there was the HACC model, the Commonwealth Rehabilitation Service model, and DADHC had conducted, from our understanding, whether the HACC assessment tool was as relevant or as good a predictor as the Commonwealth Rehabilitation Service tool, and they found that it was, based on what they were trying to assess, which was functional capacity, and SNAP is another tool that was looked at. The working group looked at all the assessment tools but they looked at the fundamental question around assessment of individuals and what that meant in the case of people with disability and whether you can make a functional assessment solely a functional assessment and then predict whether someone is work capable for work or incapable, just based on that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Am I reading you right that you said that the transition teacher fills in nine questions and sends them for assessment in Wollongong?

Ms SANDS: That is our understanding, yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: That is pretty black box, is it not?

Ms SANDS: That is right.

The Hon. HENRY TSANG: My understanding of what you are said is that the clients of the transition-to-work program are generally happy with the program. The question really is whether two years is enough and whether the five days can be continued. It is not a question of whether the transition-to-work program itself is a failure, it is a funding. Is that an accurate assessment?

Ms SANDS: Yes. PWD has the position that it should not be a two-year time limited program. A two-year time limited program might work for some people but it will not work for others. People's individual ability to gain skills, their choices and life aspirations, may not be fully developed within that two-year period. We would say that two years is a short time for any school leaver perhaps to make a transition to employment, for example—they may go straight to education—but particularly people with, say, severe intellectual disability, they may be able to achieve a great deal of skills but two years will not be sufficient to do that.

It seems that they are being labelled from the outset that they will never achieve those skills, when they are not even been put in a position to have opportunities that would gradually build those skills up over the time they require—not over the time a service system requires but over the time they require to reach those skills and those ability levels. We certainly think that the two-year time limit should not be there. There should not be a two-year time limit. Do you want to add anything, Heidi?

Ms FORREST: No, just that I agree that we need to be totally flexible and that we cannot limit time. If we limit time, we limit individual's potential. My son has autism and you give him time and he cannot cope, but if you give him a bit of a free rein it is amazing; he can access all sorts of generic services. Accessing generic services and broadening the network is what we want because, in the long run, that is going to be more cost effective. If we want that to be done properly, we need to be a little bit flexible in the way that we go about it.

The Hon. JOHN RYAN: I want to ask you some questions about individualised funding, as opposed to block funding. Prior to the introduction of block funding I understand that clients and their families had virtually complete choice about what service provider they would use, but I believe the arrangements now our that they select from a short list and provide a shorter list to DADHC and then DADHC allocates them to a service provider. Is that correct?

Ms SANDS: We understand that is the new process. I am not sure that you could say that previously they had complete choice, because obviously that depended on the service system and what service providers were available. But certainly, under the funding package, they had choice to make a decision about what was best for the individual and the family. Now, it is correct that, depending on where they live, they may be able to decide between say two service providers and that selection will go to DADHC, and they may not get their preferred option because DADHC will make the final decision.

The Hon. JOHN RYAN: One of the other advantages of individualised funding is that clients sometimes can make use of non-specialised, generic services in the community and build a program for themselves. Are you aware of any clients who do that? You may not be able to do so immediately, but can you supply the Committee with information on how clients go about doing that? That is important evidence that the Committee does not have. I understand some clients do not go to block funded service providers at all but in fact use their funding, through a broker, to develop a completely different scheme that suits them. Clearly, that is no longer available once you block fund larger providers.

Ms SANDS: That is right. As to individual instances of that, we would be quite happy to go away, look at particular situations and provide information to the Committee on how that can occur.

The Hon. JOHN RYAN: I know it is rare, but we have not got much evidence along that line at this stage.

Ms SANDS: It does happen. One example would be where PSO and Atlas recipients are using their funds to assist them with post-secondary education facilities. For example, the education provider will only provide educational support through disability support programs, say note takers, or in the way they disseminate information, or specialised examination processes, or whatever. But they do not provide other personalised support, such as transport to and from educational facilities, or perhaps attendant care while the person is at the educational facility. So people have used their money to purchase those services so that they can participate in an educational program.

The Hon. JOHN RYAN: You referred to the impact of the new funding arrangements and made the statement that most service providers "will have no option but to provide low-intensity, group based programs in centre-based congregate facilities." That is a fair aggregation of jargon that is familiar to people who work in disability services, but for the benefit of the Committee could you put that into terms so that a layperson would easily understand what is meant by terms such as "low-intensity, group based programs" and "congregate facilities"?

Ms SANDS: There we are referring to a return to the previous, old system programs, and there are still examples of those kinds of services that are still running. One of the criticisms of the old PSO program, and why we had the new Atlas program, is that many PSO services also operated in this way. What we mean by that is that the Disability Services Act places emphasis on maximising opportunities and integration into the community, and a lot of the services concentrated on transporting people with disability to a service segregated from the rest of the community, so that they did not interact with the rest of the community but interacted with other people with disability. They were given tasks that were group based, so they were not one-to-one where they could perhaps maximise skill development. By low intensity, we are referring to the fact that in many cases many parents and individuals were concerned about the meaningfulness of the tasks.

People may go to a centre and spend their day doing craft activities, or there may be rotation of groups around certain activities, but those activities were constant over a two or three-year period, regardless of their individual plan, which meant they were to rotate around a group of activities constantly. So it was not really conducive to skill development and they certainly were not pre-vocational or vocational kinds of development. Those services systems would still operate now. One of the innovations around PSO funding was the individualised nature, by which you had to look at an individual and base a service around the individual. This is the opposite of that. We would see that, with the reduction in funding, and the type of block funding, there is a real danger of moving back to the old day program model.

The Hon. JOHN RYAN: Forty people watching a video and doing an exercise program together?

Ms SANDS: Yes.

The Hon. JOHN RYAN: As opposed to learning individualised skills?

Ms SANDS: Based on their own interests and choices.

The Hon. JOHN RYAN: In your submission you say that the original Atlas program guidelines guaranteed a minimum of 21 hours a week. Was that ever enforced? You have indicated that there were plenty of young people who were receiving 10 hours a week or less.

Ms SANDS: That is right. It was not enforced. It is the reality that people did not receive even that minimum. We cannot see how, with the reduction in funding, that minimum can ever be restored.

The Hon. JOHN RYAN: It has not been restored to or incorporated in the new community participation program, has it?

Ms SANDS: No.

The Hon. JOHN RYAN: Finally, you referred to the fact that there were some people who used Atlas programs to attend tertiary education options, such as TAFE and university. I imagine that one of the arguments that might be advanced for excluding people who have participated in TAFE or university is that they are actually successfully in another program, which is what Atlas is meant to replace, so that would be a duplication of funding. If they can make it to university or make it to TAFE, they are in a program to which it is not necessary to provide additional Atlas funding. Are you prepared to remake a response to that?

Ms FORREST: I know, because I am a student at a university, disability supports basically cover research assistance, examination changes and that kind of thing. But for a lot of people with disability to access universities, they need more; they need personal care support and that kind of thing. The universities do not provide that kind of support, and that poses problems for a lot of people with disability. A friend of mine, who has just qualified and has a law degree, used post-school options to help her go through university and get a degree, and was provided with supports that the university was not going to come forward with. Now she is able to go out there and be meaningfully employed, and pay taxes and whatever. She needed the benefit of post-school options to access a generic service that might not have been adequate to support her needs.

Ms SANDS: It also illustrates the lack of structural linkage between the State and the Commonwealth. For example, in that case, if there was a structural linkage to ensure that New South Wales and Commonwealth programs worked together on funding and eligibility criteria, it may well be that you could move someone from say transition to work straight into an education setting, and then they are off and on their way, because the supports are built into that system. But that is not the case. The new programs do not allow for that kind of linkage. It is hard to see how someone could move across to a post-secondary or employment option without the supports that could come from a post-school program. That is why I believe the new program will not be able to work without those linkages.

The Hon. JOHN RYAN: The Government would say that one of the advantages of the new arrangements is that the previous programs Atlas and post-school options were time limited, potentially for two years, and that, even though they were never implemented, at any time someone who had been in the programs for more than two years could have found themselves out of the programs. Effectively, they have exchanged for the time limit on the program a generic program that is able to last the lifetime of the client. Has the reduction in funding been a fair trade for the additional advantage of security?

Ms SANDS: We would say no. Of course, individuals and families should be assured that they will be supported. But if that means being assured of a place in what we have discussed as a low-intensity, group based and congregate facility, then we are really putting people back into a day program of the mid-70s, and that cannot be in compliance with the Disability Services Act. From our point of view, new programs have to be based on the Disability Services Act. That is what the Act is there for. There need to be guarantees that the programs will meet the objects of the Act. If you reduce funding and say you have the surety that you will have that for life, that does not mean that the individual gets to maximise opportunities, to be able to integrate into the community, and be able to have some positive self-value as well as community value, and therefore that is not in compliance with the Act.

The Hon. CHRISTINE ROBERTSON: There has been a change in the executive of the Department of Ageing, Disability and Home Care. Has that made a different to the process of communication between you people and the new administration?

Ms SANDS: It has in some instances. Fore example, when the announcements about additional funding for the high needs pool came in and DADHC commenced the process of looking at how that would be distributed and what guidelines were required, as well as when they were looking at finalising guidelines for service providers around how the programs would run, they actually began then to invite consultation. So PWD was invited to participate and be involved in that consultation process, but that invitation came in January this year. The point we made to DADHC at that time was that we would participate because our main advocacy role was to ensure that the rights of people with disability were respected in that regard. But we were certainly concerned. We certainly were not condoning the previous process of complete lack of consultation, and we certainly were not therefore condoning the changes to the programs. We though that the length of the consultation process that we were invited to participate in was incredibly short, very short, but our decision was to participate to ensure that we could advocate for people with disabilities in the development of the guidelines.

The Hon. CHRISTINE ROBERTSON: I recognise your concerns about the reforms at the moment, and I have listened to what you have had to say, but do you think that some changes should have been taking place to the Atlas program? And what do you think those changes should have been?

Ms SANDS: Yes, we did think there needed to be changes across the spectrum of day programs. We were not alone in thinking that. Many advocacy organisations, parents and individuals felt there needed to be meaningful reform that would ensure people with disability would be able to maximise opportunities. As I mentioned before, there was some concern that under the PSO system service providers were not providing programs that could enable people with disability could maximise opportunities, and that that matter needed to be looked at. There was a review conducted by independent researchers on day programs in 2001, I think. That report has not been released. There were a number of transition to work pilots. As we mentioned, we certainly took part in those working groups in 2003 with the idea that that meaningful reform could occur, that all the players there—the Commonwealth representatives as well as State, service providers, advocacy organisations—and that could look at how a program could suit school leavers and adults with disability to support them to meaningfully participate in the community, increase employment opportunities, educational outcomes, et cetera.

The Hon. CHRISTINE ROBERTSON: One other thing is the increase in hourly price that has occurred by the service providers almost simultaneously with the reduction in amounts of money per person to receive the service. It has meant a reduction in hours for many people because they just cannot afford to replace those funds. Have you heard about this?

Ms SANDS: Yes. Through our individual advocacy service, we have had some complaints in that area from individuals and families. We have about half a dozen complaints around ATLAS-PSO generally and many of those are about reduction of hours. Aside from those official complaints through our service, we also had numerous calls about the reduction of hours and the impact that will have.

The Hon. CHRISTINE ROBERTSON: So these are arguing to keep up the intensity of the programs for the individual and not have large groups and the description you gave earlier. To be quite clear, the ATLAS programs were still operating of large group stuff, is this correct?

Ms SANDS: Yes, some were, which is why there was some concern, while there was some push for reform, to look at more innovation across the day program system and to provide equity and fairness for people across the spectrum.

The Hon. JOHN RYAN: What we are now going to do is entrench it.

(The witnesses withdrew)

(The Committee adjourned at 1.02 p.m.)