REPORT OF PROCEEDINGS BEFORE

GENERAL PURPOSE STANDING COMMITTEE NO. 2

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

At Sydney on Tuesday 31 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. G. Jenkins
The Hon. C. M. Robertson
The Hon. J. F. Ryan
The Hon. H. S. Tsang

CHAIR: Welcome to the third public hearing of the General Purpose Standing Committee No. 2 inquiry into changes to post school programs for young adults with a disability. In addition to the three hearings, we have also visited half a dozen service providers in Tamworth, Armidale and Wagga Wagga. This week in Wollongong and Newcastle we are visiting more services as well as meeting with experts in the field. We have held parent forums in Armidale and Wagga Wagga, and the transcripts of those forums are on our web site. We will also hold three consultations this week with people with disabilities who use the post school programs to find out what those young adults think about their programs.

I want to make it clear that despite the announcement of 22 May by the Minister for Disability Services that funding levels for post school disability programs will be increased, this inquiry will continue as planned. The committee will continue to examine the changes to post school programs for young adults with a disability, as outlined in its terms of reference, and in the coming months it will deliver a report containing its recommendations for post school disability programs. In the hearing on 17 June it will question the Department of Ageing, Disability and Home Care about the details of the changes announced by the Minister.

Before the hearing commences I will make some comments about the organisation of today's hearing. In relation to accessibility issues, Parliament House is an accessible building. A hearing room 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.

The committee has previously resolved to organise the media to broadcast sound and video excerpts of its public proceedings. Copies of guidelines governing broadcast of the proceedings are available from the table by the door. In accordance with 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 it publishes, or what interpretation is placed on anything that is said before the committee.

In relation to the delivery of messages and documents to 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 such 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. Could everyone please turn off their mobile phones for the duration of the hearing.

HELENA BRIDGET O'CONNELL, Executive Officer, New South Wales Council for Intellectual Disability, 418A Elizabeth Street, Surry Hills, affirmed and examined:

CHAIR: In what capacity do you appear before the committee? Do you appear as an individual or as a representative of an organisation?

Ms O'CONNELL: I represent the New South Wales Council for Intellectual Disability [CID].

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

Ms O'CONNELL: I am.

CHAIR: If you 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 a short opening statement?

Ms O'CONNELL: Yes, I do. The New South Wales Council for Intellectual Disability is the peak body in New South Wales, representing the rights, needs and interests of people with intellectual disability, so it is from that perspective that I make my brief opening statement. I understand also that the committee is going to meet with people with disabilities themselves who are involved in the programs, and on behalf of the New South Wales CID I applaud the committee for that initiative. The purpose of the two new programs, and their predecessors, the Post Schools Option and ATLAS programs, is to assist people with disabilities to prepare for participation in the community or to be involved in some form of employment. All of this, we believe, should be dignified and meaningful activity.

For community inclusion to occur, and this is something to which we all pay a great deal of lip service, there has to be a significant shift in attitudes within the community. So while the spotlight of media in recent months has been valuable in many ways, and perhaps it influenced the Government's recent announcement of $6 million to enhance the program up until the end of the 2006 school year, there has been an extremely unfortunate consequence to this, which is what I want to focus on now. That consequence is that people with intellectual disability have been portrayed as a burden, a burden on their families and a burden on society, and this need not be so.

If the system supported families to plan for the future of their son or daughter, this ongoing crisis response would not continuously be occurring across all disability programs. The focus of media attention has been more on the issues for families and service providers. For families, this program has been respite and so reduced hours have been the cause of much concern. For service providers, there have been issues of viability. It is not as if they are not important issues, because they are and they must be addressed. However the crucial point in this whole process that to some degree has been overlooked, is that people with intellectual disability deserve a better deal when it comes to the kind of options available to them when they leave school.

Family members of students without disability just would not accept this level of uncertainty and, I think, chaos in terms of presentation of options for young people. Without the appropriate supports, young people with intellectual disability will lose the schools they have already acquired, and the learning that they acquired at school; they will not have the opportunity to develop to their full potential; they might be denied the opportunity to move towards greater independence; and they may be stuck in a program that has few individualised supports, and does not enhance their participation in their communities.

The New South Wales CID agreed that there definitely was a need for reform to the program to improve the quality of outcomes, and to create more certainty for people. However, this reform process was not based on any sound evidence, and will not lead to increased community participation for people with intellectual disability. Most importantly, this crisis response will do nothing to create a shift in community attitudes to people with disability, and without significant changes in community attitudes things will not change for people because there will be no pressure on governments to create more inclusive programs for people.

The Hon. JON JENKINS: I wish there were a better word to use than "clients", but is it reasonable to say that among the whole spectrum of clients, some will never be able to hold down employment of any sort?

Ms O'CONNELL: That is not to say they cannot contribute in some way.

The Hon. JON JENKINS: I know. A person who is now classified as not suitable for training may become suitable at some point later in time because of many different reasons, including medication?

Ms O'CONNELL: Lots of changes, in the same way that people without disability undertake adult education.

The Hon. JON JENKINS: It is important to keep programs open to people throughout their life?

Ms O'CONNELL: Yes. In relation to the first term of reference, there does not appear to be any mechanism in the program to allow for that movement between programs, and that is why I said earlier that our concern was that people get locked into something, first, because the funding levels will keep them out of the community and there will not be the support available and, second, it will never give them that opportunity. Also, the assessment, as we know, has some difficulties: one might be just having a bad day and get locked into that program.

CHAIR: You mentioned earlier that the CID felt there was a need for reform. Was the CID involved in the consultation with the Government leading to the changes that were announced last year?

Ms O'CONNELL: The CID was not involved in the working groups that were occurring up until about the middle of last year—we had other priorities—but we certainly were in touch with organisations that were involved, and supported their input. We did not feel there was a problem that we were not involved and we were certainly in discussions with the department discussing these issues. We understood that there was quite a solid process with some pilots and some significant research happening.

We understood that when there was an outcome from that, there would be some announcements. We were all getting a little bit worried about what was going to happen to students who were leaving school at the end of last year. That time was approaching and there had not been any announcement. Suddenly this, in a sense, came from nowhere, or it certainly did not reflect, as I understand it, the input that disability advocacy groups and disability service providers and others had into the working groups. I think the working groups were a good idea. There is a lot of value in them. But if nothing comes of them, then they are just a significant waste of everyone's time and the department's resources.

CHAIR: What are the main areas that you believe need to be reformed in the existing programs?

Ms O'CONNELL: Obviously the issue of what is referred to as throughput. There were not the numbers of people moving on to employment as you would expect and as appears to occur in other States and indeed overseas as well. There was never certainty around the program. The Adult Training, Learning and Support Program [ATLAS] was announced as a two-year program, but because there was no follow-up to develop that any further, students or young people were never moved on from that program unless service providers saw opportunities and moved them on to Commonwealth employment programs. That was a problem. Probably the range of funding was never really appropriate, either. I think in other States there is a much broader range of funding levels. I think they have three or four bands of funding rather than the two or three that we had.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Does this $6 million that has been announced by the Government replace what was taken away?

Ms O'CONNELL: If you look at the figures for the whole program, it brings the funding up to more than 2002-2003. Because it does not appear to be recurrent funding, as I understand it, it is available to support some transition over the next year and is available up until the end of the school year in 2006. That is as I understand it; I might have misunderstood that. In that sense, it is not recurrent.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So it is a one-off?

Ms O'CONNELL: That is what I understand.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I gather that the Minister's position has been that the total amount of funding has risen every year, including this year, even before the $6 million. Is that correct?

Ms O'CONNELL: It would have increased, yes. It had the school leavers for that year but, as we know, there has been increased demand for a number of reasons.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Presumably the kids will graduate, if that is the word, every year. In other words, they will be of the age that if they had no disabilities they would be leaving school, and that would come on every year. So the funding would have to go up every year if people were to continue to have programs, would it not?

Ms O'CONNELL: That is right. And a proportion should move on to Commonwealth employment programs, and that is what has not been happening.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is there a shortage of Commonwealth employment programs?

Ms O'CONNELL: There have been some significant enhancements to Commonwealth employment programs in the last few years, so I would say probably not. I think the difficulty, though, is the linkages or the interface between the State programs and the Australian Government programs, or the planning for that. I do not know if the Department of Ageing, Disability and Home Care [DADAHC] sat down with the Department of Family and Community Services, which funds business services, or the Department of Employment and Workplace Relations, which funds around open employment agencies. For me, that would be an obvious place for them to be consulting quite considerably because that is how we get the throughput.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: There has been evidence that the criteria for the two are not compatible.

Ms O'CONNELL: Yes, I think that is the case. All of the States seem to be doing some reform process around post school programs. In Queensland I understand that the State Government has been speaking with the Department of Employment and Workplace Relations [DEWR]. That may have been happening there, I do not know. However, does not appear to be so.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You said in your submission that while the State may save money by these programs, the way they are pushing them onto the Federal Government will increase the total costs of support or services offered from the government to the client. Is that right, in essence?

Ms O'CONNELL: I think maybe there were a couple of things I was referring to there, but one in particular was with the reduced hours. The disability system in New South Wales will be under pressure for additional accommodation where we know that people find they are just unable to cope with reduced hours. There is a requirement for accommodation there and the need for additional respite when families have to work or do whatever they do in the daytime.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In essence, what you are saying is that the unco-ordinated state of Federal-State arrangements is increasing the total cost of these programs to the taxpayer. Is that a summary of what you are saying?

Ms O'CONNELL: No, that is not, necessarily. The increased cost to the New South Wales Government will occur. It is almost cost shifting from one program to another because if people do not have the opportunity to be somewhere during the day and if people are unable to be on their own, they will have to be supported somewhere else and people will be leaving their sons and daughters in respite, or whatever, as we know has occurred. The linkages between the State programs and the Australian Government programs just do not appear to be in place because we have not been achieving the outcomes that we should be achieving, so there is something that is not happening there; the expectations from these programs are not matching what the open employment services require for people to be able to get through there. There are two possibilities, really. I know that this cannot be true, but one is that people are not able to move on. Certainly people are able to move on in other States. It is just a poorly planned and poorly integrated system.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In essence, what you are saying is that if you scrimp on the support programs, you put pressure on the accommodation programs which are more labour intensive and more expensive. In fact, they are both State programs. Am I summarising what you are saying, in essence?

Ms O'CONNELL: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you believe that people who have intellectual disabilities may need, effectively, a lifelong learning situation in terms of the fact that their teaching will never end? Is that really what is needed in terms of support for some people?

Ms O'CONNELL: With some people I think there will always be a requirement for support to participate or use services, and for ongoing skills development and support. With the others, people will be able to move into employment and with initial support do very well. I think it takes a lot longer for some people with intellectual disability to become comfortable in a workplace. But our evidence shows that people who have a disability, once they are in a workplace, are very loyal and committed employees. This is not the nature of this inquiry, but employment processes for people with disabilities take a lot longer, so people need support for maybe a couple of years before they settle down to a job. If there are any changes in the job, they need support. Over all, once people have moved into employment and have been supported and have prepared for that well, which is the State's responsibility, then they have successful outcomes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: My understanding is that the United States of America has had a labour shortage and as a consequence has managed to place a lot of people with intellectual disabilities. Is that true? Are there any lessons for us there? They are a lot harder there in terms of their support services than we are, are they not?

Ms O'CONNELL: What do you mean by "harder"?

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: They are less welfare oriented.

Ms O'CONNELL: They are less welfare oriented but a lot of their services are of quite high quality. Yes, that is true; I understand too that they have moved more people with disabilities into work with the labour shortage, and I believe that that is what the Australian Government is trying to do with the current welfare reforms. We have some concerns about how that is working. While we support people to be working, they need to be supported to get there.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are there any general lessons we can learn from the American experience?

Ms O'CONNELL: I think at a State level, the role of the State Government is preparation for work, and so that is a little bit different. That has to be done well, but I think that at a Commonwealth and Australian Government level, there are lessons to be learnt. I think the Australian Government is probably taking that up, but to a degree it is a different issue to what this Committee is looking at.

The Hon. TONY CATANZARITI: I have just one quick question. You mentioned the issue of the awareness of the problem with disabilities rather than the burden. What need is there to change this attitude within the community, in your view?

Ms O'CONNELL: There is a great need to change it, but I really think that the only way it will change is for organisations like ours to be presenting a different picture of people. There are families out there who are working in quite different ways with their sons and daughters in terms of planning. There is a particular father who is working with some non-government agencies that develop training to empower families to support them to be able to make much better choices and to work with government. So there is work that is being done. People who I think are around this family talk about seeing their sons and daughters as gifts and opportunities for them, and that is hugely different.

I am not saying in fact that a lot of people do not see that, but I think the perception that is coming across in the media is that these people are a burden and it is too much for families. All of those issues just do not paint a good picture and things will never change while we have that perspective. We all have a responsibility. I have a responsibility for that. That is really the only way that more funding will be available, if there is pressure from the community more broadly than for organisations such as the Council of Social Service of New South Wales [NCOSS] and the Council for Intellectual Disability.

The Hon. TONY CATANZARITI: Do you think it is more a case of the community needing to get out there and say, "Hang on, this is not just a burden to the people concerned. There are opportunities out there. We have to accept these people. They are and will be with us forever," or do you think it is more that both State and Federal governments need to take up the issue as far as trying to get that knowledge and awareness out there?

Ms O'CONNELL: I think that governments are pragmatic and will only do what they are pressured to do by the community, and we accept that. I think that from within the community there has to be a drive to change that because essentially anyone of us could have a disability tomorrow, and that is the truth. People will be born with disabilities and there may be changes medically to improve their lives down the line, but that is something that is going to happen. We need to have a shift around that. That is kind of in the media. Well, it is the media that is helping the communications, so that is a definite shift that we have to make. The truth is that it has changed over time. We no longer lock people up and institutions, so it is progressively changing.

CHAIR: Why does the Council for Intellectual Disability believe that the move to block funding is a regressive move?

Ms O'CONNELL: Because it does not allow for flexibility in terms of the individualised programs for people. It does not allow for people to move on with their funding in the same way that somebody might be able to change universities, for example—which perhaps is more difficult these days. But it does not allow for that. It locks people into perhaps one program and if a person did not get on or had some kind of conflict with one staff member, in the future they will be annihilated almost because of that, and that does occur. That issue really does not allow for flexibility or support.

CHAIR: During the inquiry it has been suggested to us that some service providers have used these latest reforms to increase their fees. Do you believe that that is a widespread problem?

Ms O'CONNELL: I cannot answer that. I am not certain. I have heard of it in some instances.

CHAIR: It has also been put to me while talking to people during the inquiry that a number of service organisations were providing support for older people with a disability who had never previously acquired a funding package of any sort but who, because funds were available through the Post School Options Program and ATLAS, were able to be provided with a few hours a week because there was money available, and that is now at risk. Do you know anything about that issue?

Ms O'CONNELL: I have heard that. I think that is where people would argue that block funding is an advantage for service providers and, to a degree, for people. The funding is not targeted at one person. There are a lot of concerns around that because they may not be providing the right kind of program for that person. Again, we need to come back to the notion of individualised support for people.

CHAIR: In your submission you referred to staff development as a requirement to improve disability services. Could you elaborate on that? In particular, do you believe that that scenario would require additional funding?

Ms O'CONNELL: There are a lot of good training agencies within the disability sector that are accredited. They provide excellent training. However, there appears to be pressure on the system, both government and non-government, for people to take time to do training. Another issue is whether some kind of accredited system could be implemented in which staff are accredited. Certain levels of accreditation are required in certain positions, particularly those in this area that involve training and support for life-long learning. It is almost like an education role.

CHAIR: You referred to pilot programs that were under way. What do you know about pilot programs in post school options programs? Do you believe that they are providing some way forward?

Ms O'CONNELL: I have not seen any outcome or report from those programs, so I cannot respond to that question.

The Hon. JON JENKINS: In your submission, and reiterated in evidence today, you said you believed the outcomes from the previous program had not been achieved, at least not fully. You said there was need for review. As a general rule, who should carry out that review? Should it be done by the Government or by academics at universities who work with intellectual disability, or psychologists, or behavioural scientists?

Ms O'CONNELL: A range of people should be involved. Indeed the working parties established by the Department of Ageing, Disability and Home Care, now 2½ years ago, involved a range of people. That was quite appropriate. The problem was that the committees never got a chance to make the recommendations and have those recommendations taken up by the department.

The Hon. JON JENKINS: Did they issue formal reports?

Ms O'CONNELL: No, I do not think so. There was a lot of changing of dates of meetings, and people found that a bit frustrating. We all know who the people are, the experts who can provide a lot of input. Things are happening in other jurisdictions as well.

The Hon. JON JENKINS: Is there research from other States or overseas which effectively could be co-opted. It sounds as though the previous research was a waste of time and money. Do we really need to go through that process again?

Ms O'CONNELL: The previous one almost met the community requirement; which is something for people to do so that families do not feel pressure. That is a reasonable expectation from families. However, in developing people with disabilities, only 3 per cent of the people involved moved on to employment. That is completely unacceptable.

The Hon. JON JENKINS: Do you think that failure was the failure of the program itself and/or a failure of the post training programs? For instance, there was no Commonwealth employment program for them to move into afterwards. Was that part of the reason for failure or was it all in the program? Where do you see the failures occurring?

Ms O'CONNELL: In 1998 when the ATLAS Program was introduced, it was introduced in compartments. It was implemented as a two-year program, it was never established in that way. People have continued to come through. Everyone knew that there was going to be a problem. People are not going onto employment after leaving school, that just was not addressed. Some good innovative work was done with individual funding. A lot of people were in quite unstimulating programs as well. There was no consistency across the programs and probably very little monitoring and department.

The Hon. JON JENKINS: We really do not know whether the program succeeded or failed?

Ms O'CONNELL: If you look at it as a pre-employment program, which is what would be expected of it to a degree—not for everybody, as we discussed earlier—it was not successful in that sense. People were not moving on. It goes back to planning, there was no concept of what would happen next. People were holding on to their funding in the hope that they would not lose it without necessarily focusing on what their son or daughter needed next. The service providers have a role in that as well.

The Hon. JON JENKINS: One issue that came up earlier, about which I was quite stunned, was that the people at Wollongong—whom you mentioned in your submission—are not behavioural scientists or people involved in this area, they are statisticians. They are doing costings and other things. Is that of concern to you?

Ms O'CONNELL: Yes, research was done into the costing, that is right and also into the assessment. More work needs to be done around quality of programs.

The Hon. JON JENKINS: On a production line, for instance manufacturing a machine, quality monitoring can be done and that can be fed back into the production line to produce a better product. I have always found that very difficult to apply to people, to the production of people if you like. How difficult is it to monitor accurately the outcomes of the programs? How do you monitor success?

Ms O'CONNELL: There have to be benchmarks, some achievements are expected. There should be some expectation that a certain percentage of people will be able to move onto employment, and that is not happening. The needs to be more consistency across the program regarding the type of supports that are available to people.

The Hon. JON JENKINS: In normal teaching there has to be a program, a curriculum, teachers have to abide by the curriculum, but teachers are free to construct their own program that adheres to the curriculum. Is that what you mean by consistency? Should there be a curriculum for disabled people? I understand that it is difficult because of the variability, you suggesting that. Some organisations may say that they would be too restricted.

Ms O'CONNELL: Yes, and some people would find that too limiting on individuals, but there needs to be some benchmarks around expectations of what people can reasonably achieve. Probably within the context of an individual plan it could be done. But there is lots of work done around individual planning. The Ombudsman is reviewing individual planning for services at the moment.

The Hon. JON JENKINS: But it is possible?

Ms O'CONNELL: Yes, it is possible.

CHAIR: We have two programs; one that is the transition to work and one that is far less likely to have people move through it to another level, so to speak, onto a work program. That will be a long-term and supported daily program. Is it the view of the Council for Intellectual Disability that some people in the community participation program should be able to transition to a work program with the correct training? Or will they have been misplaced?

Ms O'CONNELL: It is quite possible that could occur. If it does occur, the does not appear to be a mechanism for people to be moved out of there as an ongoing assessment or review or opportunity. The answer is that we do not know whether people are placed accurately or correctly. If that does occur we are very concerned that that is where people will stay. With the funding levels we cannot see truly inclusive community participatory programs happening. Service providers tell us that as well.

The Hon. JON JENKINS: Do you think a funding model based on individual clients would be a better approach? In other words, each client is assessed as to his or her needs and rather than having stepped $9,000, $13,000, $16,000 funding, there should be a graduated scale? Is that possible?

Ms O'CONNELL: A lot more work would need to occur on some levels for that to happen. It would be ideal and it could happen if things were planned better. I heard the Minister announce a plan for disability services to commence later in the year, and we were very pleased to hear that. However, a plan would take several years to implement. It sounds absurd but we need to take all the money back from the programs and give people bridging funding for a few years and then look at individuals as they come through school, right from pre-school almost, and look at where they are likely to be heading. We need to do some planning for that. Families need to be supported in that way as well.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Have any longitudinal studies on what works been carried out? Has a university looked at this systematically? It seems as though we try ideas and they become fashionable. Does anyone carry out a scientific systematic study?

Ms O'CONNELL: I am not able to identify people immediately, but I think Eric Emmerson and the Lancaster University has done work around that. He is often invited out here by the Centre for Developmental Disability Studies, Professor Trevor Parmenter's organisation. I can provide some research on that Important Issue. I agree that things are often the flavour of the month, but life planning has been tried for centuries. That is something we really need to focus on.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In Australia there is no centre of excellence for that sort of research?

Ms O'CONNELL: When you say "that sort of research", do you mean life-long learning or life planning?

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Looking systematically over the long term at programs for individuals with a disability and the long-term outcomes?

Ms O'CONNELL: Nothing I am aware of. In each State there is a centre such as the University of Sydney's Centre for Developmental Disability Studies. I would be surprised if no research had the done around that. I can provide that information.

CHAIR: Thank you for your submission. If you think any additional material should be brought to the attention of the Committee that would be welcomed.

(The witness withdrew)

BARBEL WINTER, Executive Officer, Multicultural Disability Advocacy Association of New South Wales, Post Office Box 9381, Harris Park, sworn and examined:

CHAIR: In what capacity do you appear today: as an individual or a representative?

Ms WINTER: As a representative of the association.

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

Ms WINTER: I am.

CHAIR: If at any stage you should consider 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 WINTER: Yes, I thought I would set some of the themes as they occur to us. I want to make some general comments about any new program or any revitalised or changed program in this area. We think that any program needs to focus on the skills development of all the participants. It needs to provide funding to meet the learning needs of individuals, irrespective of their race. It needs to encourage transition to work and participation as a lifelong activity, and it needs to provide funding that is individualised, portable and, most importantly for the people that I am concerned with, equitable.

The various iterations of the post-school program had not been designed with the whole target group in mind. The Department of Ageing, Disability and Home Care [DADAHC] in their submission to the Committee state that improving the cultural appropriateness of the post-school programs is part of the next phase of the development for 2005. The policy framework of the new program does not include any outcomes in terms of achieving greater racial equity. We were part of the organisations that worked—the working groups that you referred to earlier a couple of times—and tried to assist in reshaping the program. We provided ample advice on how to achieve greater equity for people. It appears that none of that advice has made it into the two new programs and has not been taken on board, which leads us to believe that the department and therefore the Government are content to run a racially biased program.

CHAIR: In the submission from the Multicultural Disability Advocacy Association you refer to statistics. You refer in particular to statistics that were given by the Deputy Director of the Department of Ageing, Disability and Home Care, Robert Griew, to the Legislative Council social issues committee that only 3 per cent of all disability users were from a non-English speaking background [NESB]. You suggest that it is approximately 5 per cent but in actual fact there is even a suggestion that it could be greater than that. How do you believe there is a lack of clear knowledge by government departments about the background of people in terms of whether they are from non-English speaking backgrounds?

Ms WINTER: I think they have no idea; that data is obviously not available. We have asked for it and we would like to encourage the Committee to ask for it the next time that DADAHC appears, and maybe they can assist. We have certainly tried and all we have come up with is what we have got and what we have presented to you.

CHAIR: Have you made a submission to the department at any stage about the statistical issue?

Ms WINTER: We have raised it on numerous occasions, yes. I have been involved in this for the last eight years and there has apparently been work done for the last seven.

CHAIR: Are you aware of any up-to-date statistics used by the department?

Ms WINTER: In 2003 in the Post School Options Program there was an attempt to target people from a non-English speaking background in the acknowledgement that the access rates were very low. I have heard that that yielded some success and that the access rates increased but I have not seen any data and I do not know whether that is available.

CHAIR: What is the impact of postponing the so-called "cultural appropriateness" issues until the next step of the reforms? Does this mean that potential clients from a non-English speaking background may slip through the gaps as they leave school this year and next year?

Ms WINTER: Yes—it is as simple as that. These programs made no attempt to address some of the issues that we have raised over and over again. A flat payment does not take into account any additional needs so I have no doubt that it just perpetuates what we have had in the past, which is really low access rates. I think it needs to be seen in the context of the ethnicity of people coming out of school. We know from the Department of Education and Training that about a quarter of the school population is kids from a non-English speaking background and about 30 per cent of the kids in special school support programs are kids from NESB. So, if nothing else, we know that about one in four of the people in post-school options programs should be from a non-English speaking background.

CHAIR: Could you tell the Committee about the usage by DADAHC of translation and interpreting services?

Ms WINTER: That is a difficult question because that clearly is a policy. I believe there is a memo from the Premier that says interpreter services need to be used, governments need to use that, and the government departments that fund non-government organisations need to ensure that those are used. The reality is it is perceived that there is not enough money and that $13,000 a year will not stretch to using an interpreter to work with the family, to looking at culturally appropriate work force development or whatever is needed to make the services accessible.

I think for those population groups interpreters and translators are not the key issues. They are clearly important and they are important when you want to do some work together with a family and involve the family in whatever program you are designing. But we think it is much more of an attitude issue. It is in the too-hard basket to look at cultural needs, and therefore they fall by the wayside. Because they are resistant to maybe the way that programs are designed it is really jeopardising the outcome of the programs for those people.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In essence, your submission is that there are no figures on the demand by people from non-English speaking backgrounds for disability services and there are no figures on the number of people from non-English speaking backgrounds in disability services. So there is no data either way. Is that what you are saying?

Ms WINTER: There are bits and pieces that we have put together. We have pulled everything together. We have previously done some work around that, so everything we know we have put in there. But some of it seems to be guesswork.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So you have taken figures from the Australian Institute of Health and Welfare, for example, for the percentage of disabled people, multiplied that by the number of people from non-English speaking backgrounds in society and you have gotten your number.

Ms WINTER: Roughly. There is very little evidence that the incidence of disability in children is smaller or greater in ethnic communities than it is across the Anglo Australian community.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: If you were a gambler, you would say it is the same, would you not?

Ms WINTER: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But there has been a lack of enthusiasm by governments to quantify unmet need everywhere, has there not?

Ms WINTER: I think the population we are dealing with are beyond the level of unmet demand, let alone unmet need. I think the people we are dealing with do not demand the services, let alone not get them met. So we have a problem that is earlier than the unmet need. The problem with running a system that is based on the squeaky wheel is that those people who express their need get the service. Those people who do not express their need because the system does not operate on a level where they can—

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So you are drawing a distinction between unmet need and unmet demand.

Ms WINTER: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you suggesting that, perhaps because of cultural factors, it is a shame on the family to have a disabled person so they do not demand?

Ms WINTER: No, because of cultural factors the system that is designed for Anglo Australians cannot meet the needs of people from a non-English speaking background. I am saying that there might be different cultural expectations, values and a whole range of issues but because we live in a multicultural society and the system is supposed to deliver to all people, the system needs to deliver. The system needs to be redesigned to meet the needs of those people. Do you know what I am trying to say? It is not that people have different cultural expectations and therefore there are barriers; the system has one approach to delivering services, which creates barriers, and is unable to meet the needs within people's cultural framework.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you speaking about post-school options programs or are you talking more generically?

Ms WINTER: I understood your question to be more generic.

The Hon. JOHN RYAN: I do not understand the answer you gave a moment ago, Ms Winter. Could you illustrate it with specific or particular examples that might explain why someone in a family from a non-English speaking background that has a disability might not access services or think to access services? To be truthful, I kind of get it but I do not get it completely.

Ms WINTER: I will give you a really practical example that is quite simple in the way that I understand it. Let us say there is new money in respite—there is always money in respite so it is a good example and respite is underutilised by people from a non-English speaking background. So new money gets released. The new money is promoted to the usual services and the usual services go out and promote respite. Except they fail to communicate that to ethnic communities, to whom the whole concept of respite is completely alien. There is no word for "respite" in their language—imagine having no word for "respite"! The system fails to communicate in the most simple way what it has to offer. I have used a language example but it is the same with cultural aspects—the system fails to communicate to that group of people that that service is available.

The Hon. JOHN RYAN: We are dealing specifically with ATLAS and post-school options programs. One imagines that people from non-English speaking backgrounds would be represented in the school system fairly similarly to how they are represented in the community.

Ms WINTER: Yes, 25 per cent.

The Hon. JOHN RYAN: A fair effort is usually made within the school community to communicate what happens to those families after school. Where do they go between school and entering ATLAS and post-school options programs? While I can see there being a problem with things such as respite and perhaps even supported accommodation—in fact, one of the biggest problems with disability services is the fact that there is so much technical jargon that even people who speak English do not understand it—I would have thought there would not be such a large problem. You would think it would be normal to say, "My child is no longer at school; what am I doing next?" There is some effort particularly if they are at special schools and so on. Why do they move from school off the cliff, so to speak, into nothing? Do we know what is going on there?

Ms WINTER: That is anecdotal evidence—

The Hon. JOHN RYAN: We have visited a number of services and obviously in my other capacities I have visited many more, and it would be fair to say that the population within the ATLAS program generally appears to be very much an Anglo-Saxon population. It is the exception rather than the rule to see people from different ethnic backgrounds in those services. Whether there are any statistics or not, on face value from what I have seen myself it appears that certainly not a third of people from non-English speaking backgrounds are in those programs. Where do they go?

Ms WINTER: Something must happen in the interface between school and the delivery of post-school options programs. Somewhere the communication is broken down, and that is what I refer to as systemic racism or a systemic failure to meet the needs of people from NESB. Obviously people have different expectations and there might be a different understanding of what will happen, but whatever that is it is the responsibility of the system to communicate that problem.

The Hon. JOHN RYAN: Have families come to you that have post-school age children and young people aged in their twenties who are living at home and doing nothing and are not in ATLAS programs?

Ms WINTER: Yes. When this whole issue came up we started talking to our client base through our eight individual advocates who work across the State. We said, "Have you done some work?" And we found two families that are in post-school options. This is advocacy so it is limited, but that is a very, very small group of people.

The Hon. JOHN RYAN: Have you found families that are not in programs?

Ms WINTER: Yes, absolutely.

The Hon. JOHN RYAN: What are they doing? What are their stories?

Ms WINTER: They are at home.

The Hon. JOHN RYAN: Why did they not go on?

Ms WINTER: Most of them did not know. That is my understanding. It is a case of, "She's had the schooling and now she stays at home". There is very little knowledge about ongoing programs.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you saying that they were at school and that other children, presumably from similar classes, went on to post-school options while they went home to the family and didn't do anything?

Ms WINTER: That is what must have happened.

The Hon. JON JENKINS: Are you saying that it is not really a language problem in itself, it is not a cultural problem, it is just a lack of communication problem?

Ms WINTER: That might be it.

The Hon. JON JENKINS: I presume that is the school's responsibility. As the students come through and are acknowledged to have some disability, parents are not being made fully aware of the options available after school. Would you say that that is the main problem?

The Hon. HENRY TSANG: Maybe it is members of the extended family who are helping the parents to look after these post-school students.

Ms WINTER: Maybe.

The Hon. HENRY TSANG: Maybe, also, the people have networking and influence in getting into the services, whereas people from non-English speaking backgrounds [NESBs] might not know how to access them.

Ms WINTER: If they had influence, at some stage we would see those people in services and we do not, so I do not think that happens. My experience around the extended family is that certainly that happens for some people, but I think there is a bit of a myth which feeds into some of the perception, that is, that ethnic people look after their own. That is a myth and it assumes that there are a whole lot of extended family who can actually do that. For most of these people, like everyone else, there is no extended family to do that. The pressure often falls on the mother, or the grandmother at best.

The Hon. TONY CATANZARITI: Are you suggesting that while they are attending school the presence is there of ethnic communities, but once they get past that and reach the post-school level they tend to go back to their homes and are hidden away?

Ms WINTER: what I suggesting is that post-school options is basically a system that works for Anglo-Australians. That is what I am suggesting.

The Hon. TONY CATANZARITI: I am sorry but I just cannot grasp it, that that is the case. I am myself from ethnic background and I do know that in the past there were difficulties associated with people who had disabilities trying to integrate into the system and, therefore, parents felt they could better care for those children at home; that perhaps that is where they should be, not out in the community. I am a little at a loss to understand that that is still happening in 2005. Why do you think that is happening?

The Hon. HENRY TSANG: Because it is too competitive—access to services.

Ms WINTER: I think there is something that. I think there are a couple of answers. I heard you talking about community education earlier and I think one of the issues is around community education. When you look at what we do in terms of community education, we hardly ever address ethnic communities around some of those issues. So, that is an issue. There is traditionally suspicion of government; there is traditionally the response that maybe we need to look after our own—all those things you mentioned. But what I said earlier still stands, that the system has a responsibility towards those people, and as a system there is a responsibility towards kids from a non-English-speaking background, irrespective of what their parents believe or do not believe.

The Hon. TONY CATANZARITI: Do you believe that it is possible that older members of community are not taking the interest that they should be taking, not only when they have children with disabilities but within their own communities? Or is it that they do not want to know? Do you think that there is a possibility they do not want to find out?

Ms WINTER: Well, who wants to know? In no community—except, maybe, the deaf community—will people say, "We have a child with a disability." In most communities across the world people will say, "Oh, my God. I have a child with a disability." In most communities, not every one, the response is shock, horror, grief, and there is a process. In most communities that process goes through stages for each individual and then there is a level of acceptance. And there is acceptance at community level as well as on the individual level. That would be my answer, really, that there is not grounds for celebration in most communities when there is a disability, but most communities somehow deal with it. There is a bit of a perception, I think, that ethnic communities are a bit backward. I dispute that. Now we know that institutions are not such a great thing.

The Hon. TONY CATANZARITI: Is any information given out through their community newspapers and radio about these types of things?

Ms WINTER: That might be a useful question to ask, what they do to promote such things as disability awareness. There is an International Day for People with Disabilities, and ways in which the Department of Ageing, Disability and Home Care [DADHC] promotes its services. It might be an interesting question to ask how much of DADHC's budget is spent communicating its services to people from non-English speaking backgrounds.

The Hon. HENRY TSANG: Do you think perhaps this Committee should recommend to the Government that government should have an access policy for people of multicultural backgrounds? In this State people from non-English-speaking backgrounds make up 40 per cent of the population. Perhaps the department should look at the research and statistics on the services delivered—what per cent of services are delivered to people from non-English speaking backgrounds—and develop an access policy. Perhaps the aim should be, in the next five years, to reach half of that 40 per cent I referred to and that, hopefully, in 100 years time it will reflect the true population.

Ms WINTER: Something like that.

The Hon. HENRY TSANG: Do you think we should have a proactive policy to reflect the service delivery to the population?

Ms WINTER: There are probably two answers to that question. One is yes, if you take money from all the taxpayers it cannot be right that that money is used to promote services to predominantly one race. There is something wrong with that. Secondly, we have been advocating for that sort of targeted approach for a while. The fact that—what is the word—the cultural something we will look at next year, in DADHC's commitment thing tells me that it is not high on the priority list; that is not part of an integrated approach to service delivery, and that it is an extra. People from NESB will always be an extra. They might be a quarter of the population, but they are extra to what is already there.

The Hon. HENRY TSANG: Extra rather than part of the mainstream?

Ms WINTER: Yes.

CHAIR: On friday, in the Hunter, the Committee will meet with some principals and teachers of schools where there are some children with disabilities. What questions should the Committee be putting to them about students of non-English speaking backgrounds?

Ms WINTER: We have just done some work looking at what happens in school what happens to parents in school, what their experiences in terms of input, and what they learn about expectations for the children and those sorts of messages. That will be available in the next six weeks or something like that. We will send a copy through to you. One of the things we will be recommending in our report is something like a cultural access worker in the school regional—I don't know. Depending on how big and how many people there are. Some of the problems we find with the people we work with is that there's a huge gap between what is available and what people understand to be available.

That lack of information put people really behind. They are not even out there competing for the limited resources. They are way back there, not knowing that the resources are available. As a school principal, what do you do to assist people to at least have the same starting point to compete for what is available? At the moment that is not there and schools do not provide that, I believe. Schools do not provide that support to parents and the NGOs—or whoever provides the program—are not receptive to that. There is no offer: "This is what we can do to meet your cultural needs." There is no understanding about how to work those issues into a program. As a principal what support do you provide to assist people from non-English-speaking backgrounds?

The Hon. JOHN RYAN: Could I ask about your organisation for a moment. Are you the only disability advocacy group that specifically advocates for people with disabilities from a non-English speaking background?

Ms WINTER: Yes.

The Hon. JOHN RYAN: How big is your organisation?

Ms WINTER: Until three years ago we were very small and were funded through grants from the Commonwealth. With the announcement of the advocacy and information services review there was announcement of an additional $1 million. We tendered for that and got about half of it.

The Hon. JOHN RYAN: How big is your organisation? How many people work in it?

Ms WINTER: About 20, but a lot of part-timers.

The Hon. JOHN RYAN: Roughly in full-time equivalents how many staff do you have, about 10?

Ms WINTER: Ten or twelve, something like that.

The Hon. JOHN RYAN: Do they conduct research or do they provide direct advocacy services for clients?

Ms WINTER: Both. The bulk of our work is in individual advocacy. We do systemic work and a bit of research. We do what the buzzword was then, industry development, the aim of which is to support the disability services sector to better meet the needs of people from NESB. So there is an education function, a training function and a providing resource function.

The Hon. JOHN RYAN: Where is your service located?

Ms WINTER: Harris Park, and we have three people in the regions, three individual advocates doing—

The Hon. JOHN RYAN: Individual advocacy work with families?

Ms WINTER: Yes.

The Hon. JOHN RYAN: The number of families you would be able to touch would be quite limited, would not?

Ms WINTER: Yes.

The Hon. JOHN RYAN: What service are you able to provide to, and what experience have you been able to gather, from rural areas. I must say that, in my experience, the discrepancy between people from non-English-speaking backgrounds and users of services is quite significant in rural areas. Do you have any representation or capacity to find out what is going on in rural areas with families from non-English-speaking backgrounds?

Ms WINTER: We have a worker in Griffith, which is one of the big NESB communities outside of the Wollongong-Sydney-Newcastle spread. We provide an advocacy development program in the regions across cultures, that includes Anglo Australians, and we will make an effort to involve ethnic communities. So that is going to Tamworth, Queanbeyan and other communities. Through that we would hear a fair bit.

The Hon. JOHN RYAN: I have forgotten what the Act is, but my memory is that there is an Act of Parliament, of the order of a decade ago, that required all government departments to prepare a multicultural statement.

Ms WINTER: Yes.

The Hon. JOHN RYAN: I imagine the Department of Ageing, Disability and Home Care had to do the same. Is that right?

Ms WINTER: Absolutely.

The Hon. JOHN RYAN: I think they were called LEAPS, were they not?

Ms WINTER: That was for local government. The State Government equivalent is entitled "ethnic affairs policy statement" [EAPS].

The Hon. JOHN RYAN: That is right. So the department would have prepared one of those.

Ms WINTER: Yes.

The Hon. JOHN RYAN: Are you aware of whether DADHC has an EAPS?

Ms WINTER: Absolutely.

The Hon. JOHN RYAN: Are you aware of whether they are making any progress in reporting against it?

Ms WINTER: I am sure that make progress with the EAPS—I am sure. Whether that translates into outcomes for people, as I said, is a separate question.

The Hon. JOHN RYAN: My one concern is this, that if anyone was going to know what the specific needs are and co-ordinate the specific research required for people from non-English-speaking backgrounds—and I think by any stretch of imagination you made that a compelling case that very little is known within the system about what is going on—it would have to be your organisation that would know the most.

Ms WINTER: Yes.

The Hon. JOHN RYAN: In my view—and I do not mean this to be a critique of you—the amount of information you have been able to provide to the Committee is scant, is it not?

Ms WINTER: Yes.

The Hon. JOHN RYAN: There is not much of it. What would we need to do? This is but one area of disability services where this is an issue; I believe it is a much broader issue. What recommendations should this Committee make? What would pull this together and actually make progress for a variety of communities in the near future?

Ms WINTER: Your colleagues from the Social Issues Committee made some recommendations and we have included those in our submission. They included performance targets.

The Hon. JOHN RYAN: That was in relation to making it happen, the two-year-old or three-year-old report?

Ms WINTER: Yes. They suggested targets for vacancy management, service growth within the existing programs, and new programs. They actually said any new money basically needs to be targeted. They said any new vacancies need to be targeted to meet the needs of the community and reflect the diversity of the community. They looked at performance targets, and how to monitor those and report against them. They also looked at an implementation plan, which is what you said. In five years time we will move from 5 per cent to 10 per cent. And I have had conversations with senior staff in the department who said we would be lucky to keep what we have got.

The Hon. JOHN RYAN: Did the Multicultural Disability Advocacy Association have any part of the consultation process prior to changes to post-school options or ATLAS?

Ms WINTER: Absolutely. We were heavily involved in those working groups and we put in huge amounts of work.

The Hon. JOHN RYAN: What about the expert panel—I think it is called the expert panel?

Ms WINTER: I cannot remember what it is called. I personally was not on it, but colleague of mine was. I know she spent a considerable amount of energy and time thinking and talking.

The Hon. JOHN RYAN: What was your experience of the consultation and the announcement? Do you recall the announcement being made?

Ms WINTER: I think my colleague described it as frustrating.

The Hon. JOHN RYAN: I was after something more specific. Were you being consulted prior to this announcement? Did the announcement arrive as a surprise to you? I am talking about last June.

Ms WINTER: We knew there were going to be changes. We did not expect them to look like the changes are looking. We did not expect them to come about the way they came about. We expected that the expert reference group would develop something a bit more practical.

The Hon. JOHN RYAN: Do you recall working on something? Was the expert reference group actively making recommendations to government?

Ms WINTER: Yes, but how formalised they were I am not sure because I was not personally involved.

The Hon. CHRISTINE ROBERTSON: I would like to know how your group accesses disabled persons when they are still in the school program to try to get the information across about post-school programs. Do you know the process for that to happen?

Ms WINTER: That is not our role. We are an advocacy body. Our role is not information provision to parents. We would expect that that happens as part of how it happens to all parents, in discussions about what is next. I think there is a whole lot of misinformation to parents from a non-English-speaking background.

The Hon. CHRISTINE ROBERTSON: So, your educational role to the community about issues for non-English-speaking-background people does not include working with the community?

Ms WINTER: Yes. We work with the community but we are not specifically working with parents. We are about to run a program specifically for parents, but that is not part of our core function, if you like.

The Hon. CHRISTINE ROBERTSON: So, do schools in highly non-English-speaking-background areas get extra information from you, or do you know any way in which they get information?

Ms WINTER: The information we could provide would be about advocacy. That is our role. The question would be who is providing information about post-school options in those areas, and I do not know that. I would think whoever's responsibility it is, which I presume is the school, they would take care that.

The Hon. CHRISTINE ROBERTSON: What advice did you give to the consultation process that was not taken up, and how could that be taken up—for the changes, I mean?

Ms WINTER: We gave extensive advice on how to restructure, if that was the case, the post-school options program to make it more accessible for people from a non-English-speaking background, and that was not taken up at all. It will be taken up some time in the future.

The Hon. CHRISTINE ROBERTSON: So, we do not have those specific recommendations?

Ms WINTER: They will be owned by the Department of Ageing, Disability and Home Care.

The Hon. JON JENKINS: I am still trying to ascertain where the problem is or whether there is more than one problem. When a child with disability comes through school, presumably that is detected by the school? My wife is a schoolteacher and I know the first thing they do is drag the parents in and try to discuss the problem with parents and then discuss the options available. In the normal school settings they have various options, of councillors and so on. Is that not happening with some people of ethnic backgrounds? Is the system failing or are parents not understanding? Is it simply a matter of language, explaining to them what is going on? Where are the problems?

Ms WINTER: I think it would be simplistic of me to say this is the problem. There are a whole range of problems. It goes from a mother telling me after me explaining to her what autism is to what drugs they can take to make it cured. So, there is a huge gap of understanding.

The Hon. JON JENKINS: Parent education?

Ms WINTER: Parent education. We think they understand, but then you double-check and there is a whole gap missing, right to an ability of the system to communicate so people will understand. Without pinpointing, there is a lack of understanding here because people do not have access to information. People traditionally might come from communities where there is a taboo about it. People do not read the *Sydney Morning Herald* or listen to the ABC. All that sort of stuff does not happen. So from there to a school counsellor trying to explain post-school option programs, which is such a western concept, if you think about it. It is a long stretch. And anywhere along that line communication might break down.

The Hon. JON JENKINS: It is not just a simple language problem?

Ms WINTER: No.

The Hon. JON JENKINS: You are saying you need to get a culturally aware social worker?

Ms WINTER: You know how people talk about disability. In the 1980s we used to talk about if only would we could get ramps, everything would be fine. I think the interpreter argument is a similar one—it is like the ramps. If we get them in, everything will be great. But now we know, yes, we have the ramps but we still have issues with quality, communication and service delivery. So, interpreters are the equivalent to the ramps.

(The witness withdrew)

(Short adjournment)

TIMOTHY JOHN HART, Disability Coordination Officer for Northern, Central and Southern Sydney, Centre for Developmental Disability Studies, PO Box 6, Ryde, 1680, sworn and examined:

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

Mr HART: Appearing in my professional capacity as the Disability Coordination Officer for Northern, Central and Southern Sydney.

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

Mr HART: 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.

Mr HART: Thank you.

CHAIR: Do you wish to make an opening statement?

Mr HART: Just to explain the program that I work under. The Disability Coordination Program is funded by the Department of Education, Science and Training federally, by allocating grants to host organisations in 20 locations across the country. We also work with the regional disability liaison officers. They have a similar program except that they are funded out of the higher education part of the department while we are funded by the VET sector.

The Hon. JOHN RYAN: You are a Commonwealth public servant then?

Mr HART: My host organisation is the Centre for Developmental Disability Studies. I am paid by the northern area health fund. It is technically my employer.

The Hon. JOHN RYAN: I guess what I am trying to work out is whether you are in the Commonwealth public service or you are working for a non-government agency.

Mr HART: I work for a non-government agency that is tasked to employ its people through the health department.

The Hon. JOHN RYAN: Do you have any observations to make about how the ATLAS Schemes have changed and links between transition to work programs and Commonwealth programs?

Mr HART: Essentially, I would like to say that the changes to the programs disadvantage students who wish to access higher education, in particular at university. I understand that on the application form there is a box to tick to indicate that if you want a TER you will not be eligible for the program. This disadvantages students in a number of ways. It not only disadvantages them in regard to their peer group in seeing how they did; they cannot access higher education.

The Hon. JOHN RYAN: So the very act of applying for a TER score invalidates you from the program even if you do not actually successfully enter—

Mr HART: Yes, that is my understanding.

The Hon. JOHN RYAN: That is unbelievable.

Mr HART: I understand that one student did tick the box and did not get the TER to get into university. He appealed and won his appeal.

The Hon. JOHN RYAN: Is that the same as a UAI?

Mr HART: Yes. I am thinking of the old—

The Hon. JOHN RYAN: It used to be called TER. It is now UAI. I have a child doing the Higher School Certificate at the moment. I thought we were talking about something different. Are you aware of any students who have successfully used tertiary education as a means of making a transition to work?

Mr HART: From the program?

The Hon. JOHN RYAN: Yes.

Mr HART: Only one personally. That is Fiona Gibbons. I understand she has appeared before the Committee.

CHAIR: ACROD stated in its submission, "The exclusion of university students is a necessary, if unfortunate, requirement for the success of the new programs." What is your response to that?

Mr HART: I would disagree. That would try to limit the program as a simplistic attempt to put people with disabilities into a box where they are not capable of higher skills and performing in society at the level they are capable of. It is denying people access to education.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you speaking for people who would go on to university? Is that the group of people with disabilities that you are speaking for here today?

Mr HART: My job encompasses all people with disabilities, so I would not limit myself to just one group.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But your submission in a sense concentrates on that aspect.

Mr HART: Yes.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is that because you think that other aspects are covered by other advocates?

Mr HART: No, I am not qualified to comment on other aspects.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So this is the area in which you personally are working?

Mr HART: Yes.

CHAIR: Coming back to tertiary students, is it not a fact that students accessing tertiary education are accessing programs that are largely federally funded, so why should funds be used to support students accessing tertiary education?

Mr HART: The Federal Government allocates additional support funds to students with disabilities. I think it is more than $6 million this year. That is broken down into three programs, one of which involves regional disability liaison officers. It takes close to $1 million a year. The Higher Education Disability Support Program, additional support for students with disabilities, is one of the programs that is for students with high support needs that incur costs for the education provider—in this case universities—of more than $500 per year.

Depending on the amount the student incurs for the higher education provider, that goes into a formula and a portion of the remaining money—not all the remaining money but a portion of what is there—is then allocated to the host organisations afterwards. It is not before or during but in the financial year after. So the host organisation has to incur the cost first. On top of that support, personal care is specifically excluded from the funding. The third program is a new program that the final amount of funds comes out of. It is performance-based disability support funding. I have the necessary document here if the Committee would like that.

CHAIR: Thank you. How much does the move to block funding impact on students with disabilities seeking to access higher education?

Mr HART: Unless they have very wealthy parents there are costs such as transport and attendant care that have to be met by the individual if they are to access university. Instead of going off to the transfer to work program or community living and getting some of their needs met for three days a week at least, if they go to university those costs have to be met by their parents, and the universities currently do not meet the cost of transport or attendant care or a number of other things that a student with a disability with high support needs might require such as wheelchair modifications et cetera.

CHAIR: Are you aware of interstate comparisons?

Mr HART: My understanding is that in most States there are funds similar to what ATLAS used to be, providing access to university and TAFE without any questions. I believe South Australia allows the use of the funds for university.

CHAIR: Could you take that question on notice and provide us with more specific information about what other States provide for students accessing higher education?

Mr HART: I can do that.

The Hon. TONY CATANZARITI: Are these people eligible for HECS?

Mr HART: Yes, they incur HECS debts, like any student.

The Hon. TONY CATANZARITI: But they are able to access HECS—

Mr HART: Yes, if they are accepted by a university they incur a HECS debt unless they pay up front, which is still incurring a debt but you are paying it off.

The Hon. TONY CATANZARITI: Are there any difficulties in accessing HECS?

Mr HART: The main problem for students with disabilities is earning enough income afterwards to pay it off at a reasonable rate. If they get the necessary support at school and perform adequately in the HSC or whichever way they might access university there is no problem with accessing HECS, but they are incurring a debt and that can be an impediment in itself.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: How many members do you have in your organisation?

Mr HART: Regional disability liaison officers and disability coordination officers total 32 nationally.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: And you are all in the universities or TAFEs so you are in the tertiary education sector?

Mr HART: We exist to enhance postsecondary options for people with disabilities in regard to education, training and employment. Some of the disability coordination officers are in universities. A couple are in TAFEs but most are in employment or community groups. It is the regional disability liaison officers that are solely within the universities.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you mean 32 people in paid positions or 32 members altogether?

Mr HART: Thirty-two people in positions. Twelve of those people are part-time.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But you said that you are an organisation for staff and students. Do you have a lot of students in your organisation too? You are an advocacy group for them. Are they members or how does that work?

Mr HART: The host organisations are given funding by the Federal Government to employ a person to promote postsecondary education as well as training and employment. We work within a region. We do not exactly have members. There are just 32 of us.

CHAIR: In relation to training, one of the issues that has been put to us is that with some people accessing the two-year funding of the transition to work program it is unclear at the end of two years what skill levels they may have, comparability with what the Commonwealth is looking for for people to take up training. Can you elaborate on what you know about this issue of the standards across State and Federal Government in terms of training?

Mr HART: I do not think I understand the question. Could you repeat it, please?

CHAIR: What we have been told is that if you are accessing funding for training through the Federal Government support there may be different standards required for being able to be given funding support.

The Hon. JOHN RYAN: For support in employment. For the transition to work to supported employment. It has been said to the Committee that supported employment places are somewhat limited by the Federal Government: they are capped. There is a difficulty in working out who qualifies for those. It has been put to us that whatever the transition to work program is going to be, there are no outcomes specified to make sure that the people who complete two years of transition to work will qualify for Federal programs afterwards.

Mr HART: Now I understand. As far as I know there is the likelihood that they will not reach qualifications to get employment, depending on the field that they are interested in, but as far as I understand if they are in the program and if the State Government decides they are out of it I would imagine the Commonwealth Government would take them up no matter what. But other than that I cannot really say.

The Hon. CHRISTINE ROBERTSON: We have heard that there is potential for people then to move to community programs. I have forgotten the new name for them but the old sheltered workshop situation is decreasing and persons who are being accepted into those business units or whatever they are called now have to have a fairly high level of skill. They have to be achieving a certain amount of output. Do you know about this?

Mr HART: I have not heard about that.

The Hon. JOHN RYAN: As a result of a court case which requires people to be paid a market equivalent wage or a productivity based wage in supported employment there are now difficulties in that a significant number of people in supported employment are incapable of reaching that standard. They have been slowly but gradually transferred to Commonwealth day programs. But the difficulty is with the cap on supported employment basis there may well be a group of people who have completed the support teacher transition to work and then have nowhere to go but community participation and who could, in the interim, lose their skills between the two?

Mr HART: I had not heard of this. If you do not utilise a skill you do lose it, so I would say there is a good danger with the skill loss, but I cannot comment further than that?

The Hon. JOHN RYAN: What do you do in your position? As the shadow Minster for Disability Services I was not aware that the Commonwealth had a group of co-ordinators out in the field. What service do you co-ordinate people into? How do you interface with State services?

Mr HART: I work with the Department of Education and Training in New South Wales, like most of my colleagues. We also work with community organisations and a number of other organisations. We disseminate information. We refer people to services. Some of my colleagues work on projects. We basically disseminate information to people with disabilities. The regional disability liaison officers have been going since 1992, and the disability co-ordination officers come under the Australians Working Together fund whose funding was first allocated in 2002.

The Hon. JOHN RYAN: From where do your clients come? What service do you provide to your clients?

Mr HART: The service we provide essentially is information. I offer seminars and so forth working with the support teacher transition in my area. I offer information. We have a national web site and we also do systemic advocacy like this. But essentially what we do is hand out information.

The Hon. JOHN RYAN: I do not want to be disparaging, but I still do not have an idea of the service. It seems that providing information is not a particularly lengthy task, and there would be a limited number of people who would probably be interested in asking for it. How does a client get referred to you? Are your offices located within TAFEs and schools?

Mr HART: Some of them are in TAFEs but not schools. We work with people in our region.

The Hon. JOHN RYAN: Who sends people to you?

Mr HART: The support teacher transition, community groups and a number of other groups. We also promote links within our areas. Essentially people are referred to us by other people and we refer them on. We help them how we can.

The Hon. JOHN RYAN: A person who might be at high school seeking to enter TAFE or university would be referred to you?

Mr HART: Yes.

The Hon. JOHN RYAN: Typically, how would you handle a case such as that?

Mr HART: I would disseminate information relevant on accessing what they wanted in regards to accessing university or TAFE.

The Hon. JOHN RYAN: Would you have an hour meeting with them or would you meet them regularly to help them through the process?

Mr HART: I am not a case worker. I have 2.6 million people in my area. I essentially disseminate information by email. If they ring me I post out the information to them.

The Hon. JOHN RYAN: How many equivalent co-ordinators are there serving Sydney?

Mr HART: I am the only disability co-ordination officer, and I have northern, central and southern Sydney. Currently there are two regional disability liaison officers for Western Sydney because they are job sharing. You will be speaking to Larissa after me. There are basically the only two positions for the whole of Sydney.

The Hon. JOHN RYAN: So the 32 you were talking about are provided nationally and so in New South Wales you might have three or four people working?

Mr HART: We have seven, counting the ACT.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: How many clients do you see? Do you have a register from which to collate information as to how many clients? Presumably you do that to justify your Federal funding?

Mr HART: Yes, we collect information on who we see, and what we go to, which the department collects in six-monthly reports. We do not keep a register of actual people with disabilities we deal with. We do keep lists of service providers we do deal with, and contact lists.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: How do you liaise with the State people? How do you find out that course X at Sydney university can take disabled people and have wheelchair access to its lecture theatres, for example?

Mr HART: For a start, I would not hand out exact information regarding what courses are or are not accessible. I would find out information the student required. I would then give them the necessary generic information, and then refer them on to the disability liaison officer for Sydney university with her contact details and everything. She would like to talk to any student with a disability who wishes to come to her university within the next year.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is she a member of your association?

Mr HART: I do not have an association. Are you referring to DEAN?

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Yes, the Disability Education Association of New South Wales [DEAN].

Mr HART: I am associated with DEAN and I am the treasurer of DEAN, but I am not here representing DEAN. Yes, we do have disability co-ordination officers as well as DCOs, regional disability liaison officers, disability liaison officers and the support teachers from TAFE are members of DEAN.

The Hon. JON JENKINS: Are you a facilitator for people with disabilities entering higher education?

Mr HART: Yes, that is a reasonable way to describe it. Our job description is more than two pages.

The Hon. JON JENKINS: Do you only take school leavers?

Mr HART: We take any person with a disability.

The Hon. JON JENKINS: Of any age?

Mr HART: Yes.

The Hon. JON JENKINS: Any ethnic background?

Mr HART: Yes.

The Hon. JON JENKINS: The reason you have put in a representation is because the extra funding that is needed will disappear?

Mr HART: Yes, and it will be a barrier for students with high-support needs accessing university.

The Hon. JON JENKINS: Obviously you do the same for TAFE?

Mr HART: Yes, TAFE is a concern. I am not sure exactly how the funding is working for TAFE but it is a concern at the very least that two years is not adequate for a decent course, as most students with a disability, not just students with high-support needs, take additional time to complete their degree or course to obtain their certificate. It is not unusual for some students to take more than four times the normal time length of time to complete a degree.

CHAIR: Do you have statistics on that?

Mr HART: I do not, but the Federal Department of Education, Science and Training would as well as the New South Wales Department of Education and Training.

The Hon. JON JENKINS: Do you have access to those statistics?

Mr HART: No.

The Hon. JON JENKINS: Can you extract them for the committee?

CHAIR: We may have to seek those statistics on a very pertinent point.

Mr HART: I can ask for them but I cannot guarantee that I would get them. I have asked for statistics from the Federal department before and been told that I have to purchase certain statistics.

The Hon. CHRISTINE ROBERTSON: Your third recommendation refers to the Commonwealth Department of Education, Science and Training negotiating to get something worked out for the extra funds that these people require to go to university. What is the best way for the long-term security of assistance in these negotiations? If they are tacked onto a program and it is good luck if they get the funding, what outcome should happen?

Mr HART: I think that the Commonwealth and State governments should get together and basically decide who pays for what, and the departments are a good place to start. There are a number of issues regarding access to education for all students with disabilities, in particular, those with high-support needs. There is a real need for the departments to settle who pays for what and I am not just referring to on-site on-campus support. There is a real need for the cost of transport to be met for a number of students with disabilities, not just those with high-support needs. Basically there is a need for governments to get together and decide so that people with disabilities can get on with their lives without having systemic problems in their way.

The Hon. CHRISTINE ROBERTSON: Is it possible for a realistic assessment to be carried out on a person to see if any progress has been made, rather than a cut-off? A decision could be made about whether it should be a cut-off or a continuation?

Mr HART: I think that would be possible, I don't know if it is desirable. If a student wishes to go to TAFE and they are capable and, like, if we were to make an assessment on some people in their studies, at the beginning of their studies they might muck around and not apply themselves. One of the jokes is that a lot of honour students at university spend the first two years not doing their work—attending the bar more often than lectures—and in the third year of study they knuckle down and do very well and get into the honours course.

The Hon. CHRISTINE ROBERTSON: That is in the university, but is it a possibility in TAFE?

Mr HART: It would be a possibility but I would be concerned that if you were to take a student's academic progress on how they had gone so far as the sole measure for them to continue to have funding, I would be concerned that it would be a bit unfair.

(The witness withdrew)

LARISSA ADELLE BURNS, Regional Disability Liaison Officer, Disability Education Association of New South Wales and the Australian Capital Territory, University of Western Sydney, Locked Bag 1797, Penrith South, and

GEOFFREY MADDOX, council member, Disability Education Association of New South Wales and the Australian Capital Territory, University of Western Sydney, Locked Bag 1797, Penrith South, sworn and examined:

CHAIR: In what capacity do you appear before the committee, that is, as an individual or as a representative of an organisation?

Ms BURNS: I represent the Disability Education Association of New South Wales [DEAN] and the Australian Capital Territory.

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

Ms BURNS: 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?

Ms BURNS: Thank you.

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 MADDOX: I am appearing as a representative of the Disability Education Association of New South Wales and the Australian Capital Territory [DEAN].

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

Mr MADDOX: Yes.

CHAIR: As with Ms Burns, if you believe that any evidence should be taken in camera, we will accede to your request. Does either of you wish to make a short opening statement, or both?

Ms BURNS: Yes. I will be making an opening statement on behalf of DEAN.

CHAIR: You may proceed.

Ms BURNS: Under the former Post School Options and Adult Training, Learning and Support [ATLAS] programs, a small number of participants attended or are still attending university. The majority are people with physical disabilities with very high support needs who utilised the funding to further support their attendance or participation at university. Most use the funds to assist with transport costs, attendant care, assistance with study at home, or sometimes with technology or equipment. Our understanding is that previous funding arrangements have been grandfathered for the current students who commenced study before 2004.

For post-school funding recipients, university attendance is often an important first step in achieving a future vocational outcome. Because of their disabilities, most are unable to do physical work or manual work, so it is essential that they are equipped to do intellectual work. To be competitive in that particular employment environment, a person really needs a university degree and often a masters level qualification. If one of the aims of the ATLAS Program is set to work towards a vocational outcome, then attendance at university is appropriate for some participants.

Universities currently provide a range of education specific supports to students with disabilities. This includes on-campus assistance such as note takers and scribes, Auslan signing interpreters, readers, material in alternative formats, such as large print or braille, and alternative arrangements for examinations and assessments. However, universities do not provide assistance with transport, attendant care or personal equipment because they are not specific to educational access. These services are whole of life services and are not specific to the educational environment. They should not be compartmentalised. Ideally they should be provided seamlessly across all environments and activities. For example, assistance with eating and toileting is needed in all environments, not just the educational setting.

Under the new post school programs, participants are able to utilise their funds to attend training courses at TAFE and private registered training organisations [RTOs]. However, they are not eligible for the program if they wish to attend university. This criterion seems to be based on a general assumption that a person with a disability should (a) aspire to go to TAFE but not to university, and (b) that if a person has the intellectual capacity to attend university, then he or she no longer requires support. However, a person's decision to attend university does not change the fact that they require high levels of physical support needs. Miss CM, as referred to in our submission to the inquiry, is a current student at the University of Western Sydney [UWS]. She has cerebral palsy, uses a wheelchair and requires a carer for transport, toileting and eating. She is unable to write, type, turn the pages of a book or use speech recognition software due to her speech impairment.

The UWS disability service has established an innovative partnership with Ms M's ATLAS service provider whereby UWS pays for educational supports, such as note taking, library assistance and scribing for assignments and/or examinations. The ATLAS Program pays for transport and attendant carer for toileting, meals and for travel assistance. These services are provided by one worker and are therefore seamless, enabling the student to take breaks or go to the toilet when she chooses. This arrangement has worked exceptionally well and the student is achieving. We are extremely concerned that this type of service is not available to 2004 school leavers and will not be available in future without a change in policy. This situation is both manifestly unjust and absurd in that it prevents some school leavers from achieving their goals and aspirations.

CHAIR: Can you give us an indication of the number of students in New South Wales who are currently accessing university and TAFE who have a disability and are receiving post-school funding?

Ms BURNS: The exact numbers are unknown. However, we believe the numbers are quite small. From my discussions with disability practitioners at universities, there have been between about two to four people using ATLAS funds to attend university at most universities. It is important to emphasise that the population we are talking about is a low incidence high support needs population, so we are talking about quality rather than quantity.

CHAIR: Using the example that you gave of the student at the University of Western Sydney who has one carer providing services that are funded both through the university and through ATLAS, do you know what the total funding package is? Do you know how it is broken down between the university and the State?

Ms BURNS: I think that Mr Maddox can probably speak to that one.

Mr MADDOX: She gets about 20 hours a week of service paid for by the university and in turn we try to recoup all or most of that from the Federal Department of Education, Science and Training [DEST] which provides funding for university students with high support needs through an additional support program. Her ATLAS Program gives her considerably fewer hours than that. I know that her service has been grandfathered but at a reduced level, not the level it was that when she started university. I think she is not getting much more than about 10 or 12 hours a week from that because it is a totally new service, of course. In fact, that actually limits the number of hours of university service that she can use because universities will not pay for any attendant care. Therefore, she cannot use hours paid for by us unless she has got enough ATLAS hours left to pay for the toilet breaks and the meals.

CHAIR: As a student at the university, there would be times when she would want to access the library for extended periods prior to exams, for example. Is her funding package as it is now flexible enough for her to do the increased number of hours to do this sort of work that most students do before an examination?

Mr MADDOX: Yes. From the university's point of view, it is flexible. I have approved increases in support hours for her and some other university students with severe disabilities coming up to examination time and so on, but the DEST additional support needs program is a fixed bucket of money, and if it reaches the point where we are not able to get the lion's share of that money back, then the UWS cannot afford the increased number of hours. We really are crossing our fingers that we will be able to continue to recoup all or most of it from DEST. There again, as the university will not pay for attendant care, those numbers of hours in the library would be limited by the ATLAS Program being able to pay for toilet breaks and meals. If she cannot, the university will not pay for studying at home and, of course, the higher your support needs are, the more you would like to get out of your wheelchair and have a rest and so on, and the more you would choose to stay at home and the less in the library.

The Hon. HENRY TSANG: What course is your client studying? When she has completed the course, will it be difficult to get postgraduate training? Most people get a cadetship or work for someone in training. Is it possible to have a continued working experience? What is the opportunity for employment?

CHAIR: Before you answer that question, I point out that we try to make sure that an individual is not able to be identified. We like to keep the evidence as broad as possible. In answering that, if you believe that your answer will give some undue recognition to the individual student, you might need to keep you answer fairly broad.

Mr MADDOX: Right. She gave permission for the information to be given in the way it is presented in our submission, so I will try to keep it broad. She actually started off in community welfare, which has a large practical component, and she was actually going out and doing work in community welfare organisations as part of the course. That was looking like being extremely difficult for her so she actually transferred to a Bachelor of Social Science, which is a more theoretical course. But I know that her aim is actually to work in advocacy, which is work that you can do to a fair extent by emails and writing.

Ms BURNS: Could I add to that point?

CHAIR: Yes.

Ms BURNS: As I mentioned in my opening statement, for many of the students who are using ATLAS to attend university, really, intellectual work is the only option for them. As I also mentioned, to be competitive in that employment environment, people often require not only a bachelor's degree but a masters level qualification. It really is that competitive. Add on top of that the fact that you have a disability and you really need to be well qualified. One of the problems with the ATLAS Program is that the funds are only available—when they were available to university students—for a two-year period. I have spoken to some service providers and students who in the past have been able to negotiate with the Department of Ageing, Disability and Home Care [DADAHC] to extend that funding provision, but very often it is on an ad hoc basis. It relies on the ability of the service and on the individual to advocate for their needs to get additional support, and then often it is only in a six-month block. So the person is on tenterhooks every six months or at the end of each semester, wondering whether they will get the additional support they need to continue with their degree.

The Hon. JOHN RYAN: Earlier you used the expression that a number of students who commenced their studies prior to 2004 had had arrangements grandfathered for them. Has that happened to all students who have funding to pursue tertiary studies using ATLAS grants under the new arrangements, or is that an ad hoc arrangement? What is the extent of the grandfathering?

Ms BURNS: As far as I am aware, I was led to believe that it was an arrangement for all students. However, after speaking with a number of disability advisers, there have been situations that people have informed me of where students have actually been completely cut from the ATLAS Program. There was one young gentleman, and I will just get his specific details in front of me, who had paraplegia. He was receiving ATLAS funds last year. He attended university and most of the funding was used to assist with transport costs. This year his ATLAS funds were withdrawn, though, so he was not grandfathered, and so there are situations or examples of students who are not grandfathered but have just been completely cut from the program.

The Hon. JOHN RYAN: Are you aware of any formal policy that exists within DADAHC about grandfathering, or are these arrangements that have been made with specific non-government organisations that might be funding it themselves, such as the Spastic Centre continuing the funding out of its fundraising resources rather than funding from the Government. Are you aware of any formal arrangements within DADAHC to continue those?

Ms BURNS: I do not know what the formal arrangements are within DADAHC. I am sorry, I cannot comment.

CHAIR: Can you help me with that student? Is he still accessing a university course?

Ms BURNS: When I spoke to the disability adviser, she actually informed me that there was a lot of turmoil and difficulty for that student, who is extremely concerned that they would be unable to attend or continue with their course. He was halfway through his degree. Of course the university wants to try to support students as much as it can to continue with their studies, and in this situation the disability adviser supported—obviously advocated on his behalf—and tried to make other arrangements for funding, and finally supported him to make an application for a scholarship which he was thankfully successful in gaining. It is a very difficult situation when you are halfway through a degree and someone says, "Sorry, you cannot have funds anymore".

The Hon. JOHN RYAN: The new arrangements involve a program called the Transition to Work, which one imagines might be the most applicable scheme for someone going to university for vocational reasons. Unlike the previous ATLAS program and post school options arrangements they are certainly limited for two years only. You mentioned that previously it was possible to negotiate other things, quite often ATLAS, even though notionally the program was supposed to end after two years. In reality it went for up to eight years and four some clients continued year by year. No doubt that provided some flexibility, albeit not certainty. What would happen if the only means by which university student can study is limited to the two-year limited Transition to Work program? What will happen to the usefulness of that program to university study?

Ms BURNS: As it stands, any student wishing to attend university is no longer eligible for the ATLAS Program. However, if they were, limiting it to the two-year creates major difficulties, because there is not agree that one can complete in two years. As the previous speakers said, many students with disabilities require an extended time to complete their degree rather than a reduced time. Not to mention the personal upset and emotional of turmoil that students have to go through every time they try to gain funding to attend university the next year.

Mr MADDOX: That is why we used the word "absurd" in our opening statement. It is not a transition to work if you do not complete the degree. It may benefit the individual but it is a waste of time for transition to work. Miss M normally does three units per semester, which is three-quarters of the full-time load, she will finish at three-degree in four years. She certainly hopes to do post-graduate study, and to work in her chosen field she should. She will be looking at six or seven years. My biggest concern is that she was one of the first cohort of kids to come right through the mainstream school system with full-time assistance at school—getting personal care and note-taking by someone in school classes. The 2002 school leavers were the first ones to really get a good run at qualifying for university; that is kids with very severe physical disabilities. So, one would expect an increasing number of kids with very severe physical disabilities will qualify to go to university. Just at the time that that is happening they have been cut off. Our concern is with those who have not even appeared on our radar, not the ones there now,

The Hon. JOHN RYAN: Are you aware of a policy that even the act of applying for a university admissions index [UAI] would disqualify someone from community participation or transition to work?

Mr MADDOX: Yes, and it boggles the mind.

The Hon. JOHN RYAN: They may not make it. Someone could apply for UAI and not have a sufficiently high mark, then they would be nowhere.

Mr MADDOX: Yes. And I would hope they would reconsider, but that is not what the documents say.

Ms BURNS: On the screening test administered by the support teachers transition in school, the front page of the screening test has a big box stating that if students intend to attend university they are not eligible for this program. They are being turned away prior to completing the forms, despite the fact that many students have extremely high support needs. They should be eligible for the program in every other circumstance, but if they say that they are interested in attending university they are turned away right at the very beginning, at the school level, by support teachers transition.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Tim Hart produced a flyer about grants to promote a quality of opportunity in higher education, which would appear to have come from the Federal Government, Department of Education, Science and Training. It identifies some programs. Are they alternative Federal programs for people accessing higher university? Are the ATLAS and PSO programs ineligible to dovetail with Commonwealth programs that do the same thing for higher education students?

Ms BURNS: The Federal Government disability support programs, as Timothy mentioned, are divided into three aspects. One is the additional support program, in which universities can reclaim some funds they have spent on direct support costs for students with disabilities. The second one relates to performance funding, and that is based on the number of students with a disability who have their retention and success. And the third aspect of the funding is the regional disability liaison officers located in various universities throughout Australia, and I am one of those. The difficulty is that those programs provide a lot of support and assistance, indirectly and directly, to students with disabilities. There are no Federal Government funds available for personal care, transport assistance and purchase of equipment and technology. The additional support program specifically states that universities cannot claim or recoup costs related to personal care or transport.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: They may be able to get PADP funding for some of their teaching aids, such as mechanical aids. One witness before the Committee had a fancy talking computer that had been bought partly by PADP.

The Hon. JOHN RYAN: Under previous PADP policy.

Ms BURNS: That is separate from distance funding.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The PADP is a State program. There would be educational money from the Commonwealth under this program, and they would have mechanical aids paid for by PADP but not personal support. Is that what you are describing?

Ms BURNS: Yes, it can be. For example, there is no funding for students who require equipment. Often the student what have to approach service clubs such as Quota or Rotary to try to gain funds to provide equipment or other technologies that they may require. Often they rely on charity organisations as well for services or equipment.

Mr MADDOX: For example, if one cannot write one would need a computer to talk to. There is no Federal or State government program for that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So PADP will not cover that?

Mr MADDOX: I believe they cannot but I am prepared to bet they will not because of the queue of people needing wheelchairs and so on.

The Hon. JOHN RYAN: They cannot even get powered wheelchairs under that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I wondered whether theoretically they would they meet that? You say the theory is irrelevant.

Ms BURNS: The practical examples demonstrate that.

The Hon. JOHN RYAN: Ms Burns, you made a statement about some of the things that the ATLAS Program had funded were not specifically related to education, and that is the reason the Commonwealth does not make them.

Ms BURNS: Yes.

The Hon. JOHN RYAN: Public servants from the New South Wales Department of Ageing, Disability and Home Care might argue that that is an artificial demarcation in some instances between services that are specific to study as opposed to hole-of-life services and one that could be referred to as transport. In similar circumstances of young kids going to school, the transport costs are not picked up by a separate transport department but by the New South Wales Department of Education and Training. It could be argued that getting to university is a study-specific cost and that the Commonwealth should pick up those costs. Would that be a fair argument? You see any problems in that? Perhaps the attendant care is more difficult, but it would be hard not to argue that transport was not study specific, because students are accessing transport to get to university. If the university is to make itself accessible to the wider community, transport should be provided to people with disabilities.

Ms BURNS: It is not my position to say which level of government should fund which services. However, I am here to identify a gap in the service and certainly transport and attendant care for people with high support needs attending university is a major gap.

The Hon. CHRISTINE ROBERTSON: In relation to personal care and attendant care for people with a disability who want to go to university or who are already there, are there any funds or programs that can be tapped into the personal care or attendant care?

Ms BURNS: The universities provide education-specific support. Attendant care does not fall under that. I can give an example of a young woman in the south of the State who was completing her master's degree at university. She was receiving personal care and support from Homecare, whose representatives went on to campus to provide that support. Half-way through her masters program, for some reason Homecare believed that the university should provide that support and it withdrew funds. Homecare refused to go on to campus to provide assistance. The student and her parents were furious with that decision, because if the woman had decided to stay at home she would have received Homecare assistance, but because she was on campus she was ineligible to receive that support.

The Hon. JOHN RYAN: It was jointly funded by the State and Commonwealth.

The Hon. CHRISTINE ROBERTSON: Yes. Is Homecare utilised within universities elsewhere?

Ms BURNS: I know only of that particular example.

Mr MADDOX: I certainly have not heard of Homecare ever helping university students on campus.

The Hon. CHRISTINE ROBERTSON: Obviously Homecare was contracted to provide that service but was covering the cost itself?

Ms BURNS: Not by the university.

The Hon. CHRISTINE ROBERTSON: But by the family.

Ms BURNS: The young woman was entitled to Homecare assistance with personal care. When she attended university to complete her masters degree the attendant care was continued. Instead of going to her home to provide assistance with toileting and feeding they went to the university campus. That is one example I know of. The point I am making is that that service was provided initially but for reasons that we could surmise, based on who should provide what funding, that service was withdrawn.

The Hon. CHRISTINE ROBERTSON: Do you know of any other similar program? Was that a one-off program?

Ms BURNS: I do not know of any.

The Hon. CHRISTINE ROBERTSON: Did you know that DADAHC had a review process in its implementation of the post school program, so that if people are not happy with the decisions it has made there is a process for review?

Ms BURNS: I was aware of that process.

The Hon. CHRISTINE ROBERTSON: You mentioned a gentleman with paraplegia. Has he gone to the review process?

Ms BURNS: I am not sure of his specific situation. The difficulty is that with people who have to go through a review process, either the service advocates on their behalf or they jointly advocate or they advocate independently on their behalf. It is about young people constantly fighting the system to get what they need. You can imagine it is extremely draining when you have had to do that for mostly the entirety of real life—your parents or yourself fighting the system to get essential services.

The Hon. CHRISTINE ROBERTSON: The Committee has heard about our lot of issues with the review process, particularly with service providers not being well informed. So we understand. Have you heard strange stories about the different review processes?

Ms BURNS: I do not know enough about that to comment.

The Hon. CHRISTINE ROBERTSON: Recognising that both of you are involved with universities, do you think that, if the post-schools program, particularly with regard to TAFE, supports students for two years, some sort of reasonable assessment program could be designed? Rather than the old ATLAS program—under which it seemed that if the provider thought you were worth it, they would give it to you for another two years—do you think some sort of performance measures could be delivered after two years for people in TAFE programs so they could continue or not continue? Am I being confusing?

Mr MADDOX: I believe there could be, but I agree with Timothy's reservation that it can take people a while to settle to study. Certainly if you are talking about TAFE, quite a few of those students have intellectual developmental disabilities and there is very real issue of maturity. I was a caseworker for people like that for many years and I would say to parents all the time, "Look, your son or daughter will probably do at 28 the things some other kid does at 18". So progress in the first couple of years of study may not be a guide to eventual outcomes. But, yes, with university I am sure that could be done also. However, there is big scope for it to easily end up being too tough and excluding people.

Ms BURNS: I would like to see the program available to students to complete a university degree rather than halfway through that degree continually having to sit through assessment processes.

Mr MADDOX: Absolutely.

Ms BURNS: People with disabilities are constantly being assessed for services and programs. You can imagine that it is extremely draining to be doing that. Surely there should be an option available for people who aspire to go to university and who have the intellectual capacity to go to university to receive the supports they need to complete a degree.

The Hon. CHRISTINE ROBERTSON: That is a very good point, but I ask whether you have considered the recommendation about the Federal and State governments' negotiating to ensure that this happens. My question related to TAFE students but I understand your point. Perhaps you could let us know what you think the outcome of the State and Federal negotiations should be in order that university students can participate like this.

Ms BURNS: I would like to see the provision of services so that students can receive a seamless service to attend university.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: How many disabled people do you think would go to university if they could? Do you have any idea of the demand?

Mr MADDOX: We probably can get some idea of the demand. I am looking at the Wollongong figures for the profile of 2003 ATLAS applicants. Some 9 per cent of them had a primary disability being physical and for nearly 80 per cent the primary disability was intellectual. Some of that 9 per cent physical would have had intellectual as a secondary disability, which might make them unsuitable for university. But looking at that, you would have to say that maybe 4 per cent or 5 per cent of ATLAS applicants could be candidates for university if they had the right opportunities at high school.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: What is that in numbers?

Mr MADDOX: The total number is 648 in that year so it comes to 26 people a year.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Do you think they should be in a separate program as opposed to an ATLAS program or do you think ATLAS is enough?

Mr MADDOX: I do not see that there needs to be a separate program.

Ms BURNS: I reiterate the point that it is not about the program; it is about providing a seamless service for the students. As Geoff mentioned, we would expect to see a greater number of students coming through the system and capable of and interested in attending university because they are receiving better quality, more intensive supports at school. That would enable them to achieve better and then potentially go on to university. So we expect that the numbers will grow in future years.

Mr MADDOX: I would like to make one final point, which is that the new Community Participation Program, as opposed to the work preparations program, has a supplementary funding component for people with very high support needs. I would ask the question: University has never been viewed purely as a pathway to a job so should not people with extremely high support needs who may or may not have the prospect of the job be eligible for these supplementary funds in order to attend university? Reading the guidelines, you could have a very severe physical disability and be eligible for them.

CHAIR: Ms Burns and Mr Maddox, thank you very much for joining us today and for your submission. If there is any additional information that you would like us to be made aware of, the Committee will be pleased to receive it.

(The witnesses withdrew)

(The Committee adjourned at 12.20 p.m.)