

**REPORT OF PROCEEDINGS BEFORE**

**GENERAL PURPOSE STANDING COMMITTEE No. 2**

**INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS**

---

**PARENT FORUM**

**At Armidale on Tuesday 17 May 2005**

---

**The Committee met at 2.30 p.m.**

---

**PRESENT**

The Hon. P. Forsythe (Chair)

The Hon. A. Catanzariti

The Hon. Dr A. Chesterfield-Evans

The Hon. K. F. Griffin

The Hon. J. Jenkins

The Hon. J. F. Ryan

The Hon. H. S. Tsang

**CHAIR:** On behalf of the members of General Purpose Standing Committee No. 2 of the Legislative Council I thank you all for giving us your time this afternoon to add to the Committee's process. My fellow Committee members and I acknowledge the important role played by parents and carers of young adults with a disability. We appreciate the effort made by everyone to attend today, particularly the parents. Our appreciation is even greater given the evidence that the Committee has heard from parents concerning the time pressures and stresses that they face. The Parent Forum is an important part of the Committee's inquiry: It is a chance to hear at first-hand the views of parents and carers concerning the changes to post-school programs. In particular, the Committee is eager to hear about the difficulties faced by families in rural and regional areas.

I understand that parents speaking here today will be sharing extremely personal details about their family lives. The Committee thanks those parents who are speaking today for sharing those details with us. Indeed, I understand that we are to hear from relatives of a participant in the program, whom I thank in particular. I ask speakers to respect the privacy of others and to avoid naming third parties, those outside their immediate family. Although these forums are a parliamentary proceeding, it is important for speakers to avoid adverse mention of third parties. After the conclusion of the forum the Committee members invite all attendees to stay for afternoon tea: we welcome that opportunity to meet informally with as many people as possible.

I will briefly explain how the Committee works. We are a Committee of the Legislative Council, which is the upper House of the New South Wales Parliament. The Committee is made up of seven members of Parliament and includes representatives of the Government, the Opposition and the crossbench. The Committee does not represent the Government or the Minister for Disability Services. The Committee is looking at the recent changes to post-school programs for young adults with a disability. The Committee is examining how those changes were made and their effect on young adults with a disability, their parents and carers.

To do this, the Committee is holding hearings and discussion groups with people with a disability who use post-school programs and is visiting service providers. In addition the Committee is holding parent forums in regional New South Wales. The Committee will write a report on its findings and that report will be given to the Government. The report will include recommendations of what we think the Government should do and the Government does not have to accept the recommendations made in the Committee's report, but it must respond to each recommendation. The report will be available to the public.

I turn now to housekeeping matters. The Committee secretariat can assist with any inquiries about the operation of today's forum. Anyone who has not given his or her name to the secretariat but would like to speak should approach the secretariat. Each speaker will be given five minutes to discuss any issue he or she considers relevant to the inquiry. The contribution may include personal experience or more general comments on post-school disability programs. Speakers are welcome to read pre-prepared notes but, as I mentioned before, are asked to avoid naming people outside their immediate family. I will read the name of the next speaker from the list of people who have indicated they wish to speak, and that person is asked to stand and the secretariat will bring a microphone to the speaker.

All comments made at the forum will be recorded in a transcript. That transcript will be publicly available and placed on the Committee's web site by Monday of next week. The Committee will use that transcript in its report. Speakers are asked to provide their address details to the secretariat, who will send speakers a transcript of their speech to correct. I understand that no media is present. However, should the media be present and speakers wish the media not be present during their presentation, they should notify the secretariat, who will arrange for the media to leave at the end of the forum. At that time speakers may make their presentation in the absence of the media.

As I indicated earlier, each speaker will have the opportunity to give a five-minute uninterrupted presentation. The Committee members will not interrupt with questions. At the end of each five-minute presentation, Committee members will have an opportunity to ask a question arising out of something that was said. That will be limited to one or two questions. The first speaker is Kate Thomas, a parent, who has given a submission to the Committee.

**KATE THOMAS:** I suppose I should preface my remarks by saying that I wish you had all been here more than seven months ago, before the cuts were made. This whole process should have taken place last year. The Committee has probably heard by now all the stories about the amazing good and exceptional parents who care for the disabled children. I am not one of them: I am an ordinary mum faced with extraordinary circumstances. My son, Edward, is 14, going on 15. He is taller than me and stronger than me now. He attends high school in Armidale and has autism. He is largely non-verbal but has some words and phrases that he can use quite effectively.

My life is a daily constant and unrelenting challenge. And I need help to manage. It has taken me 14 years to admit that, and today is the first time that I have. I can see that in a very short time, in four years in fact, should nothing happen and things continue as they are I will have to resign from my job, resign my study at university, and have my son at home with me for five days a week because there will be no places in day services for him, regardless of the amount of funding he may or may not get. If that happens the likely scenario is a sort of Christmas holiday writ large. Christmas holidays for us is the time when there are very few respite workers available, if I can afford to pay for them, which is often a challenge.

For Edward, the extended period without the routine of going out into the world, meeting people, talking to his peers and doing all the things that average teenagers do, results in him becoming bored and unhappy. It is boring living at home with mum, no matter how much you love her, no matter how much she loves you. It is dead boring when you are a 14-year-old boy; you have to get out and do things. Edward is no different, in that way, from any the 14-year-boy. He will be no different to any other 18-year-old boy who will leave school—although I have lost track of what 18-year-olds do, they certainly do not stay home with their mum every day.

One irony of this situation is that I am now faced with a child who is physically stronger and taller than me and I get no services for him. If we lived in Sydney that might be different. His file is opened every January at DADHC and he is supposed to get speech therapy and OT. But by 27 November every year they close his file because of the committees that have to prioritise service delivery just do not get to him. You can make what you like of that travesty! Another irony is that when he was three, and I could carry him around on my hip and we could do just about everything, I had services bending over backwards. We had speech therapy, physio, hydro, OT, everything. Now, when I need them most, and I am getting weaker and more tired, the services are not there.

Basically, I cannot do what I have to do for Edward for 24 hours a day, but that is what I am looking at. I do not know how else to say it. On top of that, the sums do not make sense. I know that you can cut costs in the short term but that will result in crisis management rather than planned programs. Crisis management is more emotionally and financially expensive than any other sort of management whatsoever. If I had to give up work, although I do not pay taxes, I will have reduced spending power, I will never pay my HECS, and I know that is a Federal Government concern. I am one of the parents who gets bounced like a ping-pong ball, backwards and forwards, between various political concerns of the Federal and State governments. In my ideal world disability services would be under the province of local government, or one particular area of government, rather than allowing people to swap responsibilities when it gets too hard.

**CHAIR:** Kate, your five minutes is up. Do Committee members have any questions?

**The Hon. TONY CATANZARITI:** You mentioned the closing date of 27 November of each year. Could you elaborate on what you need to do by that closing date?

**Ms THOMAS:** We do not know why they close their files, no-one has ever said. At the end of November, generally around the 27th or 29th, we get a letter stating something like, "Dear Kate, Edward's file has been closed. If you ever wish to have services again from DADHC please contact us and we will reopen the file." The process of reopening the file takes something like nine weeks, plus a 15-page form, plus an IQ assessment and various other requirements.

**The Hon. JOHN RYAN:** Does your son attend school?

**Ms THOMAS:** Yes, he does.

**EMILY THOMAS-MOORE:** My name is Emily Thomas-Moore. Madam Chair and members of the Committee. I have one word to say to you: Life. Yes, that is right, life. Now that you have this word in your heads, pretend that you are a year 12 student who is just about to leave school, and know that the biggest question in your head is: What on earth am I going to do with my life? Now, do not stress, this is a multiple-choice question. Option (a) is: You can get a job after schoolies, and a few weeks of holidaying, you can travel or teach and you can go out with friends every Friday night. You can even join the circus. Option (b) is: You can stay at home six days a week, in front of television, when you are not at day care. Which option would you take?

Personally, I have to say that the majority would go with option (a). Those of us who go with option (b) can be divided into two categories: first, those who really would love to lead that life, and, second, those who have no choice. It is the second group that I will focus on today. Question 2: Do any of you have brothers and sisters? If the answer is yes, would you be willing to go to the ends of the earth to get justice for them, and to get what is right and proper to give them a really good life, and to see them happy? I have a brother. He is 14 years old, and his name is Edward. He finishes school in four years time. At that point in time he will be forced to leave the Option B life. As a sister, that is the last thing on earth I want to see him do. I will go to the ends of the earth to stop that happening. But, right now, it seems like I can't do very much. But I can tell you how I feel.

We all love to be with our friends. We live on our friendships. Every day, in whatever we do, we are always conscious of different relationships around us; we are always maintaining existing ones and giving rise to new friendships, even when we are not aware of it. But it is a bit tricky to do this when you're stuck at home in front of the little square box. When I was in year 3 my brother first started school, and I felt it my responsibility to just keep an eye on him, just to make sure he was going okay. I did this every day. And every day I became more aware of how different Edward was from every other boy in school.

Edward would not be able to do things that other boys do, like play soccer, talk about school with you every afternoon, or even fight over Play Station controls—because he cannot talk; he is autistic. It is heartbreaking. Soon after, my Dad left us. The afternoon that he left he did not even say good-bye to my brother. Now, he never really paid much attention to him, but it is still no excuse for what he did. But lots of people in the world do this to people with disabilities; they ignore them, and they have no reason to.

Edward would wait on the front veranda soon after my Dad left, just waiting for him to come home. My mother and I could not really do anything but wait for him to come back inside. You see, we don't see things or understand things the way Edward does. He sees and understands things totally differently. So the best thing that we can do is to try to provide for these people with disabilities as many as we can of the luxuries, possibilities and prospects that could just make them happy. But it is a bit hard to do this when you do not have the financial backup to help you do it, to pay for day-care services while you go out to earn money to provide these things.

We are all human. We all laugh, and we all cry. And we all get angry. Denying people basic rights to a life of their own is criminal, and it makes me very angry. I'm so angry that, due to these funding cuts, Edward's future as well as the futures of many others in this community will be restricted to sitting in front of a square box. I have one final question for all of you. When you walk out that door, what are you going to do to make a difference in their lives? Thank you.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** How has he gone at school? Is the school making a difference to his ability to communicate and relate? Will it be easier when he comes out of school than if he had not gone there?

**Ms THOMAS-MOORE:** Edward is always going to be autistic, no matter what we do. Ever since he went to high school things have improved dramatically: his communication skills have definitely improved out of sight, and he has come home from school happy, which is a big thing. But there is only so much that the school community can do to enrich a person's life. There is only so much training that can be done: matching colours, teaching context and that sort of thing. There is only a limited amount we could do to make a difference. But what they are doing to help make a difference will all stop in four years time, and he will only have a life at home to try to make a difference.

**Ms TABER:** Madam Chair and Committee members. I am the carer of a young adult with an intellectual disability who is funded under the Post Schools Option, which is different from the ATLAS program. I am here today because I am very concerned that DADHC will be looking next at Post School Options and modifying or withdrawing funding, as it has done for all ATLAS participants, with very little consultation.

I would like to highlight some of the difficulties faced by young adults in rural and remote areas. My daughter is 24 years old. She is funded at a rate of about \$18,000 a year. That is very little compared with what is required for service provision to actually allow her to participate in Community Participation, which is what ATLAS participants are looking at doing. I understand their funding for high level is \$13, 500, which is poor. If you are looking at service provision for transport, you are looking at 50¢ a kilometre, plus the rate for an employee to be transporting the child. In our case, our daughter travels 57 kilometres into town to access Community Participation. I am fortunate that I work in town, and am able to transport her in the morning. She is lucky enough to be able to access a bus in the afternoon, although she is not a student any more.

Children who do not have a working parent are faced with a number of issues. How do they participate in Community Participation when the funding dollars are not there to allow transport? This is a very real issue, and I have raised it with DADHC in the past. I feel a certain amount of money needs to be allocated for transport. That has yet to be looked at. I was pleased to hear Madam Chair say that the Committee will be looking at issues faced by rural and remote participants. That surely must be addressed. I was interested, too, in how ATLAS participants will access education.

My daughter is perhaps fortunate that I am her case manager, and we actually access TAFE two days a week. How will this be managed by ATLAS participants? Will they be excluded from further education in numeracy and literacy? Will that be funded? How will it be funded? The criteria are going to change to allow Community Participation as well as TAFE? These are issues that I, as a parent, feel need to be addressed. Our young people need us to be their advocates. It is very difficult, very time consuming and very emotional. I have been very vocal, but I feel that we as parents need to pull together now, before other reforms take place without due consultation. As the first speaker mentioned, this should have happened seven months ago. I would like to say that, if there are to be any further consultations on reforms, we need more adequate consultation. That is really all I would like to say.

**The Hon. JON JENKINS:** What is the best form of consultation? What do you think is the best way for you to be consulted?

**Ms TABER:** Certainly at the schools, when the children are to be enrolled. We need a longer period of consultation. It is very difficult and very emotional for parents of children with disabilities to look into what changes are going to be happening. They need time. Parents are terrified about what changes will happen. Seven months is a very short time in the life of a disabled child. There is one other point I would like to make. I read with interest that Transition to Work is going to be funded for a period of two years. Two years! I have children. My youngest child is in her second year of an apprenticeship. She has had numerous issues with being away from home, and away from supports and other things. I have a child who has just finished an apprenticeship. Two years for a child with disability is nothing. Parents need adequate time for consultation. Start at the schools. We have service providers who come to the homes of parents. Service providers need to be involved in the consultation. But there certainly needs to be a longer period of consultation.

**Ms DEVENISH-MEARES:** I have two adult sons with semi-autism. One is 30 years of age and is in supported employment, and the other is 20 and in the Transition to Work program. Neither of them speaks. They cannot express themselves in words, and their comprehension of words is quite limited too. My eldest son passed through the system from school to supported employment almost seamlessly, even though there were no formal post school programs at that time and we were then living in Sydney. He was well known to all the service providers, both government and private, and he moved from school straight to supported employment.

Comes my younger son, it was like he never existed. There was minimal co-operation between the Department of Education and DADHC. It seemed that we had been totally lost by

DADHC. We had not used their services for quite a while, mainly because there were not any to use. We had used affiliated services. We were taken off the list. That is what Kate was referring to before. So, instead of having a lifetime of assessment and awareness of his needs passed along, his whole future was determined in an hour by the filling out of a form that is totally divorced from the needs of most of his life. I will demonstrate what I mean. Recently we went through another DADHC assessment for our younger son because we had been taken off this list. He was assessed as having moderate to severe intellectual disability, with a severe to profound language disorder. Yet 18 months earlier ATLAS deemed him suitable for Transition to Work. Who is right?

One of the first things we need is an accurate, continuous assessment that is lifelong. Secondly, we need a quality, individualised, seven hours a day, five days a week, service. You might ask: Why do we need that? The reasons are just plain commonsense—and this is one reason that parents get so frustrated. Firstly, we need a quality service for the ongoing social, physical and intellectual stimulation and wellbeing of our dearly loved family members, thus producing a happy, calm and co-operative person. Secondly, we need it for the sanity of parents, so that they may have some life of their own and be under less emotional, physical and financial stress; that is, to have an adequate service that prevents family breakdown.

Thirdly, we need to ensure the ongoing safety of parents and their sons and daughters, a good program that averts aggression and volatile behaviour, with less injury to both parents and child, and less crises that result in incidents like those recently reported in the Sydney press of parents leaving their kids at respite. Also, it avoids things like the Daniella Dawes case. Fourthly, we need cost effectiveness. Crises cost a lot, both financially and emotionally. If we invest realistically at this stage, we have fewer crises. So it is actually in the best interests of the whole community to adequately fund services.

I have been living with a disability for 30 years now. It feels like I have been in a combat zone. I'm scarred and battle weary. Yes, we struggle daily in coping with our kids, but the real fight is in the battle for adequate services. The only reason there were services in the first place is that parent groups started them. By making it so hard to access services and constantly moving the goal posts without telling us, parents are virtually forced to give up because it is too hard. An exhausted and humiliated parent has no resources left to argue and fight for services which should be provided as a matter of course. In fact, we should not have to be here today because we are wasting more time and more money locked in yet another fight with the Government over service provision, and that money could be better used for our kids. I thought I coped pretty well when my kids were small and I was younger, but now I am ageing, I am slower and physically and mentally worn out. Yet I am expected to cope with a strong adult son who is sometimes aggressive, unhappy and frustrated. I am expected to cope with him for four or five days a week and I am sorry, I cannot do it any longer.

**The Hon. JOHN RYAN:** We met your son Jonathan at Challenge. Is he on Post School Options or is he on an ATLAS program?

**Ms DEVEARISH-MEARES:** Transition to Work.

**The Hon. JOHN RYAN:** So he has now been assessed for Transition to Work. And has he stayed in that?

**Ms DEVEARISH-MEARES:** We have tried work. He lacks the motivation to do anything. It has been unsuccessful. I think he will soon be transferred to Community Participation.

**The Hon. JOHN RYAN:** Do you have any idea how many hours he will spend on that in comparison with the program he has now?

**Ms DEVEARISH-MEARES:** I do not know. We have a fairly volatile family situation and Challenge has been very generous to us.

**CHAIR:** What has been your interaction with DADAHC since your son was assessed as able to be part of the Transition to Work program and your concerns about that? How has DADAHC responded to your—

**Ms DEVEARISH-MEARES:** They lost us completely. When we first moved to Armidale we contacted them and had both our sons in the system. There were no services that I wanted to use that were DADAHC services. There were some that were affiliated, funded that way. Then the only other thing that happened was the Transition to Work assessment came up and then we were looking also for some supported accommodation for him, of which there is none, but they said, "You haven't got a case worker". I said, "Why", and it was because I dropped off the list because I had not used their service. The only thing that has happened since then is we did another assessment and then the caseworker came to visit us. He did find a couple of things that were suitable that would have been helpful but I have not heard anything else since. There is only one caseworker up here .

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Is the list you dropped off a way of managing demands?

**Ms DEVEARISH-MEARES:** Yes, or statistics perhaps. They can say then that they are providing services for whatever percentage because all these other people have dropped off the list.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Yes but effectively those people do not exist. If you do not reinvent yourself every year there is no memory of you.

**Ms DEVEARISH-MEARES:** Yes, that is right.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** Do you keep the same caseworker if you reinvent yourself every year?

**Ms DEVEARISH-MEARES:** I do not know because I have not reinvented. The others say no. But all the caseworkers, I think they gave up in disgust because they could not provide a service for us.

**Ms KRAMER:** There is only one community worker provided by DADAHC for the Armidale area. Of course, if the person leaves—we have had a bit of turnover over the past couple of years of those people. That is part of the change. The other issue is the program that has now been implemented through DADAHC means that if you do not get in contact on a regular basis—say, every month—to request services they close your file and that is it. I think it is managing the overdemand. Let us face it, if you have a disability it will not go away. You will need services along the track but because they cannot manage the work load, if the caseworker has over 80 clients how will they service all these people?

**The Hon. JON JENKINS:** When they close these files and then reopen them, do they reopen the same file or do they start from scratch all over again?

**Ms KRAMER:** They start from scratch. They open the same file. However, we have to go through the same intake process which is the aforementioned 13 pages, and a psychiatric assessment not older than two years.

**The Hon. JON JENKINS:** that is what we heard before.

**BARBARA ALBURY:** My name is Barbara Albury. Looking after a disabled child begins at birth. Post school programs are only one aspect of the whole package that families deal with. I want to tell you about an alternative way of dealing with disability. I did use a name here so I am just using the letter T. I want to tell you the story of T. T is autistic, has very little language and is intellectually delayed. He is 17. His mother J is Australian; his father is an Israeli. They have two other sons. T's family decided to return to Israel after about 10 years in Australia. There were a number of reasons for this but J told me that what finally decided her to uproot and start again on the other side of the world was the fact that the education and care available for her son in Israel was superior to that offered in New South Wales.

I will back up to tell you briefly how the education system works in Israel because you have to have the whole package, as I said, not just the Post School Options program. First, there is a belief that education, both life skills and academic, is important. It is considered to be a lifelong process which does not end when school finishes; nor, indeed, when early intervention finishes, which seems

to be the focus in Australia, as my friend J tells me. She is a psychologist in a school; she was here in Australia. Students in Israel are encouraged to stay at school until they are 21; they are not shunted off when they are 18. In Israel there is more concern for providing a rich post school environment. Parents are concerned about what happens to their offspring when they are older and the Government does something about it.

School operates six days a week, on five days from 8.00 a.m. to 5.00 p.m. and on Saturday from 8.00 a.m. until 1.00 p.m.. This is ordinary high school. Schools run full-time school holiday programs which are run at the schools. T's school has instituted a comprehensive work experience program as there is a strong drive to place people in some kind of meaningful work after they finish school at 21. T, who as I said is significantly disabled, has worked in a wedding reception centre setting tables and can cut and prepare salads. He is now 17. My son, William, who is 20 and is as able as T, if not more, has not had these kinds of opportunities. T is now living in a type of hostel which is available to all autistic people. She only knows about autism because he is autistic; I do not know about other disabled people.

It is full-time accommodation for life. The system operates as follows. The autistic association and parents fundraise to set up a hostel but after it is in operation for two years it is taken over by the Israeli Government, which assumes responsibility for it. The Government supports each client in the hostel at the rate of \$3,300 a month. This commitment by the Government to supporting people in hostels is enshrined in legislation. At T's hostel there is a commitment to ongoing education to creating opportunities for meaningful work of some kind. The hostel started—she calls it a boarding school; it is a kind of hostel—a bakery and a nursery, and there is a focus on providing in-house opportunities for clients who would find it hard to work in the open market.

T has many learning opportunities. First, there is school where there is an effective work experience program and later after he finishes school he will be able to continue training either at the hostel, day services programs or possibly in a more mainstream environment. I compare it to the basic part-time provisions for my son in his post school program—22 hours per week and no possibility to be in supported accommodation at this stage. In Israel there is a strong focus on training and finding jobs for the disabled. However, there is no climate for clients to be economically productive. The purpose is to create opportunities for meaningful involvement in some kind of work-related activity. This is in contrast to the shrinking educational and work options available in New South Wales because of the need to be economically competitive and productive. It is a catch 22 situation.

For example, you establish a good skills-based program such as a woodwork workshop but because the clients are not productive enough, cannot manage due to their disability, the workshop may be discontinued. So more and more clients who are not able to work in the mainstream or well enough in a workshop end up in day service programs, which really are socially based and I do not think they have the funding to create these other work opportunities. And even if the clients receive work training there are very few opportunities for them to put their skills into practice. Even the Commonwealth public service, which was a recognised employer of those on the margins, has reduced its percentage of disabled workers by 2 per cent, from approximately 5.75 per cent to 3.75 per cent. I heard this on the Terry Lane show on ABC radio the other day.

Many of the jobs that used to be available for less able people simply do not exist anymore. They used to be incorporated by the public service. So you have an expanding pool of unemployed and unemployable people. Lastly, it seems that for my son who will never join the mainstream the only option for him to get into some work environment and be part of the community in that way is for us to set up a business, which is rather a big ask at this stage of our lives. To get back to T, T lives in the hostel during the week and comes home on the weekends. He likes coming home but he also likes going back to the hostel. That speaks for itself. Everyone in Israel is entitled to have this kind of opportunity. What it means for parents is this. A home away from home exists for every disabled person for life. This takes a huge burden off parents and enables them to lead more of a semblance of a normal life. They are able to continue in their jobs, thereby adding to the common wealth of the country.

My husband—I will just mention this; he has talked here before and he was not able to come today partly because he is picking up our son. My husband, who was Pro Vice-Chancellor at the University of New England, left his position at the end of 2004 before his contract finished partly

because he felt there were no adequate provisions for our disabled son after he left school. I also left a tenured lecturing position in creative arts at the Australian Catholic University in 1996 because again it was too difficult, too stressful to try to raise a son with significant problems, epilepsy, autism, intellectual delay, without adequate support.

We have literally spent hundreds of dollars per week, and we were able to do that—we were lucky—over many years on private care, therapy, education in order to improve our son's functioning and quality of life and to be able to manage our lives in a rational way. In conclusion, what I want from this Government is this: first, leadership, ingenuity and commitment to providing the best that is possible for disabled people both in terms of education and training and accommodation—this requires reassessing priorities, including financial and looking around for models of best practice—secondly, the development of programs which are intensive and specifically focused on skills acquisition, personnel, social and workplace, using the most up-to-date teaching methods available; thirdly, permanent quality accommodation and care for our children when we are no longer able to look after them. I am sure that parents would rally and join together to get these initiatives started but it requires the government of the day to pick up the tab and continue on.

**CHAIR:** Before I call the next presenter, I remind speakers to keep their presentations to five minutes. I acknowledge the presence of Richard Torbay, the honourable member for Northern Tablelands. I thank him for attending.

**JENNY THOMAS:** I am not a parent of a person with a disability. I am fortunate in that respect, because I now respect what parents of children with disabilities have to live with. With reduced funding, I can only imagine that things are getting more difficult for them. I will outline my personal background. My last 10 years of full-time teaching, 1993 to 2002, were spent as head teacher of the support Faculty (Special Education) at Armidale High School. In that role I worked with and supported all students with a disability who enrolled in that school. These students were enrolled in either the mainstream of the school or in one of the four support classes for students with an intellectual disability.

Throughout 1993 to 2002, I witnessed both the introduction of the Post School Options Program in 1994 and the ATLAS mode of funding a few years later. The constant cutbacks in funding levels for individual persons during that decade were alarming enough, but to now face in 2005 further funding reductions and therefore reduced services, particularly for the group with the highest support needs, defies understanding. In 1993, when the first cohort of six students finished their high school program, their Post School Options Program funding provided them with programs for five days a week with hours that replicated their school days. They were a very happy band of young adults who went off to the local service provider, Challenge Armidale, where they enjoyed quality individual programs that looked at their individual needs from community access programs through to entry to work experiences.

With the change to the ATLAS mode of funding, the reduction in program time available for all ATLAS-funded young persons per week became evident all too quickly. This was particularly the case for those young people with high support needs who often needed individual support to be able to participate in many of the community access activities. You can imagine the disappointment and concern of families and carers when informed of this situation. How can the New South Wales Government rest easily in the knowledge that people with the same level of support needs as those catered for in the Post School Options Program are to be punished with a further reduction in services because they just happened to be born too late? How equitable is this?

The major focus of the individual educational programs for the students in the Support Classes at Armidale High School throughout their secondary schooling was the preparation of these students for a quality adult life. My colleagues and I worked hard, in collaboration with families and carers, to provide quality individual education programs. Programs always had functional and community-based outcomes as their goals. For students with high support needs, these programs included swimming, horse riding, bike riding, ten pin bowling, eating and shopping in the community, attendance at community events, pedestrian and travel training. For many students it was realised that at no time in their lives would they ever be able to participate independently in these activities. They would always need varying degrees of support, including one-to-one support. This knowledge never

deterred us in our inclusion of such students in each of these activities. As for our students, they just loved every minute of their involvement. They led very fulfilled and challenging lives.

It was always anticipated that these activities would continue to be available to these students when they left school. Their transition to their post school provider was always carefully planned and it is known that local providers have admirably met these interests and needs for graduating students. How wonderful to have such a great choice of activities continuing into one's adult life. How terrible to not be able to continue with these activities because of the lack of funding. When denied such regular full-time activities, many young people have displayed their frustrations when time at home lagged and the stimulation of community and leisure activities was not available on the regular basis that they were accustomed to in their school programs. Such young people, who are often unable to communicate verbally, have resorted to physical abuse of their loved ones in an effort to express these frustrations. How appalling is this!

These young persons enjoy being occupied and participating in preferred activities, but many are just unable to organise their own independent participation, needing a range of support from others to be able to do so. At the time that students with a disability leave secondary school, parents and families have already provided 18 to 20 years of nurturing and caring. These parents and families are deserving of more time to themselves when, for the first time in their lives, they can institute life choices of their own. Instead, reduced funding and the subsequent reduced services are dictating a lifestyle when more time rather than less time is being directed to caring for their child with a disability. The expectation that parents and carers face this as they age and no longer have the physical energy to provide the care required by some of these young people is deplorable.

As someone who has worked as a classroom teacher with this group of people with high support needs for 15 years, I am full of admiration for the families and carers who provide the love and care for these young people on an ongoing daily basis. When it is realised that many of these young persons will never be toilet trained, never dress independently, never be able to eat independently, or sleep through any night without disturbance, and never be able to communicate verbally resorting to challenging and aberrant behaviours to communicate their needs, one can start to appreciate the time-consuming and emotionally demanding nature of the care involved in having such a family member. The value of the regular attendance at day service programs for these young persons is often the only survival strategy for families. And the Government is about to reduce this lifeline for such families!

Surely, the Government of today with all the information that it has at its disposal should be looking to increase funding for these people so that their days are as richly spent as are the life expectations of all other people in the community. The expectations and the stress that this Government is placing on the families and carers of these young people by further reducing their access to day service programs will have far reaching consequences that should not have to be contemplated. Most of us live in households without a person with a disability. Many of us have raised a family that did not include a child with a disability. How often have we complained about the stress of doing this? Probably daily! What a sigh of relief we have all given when our children reach the age of responsibility and independence and make the decision to lead their own lives beyond the family nest. At that stage these children have acquired enough skills and knowledge to be able to enjoy fulfilling and productive lives without the need of parental support.

The realisation that ATLAS funding to support young people with significant disabilities in their enrolment in the higher education institution of their choice is also to be axed has also caused me great concern. How wonderful it was during my time at Armidale High School to successfully support the application of a student with a physical disability for ATLAS funding to allow that person to attend a university beyond Armidale. The funding was targeted to provide the extra support required by that person to attend university as a residential student—a significant step in the realisation of an independent lifestyle for that young person. Are such young persons to be denied that support in the future. How shameful!

**CHAIR:** I have been informed that the next speaker, Donna Biddle, will not attend today as her son is unwell. If Donna would like to provide a written submission to the Committee we will be happy to take it.

**JUDY SCRIVENER:** I am a parent of a disabled child and a member of the board of Challenge Armidale. I do not have much more to add to what has been expressed already. However, I find it extraordinary that as parents we are before a group of total strangers endeavouring to say why our children are worth a good quality life. It is amazing that in this country, where people have worked hard to establish a good quality service provision, a good quality of life, a good standard of life, generally report that it is bad and we attempt to justify it by words. We have a medical system that intervenes with viable babies at 24 weeks gestation, and allows them to live with intensive input and gives early intervention by pushing them through school. These young people deserve a quality life.

And when they leave school what happens? We are fighting to save these young children that have been helped through the medical profession and the education department. Now we are saying that these are still the same people: let them have a quality life. We hear of many groups that assist young people, including Youth Off The Streets, and those with indigenous issues. Almost without exception if you pick an area there is a choice involved. People who have cognitive or verbal inabilities or even a minimal understanding of the system, can survive and make choices.

We are talking about a group of people who really do not have the ability to make choices. As parents and service providers of group care, we fight for that standard of life, because those people do not have a voice. My son, Michael, is here with me today. I will introduce him to you later, because you are the people who are making decisions about his life. It is important that the Committee understands that it is people like Michael that we are talking about. They are not just numbers, not just statistics. They are people and they are worthy of a life, just as we are.

**COL SCRIVENER:** I spent the first 50 years of my life running the odd chook raffle for people with disabilities. In fact, I was probably trying to avoid them, like most people do, because people who spit on you when talking to you are really not very nice. A few years ago I met a very lovely lady and now have a stepson, Mike. In that time I have learnt quite a lot about this. I met a lady who, for 32 years, has never had a dinner party, never had a Christmas dinner, never done any outside activities. In the last budget, Mr Egan said that the bounty provided by the strong economy should spread through to everyone. He really made that work. They gave teachers an increase of 12 per cent, funded out of Treasury not out of the Education budget. They gave nurses an increase of 9 per cent, and when they complained they got another 9.5 per cent. That is not too bad for two years. But they did not like that and are now going on strike for another 4 per cent, which is to be funded.

The Olympics, although a Federal matter, picked up \$12 million, those people are heroes. Mr Carr has just announced \$72,000 for every sawmiller who wants to quit and find another job. That will be funded by cutting Mike's budget by 50 per cent. But that will backfire, because sooner or later a lot of people will go into respite, and that will cost the government an extra \$100,000 per client. So it may lose a little bit, \$10,000 here and there, but it will not take much to bring in another \$100,000. Another point of interest is that DADAHC does not employ anyone with intellectual disabilities. They do employ a few people with physical disabilities. On our latest information no-one with an intellectual disability is employed in Parliament House. Really, all I want to say is that you are quite prepared to fund the lucky people of the world, but it really is time to start putting money back into funding programs for those who have no ability to do things on their own. Thank you.

**Ms ROWE:** I am the parent of a 20-year-old girl. At the moment, we are in the middle of a Transition to Work program. Sally did her first year in transition last year. At the moment, Stephanie receives 2½ days a week, so she is home with me for the other 4½ days a week. We seem to clash; we probably are not at our best, but we get on. Stephanie is my second child of five, so I have four others that I must consider as well as her. We live out of town, so I have to travel to town to access services. This means I come into town and I go home again, because I cannot sit round for the full day. This often means a round trip of anything up to 150 kilometres for me to come into town, go home again, come into town again and go home, because there are no services that we can avail ourselves of to get Stephanie into town. She is currently in early supported employment. I suppose the best way to describe it is to say that she has her L-plates on; she is learning in two areas, to see which is most suitable for her.

We started in the system with early intervention, when Stephanie was 15 months old. She is classed as moderately intellectually disabled. A special class was set in one of the primary schools,

with just the one class of nine children. She did her eight years of schooling there. For her extra year, the teacher basically repeated her in kindergarten, to make her supposedly more age appropriate. She then proceeded to the Armidale High School special unit, where she spent six years of education. We watched children that had been older than Stephanie in primary school progress in front of her going to high school and then going out into programs such as Post School Options and ATLAS.

Every time we took a year up, or a step up, a door closed. We felt, by the time we got to the end, there was just nothing left. In year 12 we were given a form by the Department of Education. The number of questions on the form had been condensed from 150 to 15, and we had to fit in a box. None of these clients/kids fit in a box. They are all individuals, as you are. It was very hard to get an assessment. Stephanie got her Transition to Work, which in her case is appropriate, but two others that year got the same when they should not have been in that program. It was just a result of the questionnaire that we had to fill out.

We have been progressing through, but we still do not know what is ahead of us: whether we will be able to get four or five days. Ultimately, what we want is independence for our children so that they can make the best of their lives that they can and have a very happy life. Parents know that often we get, "My husband and I are going on holiday." We cannot do that, because it is not an entity of two; it is an entity of three. Stephanie will be with us for the rest of her life. We worry what will happen to her when we pass away. It will fall then to siblings, if there are siblings, or family. In a lot of cases there are no families. Many families do not understand, until they have a child in the household and get to know first-hand what it means to have a child with a disability.

I personally would very much like to see this money situation reviewed. I think it is very unfair that these children are being victimised because of the date of their birth, with one lot getting so much funding when we will get less. It is just not fair. There has to be an equality for these kids. We fully realise that our child will never be totally independent, but with supported life she would hopefully live a happy and adjusted life.

**CHAIR:** Robbie Duff, who is a service provider, will be speaking on behalf of parents.

**Ms DUFF:** First of all, I would like to speak about the Community Participation program and how it affects our centre. Most people assessed for this funding have moderate to high support needs. In a lot of cases these people require one-to-one support because of their complex needs. My point here is about the individuals and their assessment. Funding needs to reflect the needs of each individual. The current funding cuts represent a huge step backwards in services provided to people with disabilities.

The needs of the individual are not being met. The individual needs of people accessing our services are restricted as group arrangements are the only way to stretch the dollars allocated to Community Participation funded people. Group situations often lead to challenging behaviours. People with disabilities need support to grow. We need the support resources to create person-centred plans for each individual so that they may reach their chosen goals. It is their right. Let the intent of the 10 disability standards be reflected in adequately funded programs.

Family Advocacy poses the question: What will it take to deliver effective support for school leavers and adults with disability? There are five points to be considered in answering this question. They are funding, effective support, effective service design, improved capacity of the system to deliver contemporary supports, and an effective reform process. These are all paramount in providing the realisation of person-centred plans for people with disabilities. The extra demands placed on families due to inadequate funding—as others have been saying this afternoon—will result in reduced day program access. This will cost the Government, as an increase in the need for respite will become apparent.

I would now like to share with you the concerns of a family who could not be here today but attend our centre. This comes from the mother of a 19-year-old Community Participation person:

Consequences of reduced support hours

- Life skills, which are paramount for independent living, take far longer to learn, putting back her transition into independent living.

- Activities she is involved in now would reduce eg Meals on Wheels, TAFE, work experience, tutoring, self-defence, etc. Some of these will stop due to the simple fact of not enough support hours. The skills she learns from these activities are crucial to her self-esteem and life skills.
- Community Access will reduce, leading to dangerous situations. She learns the very important skill of being able to feel safe in her community because she is able to locate different places and addresses, and if this is taken away or even reduced, in an emergency situation she will be unsure of where to go for safety.
- Her behaviour will become withdrawn, unsettled, unco-operative etc, simply due to less time spent with other people—less company, conversation, activities, laughter, all will be affected.
- Relationships: lack of time to spend with others, to be able to form friendships and to maintain those friendships, also to learn how to tolerate different types of people.
- Acquiring new skills will take far longer, and the ability to retain skills learnt will be harder for her because the repetition needed for her to learn and retain new and existing skills will be reduced.
- Further educational opportunities will be reduced, due to hours being cut back.
- Her happiness will be greatly affected. She lives for her day program centre. It is a place where she feels good to be there. She loves meeting up with the carers and other clients. When she has achieved something, be it pottery, meeting a new person at Meals on Wheels, being able to complete a task at tutoring or TAFE, or whatever it is, she will come home and tell me all about it. The pride and happiness in her face is priceless. The consequences of her losing support hours will be detrimental.
- ...
- Being a single mother with an intellectually disabled child who also suffers from epileptic seizures, I need respite time. Perhaps I will be needing more. Consider the cost of emergency when this family is unable to cope.

**Ms KENNEDY:** Chair, ladies and gentlemen, I am not here as a parent. I am here as someone who started work here and was doing voluntary work in special education at the age of 14. I am now 36, so on my calculations that is 22 years. I have made this almost a lifetime commitment, because I believe these are the most vulnerable and disadvantaged group of people in our society. When I worked all those years as a special education teacher, people said to me, "You keep working in special education for us; you're special people." I never believed I was. I believe the parents were the special people, because I saw the strain that they had to deal with, I saw the fights that they undertook, and I saw the battles that they had to fight for their basic rights. Those battles are still continuing.

I fought battles with the education department. I still do casual work with the department in special education three days a fortnight. I still battle for funding, and I have been battling for years. I am now studying law. I am working for justice, and I will continue to have that as my goal. I believe that these people have had enough. I've had enough. All of us who care have had enough. It is time that our society did care, because all these people who are here today are fighting for basic human rights. They are fighting so that their children will have the opportunities that normal children and normal young people have. I will not stand by and see what has happened happen again. I fought with people in district office in the education department when they cut my funding, when they tried to stop my students cooking and horse riding and doing things that made a huge difference to their lives.

I will not stand by and see it happen again. It has happened so many times before! It makes me angry and upset and furious beyond belief that we are standing here today to fight for what other people have got. I cannot believe that any government and any politician can implement these changes and expect us to sit here and go, "That's bloody wonderful!" I think it's bloody dreadful! I think we have all had enough. We have all had bloody enough. I say give us a break, give the kids a break, give the parents a break, and make special education do what it was supposed to do. Make it be inclusive. That is what it was supposed to do. If it is not doing that, then it is failing.

**CHAIR:** Thank you, Helen. That is the last of our scheduled speakers. I have indicated that I would give Kevin Meade from Challenge an opportunity to say a few words. We now have just a few minutes left, and I would ask whether there is in the audience anyone who did not indicate they would wish to speak but now feel they really would like to say something. If not, there certainly will be an

opportunity for all of you to talk informally to members of the Committee after we have finished the process. I will now hand over to Kevin.

**Mr MEAD:** Madam Chair and Committee members. I have been in disability services for over 30 years. It has always been my goal to look for improvements. At the moment, we are looking at a system that is going backwards, and that is a very sad thing for me. I would also like to make the point that today we have been hearing from parents. I have been listening to the parents who have been talking to us since July last year, when the announcement was made. I would have to say that, in my career of over 30 years, I have not seen people experiencing so much stress by decision of government. It is very hard to believe that people who are the most vulnerable in our society and those with the higher support needs and their parents, those wonderful people who look after them, have had to go through this situation of basically not being consulted and told that their services will be reduced or the quality will be reduced by spreading a limited number of dollars further.

Instead of blaming services for not achieving employment goals, the realistic point of view is that there are more and more people coming into services and the Government has realised that there are not enough dollars to cover the services for all of those people. We hear the statement that more money has gone into the program, and maybe that is true, but there are far more people now entering the program and the program in the future so the methodology is to cut the amount of funding to each individual person. So while the Government might say that there has been an increase in overall program funding, the reality is that there are far more people coming into it the system—and the numbers have been done. There will be more people coming into the system over the next couple of years than the current Government budget can afford.

But to then blame services and systems and put the onus back on families, I believe, is a shameful thing. Coming back to the point about stress, I believe the department and the Government need to make an apology to the parents for their decisions without consultation and for generating stress beyond belief in families and people with disabilities, and also an apology to the service providers who over the past eight to 10 months have almost been fully engaged in answering the questions, putting forward the submissions, which has cost inordinate amounts of time and money, pushed us away from other tasks in our service provision that we wanted to achieve. I could give you examples of projects which were around fundraising which we have had to abandon because we did not have the time to complete them because we are doing this.

So the knock-on effects of the decision making are not singular; there are multiple effects happening because of this decision. I believe the Government should be honest and express that it is really a cost-cutting measure, that it is a decision principally from Treasury, to say, " This is all the money you will have", and that that acknowledgement takes place. But at the same time I believe, and I am hopeful, that through this inquiry that situation will be re-looked at, that the new Minister will look favourably upon the program and the people involved and review the assessment processes, the funding processes, to restore what is rightfully needed by the people in the program.

But not only that, to look realistically at what is needed because it is not just a matter of restoration; it is a matter of improvement, bringing it up to the five days that people need. There are a whole lot of other issues that I enumerated at the presentation we made to the Committee earlier today. We appreciate that and I will not repeat that now. Finally, it is very important that the Government acknowledge the stress and strain placed upon so many people by this decision. I believe that there needs to be an acknowledgement, if not an apology, for that situation.

**CHAIR:** On behalf of the Committee I thank everybody who has participated today. To all of you who are caring for a young person with a disability or indeed as a worker in the system, I express our admiration for what you do. We do not underestimate the challenges and tasks that you perform. I hope that we will have some positive outcomes from this inquiry but that is for some time ahead.

**(The Committee adjourned at 3.50 p.m.)**