## **REPORT OF PROCEEDINGS BEFORE**

# **GENERAL PURPOSE STANDING COMMITTEE No. 2**

## INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

## **PARENT FORUM**

At Wagga Wagga on Wednesday 18 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. C. M. Robertson 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. This Parent Forum is an important part of the Committee's inquiry: it is a chance to hear 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. I ask speakers to respect the privacy of others and to avoid naming third parties outside their immediate family. Although these forums are a parliamentary proceeding, it is important for speakers to avoid adverse mention of third parties. At 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 and ask questions on an informal basis. Our time for formal questioning will be very restricted, so we welcome the opportunity to chat with you later.

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. The Government does not have do accept the Committee's recommendations, 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 now. Each speaker will be given five minutes to discuss any issue he or she considers relevant to the inquiry. I will be ruthless with that five-minute limit, because a number of speakers have indicated they would like to make a contribution. The remainder of any written contribution that has not been presented can be incorporated. Unless a Committee member has a really burning question to ask on an issue, I ask them to hold back on questions. 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 the speaker a microphone.

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 media are present. If any speaker has a concern with providing a contribution in front of the media they should notify the secretariat. That speaker will go to the bottom of the list and at the end of the forum I will ask the media to leave and the speaker can make their contribution in the absence of the media.

I welcome the local member for Wagga Wagga, Daryl Maguire, to this forum. I am sure you all have had discussions with him on this issue. As I indicated earlier, each speaker will have the opportunity to give a five-minute uninterrupted presentation. I have received two letters, which I will read onto the record at the end of the presentation.

**BERNIE BENSON:** Thank you for the opportunity to be here and speak at today's meeting. I wish to speak on behalf of my wife, Judy, and myself. We have a beautiful daughter, Katie, who is 23 years of age. Katie loves people, music, dancing and being occupied and busy. I find it difficult to talk about this and at the same time fight for funding; we should not have to do that. Katie was born with Smith Magenis Syndrome [MSS], an intellectual and behavioural disability. It is where the body's seventeenth chromosome is missing and/or damaged. Katie wets the bed most nights and wakes at least once if not twice a night, when she wakes often it is to go the kitchen for a biscuit and drink. We have to address what she is doing at night, but we usually know. Sometimes she takes a little longer, so we have to get up. However, the noise she makes wakes us and if she takes too long we are up to see what the problem is.

She wakes at night, because part of her disability is the serotonin fluid in the eyes. Her situation is in reverse to ours: when we go to sleep at night the serotonin in our eyes changes. In her eyes it reverses. Where for us it allows us to be awake during the day and sleep at night, for Katie it is the reverse, so you can imagine Katie can get tired during the day and her behaviour very erratic at times. That is part of her disability with MSS. Katie attended Willans Hill Special School and moved to Kurrajong Waratah [KW] skills option at age 18. She attends skills option from 9.00 a.m. to 3.00 p.m. at the moment simply because KW is experiencing deficit funding for the community placement program.

Katie needs to be occupied all the time. It takes all our energy and resources from Friday afternoon to Monday morning to think of things to do, game to play, places to go, there is little time for rest over any weekend or holidays: it is constant go, go go. If KW ceased deficit funding, Katie's program would mean that she is at home an extra two days a week. That would be catastrophic for all of us, as it would be for all families here today and those around New South Wales with disabled children. Katie would not understand that she had to stay at home, after all she attended school from age five years between 9.00 a.m. and 3.00 p.m. each day and attended skills option from 9.900 a.m. to 3.00 p.m. for the last 5 years. How do we explain to her, or anyone with a disability, that she can no longer go to school to see her friends every day? It would be a regressive step for her, and her behaviour could become very aggressive. It would place more agitation on the family.

Most importantly Katie would suffer enormously as she would be isolated from her friends and the community, she would retreat into herself. That is something she would have done over the years, but through the excellent work at KW Katie has progressed. What they have done is excellent. The pressure on our family would be intense. My wife was diagnosed with breast cancer five years ago and has had three operations over the last five years. Judy is limited in her ability to help Katie. Other families have similar problems. This impacts on what we could do. Our young adults have limited opportunities in all areas of their lives, yet it appears that we have a Government wanting to even further reduce their opportunities to enjoy any small part of life, that you and I take for granted.

The wonderful improvements Katie has made over the past five years at skills options, could all be lost if Katie were to sit at home for two days a week and do nothing, because quite seriously that would be the outcome. As I said before, Katie would have no social contact with her friends, they would be as isolated as she would be. The need for respite will increase, pressure on families will increase and the family unit will disintegrate. The cost to the State and the community will be a lot greater than any savings from the current funding cuts.

The financial burden on our family would be very high. I am 60 years of age and would need to have my work hours reduced and subsequently would earn less money to support my family. I would be forced into this situation because I would need to be at home to assist my wife with Katie's needs. If I stayed at work and we were able to pay for respite care we would still be suffering financially, either way the family unit suffers. My family and other families also have to endure those costs. Along with the fact that we have a child with a disability, we do not complain. We understand that we will to look after our child for all of our lives until we are no longer capable of providing adequate care, and then this responsibility could fall to one of our two sons. Otherwise Katie will have to go to a home. That is our last resort.

The decision to cut funding is outrageous and one drawn from the Dark Ages. I just cannot comprehend how the Government can do this. How can anyone make a decision without proper due diligence involving our young adults, the parents, guardians and carers? I just cannot understand that,

it is an insult. It is an insult: after all, the decision is made around a date of birth. People born with a disability prior to a certain date will continue to be funded and keep all their hours and those born with the same disability or similar disabilities after a certain date will have their funding and hours cut.

CHAIR: Mr Benson, your time has expired. Are you about to wrap up?

**Mr BENSON:** Yes. As I speak, the same tone is evident: Apart from the families being impacted on, our young adults with a disability are the suffers on all fronts, it is simply unacceptable. I wonder what sort of people are governing this State when this type of funding arrangement gets passed without adequate and appropriate consultation. Unless you are a parent of a person with a disability you would have no knowledge of what people are grappling with in the community. Frankly, I am embarrassed to be a resident of New South Wales.

CHAIR: The remainder of your written submission can be incorporated. It states:

Our young adults have an inexhaustible capacity to give and give always with a loving smile, they ask for very little, they are defenceless, unless we speak up for them at today's meeting and defend the little they have. It should never have got to this, in this day and age.

I simply hope that our state government made a decision on very very bad advice and in hindsight realise that the decision needs to be reversed.

I implore you to recommend that the individualized funding be reinstated to the post school option level which was a realistic level of funding and allow our young adults to live their lives with respect and dignity in our society.

**ANNE NAPOLI:** Madam Chair, ladies and gentlemen. Thank you for allowing me the opportunity to speak today on the Post School Options Program. I am a mother of four children, my eldest, the son, has had brain damage since he was three months old as a result of the triple-antigen vaccine. It has been 29 years of constant care, attention and heartache and hard work. The Post School Options Program [PSO] has been an essential service to many young people with disabilities and their families for the past 10 years. The service assist persons with a disability to achieve their full potential, by enabling each and every person to reach the standard of quality of life and also become a valued member in our community. PSO also strives to allow each individual to become independent and also to support them to access services and information that may be available in our community and to encourage and assist them in the making of informed and individual choices. Without that funding for the PSO they would not have that.

I wish to register my objection to the Government's decision to reduce funding levels, restrict program entry and decreased the opportunities available for skill development. These funding cuts will dramatically affect the programs and the hours that our sons and daughters will receive. These cuts have had a bigger effects than we originally thought. Some of the services uses levels have gone from \$20,000 down to \$13,500. These drastic cuts will impact greatly not only on our children's lives but also on our families. The captain funding will mean that people in these programs will do little more than watch television. I, as a parent, and my son expect more than just to sit down and watch television all day. These young people should be given the dignity of being afforded opportunities to learn skills so that they can contribute and the part of the community.

I urge the Government and you the members of this Committee to look within your hearts and assess our submissions, our pleas and our concerns, and only then make a decision, not only with your head but also with your conscience. You have heard some of my concerns. Now let me tell you what PSO has meant to me and my son Patrick. It has given my son the opportunity to be involved in community activities like athletics. He has had the opportunity to express and develop his arts ability, not only doing enough work to have a solo exhibition but also in doing paintings and giving them on loan to community centres. So he is contributing to our society. Also, I must mention he has won many awards, not only with his arts but also within athletics. His achievements are too many for me to mention now.

But the reason he has been an achiever is due to the opportunity Post School Options has given him. Otherwise, he would be stuck at home, doing very little. So I cannot thank the New South Wales Government enough for its initiative and for side in establishing this wonderful program Post School Options about 10 years ago. Post School Options has given me the flexibility to be able to be involved in our community and to feel that even though I am a primary carer of my son I can still contribute some of my time to committees and charities, and in return I get satisfaction and respite, and this helps to make me feel good about myself. So, if funding is cut or abolished, it will have an enormous detrimental affect on everyone who is involved with Post School Options.

I would like to conclude by saying that the Australian Government and its people are very concerned and generous towards supporting those less fortunate. Millions of dollars are contributed each year for overseas and local aid. I hope the Australian Government will endeavour to make sure that enough funds will be made available each year to support people with disabilities and their carers. Let us look after our own people, and in return we will be capable of looking after others. Thank you for allowing me this opportunity to speak.

**LYNNE LYNCH:** My name is Lynne Lynch and I live in Leeton. I am the parent of a 19year-old daughter, who is in her first year at Post School Options. This last year has been a very traumatic year for me—not knowing what would happen with Post School Options last year with regards to cuts in funding, the rallies and the publicity generated by this uncertainty. As a parent whose child was firmly entrenched in a special school for 14 years, it was extremely difficult for me to have to accept that she was no longer a child and was now a young adult. However, she was accepted by Griffith Post School Options with open arms and has settled in extremely well—much to my relief. I cannot speak highly enough of the professional and caring staff at PSO Griffith. The biggest pleasure both my husband and I get every day is when Erin says to me, "I'm so happy, I go to Griffith today." The sense of relief that I get every day that my daughter is so happy is absolutely overwhelming.

As parents of disabled children, you fight for them from the moment they are born: you fight for them to survive their birth; you fight for them to be able to access adequate early intervention services; and you fight for their right to be able to attend mainstream schools. At least whilst your child is at school you know that they will be cared for and educated from 9.00 a.m. to approximately 3.30 p.m. from the age of 5 to at least 18 or 19. It is in this schooling period that mothers are able to get a life of their own. Some, like me, are able to go to work. However, now that Erin is at PSO suddenly her hours are cut to 18 hours per week. What are working parents supposed to do with the extra hours that your child is at home—give up work, pay a carer to come to your home, or like me let her 90-year-old grandmother become her carer whilst I am work?

Both my husband and I have no other family at all in Leeton. I have had to continue working as I have just finished educating my son through university. I also need to continue working at this point of time as I am only three years from being able to retire and I need to continue contributing to my superannuation so that I will retire with sufficient money to hopefully support myself and not be a further burden on an already overloaded welfare system. Besides, I feel the skills I have are a very valuable contribution to my workplace. What other options do I have? Respite is not an option because there is no respite at all to access in Leeton and my closest respite is here in Wagga Wagga, through Northcott. For the Committee, that is at Leeton, and Leeton is 130 kilometres from Wagga Wagga. I am only able to access some respite at Northcott in holiday periods, but I always wonder when this will cease.

The other fact that I find most distressing is the drastic cut in funding for ATLAS funded adults. Some of their funding has been slashed from \$20,000 to \$13,000. Take out an administration charge and providers are left with approximately \$9,000 to run suitable programs for these adults. It should be remembered that a vast majority of Community Participation clients are completely wheelchair bound, unable to wheel themselves, feed themselves or even toilet themselves. Take out the wages for staff members to do this for the clients and you are left with basically nothing to implement any worthwhile programs. What are PSOs supposed to do—sit the clients in their wheel chairs and turn on the television? Is this what parents want for their children? I do not think so.

In my daughter's case, she is receiving \$15,700 as a Transition to Work client, but because we live in Leeton and she attends PSO in Griffith we have to pay for her travel out of her funding or try to supplement it the best way we can. Leeton to Griffith is approximately 55 kilometres. Travel at the moment is costing between \$500 and \$600 per month, which is a massive amount to pay. This amount of money is supplemented by her mobility allowance of \$69.70 a fortnight. At the moment we are trying to source some financial support through our local community.

As I stated in my submission to the Committee, my daughter is my third child and I think she should be given every opportunity to succeed at her level in the community. My other children have successful careers, one having completed a trade apprenticeship and the other completing university to enter the teaching profession. Why should not my daughter have the same additional learning period after her schooling as her brothers did? How can you expect an intellectually disabled young adult to be "work ready" in two years, when a trades person or a student studying to be a teacher each has four years of training before they are work ready? Some Transition to Work clients may be work ready at the end of their two-year period, but I imagine the vast majority of young adults will need much more time to be work ready.

Funding for post school programs should be adequate to enable young adults with a disability to be given every option to see if sustainable further education and vocational training and employment outcomes are likely to be achieved. Any reduction in the current funding will mean that all opportunities will not be explored to realise the full potential of these young adults. Disabled people have every right to be able to access funding to give them the best quality of life that they and their parents can expect. We did not ask for our children to be born with disabilities, but as parents we willingly took them home from hospital and have given them the best that we are able to do. However, I am emotionally exhausted and disheartened at the constant fight and battle to get funding for our children. I never envisaged that I would be standing in front of parliamentarians and speaking to you today as I am. If nothing else, being the parent of a disabled child makes you very vocal. [*Remainder of speech incorporated*.]

You raise your children to adulthood and then they get a job, move out, support themselves and have their own lives. This is not the scene playing out in our lives. We love Erin more than anything, but she will never be able to do any of these things and she will live with us all of our lives. This is the case for the majority of families. We all need your help to support us in meeting this challenge.

I appreciate that the Committee acknowledges the work we as parents do for our disabled children. However, I wonder how many parliamentarians and decision-makers are actually the parents of a disabled person. I can assure you that if they were this inquiry would not be held—in fact, I am sure that additional funding would be immediately found. You need to walk a day in our shoes. Better still, live a month in our shoes. You would then soon find out what a lifetime is like for families with disabled people. I thank you for this opportunity to speak to you and sincerely hope that you will see that Post School Options plays a vital part both for clients and families and that an urgent increase in funding and hours is the only way to go.

**CHAIR:** Our next speaker is Chris Lennon, who is the Principal of Willans Hill public school. I understand Chris will read a letter on behalf of a parent and family.

**CHRIS LENNON:** All parents, I think. My speech today is in two parts. In the first I would like to speak as a special educator with over 25 years of experience and in my current position as Principal of Willans Hill special school. Secondly, I would like to talk to you as a parent. In both instances I want to advocate on behalf of young adults with disabilities and their families who are in no way getting a fair deal! As educators we endeavour to develop students with disabilities with the same, if not more, passion and commitment than their non-disabled peers. Education for our students is expensive with additional personnel, specialised equipment, modifications to the curriculum, individualised programs, parents as partners in learning, community involvement, quality teaching, et cetera. My question is: What on earth are we educating these young people for? I am really and tragically said about this. We work really hard, and to let our kids go at graduation is not something for us to celebrate. We are really concerned about the next step for them.

Unfortunately it seems that when school ends so do our students' learning opportunities. We have wonderful service providers doing the best they can with little funding. Two days per week will not provide programs and support for families with any hope of achieving the outcomes that are vital toward achieving independent living and a full and meaningful life as a member of the community. The Department of Education and Training admirably talks about "lifetime learning". That is incredibly important in our changing world. But please read the fine print. It must also say "unless you have a disability; and the greater your disability, the less chance of any access to post school programs." Are we using all this manpower and government funding to educate our students to stay home with their parents? I believe that as Australians we want more for these young people with disabilities.

Secondly, I would like to look at this area in terms of my parents. We have come an awful long way since the days some 30 or 40 years ago when parents were encouraged to leave their

disabled children at the hospital after their birth, when institutionalisation was the norm. This generation have taken their children home just like my husband and I took our two children home. The only difference is that my children do not have a disability. Together my husband and I raised our kids. Although we did not have family support, we could get a babysitter occasionally and after school care enabled both of us to pursue careers that we cared about.

For parents with children with disabilities the story can be vastly different. In this regional part of New South Wales these families have worked very hard. Marriages are often strained, or fail. Siblings have their own unique problems. Medical issues can cause endless trips to specialists in a variety of locations. Children's unusual behaviours and needs cause social isolation. Our families live in a community still struggling to accept children and adults with intellectual or mental health issues. They have done this with very little respite, and with very little assistance. They are doing an excellent job! I see that day to day.

During the school years these families are assured of at least that precious time between 9.00 a.m. and 3.00 p.m., school hours, school days when many organise their lives, attend to their other responsibilities, prepare for the evening, and many use this time to enter the work force. In four years my children will complete their schooling. They will get a job, and continue their training at TAFE or at university. Even if they are at home, they will be independent. They will have a driver's licence, they will have interests and they will have a life in their community. For parents with students with a moderate or severe disability this is a world away from their reality.

Currently, and often, I am hearing of families that struggle with the notion of supporting their young adults for five days a week for the rest of their lives! No babysitters for these young adults. No alternate placements. Many of my parents are looking at giving up work to look after these young people. In a country where we have a Federal budget in surplus, with a budget under which some parents are being encouraged back into the work force when their children reach school age, it seems amazing that our parents have to consider leaving the work force and continue their role as carer, really, until they die. This is the reality. These families are struggling, particularly the rural families in this extreme drought. They need our support. Our young people need access to continued training and education. To ignore their plight is criminal. Thank you.

CHAIR: Ms Lennon, are you also reading a letter on behalf of a parent?

Ms LENNON: That was my letter on behalf of the parents.

**DEB HOCKING:** My daughter Michelle has cerebral palsy and is with Kurrajong Waratah under the ATLAS program. The 30 hours a week that Michelle receives now is allowing her to maintain and further develop written and verbal skills, social interaction with her peers. The cuts in funding will result in less hours, reduce her progress in developing these important life skills, thus meaning she will have to stay at home. This means that she will end up vegetating and losing all her enthusiasm in being a member of the community. I am a single parent and have no family that could help and support myself and Michelle. I would love Michelle to be able to get out and have the life of an average 24-year-old, to be able to have employment, have a social life and be able to have a family of her own but I know that this will never happen.

**CHARLIE SHEAHAN:** I put my family situation to this Committee as a way of representing many other families in a similar situation that live in isolated areas or isolated communities. We live on a farm at Coolac some 100 kilometres from Wagga Wagga. We have a son who will be 18 in October who has a moderate to severe intellectual disability from birth. After his birth we accessed the early intervention services at Wagga Wagga which helped to put home-based programs together with a regional professional base closer to where we live. Our son's first three years at school were at the local primary school with the support of an aide and an aide to travel on the bus with him.

From the age of eight until now our son has attended school Willans Hill, Wagga Wagga. He is able to do so through the accommodation services provided by Kurrajong Waratah, the children's accommodation service for children with disabilities attending school in Wagga Wagga. Our son travels to Wagga Wagga by bus on Monday mornings. He is accommodated in the group home from Monday night until Friday when he returns home by bus. This has been an invaluable resource for

both our son and us. He has been able to access the best possible learning environment as well as being part of a community which he has a strong bond with. It has also provided the family with respite that is invaluable and has allowed us to work and provide some time for our other children.

At the end of this year our son finishes school. For the past two years we have anticipated this event and have been looking for a post school program that our son could access and find suitable to his ability and meet some of his needs. We have had several interviews with service providers at Cootamundra, Tumut and Work Solutions, Wagga Wagga. One positive thing we have witnessed is that there are some outstanding organisations providing excellent services with the support of their communities. But regardless of what post school programs are available for our son, it will be extremely difficult to access them. The major problem we have is isolation. To access these programs requires extensive travel as there is no public transport.

The appropriate solution to this situation is accommodation in association with the proposed school program. Some service providers have accommodation. We have been told that this is limited to the point that there are long waiting lists and positions only become available through the death of a client. This highlights an acute shortage of funds available to service providers to meet the needs of the regional community. It appears that after school our son will return home. This has happened with other families in similar situations. Is this the scenario—the young adult lives at home, isolated from his peers with little or no education, social or entertainment programs or options available to them? The pressure on the family is enormous as they try to cope with work and providing for their family's needs as well as supervising and stimulating a young adult with a disability.

We do not fully understand the impact that this change will have on our son. His only desire over school holidays is to return to school. Any post school program should, where possible, be an extension and transition from the school environment. People with disabilities need the security of a routine and major disruption to their daily routine can be detrimental to their wellbeing emotionally and physically. We feel we have been extremely fortunate that our son has been able to attend for 10 years and one of the best educational facilities in this country for children with disabilities. We have had wonderful support with housing provided by Kurrajong Waratah services over the past 10 years. I will just read two paragraphs from a letter of reply we received from a service provider:

From feedback that I have received from some people who attended the Wagga carers' planning forum, I understand that families were essentially advised by DADAHC that a family member had to be deemed homeless or in danger of being homeless to receive government interim accommodation assistance. In this tight government funding environment where demand for adult accommodation services far outweighs the supply of accommodation places, there are no vacancies, nor to our knowledge from DADAHC sources anywhere else in the entire western DADAHC region. This situation is likely to remain for the foreseeable future if the information provided to the families at the department's planning forum that there is to be no new funding is correct.

The outlook now is less than clear. It is clouded with uncertainty and a great deal of concern as our family comes to terms with the possibility or lack for our son's future. We have to ask: does the Government have any sort of vision for the future in disability services? Does it have a plan and well set up infrastructure to implement it? How will it cope with the aging disabled when their elderly parents and carers pass away? Are they aware of the present embarrassing obvious shortfalls in funding within the disability sector? How can governments announce funding cuts to disability services while Treasurers preside surplus budgets?

**CHAIR:** Is that a letter from DADAHC that you were quoting?

Mr SHEAHAN: That was from a service provider. I quoted two paragraphs.

CHAIR: Can you make a copy of that letter available to the Committee?

Mr SHEAHAN: Yes.

**CHAIR:** That would be useful information as background to our report.

**KATHRYN JENSEN:** My name is Kathryn Jensen and I am a parent. My daughter Rochella is 27 years of age. She is currently receiving Post School Options funding and is with Kurrajong Waratah in the schools options. Today we have heard a lot of points covered, particularly reduction in funding. But I would like to speak on a different point with regard to points one and two of the terms of reference for the inquiry. I would like to comment on block funding. It is my understanding that a grant is not owned by an individual and they do not have portability. This concerns me. There are occupations that require transfers to other areas such as the armed forces, police, teachers, itinerant workers, retirees. Unfortunately not all promotions and transfers occur at the beginning of the year and also not with plenty of notice.

As parents we need to know that if we are transferred to another town and our child has been granted a placement in funding, that they will be entitled to an ongoing program in that new location and not have to wait until the next round of funding is given. Adequate funding, not reduced funding, that is flexible and portable will allow a program to meet the needs of the individual. In the policy framework, the transition to work policy—I think it is on page 8—states that people with disabilities have a right to exercise choice and have a commitment to ensuring this principle is maintained in all aspects of an individual's service.

With regard to those, I would question the appropriateness of funding arrangements for the new programs, to change from a program that allowed an individual's movement between services both within their community and on rare occasion to new geographical areas. What is offered now, to the best of my understanding, is definitely a backward step. I would like this inquiry to consider that, along with all the other points that have been issued in the reduction of funding which will cause a reduction in hours and all that has been highlighted today with the necessity to stay with individual funding and not block funding.

**JENNY HARWOOD:** My name is Jenny Harwood and I am a parent. My son Scott is 20 years old and he is presently in his second year of the Transition to Work program. The first concerns I had were centred on the assessment process that we went through when he was leaving school. I found the forms very frustrating because you have to assess your child's abilities on a scale of zero to two of whether he could do something at all, whether he could do it with assistance or whether he could do it completely by himself. He was assessed as being Transition to Work but this is a child who has massive health problems, who is in a wheelchair, and who has behaviour problems. Basically he is quite functional but he has to be supervised 24 hours a day on a one-to-one basis for him to be able to do anything. He is longing to transition to work and he does work experience and he is doing some training for work but it is not working out because of the one-to-one supervision and his bad behaviour.

I did not feel that I had the scope to tell them what he was really like. I did not get to say that he was degenerative or all the problems that he actually had. We have ended up in this Transition to Work. At the end of this time I still do not know whether he will transfer to Community Participation. I do not know whether he will be able to stay with the service provider that he has at the moment. At the moment we have about 16 hours a week, which is spread part time over four days. I do not know what that will be reduced to. I am doing casual work which is very valuable to supporting my family because my husband only works part time as well. I have two other children that I need to keep supporting. It is the frustrations of the whole process, that is what I want to get across to you.

**LYALL METCALF:** We, Lyall and Jeanette, are here on behalf of Erin, to express our views concerning the reforms to programs for young adults with disabilities. Once again, we have to publicly expose our personal situation in the hope that decisions made in relation to ATLAS funding will be changed for better outcomes. Erin is our 23-year-old daughter who has multiple disabilities that will prevent her from ever moving into the work force. She will always need a high level of support to participate in life. We are providing a loving and secure home environment, but for Erin to reach her full potential she requires a program for five days a week. She needs a meaningful program that will encourage personal development, involvement in the community and social interaction with her peers.

Surely this is a reasonable expectation and one that our community would want implemented for our special and vulnerable young adults with disabilities. However, what the Government has really indicated in the ATLAS reforms is that people with disabilities—particularly those who have high support needs—are a cost to the Government and society, too big a cost. Therefore, adjustments, savings, changes, whatever they are called, must be made and will be done under the dubious jargon of "reform". We feel it has been a discriminatory process. New programs and reform are supposed to provide long-term support and greater flexibility in program delivery.

What this really means for Erin is that in reality she has a dramatic one-third reduction in the hours of support. This means that Erin's funding allows participation in a program for two days a week during school terms. Previously she had 19 hours, three days a week during school terms. Now it is 14 hours a week for two days a week. The rest of the time Erin is home with us. Although we live in town, if I am out at work, on our farm out of town, Erin is in full-time care of my wife. If she wants to go shopping she does it in the 14 hours she is given. While the Government makes a saving, Erin becomes more isolated and dependent on her family. With all the surveys, forums, reviews and interviews undertaken in the past two years one would think that the agencies and committees would now be fully aware of the huge sacrifices and contributions that parents of adults with disabilities have already made.

We feel that the Government, representing society, has an obligation to assist us with our long-term commitments, not degrade the worth of our children and thereby increasing our hardships. We know very well that services for our most vulnerable members of society cost a lot of money. However, it should be noted that these services also create a work force and a very good source of income for a lot of able-bodied bureaucrats in the public service. In a society that prides itself on justice, how can a reform that decreases the level of support for a basic requirement such as having access to a meaningful day program five days a week be justified?

Our young adults are first of all valued members of our families. They also need friends, opportunities to grow, interaction with peers and community, a purpose to their day and a life independent of their parents—the same needs as every other individual. This cannot be achieved by staying at home, isolated and predominately in the company of an ageing parent. We do not encourage a home-based lifestyle for our so-called normal adult children, and we do not want to accept that type of imprisonment for Erin. Obviously, our point of view is influenced by our desire to ensure that Erin is recognised as an individual, an adult in her own right, and that she is given a fair go.

We want the Carr Government to give much greater support in providing disability services so that families are acknowledged and can continue their caring roles, giving their young adults happiness, respect and most of all dignity.

The Hon. JOHN RYAN: What services do you access?

Mr METCALF: Erin goes to Community Access Support Services.

**KERRY BAUMER:** I am the parent of a 17-year-old boy. This is all new to do us, as our son still has 18 months of schooling. My husband and I are thinking about what will happen when he leaves school. He has Down syndrome, but is very active and understands a lot. At the moment he is doing work experience at a local supermarket. On a Wednesday he gets up and knows he is going to work, as he calls it. It is fantastic to see him happy, he was to be out in the community. He is always talking about going to work at McDonald's, which will not happen. He likes to think it will happen. In the holidays he gets hours of bed very late, I suppose that is typical of a normal teenager.

He does not want to do anything in the holidays, he just lazes around. At the moment when he gets up every morning I do not have to force him to go to school, he loves school. He gets dressed and is ready to go. He loves all the activities available at Willans Hill Public School for him. We would hate to see that disappear when he turns 19 and finishes school. What is he going to do? That is what we are worried about.

**CHAIR:** One parent wants to make a presentation in the absence of the media. I ask that the media withdraw.

**PARENT S:** I am a bit like Kerry Baumer: We have all this in front of us, as opposed to being experienced. I have three sons, and we have brought up our sons to be contributing members of the community, to have jobs, their own home and to go forward in life as we all would want our children to do. One of our sons has a disability. We have helped him access mainstream school from preschool right through to year 8. He likes to get up every morning and gets himself organised for school. He is already looking forward to what he is going to do. He wants a job, the same as his brothers.

I would like to think that when we get to the point of needing services to support him to get a job and contribute to the community, possibly even pay taxes in his community, that those services will be available in a flexible form that can meet his needs and contribute to him. I would like to think that our State services are sufficiently flexible and co-ordinated to support him. I would hope that the Commonwealth services could be matched with State services so that we have something that works for him in the same way as things work for our other sons, who also had ambitions.

When I heard about the changes to the Post School Options Program, the reform process, I despaired. I felt totally despairing that in this day and age when we have been working towards having people with disabilities included in mainstream society and have been working hard at it, that the little bit of support that is asked for to get it to happen properly, so that those kids can have the same sorts of things that other kids take for granted, will not happen. If they want to go somewhere, to do something, to contribute something for five days a week and get some income or support or even pay taxes, that should happen without people having to carry on about it. Families seem to have to talk about it and have consultations to get the services they need. I hope that today we can resolve something very quickly so that it does not go on causing pain and anguish to people.

CHAIR: All today's contributions will go on the Committee's web site. Do you want your name deleted?

### PARENT S: Yes.

**CHAIR:** The Committee has received two letters, which I will have incorporated in the transcript. The first is from Robyn Mulloy. It states:

To whom it may concern.

I am writing to voice my concerns related to the changes to Post school options: for young people with disabilities.

When these changes were made it was conducted in a way that people needed a degree just to understand the changes of the system and how they were being carried out. We were consulted by mail although the facts were not explanatory enough as well as we were not told why the changes were being made and how it would benefit the many disabled people when they left school. A majority of the careers of these disabled people are in some form or another disabled themselves whether it be intellectual, physical or both, this made it impossible for these careers to understand how this was conducted.

The two categories that these people were placed in, *community participation or transition to work* placed a fine line between one or the other—whereas a large number of these people are in between these two categories, where were they supposed to be put, which category suited them better so which amount of funding were they to receive.

The funding that was awarded to *Community participation* was inadequate for the program to be carried out by the careers on a daily basis to meet the needs of these disabled people. If they had sufficient funds they would be able to do more activities and the necessary daily skills on these people's level.

Upon registering my daughter into a the local TAFE we found there to be a lack of communication between my daughter's higher school and post school as well as this we found there to be a insufficient amount of choices in what she could do at TAFE. There was only one course that was suited to somebody with my daughter's needs and even that one course wasn't suitable to completely meet her needs and wants. The things that she was interested in acquiring more information in were not available to somebody with a disability. I feel if there were funding given to TAFE and universities we would have a boarder range of courses that these people were interested in to meet their needs.

Half way through year twelve we were asked to be at the children's school for a meeting that lasted approximately forty-five minutes where we were asked questions with yes, no or sometimes answers by a person who was not familiar with these young people personally or there disabilities. Our answers were recorded on a three or four page form and then the answers were added up to decide which category the fitted in and where about. I oppose that the rest of the peoples lives can be based on one form and a person that didn't even know these young people. I feel that a broader assessment over a period of time would have been more appropriate to decide where these people should be most suited to meet their needs.

The complaints and appeals process I feel is inadequate as it needs to be explained in greater detail to the people involved. We were not told much about this area and so my complaints have going to local people and carers as I did not know who to talk to.

If you further require my assistance in any way please contact me on the above details and I will help in any way possible.

Yours sincerely

#### Robyn Mulloy.

#### The second letter is from Robyn Deacon. It states:

To whom it may concern,

Our daughter Rebecca is currently receiving funding through the ATLAS program. Her funding has been cut so that she has lost 3.5 hours per week. This loss of hours at her support service means that she has lost the opportunity to attend Riding For the Disabled, an activity that Rebecca thoroughly enjoyed.

Rebecca was born with Mowat Wilson syndrome, a genetic disability which has affected all areas of her development. She is developmentally delayed physically, mentally and is like a small child in a bigger girl's body. Rebecca needs help in all areas of her care.

She is unable to dress herself, feed herself, toilet, shower, or any other personal care. She is totally dependent on her family for her care. She does not have a social life except for that which her family provides. Other than going to the Community Access Support Service, Rebecca spends all her time with her family. Her funding with ATLAS provides 19 hours per week. Rebecca spends 6 hours at CASS on Tuesdays, 7 hours Wednesdays and 6 hours on Thursdays. We have a long weekend every week.

Rebecca is unable to read, draw, or amuse herself in other ways. She spends a lot of time watching videos of preschool shows unless we go shopping or other adult activities. I am finding her becoming more dependent on me as her time with others is being cut. She can be very difficult to handle if she does not want to do something. She has a very low "patience" level and would prefer to watch her videos at home than do some of the things I have to do when I have her. It is so important to Rebecca that she be part of the community. Her activities at CASS allow this. She is in a supported group with her friends and she loves going it is so hard when Monday comes around and Rebecca is still stuck with her mother and not her friends at CASS.

We are also very concerned that the funding for Rebecca is tied to one service provider and not to her personally. We are tied to the one service for the year and are unable to access another service unless there is a vacancy. We are tied to the service in Wagga Wagga and if Rebecca's dad is transferred in his work we would be concerned that services for Rebecca may be unavailable if we were to move. I personally find the restriction on Rebecca's funding very unsympathetic. Why would a government body want to intrude in such a personal part of a family's life? We are trying to do our best regarding our daughter's care, and to be restricted in our choices for our future is very scary. A government that can intrude in such a way can only hurt the people they are supposed to be helping.

Rebecca's time at CASS is spent doing activities that she enjoys. She is encouraged to be independent and is continually having her skills reinforced. She spends her time with other young people; in fact these people are her very own friends. They are an important part of her life and this needs to be encouraged, not cut back! Rebecca deserves to have a life of her own that doesn't revolve around her family. She is 20 years old and needs to be around people her own age. They accept Rebecca how she is and her family appreciates this very much.

Rebecca's 19 hours at CASS is the only time she is away from her family. We have no close relatives in Wagga Wagga and regard Beccy's carers at CASS as her extra family. Since November Rebecca has been in respite for 2 weekends. We spend little time apart and appreciate the 19 hours Rebecca is out and about with her group.

I often feel that we should be grateful for every crumb thrown to us to support our disabled child. It is belittling and upsetting that we are forced to defend our children all the time. They deserve services to improve their quality of life and we deserve services that support us in our carer's role. To have a disabled child is to live in another world and this is reinforced by uncaring governments. Every decision is based on the effect it will have on our daughter, not necessarily on what we want or need. As a family we need the help of a caring government not decisions made with no thought of repercussions.

I'm sure the government hoped we would just go away and accept the changes that were made affecting our children, but we can't. It is too important to just turn away. Our children are being affected and it is up to us to be their voice. I hope it is not in vain.

I do not know whether Robyn and Robyn are present, but I would like to say thank you. First of all, I would ask whether there is anybody who has not put their name on the list but now feels they would like to give us a message.

**CHERYL FRANCIS:** My name is Cheryl Francis, and I have a daughter who is 30 years old and has Down's syndrome. With the Government making funding cuts, perhaps we could lend our children to them for 12 months and let the children live with them and see how things would go on a day-to-day basis with funding for leisure activities and other things.

**CHAIR:** I would also ask whether there any service providers present who would like to make a contribution. Then I will ask whether Committee members have questions for you.

**LEANNE FITZGERALD:** My name is Leanne Fitzgerald. I have a daughter who is 16 years old and still attending Rosehill school. It is a bit overwhelming trying to find out what is

happening with the government cuts and what is going to be there for her when she leaves school. I know that we all have the same problems, but not knowing what will be there is pretty scary. Both my husband and I work. Everybody has mortgages and bills to pay, and not know what is going to be there afterwards is very daunting.

I came to Wagga Wagga when Nicole was four. I moved from Newcastle to here because when I did a search of New South Wales for the best school it was in Wagga Wagga. I was not prepared to put my daughter on a bus at the age of four and have her travel for three-quarters of an hour each morning and each afternoon, so I packed up and moved here. That is my whole purpose in being here: to have her in this school. Even though my husband could not be here, and we did not have our name on the list, he would like you to know that he feels exactly the same as I do. It is just overwhelming not to know what is going to happen. Nicole has still got probably 16 to 18 months left at school.

**KATE JOHNSTON:** My name is Kate Johnston. I am Service Manager for Kalparrin Inc. in Albury. We are a Post School Options, formerly ATLAS, and now Community Participation provider. I feel so strongly about the sentiments that have been expressed here today. They certainly reflect the feelings of the families of clients that we service. I share their frustrations, and think that as a community we can do better. As a service provider, we certainly could provide a lot more services for people who require them, but the funding is so limited.

People in our society who do not have kids with a disability really do not understand and the problems get swept under the carpet. We are all here today to provide feedback, and I hope that it has a positive effect on the levels of funding, because these parents do a marvellous job but they cannot continue to do it forever. No-one is going to dig services such as ours out of a hole if we go into debt because we have been extra generous to support people in need.

I would also like to share some frustrations that we have had with the Department of Ageing, Disability and Home Care. The consultation that we as a service provider have had has been limited, to say the least. Even last week we had a meeting of service providers in our region with representatives of DADHC to enable them to answer questions about the fundamentals of the program that we are currently implementing. As a service provider, I do not think we can continue to provide a quality service for our consumers and our families without adequate funding. Certainly, they talked about vacancy rates and strategies. I agree with the fact that if you block fund people will be able to move around the State with their families if they are transferred. But there is just no information out there that would allow us to reassure them.

**CHAIR:** Kate, you said that the consultation with DADHC was limited. Could you take the Committee through what has been the consultation process?

**Ms JOHNSTON:** There were a few aspects to it. They announced that there were going to be changes, but without consultation the changes were announced. It was not even that it was on the books. But we knew that something was going to happen because ATLAS was meant to be only a two-year time limited program, which could be extended for, I think, two or three additional years without having another program to run in its place. When they did announce it, like I said, it was without consultation. The funding announcements came out, and the new program names and agendas and those sorts of things were put into place.

We were told that it would be block funded. We still have not even been paid since April. We have service providers who have been providing programs but do not actually have the funds to provide the services at this point of time. It seems to me that DADHC is on the back foot; they are rolling it out but they do not even have the information in order to support the rollout. This separates everyone, including the parents.

CHAIR: Do you know when you are to be paid?

**Ms JOHNSTON:** We have not yet received a variation of funding agreement. They say it is in the mail. As soon as we do have that, we can sign it and get it back. I just think the level of consultation and communication from the department to the service provider has been appalling, and

that has affected families as well. Much of the information that we are provided by DADHC has to be forwarded on to our consumers, and I think that also is appalling.

**The Hon. Dr ARTHUR CHESTERFIELD-EVANS:** The first question I would like to ask is: Are DADHC payments often in arrears?

**Ms JOHNSTON:** They have been known to be, yes. I have been in the service now for going on four years. They are usually on time, or maybe just a few days late. They get quarterly funding payments. The bulk of those funding payments are usually made on time, but if you take a service user from somewhere else, or have a transfer or something like that, they can be in arrears for up to six months—or maybe 12 months, I am being prompted.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you talking about three-monthly in advance, or three-monthly in arrears?

**Ms JOHNSTON:** We are usually paid April through to June, so it is paid in advance. But we have not received that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: In this case the April payment is behind now, and we are halfway through March?

Ms JOHNSTON: That's correct.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: The other question is: Are you as a provider scared of individual funding? Would you rather block funding, to give you security, or are you happy to be in a market where you think you will get people coming to avail themselves of your services?

**Ms JOHNSTON:** I really would much prefer individualised funding packages, because this gives people choice. I know some other service providers might find block funding easier to arrange. Certainly, from Kalparrin's perspective, we want the opportunity to be able to make the choice and make that portability available to the clients.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So you are not scared of them all shooting through to the opposition?

Ms JOHNSTON: No.

**CAROLYN ECKERSALL:** My name is Carolyn Eckersall, Post School Options, Kurrajong Waratah. The beauty of individualised funding is that people can have a choice. At the moment the Leisure Company has Post School Options, and it is much more preferable that the service user that comes to your service is happy with your service, and if your service is not meeting their needs that there are other services available to them and they can go and check out that service. That works so much better for our clients. As far as pressure goes, I would much rather have a bit of financial pressure or whatever than have a client in your service that is not happy with your service.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Is that the position of Kurrajong Waratah, or is that your personal opinion?

Ms ECKERSALL: That is my personal opinion.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: So you would not support the opinion of ACROD, which is that the providers would prefer block funding? You do not agree with that position?

Ms ECKERSALL: Personally, in my experience, I feel individualised funding works better for the service user.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: But you have not been asked to speak on that issue on behalf of your service provider?

#### Ms ECKERSALL: No.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: You are not saying that your organisation does not support that position; you are just saying that you are not authorised to speak on that position from the point of view of your organisation.

Ms ECKERSALL: I do not really know. That is just my personal opinion.

**LIBBY CLAHESSY:** My name is Libby Clahessy, and I am the Service Manager of the Leisure Company. As far as individual funding goes, when these programs were first initiated that was one of the conditions. The guideline was that the funding was an individualised package aimed at meeting the service user's needs. So, as service providers, we need to respect that that is what the money was there for.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Are you speaking on behalf of the Leisure Company on this point? What is the Leisure Company's position on block funding?

**Ms ECKERSALL:** We are there to meet the needs of the service users, so block funding from a service perspective is good but that is not what we are about. We are about meeting the needs of the clients who access our service. My personal opinion—and perhaps there is a board member present today—is probably the same.

**ANN BAKER:** My name is Ann Baker and I am from Community Access Support Service or CASS. I have worked in disabilities now for a total of four months but that does not preclude quite a bit of time in other community services areas. One of the big things in any human service is about cultural appropriateness and choice. When we are looking at block funding, that reduces any service's ability to provide cultural appropriateness and choice for the consumers of that service. Disability services should be perceived as nothing different from any other human service.

The Hon. HENRY TSANG: In country and remote areas where a lot of your clients have to travel a long way, if there was an opportunity for block funding to be closer to where there is demand and it can only happen with block funding, would you see that as a good reason that block funding could help to take the services to your clients rather than your clients travelling a long way to your service? If you were given a guarantee of block funding from the Government to provide your services where they are required, particularly in regional or remote areas, would that encourage you to set it up rather than have the client travelling a long distance to your service?

**Ms BAKER:** I personally would still put the choice of the client first and foremost, and individual funding provides that. One essence of Community Participation is that if a client and a staffer or carer are not well matched it will not work. There needs to be care support happening as opposed to high-level carer support. For it to be truly effective they need to enjoy doing the same things together or it becomes a chore. Block funding has the possibility of reducing that availability by providing the peer support that in essence ensures the success of that person's access to the service.

**CHAIR:** I wonder whether any parents, particularly those whose son or daughter has been placed in Transition to Work and who believe they should be in Community Participation or have had hours cut back, are aware of an appeal process and, if so, what it is.

**CHERYL ROBERTS:** I am not a parent. I work with that Department of Education and Training. It is my role to facilitate this program and promote it to the parents. One of the things that through this meeting I decided I would like to say is that it is a very difficult job to sell this program to people when we are not given a lot of information. We are not given a lot of information early enough and when we are given information it is in small amounts. One of the letters that you read, I am the person who did that job and I know that that is an issue and I cannot know individually all those people but I am bound by the process that is given to me. I also know that if I am not present at those meetings where the children are screened then a lot of the finer points of those very basic forms are not understood.

To the department's credit, we have had quite a lot of in-depth training to understand the forms and where the forms come from. At this point I am quite sold on the forms even though on face value they do not present well from a parent's point of view. I understand that there has been a lot of research and a lot of university involvement in the designing of them and I think that they actually in most cases accurately capture the appropriate level of funding, which brings me to the appeal question. The appeals process is very limited. As I said, I am the person in the department who gets told I am the go-between. In my experience the appeals process has been that I have registered something with DADAHC and never heard anything and being told that it will be looked at, never had any involvement with it. It is a very limited appeals process. Some years we have been told there is no appeals process and then I have found out later on that there was but the person who told me that was not the person who should know. It is not a very well organised system at all.

The Hon. TONY CATANZARITI: Why do you think the consultation has not been activated as it should be?

**Ms ROBERTS:** Dare I say it is bureaucracy. I have been involved with this process for many, many years and I has been to forums where my peers in the specialised role have sat with DADAHC personnel and we have expressed all these concerns on behalf of our parents. They are our kids too. We are like parents to them as part of the school system and we hate to see them leave to this uncertainty that they leave to. We are also advocates for the service providers because we work as closely as we can with them as well. So we are the go-between but we are not given much to go on basically.

**The Hon. TONY CATANZARITI:** The reason I ask that question is that yesterday and today one of the things that has mostly come up is the lack of consultation. Whether it was at Tamworth, Armadale or Wagga Wagga, the lack of consultation has arisen consistently.

**Ms ROBERTS:** As far as the Department of Education and Training is concerned, we have had lots of consultation but none of it has been acted on. What has been acted on now is nothing like what we have ever said. We have spoken with them at length at conferences. I get paid to spend two or three days in Sydney and spend time with DADAHC personnel and talk about these issues, and this is definitely not the outcome that we asked for. So DADAHC is not listening to us. We know our clients. We had consultation with DADAHC regarding the reform to the assessment process. It did listen to us. We wanted, as a support teacher transition to the Department of Education and Training, to be representatives at those meetings because, as I said, we knew that it was a valuable role to be the go-between because parents would look at the forms and go, "tick and flick" and that is not the way they were designed.

That is the one thing they have got fairly right but even with the form, as various people have said today, there is always going to be a certain number of cases where the form does not fit the client and you did not have the scope or the capacity to explain the specific individual issues. They do cover behaviour challenges and whatever but the students do not always fit into the boxes that they need to fit into or show what level of support they really need.

**Mr SHEAHAN:** We were speaking with one service provider—our son is still to be assessed—as to whether he could provide a service and we were told that the level of service he could provide would be determined by the price tag that came with him. So in our isolated situation where transport was going to be an issue we have to wait and see what the assessment will tag him with as to what service or what level of service he would be able to achieve.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: Cheryl, you are the first person we have met who has supported this assessment process, interestingly enough.

Ms ROBERTS: It is better than what we had before.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It was said to have come from the home and community care forms for older people.

Ms ROBERTS: It was based on that.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: I understand there was a better one from someone called Vivienne Richards from Macquarie University. I think the director-general said that they had 10 per cent appeals and they had approved all of them, from memory. I think it was 70 appeals and all of them had been upheld or allowed. But many people were not aware that they could have appealed.

**Ms ROBERTS:** As I said, some years I have been told—whether it was right or not—there was not an appeals process. I think the reason that I got told information like that was because with the reforms the people on the ground at DADAHC were always chasing their tails so badly trying to get the process happening that anything outside like an appeal or whatever was just all too hard.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: It appears that most people were not aware that there were appeals.

**Ms ROBERTS:** There is not a lot of information about appeals promoted in the packages that are sent out, and we are not given a lot of information and it has been varying from year to year. Each year I cannot tell parents confidently that if it does not pan out the way they want it there is an appeals process because I do not know that for a fact.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: We got an assurance from the director-general that there would be a transparent appeal process that would be well publicised, and that would be developed.

#### Ms ROBERTS: That is encouraging.

**Ms HARWOOD:** With the appeal, Cheryl and I assessed my son and he got assessed as Transition to Work. I said this was inappropriate and when I told the person at DADAHC that that was true he said, "Let it go because you'll have more money this way for two years." That is the reality. There was not an appeal because my service provider actually had more money. My concern is he always should have been Community Participation, but will we be able to stay where we are? There is no certainty about that so that has been a concern that maybe I did not have to have. We did not appeal because we were told not to.

The Hon. Dr ARTHUR CHESTERFIELD-EVANS: We have had a number of other Transition to Work parents who said they would appropriately appeal but since they were getting more money they would not. It is a reasonably response, I think.

**Ms LYNNE LYNCH:** I support the previous speaker. Erin was assessed last year and much to my absolute horror she was assessed as a Transition to Work. Never in a million years is Erin ever going to go to work. I did not actually approach DADAHC but when I approached service providers I said, "She won't go to work". They said, "Take the money. You've got it probably for two years. It's the highest funding." They will reassess her. I do not know whether she will be reassessed this year or at the end of next year. She will then go into Community Participation. Take the money.

### (The Committee adjourned at 4.00 p.m.)