

Report on Consultations with People with Disability

NSW Legislative Council General Purpose Standing Committee No. 2 (GPSC No.2) Inquiry into Changes to Post School Programs for Young Adults with a Disability

June 2005

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Executive Summary

The three discussion groups described in this report constitute part of the NSW Legislative Council General Purpose Standing Committee No. 2 (GPSC No.2) Inquiry into Changes to Post School Programs for Young Adults with a Disability.

The aims of the discussion groups were to:

- provide young people with a disability with a chance to express their own responses to changes to their post school programs
- give members of Committee an opportunity to interact with young people with a disability and hear their stories.

Discussion groups were held in Sydney, Wollongong and Newcastle from 31 May to 3 June 2005. A total of 25 people with disability participated.

This report presents the findings of the discussion groups. Individual statements and summaries of responses to set questions posed by members of the Committee are provided.

Key themes that emerged from the discussions were:

- uncertainty about the future regarding adequate funding for post school programs
- lack of information and communication about changes
- concerns over reduction in program hours and consequent trade-offs in quality of service to offset these reductions
- lack of choice in terms of program, with no clear mechanisms for review and appeal
- loss of flexibility in regard to paid work, work experience, study and training opportunities, and other choices
- reduced support for those with physical disability to attend higher education
- limitation imposed by 2-year timeframe of Transition To Work program for young adults with a disability seeking to achieve training and education outcomes
- concerns about adequate funding for those with high, complex, or changing support needs
- reliance on service providers and families to make up funding shortfalls
- concern about the change from individualised to block funding.

1. Introduction

People with Disability Australia (PWD) was contracted by the NSW Legislative Council General Purpose Standing Committee No. 2 (GPSC.No.2) to organise and facilitate 3 discussion groups for service users of post school programs in Sydney metropolitan, Hunter and Illawarra regions. These discussion groups provided evidence for the Committee's *Inquiry into Changes to Post School Programs for Young Adults with a Disability*.

The discussion groups offered an innovative means by which members of the Committee heard directly from people with disability, and discussed their experiences in an interactive, small group setting.

The primary aim of the discussion groups was to provide an opportunity for people with a disability to 'have their say' about the changes to their programs that took effect from the beginning of 2005. These changes refer to the NSW Government's decision to reform the existing Adult Training and Learning Assistance Scheme (ATLAS) by establishing two new programs into which people with a disability are streamed: the Transition to Work (TTW) program, and the Community Participation (CP) program. This reform entailed major changes to ATLAS funding formulas that has impacted significantly upon the lives of the young adults who access these services, as this report illustrates through the responses of discussion group participants.

The brief of People with a Disability Australia (PWD) involved:

- recruiting and providing information to participants
- organising venues, catering and other logistics
- providing a facilitator and recorder, both of whom have wide experience with the communication needs of people with a disability
- reporting findings of the discussion groups to the Committee.

This report provides information about:

- discussion group methodology
- findings of the discussion groups, in the form of reports of the young people with a disability about the impact on their lives of changes to their post school programs.

2. Objectives

The primary aim of the discussion groups was to enable people with disability from different areas of New South Wales to express their own responses, either personally or through a support person/interpreter, to the changes to their post school programs in an interactive setting.

In order to promote this aim of hearing directly from people with disability, the following facilitation objectives were followed.

Discussion groups in Sydney, Wollongong and Newcastle would:

- consist of not more than 8-10 participants (plus support people/interpreters);
- involve participants with different needs and life goals, with a representative sample of users of Transition to Work and Community Participation programs;
- give participants from culturally and linguistically diverse (CALD) and indigenous backgrounds an opportunity to participate, whether in the discussion groups or in individual interviews with interpretation if necessary;
- provide a range of participation supports (see section 3.5).

Several members of General Purpose Standing Committee No. 2 were to be in attendance at each discussion group to hear the views of participants and to pose questions. These questions were to be developed in consultation between Committee members and PWD and were to be sent to participants before the meeting to give them an opportunity to think about and prepare their responses. Also in attendance as an observer would be an officer of the Parliament.

3. Methodology

3.1 Recruitment of participants

In order to source participants with intellectual and physical disability in the 3 target areas of Sydney, Wollongong and Newcastle, the following organisations were contacted:

- service providers of Transition to Work (TTW) and Community Participation (CP) services
 - in Sydney, specific services were targeted from different geographic areas (metropolitan east, north, west, inner west and south)
 - in Wollongong and Newcastle, a large proportion of all service providers were contacted
- advocacy groups
 - Illawarra Disability Trust, Disability Advocacy Service Hunter (DASH), NSW Council for Intellectual Disability (CID), Family Advocacy, Multicultural Disability Advocacy of Australia (MDAA), specific members of People with Disability Australia (PWD).

Service providers and advocacy groups were informed that the primary aim of the discussion groups was to hear the views of people with disability themselves.

Some issues concerning participant recruitment that emerged through this contact were:

- services providers had limited resources available for identifying, encouraging and supporting the attendance of service users
- people with high and complex support needs found it difficult to attend because of the significant co-ordination and personal effort required; this difficulty was compounded by the short time-frame available for notifying participants
- the peak multicultural advocacy group, MDAA, reported that very few of its members participated in these post school programs, with no clear reasons for this low participation rate
- a very high proportion of people were streamed into the Community Participation program, compared with people in the Transition to Work program; the representative sample reflected these proportions.

3.2 Participants and those in attendance

Participating people with disability

Final numbers of participating young adults with a disability are as follows:

Table 1: Number of participants by venue

Venue	No. of participants
Sydney	10*
Wollongong	5
Newcastle	10

* This includes 2 participants who were unable to attend on the day and submitted written responses after the discussion group

For the full list of participants, see Appendix 2.

The profile of participants appears in Table 2 below. People with a wide range of disabilities were represented, including those with physical, intellectual and sensory disability.

Table 2: Profiles of discussion group participants

Venue	Physical disability	Intellectual disability	Multiple disabilities	Total
Sydney	4	5	1	10
Wollongong	-	3	2	5
Newcastle	4	4	2	10

Table 3 below presents the breakdown of participants according to program. A much higher proportion of participants took part in Community Participation (CP) programs, which appears to represent the relative proportions of service users in the community.

Table 3: Participants by program type

Venue	Transition to Work	Community Participation	Other*
Sydney*	4	4	2
Wollongong	1	4	0
Newcastle**	2	7	1
Total	7 (28%)	15 (60%)	3 (12%)

* 1 participant had been exited from his program this year due to loss of funding. 1 participant is a Post School Options service user.

** 1 participant is a Post School Options service user.

Members of General Purpose Standing Committee No. 2 and Parliamentary officers

The following members of General Purpose Standing Committee No. 2 and Parliamentary staff attended the discussion groups:

Sydney: The Hon. Patricia Forsythe MLC (Chair), The Hon. Tony Catanzariti MLC (Deputy Chair), The Hon. Arthur Chesterfield-Evans MLC; Principal Council Officer: Madeleine Foley

Wollongong: The Hon. Patricia Forsythe MLC, The Hon. Christine Robertson MLC, The Hon. Jon Jenkins MLC; Principal Council Officer: Madeleine Foley

Newcastle: The Hon. John Ryan MLC, The Hon. Henry Tsang MLC; Director, GPSC No.2: Steven Reynolds.

People with Disability Australia (PWD) staff

PWD staff in attendance at all venues:

Kathryn Knight: Project Manager and Facilitator
Allyson Campbell: Project Support Officer and Recorder

3.3 Venues, dates and times

Venues were selected that were central and accessible for people with a disability. Venues in Wollongong and Newcastle were kindly made available by service providers. For a list of venues, please refer to Appendix 3.

Sydney: Tuesday, 31 May, 2pm–4pm

Wollongong: Wednesday, 1 June, 11am–1pm

Newcastle: Friday, 3 June, 11am–1pm

3.4 Consent and participation allowance

Consent

Along with invitations and information sheets, participants were sent consent forms, seeking their permission to include their statements and responses in this report (see Appendix 1).

Accompanying the consent form was a statement about possible media presence at the discussion groups, and the right of participants to refuse to be filmed or recorded during the process of discussion.

Travel

All participants received an attendance support allowance of \$30 to assist with travelling to and from the venue.

Participation supports

Professional attendant carers were made available to facilitate participation.

3.5 Process of facilitation

Personalised invitations and information sheets (including list of questions and agenda) were sent to participants beforehand (see Appendix 1).

The following processes were undertaken to facilitate participation:

- discussion groups were set at 2 hours' duration, with a break for refreshments after 1 hour, to accommodate the needs of people with disability
- groups were small to enable participants to feel comfortable, and to encourage interaction
- venues were accessible and non-intimidating
- the facilitator had understanding of and experience in communicating with people with disability
- all written information was provided in Easy English
- overhead projector transparencies were written in Easy English with illustrations; these were used by the facilitator to track agenda items
- interpreters were offered
- support people/interpreters were encouraged to attend
- participants were informed that advocacy support could be made available after the groups were held if necessary.

In order to enhance the participation of people with disability the Chair and Deputy Chair met with the consultation facilitator to discuss the facilitation process and communication issues for people with a cognitive impairment.

This included discussion on:

- use of plain English
- maintaining a focus on one issue and one concept at a time
- the role of the facilitator in assisting communication
- clarification of the role of Committee members
- questions to be addressed to participants.

Participants were asked to arrive at the venue half an hour before the scheduled starting time to meet the facilitator and recorder, complete paperwork, and get settled. As several participants felt nervous about their involvement, care was taken to make them feel welcome, relaxed and comfortable.

Committee members were seated 'in the round' with participants to promote interaction. The facilitator repeated and clarified statements, questions and responses as necessary. All discussion was recorded on butchers' paper in full view of the group.

Stage One

Each participant was invited to make a statement to the group about how the program changes had affected them. Some participants elected to do this with the assistance of a support person or interpreter.

After participants had spoken, there was a break of 10-15 minutes for refreshments. At this time, participants and support persons were able to chat informally to Committee members.

Stage Two

Committee members addressed these set questions to the participants:

1. Has your program changed since last year? How?
2. When did you hear about these changes?
3. Are there things you can't do any more because of these changes?
4. Are there new things that you can do because of these changes?
5. What differences do these changes make to your life?

At the conclusion of the meeting, the facilitator made a summary in simple English of the main themes that had emerged during the meeting.

All group participants were thanked by the facilitator and by representatives of the Committee.

4. Findings

This section summarises and reports the statements and responses of participants, organised by venue. Some of the statements and responses attributed to individual participants were made by their support person or representative, on their behalf.

Firstly, individual statements are presented as brief case studies. To protect the privacy of participants, individuals are identified by an initial, which does not correspond to their name. The individual statements are followed by summaries of responses to the set questions posed by Committee members.

4.1 Sydney discussion group

Individual statements - case studies

W. is a school leaver and Transition To Work (TTW) program participant. He has visual impairment and physical disability. He needs funding assistance for transport and personal support to attend the sound engineering course at TAFE he enrolled in this year. When **W.** applied for a post school program last year with the assistance of a special education consultant, he indicated on the form that he wished to obtain his UAI ranking. He was not aware, however, that a tick in this box would make him ineligible for post school program funding; he was not intending to apply for university -- he had simply wanted to find out his UAI score. But a letter arrived from DADHC (NSW Department of Ageing, Disability and Home Care) informing him that his application was unsuccessful, and instructing him to apply for employment. He decided to appeal and underwent a lengthy and complicated process before he was admitted to the Transition to Work program and was able to enrol in TAFE.

O. has a severe physical disability and is in her final year of a media studies degree. It costs her \$40 per day to travel to and from her university by taxi. Her level of funding through her Community Participation (CP) program this year does not cover these transport costs, and her family has to cover this expense. She would like to enrol in a master's degree next year, which would be extremely beneficial for her career development, but she will not be able to do this unless she receives some further funding support. She feels that she is being pushed inappropriately into paid work.

P. and his family are refugees from Afghanistan. **P.** is a participant in the TTW program. He has severe physical disability and communicates by text messaging on his mobile phone. He is undertaking computer studies at TAFE and wishes eventually to set up an Internet Service Provider (ISP) for people with disability. However, his TTW program will support him for 2 years only. He believes he needs 5 years to obtain the skills he requires for independent productive work.

K. and **L.** are participants in the Community Participation and Transition To Work programs respectively with the same service provider. Last year, both were able to combine paid work in a business service with their ATLAS programs. Now they are not eligible to do this. **L.** can participate in unpaid work experience in his TTW program, but **K.** is not permitted to undertake any work experience at all as part of her CP program (she wishes to gain experience in office work). She is currently appealing against her classification. **K.** and **L.** have not experienced cuts to their program hours because the service provider is currently covering the shortfall in funding, but this is a short-term solution.

D. comes from a Korean background. He was exited from his post school program when he took on paid work in the IT field for 16 hours per week this year. This level of paid work disqualified him from further funding assistance. Now he cannot receive additional transport funding beyond the M40 taxi subsidy. He has also lost funding for beneficial services such as weekly hydrotherapy. He feels that the system does not support his efforts toward achieving full independence.

As well as having his program hours reduced this year, **A.** is no longer able to participate in work experience. He was not deemed eligible for entry to the Transition To Work program, and work experience is not available to him through the Community Participation program. He is worried about his ability to develop skills for paid employment in the future.

C. enjoys her TTW program. However, in order for her to be accepted into TTW, her mother has had to undertake lengthy appeals on her behalf, with significant emotional costs. In addition, her mother is required to be available to transport her to her 6-hour per day program. Training to enable **C.** to access transport independently is not part of her current program.

M. , who has intellectual, physical and psychiatric disability, has had her program cut from 3 days to 2 days; this will be cut back further to one day per week in order for her service provider to meet its duty of care obligations by providing her with 1-to-1 support. **M.** becomes bored and aggressive without a structured environment. Her mother will be forced to give up her job and care for **M.** at home, which she does not want to do.¹

C. is a participant in the Post School Options program. Even though he is not directly affected by changes to the ATLAS program, he has experienced progressive reduction and decline in the extent and quality of his program. The staff-to-service user ratio has increased dramatically and the quality of activities and support has gone down. He is disturbed by the uncertainty of his program and unfamiliar staff. He becomes bored during the school holiday periods when he is unable to attend his program. His mother and primary

¹ M. was unable to attend on the day. However, a written statement was faxed to the consultation on her behalf.

carer has a progressive degenerative disease and finds his increasing dependence extremely difficult to manage.²

Responses to set questions

Q1: Has your program changed since last year? How?

Changes	Instances
Cuts to transport funding	1
No longer able to participate in work experience	2
No longer able to participate in paid work	2
Exited from program due to ineligibility	1
Reduced hours	4
Reduced quality of support	7

Two participants reported that their service provider had allowed them to maintain their level of participation by covering the shortfall in funding in the short term.

Q2: When did you hear about these changes?

Source of information	Instances
Through service providers, at the end of last year	5
Through media, no confirmation until April 1, 2005	1

Two participants (school leavers) were new to the post school program and received information at the beginning of 2005.

Two participants who submitted written responses did not address this question.

Q3: Are there things you can't do any more because of these changes?

Changes	Instances
No more work experience	1
No more part-time paid work	2
No more TAFE training	2
No transport training	1
Transport to university cut	1
Exited from program	1

The two new service users were unable to comment as they had no prior experience of the programs.

² C. was unable to attend on the day. However, a written statement was provided to the consultation on his behalf.

Q4: Are there new things that you can do because of these changes?

One participant answered affirmatively; she was now actively involved in work experience through her TTW program.

Q5: What difference have these changes made to your life?

Impacts	Instances
Uncertainty about future support for transport and study	3
Uncertainty about future work training and job prospects	5
Lack of transport funding and other services (such as hydrotherapy)	2
Lack of choice in my program activities	5
Lack of transport training to facilitate independence	1
Fewer program hours	4

4.2 Wollongong discussion group

Individual statements – case studies

P. is a young man with intellectual disability and very limited communication skills who attends a Community Participation (CP) program. He found the structure and predictable routine of his ATLAS program last year important for providing purpose and self-esteem. When he was assessed inappropriately into Transition To Work at the beginning of this year, his family wrote to Parliament and Department of Ageing, Disability and Home Care (DADHC), and underwent a lengthy and stressful review process. **P.** is affected adversely by the uncertainty surrounding the future of his program. His family will experience financial difficulty when his service provider is no longer able to 'top up' funds for his program next year, as his hours will be reduced and his mother will need to leave work to care for him.

A. lives in a group home and attends a CP program. He currently attends the centre two days per week and TAFE training two days per week. Last year he was eligible for 3 days of training at TAFE through his ATLAS program. This year, he is no longer eligible for work experience as a CP client, but participates in volunteer work. At the beginning of the year, **A.** was angry and upset when he was inappropriately assessed into Transition To Work. He did not feel ready for work, and he was afraid that if he did not get a job within two years he would not be eligible for further services in the future. He wrote to DADHC, went through an appeal process and has attended many meetings and rallies. He is worried that next year he will be forced to spend more time at his group home when his service provider is no longer able to meet shortfalls to his program funding.

G. participates in a TTW program. He attends TAFE at present, due to extra support from his service providers, but he is worried that he will not be able to continue his training next year. 'It will be hard to give up TAFE and stay at home more,' he said. 'I won't get a qualification for my work and I will lose my independence.' **G.**'s family comes from Lebanon.

R. is a young man with very high support needs. **R.** attends a CP program. His funding was cut at the beginning of the year, but his hours have been maintained by the service provider meeting the shortfall this year. A reduction in **R.**'s hours will cause considerable financial hardship for his family, as his mother will be forced to either give up employment or pay high rates for a personal carer for her son. **R.** will experience sleeping problems, boredom and social isolation caused by a reduced amount of stimulation, and quality of support and social interaction.

H. is 21 years old and has severe autism. Last year, **H.** received only 12 hours of ATLAS support due to his very complex support needs. This was reduced to 8 hours this year, but his service provider agreed to maintain his previous level of service during 2005. **H.** lives in a group home, and predicted reductions to his program in the future will mean that he spends more time at his group home with reduced stimulation and social interaction; this will impact severely upon his challenging behaviours, such as absconding. These outcomes will add to his family's anxiety about his well-being. More time spent at his group home will incur greater staffing costs for his accommodation provider.

Responses to set questions

Q1: Has your program changed since last year? How?

Changes	Instances
Reduction of participation in vocational training	1
Reduction in quality of 1-to-1 support	2

The five participants in this group had not experienced reduction in their program hours as their service providers agreed to meet funding shortfalls in the short term. Support persons reported that the two services concerned had committed to maintaining current programming levels, but were unlikely to manage this beyond the end of 2005. A further outcome was that 1-to-1 support for those with higher support needs would be replaced by group activities that would not be targeted to the specific needs of the individual.

Q2: How did you hear about the changes?

Source of information	Instances
Through the media	5

Subsequently, program participants sought information through their service providers and DADHC. One person stated that the letter she received from

DADHC was ambiguous and difficult to understand. One participant commented: 'Why did they do it this way?', as the announcements had caused him high levels of uncertainty and anxiety.

It was reported by one person that all new clients in 2005 in this region were automatically classified into Transition to Work upon entry, and existing clients were classified into Community Participation. This caused anxiety amongst families, and meant that many families had to seek methods for applying for review. Procedures for review and appeal apparently were not addressed in the information sent to participants.

Q3: Are there things you can't do any more because of these changes?

Changes	Instances
Reduction in days of attendance at TAFE	1
Fewer excursions this year	1

Due to funding 'top up' by service providers, participants had not experienced significant change in their levels of participation in their programs. One participant had had his TAFE-based vocational training reduced by one day per week. However, participants expressed great concern over the future, when their service providers could no longer meet the funding shortfalls.

Q4: Are there new things that you can do because of these changes?

One participant reported that now he helps to put together the service newsletter as part of his TTW program.

Q5: What difference have these changes made to your life?

Impacts	Instances
Fears that TAFE training will be cut	2
Fears that 'I will have to stay at home more often'	5
Fears about reduced quality of care for those with high support needs	3
Fears about impacts of changed routines and limited stimulation	3

4.3 Newcastle discussion group

Individual statements – case studies

O. and **P.** attend a CP program. Their participation has been reduced from 5 to 4 days per week this year. Last year they both attended a Cleaners' Crew course at TAFE and participated in work experience at Target. Changes to

their programs mean that their activities are now all centre-based; they feel they have lost a pathway into future employment and valuable social interaction, with consequent impacts on their confidence and self-esteem.

A.'s program has been reduced from 4 to 3 days per week, with more time spent in group-based activities rather than 1-to-1 learning experiences. Last year, **A.** attended swimming and gym every week, but he now must cover costs of transportation with a support worker to these activities himself, which he is unable to afford. He misses out on most of these activities, and he spends two days per week at home now feeling bored and socially isolated.

This is **N.**'s second year in a post school program. Last year, she attended her ATLAS program 5 days per week. Her reduced hours this year mean the loss of quality time spent with her peers in interacting, community access, living skills and craft activities. Her mother, a single parent, receives no respite or other services and has had to reduce her work hours to fit in with **N.**'s program. This has disadvantaged them both financially.

B. and **S.** live in a group home at Maitland and attend Community Participation in Newcastle. The reduction in their attendance from 5 days last year to 4 days this year means that their accommodation service must fund additional staff for an extra day per week. They both have very high support needs, and their program now entails a higher proportion of group activities instead of valuable 1-to-1 support. This means that targeted learning experiences for them are limited, and they become frustrated and anxious. In addition, transport from their home to their service one-way has been cut out, which places further burden on their accommodation provider.

Q. is currently completing an honours degree at the University of Newcastle. She has a severe physical disability, and relies on transport assistance and personal care to enable her to continue her studies. Funding for her program was reduced from 12 to 9 ½ hours per week this year; a consequence of this is that she now has daily transport costs of \$30 per day to meet personally. **Q.** had planned to enrol in a law degree when her undergraduate studies were completed, but was informed that she would not be eligible for post-school program funding for this as it was 'a new course'. Her alternative was to extend her undergraduate studies by taking up an honours option. She is concerned that she may not be able to complete her honours studies if her service provider is unable to continue to assist her with meeting funding shortfalls and her funding is further reduced next year.

Last year, **F.**, who has a severe physical disability, received individual support for 5 hours per day, 4 days per week and attended a TAFE course with personal care and transport support through her ATLAS program. This year, her individual program support has been reduced considerably and she is unable to attend her TAFE college because she no longer receives transport and personal care for this purpose. Instead, **F.** now studies for her TAFE course by correspondence. Without personal care support during the day at home, she must attend her service provider's centre for the sole purpose of receiving assistance with her personal needs, including toileting.

Q. and **F.** (above) are close friends. In order to make the most of their valuable time together, they pool two hours each of their personal care funding resources so that they can spend four hours together shopping or visiting.

Z. is a school leaver with physical disability who attends a CP program. Last year, while studying for her HSC, she received support 4 days per week and took part in work experience at a child care centre. This year, she has been granted funding of 8 hours per week of 1-to-1 support, which she uses in two blocks (five and a half hours equivalent over two days: one day of individual support, the other in group activities). These group activities, however, do not meet her needs appropriately as they are focused on the needs of clients with intellectual disability. In addition, the centre she attends is not equipped for handling complex physical needs, and she is unable to access toilet facilities there. **Z.** spends 3 days per week at home, as she is ineligible for TAFE training through her CP program.

U. left school some years ago and is a Post School Options client. He has a physical disability, and is seeking paid employment. At present he does voluntary work in reception for his service provider. Funding to his program has not been affected.

Responses to set questions

Q1: Has your program changed since last year? How?

Changes	Instances
Reduction of centre-based program hours	9
Reduction in off-site activities	3
Change in program from individual 1-to-1 support to group	3
No longer eligible for work experience	2
No longer eligible for TAFE training	3
Can no longer attend TAFE: lack of personal care, transport	1
No more transport assistance to attend centre	9
Increased costs for transport to activities	1
Reduction of personal care, transport for uni attendance	1

Q2: How did you hear about these changes?

Source of information	Instances
By word of mouth	9
Through peak advocacy group	1

A 'grapevine' existed amongst participants, with advice about changes to post school programs passed around fellow service users. One source of information was a peak advocacy group that circulated a copy of a Ministerial

press release to members; another was 'a friend of my mother who works for DADHC'. It was also reported that a service provider staff member was initially informed about the proposed changes by the parent of a service user.

Participants used these words to describe their reactions: 'I was devastated', 'mystified', 'I felt like I was kicked in the guts', 'I felt like I was hit with the rough end of a very large stick'.

Q3: Are there things you can't do any more because of the changes?

Due to time constraints, this question was omitted as appropriate responses had already been obtained in personal statements in the first stage of the meeting.

Q4: Are there new things that you can do because of the changes?

One participant mentioned that he was able to attend movies and go for tours this year as part of his CP program.

Q5: What difference have these changes made to your life?

Impacts	Instances
Uncertainty about future university and TAFE studies	2
General uncertainty about the future	10
Increased costs for transport	9
Increased social isolation	9

5. Key themes

A number of key themes emerged from the discussion groups:

- *Uncertainty about the future*
 - Participants expressed a general lack of clarity and certainty about the future of their programs, including centre-based hours, vocational training and further education opportunities, work experience, and employment.
- *Lack of information and communication*
 - Participants expressed concern about the timing and methods of communicating changes to their programs.
- *Concerns over reduction in program hours and consequent trade-offs in quality of service to offset these reductions*
 - Participants expressed feelings of social isolation, boredom, frustration and lack of structure and routine in their lives as a result of reduced attendance at programs.
 - Participants were worried about the erosion of program quality, and many commented that beneficial individualised support had been replaced by non-specific group activities such as watching television.
- *Lack of choice in terms of program, with no clear mechanisms for review and appeal*
 - Several participants had been assessed into what they deemed to be inappropriate programs, and had experienced lengthy and stressful review processes.
- *Loss of flexibility in regard to paid work, work experience, and study and training opportunities*
 - A number of participants were now in programs in which there were no discernible pathways leading to paid employment outcomes in the future.
- *Reduced support to attend higher education*
 - Participants expressed that reduced funding for personal care and transport has created anxiety for those with aspirations for higher education, and made them feel unsupported in their quest for independence.

- *Limitation of 2-year TTW program for young adults with a disability seeking to achieve training and education outcomes*
 - Several participants felt that 2 years was not adequate to develop skills for paid employment, and that their able-bodied counterparts were granted more extended training opportunities.
 - Several participants were reluctant to enter Transition To Work due to uncertainty about whether services will continue to be available to them after 2 years if they fail to meet employment goals.
- *Concerns about lack of individualised funding and consequent lack of flexibility within programs*
 - Participants felt that there was little opportunity for them to make choices about program content and activities; a 'you-take-what-you-get' mentality.
- *Concerns about continued and 1-to-1 funding for those with high, complex or changing support needs*
 - Several carers expressed fear that this group of clients could be pushed out of the system altogether.
- *Reliance on service providers and families to make up funding shortfalls*
 - A number of participants had been able to maintain existing program levels due to 'topping up' of funding by service providers, but had been informed that this was a short-term solution only, available until the end of 2005 at best. Participants expressed concerns that more costs would be transferred to families in the future.

6. Conclusion

The three discussion groups in Sydney, Wollongong and Newcastle provided people with disability an opportunity to express their own responses to changes to their post school programs in a facilitative environment. The groups also provided members of the Legislative Council General Purpose Standing Committee No 2 with an opportunity to meet and interact with young people with a disability in a small group setting, and to hear their stories.

At the conclusion of the meetings, all participants and those in attendance expressed that the discussion groups had been valuable and instructive. As well as relating their own experiences, participants were able to listen to others and share their stories empathetically. Members of the Committee expressed the value of the experience for them, both in terms of hearing these stories and interacting closely with the people directly affected by the changes.

As the report findings indicate, all participants felt the changes to their post school programs that took effect at the beginning of 2005 had impacted significantly on their quality of life. Above all, they expressed fears for the future, an increased sense of dependence on others, and social isolation.

Appendices

Appendix 1 Invitation, information sheet and agenda



LEGISLATIVE COUNCIL

General Purpose Standing Committee No. 2

Inquiry into Changes to Post School Programs for Young Adults with a Disability

INVITATION TO ATTEND A DISCUSSION GROUP FOR YOUNG ADULTS WITH A DISABILITY

A CHANCE TO HAVE YOUR SAY

Some people from the New South Wales Parliament want your help. They want to find out what people who are going to **Community Participation** and **Transition to Work** programs think about changes to their services.

They want to find out what **you** think about the changes to your program – how these changes affect you.

They want **you to have your say** about these changes.

We are inviting you to an **Inquiry Discussion Group** so you can **have your say**.

You can bring along a support person to help you. You can get some money to help you with your expenses to come to the Discussion Group.

When?

Where?

Please phone us to let us know that you can come.

Contact **Kathryn Knight** or **Allyson Campbell** at **People with Disability Australia**:



Phone: **9319 6622**



TTY: **9318 2138**

Email: pwd@pwd.org.au

Inquiry into Changes to Post School Programs for Young Adults with a Disability

What is the Inquiry Discussion Group?

This **Discussion Group** is a place where people can talk about things that are important to them. They can talk to the people who are part of our New South Wales Parliament.

What will happen at the Discussion Group?

When you come to the Discussion Group, first you will **meet some people** from the New South Wales Legislative Council (these are people from the Parliament).

We will ask you first if you **have something to say** about changes to your program. You can tell us in your own words.

Then we will **ask some questions** about these changes. The questions will be like this. You can think about them before you come.

1. **Has your program changed since last year? How?**
2. **When did you find out about these changes?**
3. **Are there things that you can't do any more because of the changes to your program?**
4. **Are there any new things that you can do because of these changes?**
5. **What differences do these changes make to your life?**

You can bring along **someone to help you** answer these questions.

If you will be bringing someone to help you, please tell us when you phone us to say you are coming.

Inquiry Into Changes to Post School Programs for Young Adults with a Disability

Please fill in the forms on these two pages and bring them to the Discussion Group with you. We will have more copies at the Discussion Group just in case you forget.

How we can contact you

Your name

Your address

.....

Your phone number

Your email address

We want to send you some information afterwards about how things went at your Inquiry Discussion Group. But you will need to wait for a while for this.

Inquiry Into Changes to Post School Programs for Young Adults with a Disability

Your Consent

Your consent for us to put what you say in the Report to the Committee

The Standing Committee needs to know what happened at the Inquiry Discussion Group. We will write a **report** about what people said.

We need **your permission** so that we can write down what you said in the report. We want to put your name at the end of the report. But we won't write down who said what things. We will keep this **private**.

If you don't want us to put your name at the end the report, we won't do this.

Please fill in the spaces below. This tells us that you give us your permission.

I give permission for what I said at the Inquiry Discussion Group to go into the Report to the Standing Committee.

.....

.....

Your name

Your signature

If people from the television, radio or newspapers are there

People from the media (television, radio or newspapers) might want to come to the discussion group for a short time. They might want to do some filming or recording of you for the news.

If this is okay with you, you can give them **your permission**.

But you don't have to be filmed or recorded while you are in the discussion group.

This is your choice.

If you don't want to be filmed or recorded in the discussion room, you can tell the people from the media. Or you can tell Kathryn or Allyson when you get there.

Inquiry into Changes to Post School Programs for Young Adults with a Disability

Discussion Group for Young Adults with Disability



What will happen

Please come at 10.30 am so we can get ready.

1. Welcome – at 11 am

You will meet the people who have come:

- other people who go to post school programs
- 3 or 4 people from the New South Wales Parliament
- 2 people from PWD, Kathryn Knight and Allyson Campbell

We will say why we are here and what we will do.

2. A chance to have your say

We will ask each person to say what the changes to their program mean to them. Each person will have a chance to say what they think.

Break for drinks and something to eat

3. Questions and answers

We sent some questions to you with your Invitation. The people from the Parliament will ask you these questions. You can tell them the answers and we will write the answers down.

4. Checking

We will talk about what people said and make sure it is all right.

5. Close

We will finish at 1 pm. We want to thank you for coming and telling us what you think.

Appendix 2 Full list of participants

Sydney:

1. Joseph Arkelidis
2. Susan Churchill
3. Walee Mir
4. Allan Dwyer
5. Fiona Bridger
6. Simon Kim
7. Bridgette Robertson
8. Kane Nolan
9. Mario Chaudhry-Lyons
10. Jackie Greenwood

Wollongong:

1. Jared Pinkerton
2. Ian Charlesworth
3. Brendon Stolk
4. Troy Cottam
5. Ellee Habak

Newcastle:

1. Dane Tobias
2. Kristy Trajcevski
3. Rachel Gudgeon
4. Deahne Mc Tackett

5. Michelle Stewart
6. Geoffrey McDonald
7. Mark Warren
8. Amy Bobeth
9. Ryan Walpole
10. Aletia Pepperall

Appendix 3 List of venues

Sydney: People with Disability Australia, 52 Pitt Street, Redfern
Tuesday, 31 May, 2pm–4pm

Wollongong: Essential Personnel, 302 Crown Street, Wollongong
Wednesday, 1 June, 11am–1pm

Newcastle: Life Without Barriers, Cnr Smith and Parry Streets,
Newcastle West
Friday, 3 June, 11am–1pm