

**Submission
No 79**

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

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Subject:

Summary



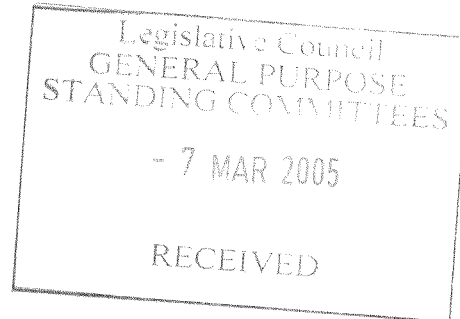
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4 March 2005

The Hon Patricia Forsythe MLC
Chair
General Purpose Standing Committee No2
Parliament House
Macquarie Street
Sydney 2001



Dear Ms Forsythe

Inquiry into changes to post school programs for young adults with a disability.

Please find enclosed a detailed submission prepared by the Council of Social Service of NSW (NCOSS) in relation to the Inquiry into changes to post school programs for young adults with a disability.

I hope that the Committee will favourably consider our comments.

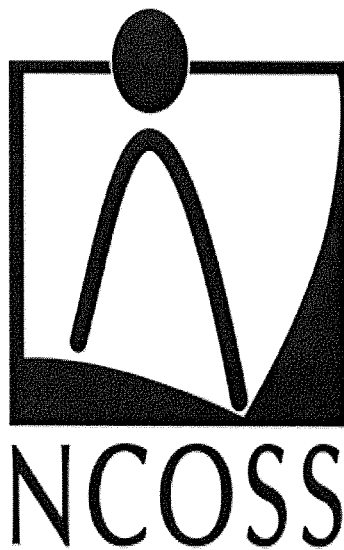
If further information is required, please contact Christine Regan, Senior Policy Officer on 9211 2599 ext , or by email to

Yours faithfully

Gary Moore
Director

Submission to the Legislative Council
General Purpose Standing Committee No 2

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



March 2005

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About NCOSS

The Council of Social Service of NSW (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in NSW.

NCOSS provides an independent voice on welfare policy issues and social and economic reforms and is the major co-ordinator for non-government social and community services in NSW.

NCOSS appreciates the opportunity to submit comments to the Inquiry.

History of the ATLAS Reform

In 1992, school-leavers with disability were able to access the Post School Options Program (PSOP), which provided pre-work and living skills training and dignified daytime activities for personal advancement and stimulation. PSOP involved individualised funding at several funding levels to support people during the day and was provided by local providers after a process of assessment, choice and negotiation by people with disabilities and their families.

In 1998, PSOP was replaced with the Adult Training Learning and Support Program (ATLAS) which essentially provided the same individualised funding and services as PSOP but for a two year period only, with the intention that the person with disability by then would be capable of work or enter an existing day program (of which there were very few and vacancies rare). In the absence of alternatives, DADHC was forced to continue funding past the two year period and acknowledged that there was a very low throughput of people with disability into employment¹ (only 3%).

In 2003-04, DADHC convened an Expert Working Group to improve the performance of POSP/ATLAS and, it was thought, to synchronise/co-ordinate all day programs to people with disabilities. The Group comprised selected experts, both consumer and industry advocates, and worked towards policy and program improvements for school-leavers and adults with disability for appropriate weekday occupation.

The final report on the Review of Day Programs had been expected throughout previous years.

The announcement of reforms to the PSOP and ATLAS programs to selected organisations on 8 July 2004 was unexpected and without prior consultation. The changes involved replacing PSOP and ATLAS with two new programs Transition to Work (TTW) and Community Participation (CP). This change would result in reduced per capita funding to almost all young adults and school leavers, transfer from individualised funding to block funding, re-tendering of all service provider contracts. Implementation would commence from January 2005.

In late July 2004, PSOP was withdrawn from the reforms and quarantined at the original funding levels for individualised funding packages. The then Minister cited that PSOP participants and families had an expectation of on-going funding while ALTAS participants, despite continued funding, knew from the outset that funding was only for two years. Some weeks later, the Minister announced that only contracts for the new Transition to

¹ DADHC Regional Service Provider Powerpoint presentation *ATLAS – PSOP Reforms July / August 2004*

Work program would be tendered and that other processes would be used to award contracts for the Community Participation program.

In December 2004, the Minister said that services to new school-leavers with disability entering TTW and CP would commence on 7 February and that the changes to existing ATLAS participants would commence from 2 April 2005.

General Comments

Appropriateness of changes for young adults with a disability

Evidence Basis

In 2004, DADHC estimated² that PSOP had 1419 participants and ATLAS had 2173 participants. DADHC reported that 160 organisations provided joint ATLAS & PSOP services to young adults. DADHC were anticipating (and planning for) around 580 new school-leavers at the end of 2004 but reportedly received applications from over 820 school-leavers.

Under the reforms, DADHC anticipates that:

- 20% of school-leavers can be channelled directly into employment or Commonwealth employment programs (requiring no State support),
- 40% will go to TTW and
- 40% will go to CP.

NCOSS agrees that the best outcome for adults with disabilities is employment where possible. However, it seems miraculous that, from one year to the next, throughput to employment or employment programs can increase from 3% to 60% for the same group of people.

NCOSS accepts that under ATLAS, pre-work programs were indistinct and depended on the initiative of the service provider. However the 20/40/40 proportions envisaged in the reforms are designated at entry not as results. They therefore seem overly ambitious without some evidence of predictable success. DADHC is using evidence-based tendering, monitoring and program development for its other initiatives but has provided no evidence that this 60% (comprising 20% Commonwealth & 40% TTW) is reasonable, achievable or sustainable.

When PSOP was converted into ATLAS, anticipated increases in throughput to employment or employment programs were also cited as the major reason for the change. To the present day, no change is evident and the throughput has regrettably remained very low. Similarly, at inception the ATLAS program was to have new in-built data collection on individual programs and results, in order to track the achievement of the changes. No data collection was implemented. DADHC is giving similar but vague assurances about data collection under the reforms.

DADHC has reported that the unexpected increase in school leaver applicants is due to a change in the applicant population. DADHC explained that the additional 240 are young people who were never specifically identified as having a disability but who have not

² DADHC Regional Service Provider Powerpoint presentation *ATLAS – PSOP Reforms July / August 2004*

achieved at school and who have disabling conditions which present significant functioning difficulties with activities of daily life. This group represents around 29% of the total applicants.

According to the anticipated reform proportions, 164 people would immediately transit to employment or Commonwealth programs, 328 people would go to TTW and 328 to CP. If at least 164 were to go directly to Commonwealth programs or employment, NCOSS questions why they were referred to DADHC in the first place?

The Productivity Commission³ reported that NSW had the lowest number (4.2%) of people with disabilities using community access services (defined as learning and life skills development) as a proportion of the estimated potential population of community access users; the national average being 7.3%. Similarly, NSW was lower than all jurisdictions besides the Australian Capital Territory and Northern Territory, for the number of people with disabilities who used employment services as a proportion of the work-age population. NSW reported a lower than national average number of Indigenous people using employment services as a proportion of work-age people as well as a lower than national average proportion of Indigenous people using community access services.

Clearly it is important for NSW to improve these results, but any proposed improvements must be reasonable, sustainable and of a quality that both respects and supports the individual and their family. To date DADHC has not provided any evidence that the reforms will meet these criteria.

NCOSS is aware of the research study commissioned by DADHC to the University of Wollongong, which was due to report on findings in early 2005. This Classification and Costing Study sought to identify the levels of support needs of PSOP and ATLAS participants and provide appropriate costings. DADHC also convened an Employment Focus Group, which acted as an advisory committee for a project conducting TTW Pilots. This was due to report late 2004 or early 2005. Neither initiative had publicly released its findings at the time of writing this submission.

The Compact⁴ between the NSW Government and the Forum of Non Government Agencies (FONGA) that is designed to 'strengthen the ability of the NSW Government and non-government human services organisations in NSW to achieve better outcomes for individuals, families and communities.' The Compact identifies shared goals and values, the roles of government and non-government organisations, principles for co-operation and the elements of improved working and funding relationships. The first principle for a strong relationship between government and the sector is an evidence-based approach asserting that 'Policy, program development and service delivery should be based on reliable evidence'. While the evidence is clear there is a need for reform, DADHC has not provided evidence that the drastic changes to program and service delivery will produce better outcomes for people with disabilities and their families.

Impact on People and Families

The ATLAS reform process has had a deep and wide-reaching impact on people with disabilities and families across NSW and the sector in general. Several families have been in direct contact with NCOSS expressing their concerns about the future of the young

³ Report on Government Services 2004, chapter 13 Services for People with a Disability; January 2005.

⁴ *Working Together for New South Wales*, NSW Government and FONGA, September 2004.

people in their care. NCOSS has directly spoken with many other people and families at community meetings since July 2004.

Families directly affected by the reforms have told NCOSS of the following concerns:

- The cuts in individual funding will downgrade the quality of services;
- Cuts to individual funding will decrease the hours of service provision for the person with disability, reducing the ability of the new programs to stimulate and progress the person with disability;
- The impact on the primary carer of reduced quality and hours of service provision possibly having to leave work, having suddenly increased caring responsibilities;
- Worry that the change from individualised to block funding will diminish particular attention to the person with disability;
- Worry that the change from individualised to block funding will necessarily spread reduced funding across increasing numbers of people;
- The change from individualised to block funding will cease the portability of funding where a TTW or CP participant might need to change providers or move to another location;
- Fear the reforms are merely a way of rationing services not improving them
- Loss of individual choice among and within programs and providers;
- Due to per capita cuts, the loss of flexibility of programs will diminish the provider's capacity to respond to the person as their needs change;
- Anger at the absence of prior consultation by DADHC on proposed reforms;
- Distress and anguish at the lack of direct information and engagement from DADHC;
- Feeling that people with disabilities and families were no longer valued by DADHC;
- Feeling that people and families had no choice but to live with the consequences of the decisions of outsiders which would cause further hardship in lives that were already more complex and intense than most other people; and
- Uncertainty for the viability of trusted providers.

Families with participants using PSOP have expressed the following concerns about the reforms:

- With such sweeping changes how long will it be before PSOP is similarly targetted?
- With many service organisations providing both PSOP and ATLAS, there is little confidence that the per capita cuts will not affect PSOP participants and families in that reduced government funding will need to support increasing numbers of people; and
- Whenever appropriate, how will PSOP participants have access to TTW without losing their funding levels.

Families of people with disabilities still at school have told NCOSS of their concerns. These include:

- Uncertainty of the quality of programs when their young person leaves school
- Uncertainty of the quantity of programs ie hours both for the development of the person and the maintenance of the working lives of the parents/family members
- Lack of confidence in DADHC processes and communications
- Should they maintain the person at school longer than planned instead of moving to TTW or CP?

Flow on Effects

DADHC has reported that it is pursuing negotiations with the Australian Government regarding increased access to Commonwealth employment programs. NCOSS is concerned that these negotiations should have been completed during the reform process and before the implementation of the new programs. While NCOSS acknowledges that it will be two years before most TTW graduates will need access to employment programs, DADHC anticipates an automatic throughput of 20%, placing an immediate pressure on Commonwealth programs. Surely this immediate increase will require substantial planning and preparation by Australian government agencies and services in order to provide a smooth transition for the person with disability and to avoid disruption to families.

If completed well in advance of implementation, these prior negotiations could have settled the issues of increased number of applicants and the synchronising of eligibility criteria to avoid people falling through the cracks thereby leaving people unsupported by either Commonwealth or State programs.

The impact of the reforms has extensive consequences within the community and among other service providers and programs. These are detailed below.

Many supported accommodation services, both funded and DADHC direct, provide support primarily outside business hours and rely on residents' access to day programs or similar. The reduced hours of service offered by CP will have to be compensated within group homes by extra staff and programs. TTW graduates whose employment is very part-time will be similarly affected. This is necessarily a more expensive alternative to community access programs, as it often requires higher staff ratios. It is also a less acceptable alternative as it reduces the opportunities of residents to form relationships outside the home. In this respect, reduced ATLAS services could put disability accommodation services in breach of the NSW Disability Services Act 1993 which provides 'that no single organisation providing services exercises control over all or most aspects of the life of a person with disabilities.'⁵

Already some respite services are reporting an increase in demand following notice of reduced ATLAS hours. Families are turning to respite services to fill the gaps in an attempt to minimise the disruption, particularly, but not exclusively, to parental employment. Many respite services already operate at capacity and existing unmet demand puts heavy pressure on service providers. Some providers have already complained that they cannot provide increased service provision as a result of ATLAS reductions⁶. Similar to disability accommodation services, respite is both an expensive and unacceptable alternative.

Consultation

DADHC states that it has undertaken extensive consultation⁷ with a variety of stakeholders, including expert working and focus groups, peak agencies, service providers and users and DADHC personnel. NCOSS is informed by members of several of the working and focus groups that, while they participated in policy and program development

⁵ NSW Disability Services Act 1993 Schedule 1 section 2 Application of Principles paragraph (h)

⁶ Discussions at the February 2005 meetings of the Carers Coalition and the NSW HACC Issues Forum.

⁷ *DADHC Policy Framework Transition to Work and Community Participation Programs* July 2004 on DADHC website

discussions, they were not informed of the upcoming reform process nor were they consulted on the three major aspects of the proposed reforms.

Several key peak agencies, including NCOSS, were not consulted prior to any reform announcement and NCOSS knows of no services users or providers who were consulted regarding the detail of the proposed reforms.

The Compact⁸ clearly states that open communication and consultation should be a government priority and that any major policy change or initiative should be preceded by a reasonable period of extensive consultation, especially involving those most affected by the change. DADHC have failed to adhere to the Compact in this first instance.

Engagement with people with disabilities and families

People and families have been outspoken in their fears and sometimes angered over what they perceive in the ATLAS reforms as an attack on their greatly needed support systems. NCOSS particularly refers to the Rally outside Parliament House on 22 September 2004, attended by between 2000 and 2500 people from across NSW. The strength of feeling around the impacts of the ATLAS reforms on people and families has not abated in the intervening period.

If there was evidence that the reforms would provide the improvements announced, NCOSS regrets that no evidence was provided to people and families in the first instance, and no assurances were made regarding consumer fears about the transition. DADHC did not communicate directly with people and families for some time after the July announcements. When DADHC did write to people and families, there was no mention of per capita cuts or provider uncertainty. However, the Minister did assert that it was not the intention of the reforms to reduce quality or hours of service provision.

DADHC information sessions⁹ for ATLAS and PSOP participants and families did not constitute a consultation process but were part of an information strategy to inform service providers and consumers about the reforms and subsequent changes to the reforms. Service providers report to NCOSS that the service specifications still remain unclear about how services offered should differ from previous.

NCOSS acknowledges that DADHC established a PSOP hotline and ATLAS hotline, which people and families could call. However there has been no published report on the number of calls to the hotlines or the nature of inquiries of calls. This information would be invaluable to DADHC and the Parliamentary Committee in indicating the concerns and problems of people and families.

The inadequacy of DADHC processes for complaints and appeals is discussed later in this submission.

⁸ *Working Together for New South Wales*, NSW Government and FONGA, September 2004, p7.

⁹ DADHC Regional Service Provider Powerpoint Presentation *ATLAS - PSOP Reforms July / August 2004* on DADHC website

Terms of Reference

1. Program Structure, Policy Framework, Eligibility Criteria

In this section, comments on both programs precede specific comments on each program.

Policy Framework

NCOSS acknowledges the DADHC Policy Framework¹⁰ for the new TTW and CP programs. This framework attempts to explain the reason for the changes and the purpose of the new programs. It further describes broadly what the new programs seek to achieve. Much of the content of the Policy Framework is both acceptable and desirable.

However, there is no mention of how the policy will be implemented in regards to the per capita funding cuts, transfer from individualised to block funding, extensive tendering and review of provider eligibility status.

The Minister's announcements¹¹ and the Policy Framework both state that the new programs will be different from existing service provision. Neither, however, provides any detail on what these differences are and how these innovations would improve on existing ATLAS services.

Program Structure

Many of the broad features of the new programs were changed subsequent to the July announcement such as:

- a) Withdrawal of PSOP program
- b) Withdrawal of CP providers from the tender process
- c) Original statement that unsuccessful TTW participants would receive no further services was reversed to offer a safety net where they could then join the CP program

Similarly, at the time of announcement, many of the broad features of the new programs perhaps had not yet been determined, such as:

- d) How to assist those with very high support needs. In late 2004, the Minister announced an amount for people with Very High Support Needs of \$1.4m.
- e) The mechanism by which an unsuccessful TTW participant can access a CP program
- f) The system by which a participant who was relocating needed to change providers under block grants, later explained through the promise of a vacancy management system, details of which are still unavailable publicly (refer paragraph 49)
- g) Originally whether or not a CP participant can access TTW when ready and then when confirmed, any mechanisms by which a CP participant can be identified as ready and then obtain access to the TTW program.

¹⁰ DADHC Policy Framework *Transition to Work and Community Participation Programs July 2004* on DADHC website

¹¹ Minister Tebbutt's Media Release July 2004

Originally, the Minister announced that the changes were designed to provide certainty to ATLAS families whose program was only ever intended for two years. Families have told NCOSS, however, that none of the above mid-way changes or unexplained features of the two new programs give rise to consumer certainty or confidence.

Transition to Work (TTW)

Service providers have reported to NCOSS that the funding of \$15,699 per annum per person is probably adequate for people with the willingness and capability to achieve employment with support. This requires appropriate assessment and must include a person's willingness, as the programs will not succeed without co-operation from the individual.

There are serious concerns, however, that the two year period of the TTW program may be inadequate for many participants to become ready for transfer to paid employment or Commonwealth employment programs. DADHC explained at a closed meeting in December that there is some flexibility around this and that this will be considered on a case-by-case basis. Minister Tebbutt however insisted that TTW would be restricted to two years only.

The outcome for the TTW program is not well explained. NCOSS is concerned that TTW will be considered successful for a participant if the program was completed and the participant is considered work-ready or eligible to enter a Commonwealth employment program. What will happen to the participant if there is no available employment or no available place in a Commonwealth program? People and families cannot be left completely unsupported for short or long periods of time. Negotiations between Commonwealth and State are critical at this point in order to ensure that:

- The exit criteria (ie outcome) for TTW matches the entry criteria for open employment or Commonwealth employment programs – to avoid policy and procedural gaps; and
- There are available places in Commonwealth programs for TTW graduates upon exit from TTW.

Consequently, participants will enter TTW with no assurance of either employment or entry into Commonwealth programs. This creates a significant disincentive for individuals and families to attempt TTW. Reports have reached NCOSS that some families are initially choosing CP to avoid further uncertainty and family disruption.

Apart from the disincentive for people to move to TTW due to the uncertainty of outcomes and ongoing support (see previous paragraph), there seems to be a structural disincentive for service providers to receive CP people into TTW. This can be explained in the following scenario:

At the beginning of each year a number of TTW places will be identified for new entrants, for example 100 places which continue for up to two years. After two years the same fixed-term funding for the 100 places will be recycled for a new group of entrants. But six people exit to employment part way through the program leaving six places for waiting eligible CP people. DADHC has made a guarantee to NCOSS that any CP person joining a TTW program mid-term will have a complete two-year program. At the end of the original two-year program assuming everyone exits, only 94 of the 100 places become available to the next group of school leavers (the 6 former CP people have not yet

completed their two years). This compounds each year with people exiting and new entrants starting at different times throughout the two-year term.

The above scenario presents several structural dangers. Assuming DADHC is relying on the original number of places after two years to become available to a new group of school-leavers at the start of the following year then increasingly fewer places will be available over time.

Further, service providers might be forced to delay the entry of an eligible school-leaver until a place becomes available. As it is unlikely (but not impossible) that a TTW person will exit to employment within the first year, applicants could wait more than a year to join TTW after leaving school. How will the person be supported during the wait? If they join a CP program, they could be lost in the system or become victim to the structural disincentive to accept CP people.

There is a danger that service providers could be inclined to become very specific about the type of person they accept onto their TTW programs in order to ensure success.

Some TTW people who have successfully transitioned to part-time employment may need CP or day program support on the days not worked. There is no mention of how DADHC will respond to this situation. The reform model does not contain the necessary flexibility to meet the needs of this group.

Community Participation (CP)

NCOSS has received family concerns that CP participants will be 'warehoused' with seemingly little or no hope for the future. They believe that the reduced funding will lead to more and larger group activities. NCOSS contends that people should be supported to the optimum level possible for that particular individual.

Further, the system of access by CP people to the TTW program should be clarified and explained to families.

2. Funding Arrangements for the new programs

In addition to above comments, NCOSS emphasises the concerns of people and families at the per capita funding cuts. There is concern that the original reform funding levels of \$9,000 for most participants & \$13,500 for higher needs participants (with then unspecified supplementary funding for people with very high support needs) amounted to a reduction of up to 50% in the programs of many participants.

With the subsequent announcement that the base funding rate for all CP participants would increase to \$13,500, people and families were now concerned that the cuts were not addressed, but simply modified to a still unacceptable 25% cut in per capita funding for many people.

Very High Support Needs Supplement

The \$1.4m funding supplement for people with very high support needs had not been distributed at the time of writing despite the commencement of programs for new school-leavers on 7 February 2005.

In January 2005, DADHC invited NCOSS to discuss the assessment tool and distribution process for the Very High Support Needs Supplement. NCOSS was concerned that, although previous assessments were not ideal, DADHC wanted to use yet another assessment tool to identify eligible people. DADHC estimated that 400 people were previously identified as people with very high support needs and gave an assurance that the new assessment tool would not be used simply to reduce eligible numbers. Given the level of need of some of the people, an amount of \$1.4m across 400 people would be insufficient to provide necessary support without an even greater reduction in hours of service.

DADHC's major imperative for the first year's supplement was to distribute as quickly as possible, explaining that the process could be refined in future years. To this end, DADHC indicated there would probably be a flat rate per eligible person offered to service providers. DADHC gave an assurance that, should this flat rate prove unviable for providers (ie that the number of eligible people remained high) they would re-assess the situation / amount. The Parliamentary Committee should inquire into the final decision.

DADHC has suggested that, when the individual no longer requires the program, the Very High Support Needs Supplement will remain with the provider until a new eligible person applies with the same support needs. This is a patently inefficient process. Should the person with very high support needs move to another location but still require a CP program, under the DADHC model the high needs person would have to await a vacancy in the new area with exactly the same support needs funding attached. This seems punitive to the person and family.

A better system would involve the return of that supplement to a central distribution pool from where it could be reassigned, possibly at a different amount (either larger or smaller), to the next person who is most in need.

Individualised Funding to Block Funding

NCOSS remains committed to the provision of individualised funding to ATLAS or TTW or CP participants. Many service providers have contacted NCOSS to advise that they were willing to continue with individualised funding because that is what affected people and families want. Efficient providers have managed competently on individualised funding for at least 13 years since 1992.

Service providers argue, and NCOSS agrees, that the losses to people and families in terms of individually targeted programming, flexibility and portability that are inevitable under block funding far outweigh the administrative gains for providers.

In discussions with DADHC about the Very High Support Needs Supplement, despite the policy change to block funding, it has become clear that the provision of this funding operates just like individualised funding. It creates a package of funding that specifically targets a named individual and must remain with that individual while they need it. Whilst NCOSS supports individualised funding, DADHC is clearly sending mixed messages to providers, people and families which is adding to the confusion and anxiety generated by the reforms.

With the withdrawal of PSOP from the reforms, PSOP participants will continue on individualised funding. Many service providers (possibly 160¹²) will accommodate both PSOP and CP participants. So these service providers will be operating simultaneous and parallel systems.

NCOSS is concerned at the loss of portability of programs in the transfer from individualised to block funding for the remainder of TTW and CP users. Portability is the means by which an eligible client currently receiving service can, without a break in service, transfer that support from one locality to another or from one service provider to another, as their needs change.

DADHC reports that the issue of portability will be addressed by a vacancy management system. NCOSS is concerned that, because the proposed TTW and CP will immediately operate at capacity and with reduced funding, a family who needed to relocate could wait an unacceptably long period before being offered another service. The availability of vacancies would depend on someone exiting the specifically required program (either location or provider) probably only through another relocation or death. Further pressures on these vacancies could come from unsuccessful TTW participants or newly identified people entering the system.

NCOSS is also concerned at the loss of flexibility of programs in the transfer from individualised to block funding. Flexibility is the term used to describe the following desirable provider mechanisms:

- The ability to be creative in responding to need;
- The capacity to meet changing needs without disruption to the client; and
- The capability, within broad parameters, to use available funding across program boundaries.

Flexibility will be more easily facilitated where TTW and CP are provided by the same organisation. NCOSS believes that many existing organisations will continue to provide only CP services.

Funding Processes

It is clear that DADHC amended their processes as they went along. Continuity has been an issue, due to changes of staff since the reform announcement. The purchasing and funding process has been complicated by sometimes welcome changes mid-stream. The attached timeline (see appendix 1) details many of the changes.

NCOSS draws the attention of the Parliamentary Committee to the University of Wollongong Classification and Costing Study which was due to report late 2004 or early 2005. This Study is expected to classify the levels of support needs and provide appropriate per capita costings for day services. DADHC has gone ahead with pre-emptive and unwelcome funding and policy changes without awaiting its commissioned study results.

NCOSS is alarmed at the expressed financial impact on families. Families have said the primary carer will lose their employment or have to leave work to support the person at home. This is unacceptable for families relying on two incomes and catastrophic for sole

¹² DADHC Regional Service Provider Powerpoint Presentation ATLAS - PSOP Reforms July / August 2004

parent/carers. The likely financial impact will be to increase demand for full carers pensions and exacerbate the cycles of poverty and dependence that service provision seeks to minimise. Families have stated that young adults are devalued by the reforms and those families feel punished.

Reports have reached NCOSS that several families are having to make the desperate decision to relinquish the care of the person with disabilities to the state government. NCOSS has directly spoken to one such family who has begun this process. In this case, the parents say they have been forced reluctantly into this decision as they feel they can no longer support their much-loved son at home with so little support. Their ATLAS program has been cut from five days to two and one half days per week. They trust and respect their service provider but the reduced hours have forced them to a decision.

His ATLAS service provider has calculated the likely cost to government of the circumstances. After the family relinquishes care of their adult son, it could cost government

- more than \$160,000 pa (individual package) to support him in a non-government group home sharing with three others; or
- in excess of \$300,000 pa (individual package) in a DADHC direct group home sharing with up to four others; or
- If no group home was available, the young man will require 24 hour one-to-one staff support.

This compares to an additional \$6,474 pa to increase their ATLAS program funding to previous levels.

NCOSS has no mechanism for calculating the increased costs to respite and other support services but recommends that the Parliamentary Committee consult with the respite peak body NSW Interchange for advice. Similarly, the flow-on financial impact on Home and Community Care services is not readily calculable due to the diverse nature of services and organisations. For this very reason NCOSS is concerned that any likely increase in demand following the reforms to ATLAS may not be attributed to the reforms themselves unless service providers directly ask consumers. Thus the extent of the wider impact could remain unknown or underestimated.

DADHC reports that \$50 million is currently spent annually on PSOP and ATLAS programs and that annual expenditure will rise to \$54 million in four years. NCOSS estimates that the \$54 million will be expected to provide for possibly twice as many participants¹³ as in 2004; an additional \$4m pa for possibly double the number of participants.

With the proposed reductions in per capita expenditure, NCOSS calculates that there will be a significant fall in overall expenditure in 2005. No plan for these non-recurrent savings has been publicly identified. NCOSS urges that any savings from ATLAS reforms must be publicly announced and re-invested into the ATLAS system.

In its 2005-06 Pre-Budget Submission¹⁴ to the NSW Government, NCOSS has called on DADHC to take action in 2005-06 by:

- Halting the per person cuts to ATLAS participants and re-instating the original funding levels'

¹³ Based on figures given at the DADHC PSOP/ATLAS Parent Information night at Penrith in August 2004

¹⁴ *Better Social Outcomes for NSW: 2005-2006 Budget priorities for a fair and sustainable community* (NCOSS 2004)

- Providing \$13.6m recurrent funding for 5 days per week programs for 2005 school-leavers with disability; and
- Provide \$7.2m recurrent funding to boost the level of ongoing support for all ATLAS participants to 5 days per week.

This represents a total increase in annual recurrent expenditure of \$20.8 million in 2005-2006 to ensure effectiveness. Without this expenditure, NCOSS argues that consequent damage control, unplanned short-term emergency solutions and long term flow-on impacts will be exponentially more expensive than a continuing modest investment in pre-vocational and day support programs.

3. Role of Advocates

In many cases, the only information about the reforms that families received has been through advocates. These advocates comprised advocacy organisations, peak bodies, parent groups and service providers. Their role was not to escalate emotionally dangerous reactions from people and families, but to direct them to appropriate channels. NCOSS has never before been directly contacted by as many people, families, concerned citizens, and school teachers etc regarding a single issue as over the ATLAS Reforms. The strength of concern and anxiety is undeniable.

Several peak and advocacy organisations have been instrumental in keeping people informed. Often the problem was simply the lack of engagement and up to date information from DADHC. While NCOSS acknowledges the ATLAS and PSOP telephone hotlines established by DADHC, families were desperate for information on how the reforms would affect them and how to express the consequences.

In many cases, families turned to their service provider to act as their advocate. Many service providers have been acutely aware of the impact of changes and have proved to be critical supports to families during this trying time. But this has not been consistent across all service providers. The strength of advocacy by providers has depended on the preparedness and commitment of the providers to act as advocates, to understand advocacy separate from service provision and their ability and skills.

NCOSS is further concerned that DADHC did not comprehensively consult with service providers, in the same way that consumers were left almost completely unconsulted. Advocacy is a priority in many of the standards statements governing DADHC funded programs (refer paragraph 76). As such a priority, DADHC could have been more meticulous in briefing advocacy organisations and service providers and then referring people and families.

NCOSS argues that the role of the advocates during the ATLAS reform has been invaluable to people and families by:

- Keeping people informed;
- Empowering consumers;
- Providing information on appropriate channels of dialogue and negotiation;
- Providing a collective voice where people and families were too fearful, anxious or exhausted to act on their own behalf;
- Actively addressing advocacy standards while conducting advocacy activities;
- Providing leadership; and
- Genuinely listening to people and families

4. Exclusion of students for Higher Education

NCOSS opposes the blanket exclusion of higher education students from assistance under the new programs. Students with disability who do not require assistance under ATLAS need not be registered by the programs. All other participants should be assessed as to their needs for support and capacities to complete the tasks of daily living. NCOSS further acknowledges that a modest investment in support for people with disabilities entering higher education could desirably result in improved social and financial independence and thereby avoid expensive possibly unnecessary longer term supports.

While NCOSS acknowledges the obligation of the higher education authority (ie university, college, TAFE etc) to facilitate the learning of people with disabilities, the higher education authority does not provide day supports nor supports outside the learning environment. This is clearly the role of ATLAS. NCOSS has direct contact with an ATLAS graduate who now works as a policy advisor. He suggests that, without that period of support after leaving school and while studying, his life opportunities would have been greatly diminished.

It has been suggested to NCOSS that the assessment of people as potential higher education students may be flawed. NCOSS has been advised that in one case, a school-leaver was asked if they wanted to attend university, answered yes and was therefore eliminated from future TTW or CP eligibility. The family indicated that the person does not have and will never have the capacity to attend any higher education facility and that this should have been obvious to the assessor.

PSOP, ATLAS, TTW and CP should be available to all school-leavers with disability and young adults based on their functional ability and support needs not on their diagnosis or disability type.

DADHC has identified the service user outcomes for TTW including 'supported and effective transition to employment and further education and training' and 'supported access to vocational education and training opportunities'¹⁵. This clearly indicates that support into and during higher education should be provided by TTW.

NCOSS supports the principles of participatory living and objectives of personal assistance described by the Physical Disability Council of NSW in its 2002 publication¹⁶ *Living On Our Own Terms*. This Paper identifies that the traditional notion of 'care' for people with disabilities is outmoded and must be superseded with support for the personal choices and aspirations of people where, when and how they require that support. *Living On Our Own Terms* also sets out desirable principles governing assessments, personal choice, method of service provision and involvement of people with disabilities in decisions that affect them.

5. Assessment methodology

NCOSS has received many concerns from service providers and families about the assessment processes.

¹⁵ DADHC Regional Service Provider Powerpoint Presentation ATLAS - PSOP Reforms July / August 2004

¹⁶ Available on the Physical Disability Council of NSW website: www.pdcnsw.org.au.

NCOSS has been advised that assessment survey forms on existing and potential ATLAS participants completed by service providers and schools were forwarded to the University of Wollongong for classification into TTW or CP programs. The success of such remote decision-making depends on the interpretation, skills and understanding of both the service provider initially and then the receiving classification officer. NCOSS has received numerous accounts of inappropriate assessments. When contacted, DADHC initially advised families and providers that no re-assessments would take place for some months, leaving families angry, anxious and confused.

NCOSS assumes that the University of Wollongong Classification and Costing Study was commissioned and initiated before the present ATLAS reforms were announced. NCOSS believes that the purpose of the Study was to provide information for the development of improved programs, not to be used as a filter or rationing tool. NCOSS supports the notion that human assessments must be done in person if responsive and effective decisions on support services are the objective.

The assessment processes for the Very High Support Needs Supplement have been previously discussed in detail.

6. Complaints and Appeals

At the time of the announcement of the ATLAS Reforms in July 2004, DADHC did not have a published complaints policy. In October 2004, its draft policy was issued but the policy remains in draft to this day. Despite having read all the DADHC complaints material on the website, NCOSS is concerned that the process for making a complaint could remain unclear for people with disabilities and families. The draft policy refers to complaints by non-government agencies and funded organisations. The NSW Disability Standards In Action paper sets the standard on how DADHC expects funded organisations to respond to complaints. It is unclear whether the draft complaints policy meets these standards regarding complaints from consumers.

Similarly Home & Community Care Validation Instrument, the NSW Disability Services Act and new Continuous Improvement Matrix (currently under trial), which equally apply to direct DADHC services or funded organisations, cover the standards necessary for good complaints handling and consumer responses.

DADHC have assured people and families that their complaints about ATLAS would be received and duly handled. Families have informed NCOSS, however that on some occasions complaints they have made have been unacknowledged or ignored, or families have been subtly discouraged from making complaints by being asked to wait for further information, which was either delayed or never appeared and that made were never resolved.

NCOSS acknowledges that recently appointed senior DADHC officers have provided genuine assurances of prompt responses where people and families are unhappy or the system fails them.

7. Outcomes achieved and sustained

NCOSS supports the need for improvement in day programs, including PSOP and ATLAS. NCOSS supports the initial intention of review to align all day programs for people with disabilities, simplify the system, encourage increased efficiencies and synchronise guidelines and program boundaries, both geographical and target populations. These day programs include day therapy programs, community access programs, community participation programs as well as PSOP and ATLAS. At present each of these programs has a particular historical context which may no longer be relevant, consumers are funded at differing funding levels, entry criteria between programs vary, support services are similar and target populations are almost identical.

NCOSS believes that the initial purpose of the review process was to simplify the system, identifying different roles of programs and determining appropriate service provision for adults with differing capabilities, aspirations, life circumstances and support needs. Instead of simplifying the system, the reform process has split one of these programs into two, thereby increasing the complexity of access to and administration of the day programs system.

While DADHC demands evidence-based approaches from tenderers and providers, the Department itself has provided no evidence that the changes are achievable or sustainable.

Service providers could be required to operate parallel programs for people with disabilities using different contract arrangements, different and unequal funding levels, and inequitable access to portability, flexibility and individual attention/support. This situation is not sustainable in the short, medium or longer term. Demand on the system will be exacerbated by the accelerating increase in people with disabilities (estimated to grow 18% between the years 2000 and 2011 compared to an increase of 8% for the general population) and the ageing of Australia's population (predicted to increase 26% over the same period)¹⁷.

NCOSS asserts that further education; vocational training and employment are appropriate and desirable outcomes and goals for people with disabilities.

NCOSS remains concerned that the reforms are not driven by policy improvements but by an unacceptable attempt to reduce expenditure. Conversely, this could result in even greater expenditure on expedient and quick solutions that benefit nobody in the longer term. The Reform process has been unacceptably non-transparent and unclear. The present funding levels are unsustainable and result from extended periods of government non-investment in opportunities for people with disabilities.

For TTW, DADHC should have awaited the results of the Pilots (refer paragraph 9) before instituting change of such magnitude because any negative consequences of such change are visited upon, not bureaucrats, but people and families. The risks to people and families are too great to proceed with change that is not based in firm evidence. This is the loud and clear message from consumers, and many service providers. The funding levels for TTW could be adequate but the time periods may be insufficient.

Data collection and monitoring are critical at this stage but there is no public information on when and how this process will begin. NCOSS fears that it will be considered later and perhaps entirely overlooked.

¹⁷ DADHC Future Directions *Older People, people with a disability and their carers*, August 2004.

It is important to recognise that people with disability whose goals do not include education, training and employment are as just important and should not be relegated to a second tier status. With appropriate support, theirs can also be an important contribution to the community and their value as members of our community should not depend on paid occupation.

Conclusion

ATLAS has provided training and ongoing support for people with disability who have moderate to high support needs. While the major aim of ATLAS has correctly been to prepare school leavers with disability for employment, ATLAS has also worked to assist young adults with disability to pursue life long learning and to develop opportunities for enhanced community participation.

NCOSS has welcomed the prospect of reform to enable improvements to both the ATLAS and the Post-school Options programs and to synchronise the system of day supports and training for adults with disability. The proposed changes announced on 8 July 2004, however, do not achieve these reforms.

The conversion of ATLAS into two programs, Transition to Work and Community Participation, could be an acceptable policy change. But when accompanied by per capita funding cuts, possible changes to providers and loss of individualised funding, the reforms are unacceptable.

NCOSS believes any potential improvements to pre-vocation and day supports for people with disability will be fatally undermined by the reforms. Service providers have advised NCOSS that they were struggling to provide responsive individualised services at the original funding levels. Many providers have expressed the fear that any drop in funding will return service provision to more generalised congregate programs, moving away from the Disability Services Act and Standards of person-centred support.

Appendix 1

Schedule of Events

TIME	EVENT
2004	
8 July	<ul style="list-style-type: none"> ➤ Announcement of reforms to select group
15 July	<ul style="list-style-type: none"> ➤ All service providers received DADHC advice on reforms ➤ No information yet to participants and families
Late July	<ul style="list-style-type: none"> ➤ DADHC established PSOP & ATLAS telephone hotlines ➤ DADHC holds information session for people and families and service providers
13 August	<ul style="list-style-type: none"> ➤ PSOP withdrawn from reforms
August	<ul style="list-style-type: none"> ➤ Decision to directly tender only the TTW program ➤ CP providers would be reviewed by DADHC officers re: capacity to continue to provide programs and per capita cost of service
August/September	<ul style="list-style-type: none"> ➤ Many community meetings of participants and families across NSW ➤ Huge sector and community outcry in protest to the changes ➤ DADHC commenced review visits to service providers ➤ DADHC PSOP and ATLAS Hotline established ➤ Assessments on ATLAS participants conducted
22 September	<ul style="list-style-type: none"> ➤ Rally at Parliament House, 2500 people attended ➤ Meeting inside Parliament House to protest the changes ➤ Minister attends small meeting, <ul style="list-style-type: none"> ○ promises that families will be notified of the results of their assessments by end September ○ promises that no family will receive a cuts in hours of service
October	<ul style="list-style-type: none"> ➤ TTW tenders advertised, announcements expected by end October ➤ 2 short notice email requests to service providers from the Minister regarding operating costs and capacity to provide ➤ DADHC holds information meetings for families in regions
November	<ul style="list-style-type: none"> ➤ TTW tender announcements ➤ High Needs Supplement of \$1.4m announced ➤ CP base funding increased from \$9000 to \$13,500 per person ➤ Commencement of reforms to existing ATLAS participants delayed until 2 April 2005 ➤ Families notified of assessment results ie their participant's eligibility for TTW or CP program ➤ Families asked to identify preferred TTW or CP providers from a short list
December	<ul style="list-style-type: none"> ➤ Parliamentary Inquiry announced ➤ DADHC working party to devise assessment tool and distribution process for High Needs Supplements
January 2005	<ul style="list-style-type: none"> ➤ University of Wollongong Study contracted by DADHC (prior to reforms) into costs of providing daytime support services to school-leavers with disability not yet released – expected soon ➤ University of Wollongong Study contracted by DADHC (prior to reforms) into service models for providing daytime support services to school-leavers with disability not yet released – expected soon
February	<ul style="list-style-type: none"> ➤ School-leavers commenced TTW & CP programs 7 Feb, no high needs supplements yet available ➤ Parliamentary Inquiry advertised