INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

Organisation: Access Community Education Services Incorporated (ACES Inc.)

Name: Mr John Faithfull

Telephone: 02 6581 2348 **Date Received**: 04/03/2005

Subject:

Summary Joint Submission with IDAFE Inc. (Individual Development and

Further Education Incorporated). Contact there is Jenni Steele (Ph: 6583 5545). PO Box 1906 PORT MACQUARIE NSW 2444, email: idafe@dodo.com.au. ACES Inc. has agreed to be chief

contact.



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RECEIVLD

Ph: 65 812348

Fax: 65 812373



7 Fernhill Rd, Port Macquarie 2444 (PO Box 2455)

Email: aces@tsn.cc

3 March 2005

The Director N.S.W. Legislative Council General Purpose Standing Committee No. 2 Inquiry into Changes to Post School Programs for Young Adults with a Disability

Dear Director,

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

Please find enclosed a joint submission by the two ATLAS/PSO service providers in the Hastings Local Government Area in relation to the Inquiry into Changes to Post School Programs for Young Adults with a Disability.

This submission is intended to outline numerous issues that fall within the Terms of Reference of the Inquiry. It is anticipated that the issues outlined will raise many questions about how the subject changes have been handled.

We would welcome an opportunity to address the Committee with more detailed evidence concerning the points we raise, and to this end we are available at the Inquiry's convenience.

Yours faithfully

ACES Incorporated and IDAFE Incorporated

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

N.S.W. Legislative Council General Purpose Standing Committee No. 2

Joint Submission by Port Macquarie Disability Support Service Providers

ACES Inc.

(Access Community Education Services Incorporated)
7 Fernhill Road (PO Box 2455) Port Macquarie NSW 2444
E-mail aces@tsn.cc
Contact Person John Faithfull

and

IDAFE Inc.

(Individual Development and Further Education Incorporated)
198 Hastings River Drive (PO Box 1906) Port Macquarie NSW 2444
E-mail idafe@dodo.com.au
Contact Person Jenni Steele

Background

ACES Incorporated is a non government community based, charitable organisation that supports approximately 50 people with an intellectual disability from the Hastings and nearby local government areas to develop social and living skills and to access the community. ACES is a PSO/ATLAS service provider and has been accredited as a Community Participation service provider under the latest disabilities sector reforms. ACES was founded in 1992 and it has a solid track record in supporting its service users to achieve their individual goals.

IDAFE Incorporated is also non government community based, charitable organisation. It currently provides quality service and support to 33 people with a disability living in the Hastings local government area. IDAFE has been a provider of Post School Options and ATLAS programs since 1997 supporting over 50 people in an 8 year period. During the past 8 years IDAFE has transitioned an average of 30% of its client base onto employment through these two (2) programs. The organisation owns its own day program centre, which in 2002 was extended to a purpose built facility to cater for many of our clients who have significant and complex needs.

ACES and IDAFE have worked together, sharing resources and commitment to ensuring choice, quality of service and support for people and families with a disability so that they can achieve greater participation in community life. The introduction of the reforms and their shortfalls has been documented by both services and will be covered in the points addressing the terms of reference of this inquiry. Our aim is to protect the rights of people with a disability and support those families who have been placed in a very stressful situation by the NSW Government and its Department of Ageing Disability and Home Care (DADHC).

The decision to cut individual funding accompanied a review of service support and delivery. There was no prior consultation with primary stakeholders in regards to funding cuts, and therefore the impacts on individuals and their families or carers was not taken into consideration. The information provided in addressing the terms of reference will clearly indicate non-compliance with the NSW Disability Service Standards by DADHC and DADHC's contempt and disregard for people and families with disabilities.

POINTS ADDRESSING THE TERMS OF REFERENCE

- 1. The program structure and policy framework, including eligibility criteria, for the new Transition to Work and Community Participation Programs.
- 1.1. At the outset, it must be noted that implementation of the ATLAS program was an act of political expedience and a stepping stone to an even greater denial of resources for people and families with disabilities. From a consumer perspective, the PSO program provided more appropriate, but often inadequate, funding levels than ATLAS and now its replacements Transition to Work and Community Participation. From a service provider perspective, the PSO program was more capable of being adapted to the individual needs of consumers. From a State Government perspective, the change from PSO to ATLAS was simply the implementation of its agenda to reduce funding and program duration for individual school levers with disabilities so that it could pursue more politically viable spending initiatives. ATLAS was the precursor to even harsher cuts in individual funding and it signaled the death knell of the ideals set out in the Disability Service Standards. It is undeniable that as a mechanism for the allocation of resources, the State Government has shifted funding to areas likely to buy more votes or has failed to address serious inefficiencies in DADHC's bureaucratic processes.
- 1.2. The premise upon which the ATLAS reforms are based is a "political red herring".

 "Employment Outcomes" is an inappropriate primary measure of policy performance for people with intellectual disabilities. This was the major criterion used by DADHC to drive a cost cutting agenda, and on this basis the entire reform process is flawed. Such a measure takes no account of the lack of real employment opportunities at the skill levels of the target group, especially in rural and other high unemployment areas. Whilst employment outcomes may be a useful minor measure of policy performance, more appropriate measures could include family functionality, family well being, opportunity to participate in the community (each relative to societal norms), and the level of an individual's actual independence (relative to that person's potential for independence). The use of employment outcomes as a measure indicates an underlying economic agenda that has little or no relevance to the needs and human rights of people and families with disabilities.
- 1.3. There was and continues to be, a lack of transparent policy in relation to the reforms and programs: There are no policies or if there are, they are not easily accessible or transparent. For example, in January 2004, services were referred to the soon to be redundant ATLAS policy for direction on transport issues for the Community Participation program. Information about the reform process has been relayed to service stakeholders on an ad hoc basis and usually over the telephone by middle managers who claim to be just "messengers" who cannot clarify the content. For instance at a Question and Answer session with DADHC middle management at Coffs Harbour on 24 November 2004, answers given by the middle managers to a series of highly relevant questions asked by service providers were predominantly "I cannot comment on that". There has been little or no structure to the information flow in either timing or content and there has been inconsistency in the information provided see the following point.
- 1.4. The policy information that does manage to filter through from DADHC is inconsistent and confusing: According to a DADHC presentation in August 2004 about the changes, Transition to Work participants who do not achieve a work outcome can transfer to Community Participation. However, a Question & Answer paper provided by DADHC about PSO, says that PSO participants who are work ready will be exited from the program. There is no information that clearly defines "employment outcome", but it is considered reasonable to assume that this means that a person will obtain paid employment. Therefore people on Transition to Work who do not obtain employment can transfer to Community Participation.

Contextually, the use of the term "work ready" implies that a PSO participant can be exited from the program without an employment outcome.

- 1.5. **DADHC** withheld information policy and program structure. When asked for information that could be passed to parents and carers about the planned PSO changes at the ATLAS PSO Day program conference at Coffs Harbour on 31 March 2004 an SSDO said "Don't tell them anything, we don't want to cause undue alarm".
- 1.6. There is ongoing confusion and fear about the eligibility criteria for service providers and the use of the criteria to actually determine eligibility. DADHC officers have verbally provided "unofficial" benchmarks for service providers to satisfy in order to be eligible to provide Community Participation services. Apart from the unofficial nature of the benchmarks, further confusion has been created because the benchmarks have changed over time. Services have been concerned at the unwillingness of DADHC officers to provide written confirmation of information such as benchmarks. Often, verbal communications about eligibility criteria have been accompanied by threats that service funding will be withheld should the benchmarks not be met. Service providers can provide evidence of feeling intimidated by the nature of the approaches, and there is a common belief that DADHC has employed "divide and conquer" techniques and duress to get individual services to commit to unachievable benchmarks.

Another example of the questionable application of the criteria is the insistence by one DADHC Service System Development Officer (SSDO) that a particular new service user be allocated benchmark hours (despite their unofficial nature), which includes sharing of services with other service users. This is despite the express wishes of the service user (through his family) that fewer hours of one on one service were required because of that person's particular support needs. In other words, choice was not an option for the service user and this is a breach of the Disability Service Standards.

In relation to the determination of eligibility, DADHC has notified services and service users of a number of significant deadlines for the implementation of the changes e.g. advising service providers of which school leavers have been determined eligible for service. In many instances these deadlines have been missed, service stakeholders have not been informed and considerable stress and confusion has resulted.

- 1.7. The eligibility criteria for supplementary funding for high support needs service users were not available just weeks before the implementation of changes. Uncertainty about support levels for high needs service users at such a late stage in the process demonstrates an absolute disregard of human rights for those affected. It also demonstrates profound ignorance on DADHC's part when it comes to establishing priorities relating to some of the most vulnerable people in our society. Notably, DADHC demanded detailed preliminary information from service providers about service users likely to be nominated as requiring supplementary funding on 18 November 2004, and gave 2 days notice for services to respond with information. More than 3 months later DADHC had not responded with criteria that would allow for formal applications to be made for supplementary funding.
- 1.8. The changes give insufficient weight to the development of social and living skills for participants in the Transition to Work stream: There are well based concerns about the ability of employment services to provide support in developing living and social skills in Transition to Work program. These skills are essential prerequisites for employment. For example, one service whose primary role is to provide employment services insisted that one of its clients use a written shopping list as part of his living skills program. Many weeks later a review of the program revealed that the client could not read nor could he see sufficiently to read had he been able to. This further illustrates the risk that inappropriate emphasis of particular program outcomes (e.g. employment) can result in less than optimal performance

and have far reaching impacts on self-esteem and confidence of service users. Under the ATLAS/PSO program some services entered into partnerships in which one focused on living and social skills support while the other focused specifically on the development of job skills and job placement. The separation of the roles helped to ensure that service users had appropriate living and social skills in order for them to be able to sustain a job should they be fortunate enough to get one.

- 1.9. The annual funding cycle for Transition to Work does not match the academic cycle. This is likely to result in a scenario where Transition to Work participants start their program after applications for training placements close. If this occurs, significant amounts of time in the 2 year Transition to Work program may be lost due to the mismatch in timing.
- 1.10. The fact that people with PSO packages have higher levels of individual funding than more recent school leavers points to a major inequity in the policy with regards to the recognition of support needs. Nothing more needs to be said other than:
 - 1.10.1. PSO and more recent school leavers belong to the same target group;
 - 1.10.2. The only things that differentiates PSO and more recent school leavers is their respective levels of funding and the year that each left school;
 - 1.10.3. On these observations, DADHC is perpetrating a gross injustice by funding the two groups at different levels.

Whilst some of foregoing points are about system deficiencies, not policies or eligibility criteria per se, they raise significant questions about the competence of senior officers within DADHC to effectively and efficiently develop and implement policy. An alternative view may be that the senior officers are competent, but the political agenda that they have been directed to implement is unachievable. Whichever is the case, from a service stakeholder perspective, there have been many months of stress and confusion caused by uncertain and inconsistent information and what appears to be an ill-defined and ad hoc reform process. Many people, including DADHC staff, have experienced stress related illness attributable to a disgracefully inadequate planning and implementation process. Service standards have suffered, and the functionality of families and other support networks for service users has diminished. One measure of the impact of the changes is the increase in numbers on respite care waiting lists.

- 2. The adequacy and appropriateness of funding arrangements for the new programs.
 - 2.1. The Block funding of services, particularly those in rural areas, will seriously impact on the ability of clients to choose services or transfer between services. It seems reasonable to assume that DADHC will not allocate more places in services throughout the State than the number of service users on its records i.e. services will have no excess capacity to accommodate additional service users who wish to transfer to the service. This creates a "gridlock" situation for all services except for the somewhat unlikely event that service users at different services wish to "swap" places. A more appropriate model would be to provide core funding to services to cover administrative costs.
 - 2.2. It is impossible for services to meet DADHC's benchmarks whilst complying with the Disability Service Standards. DADHC has unofficially set a number of benchmarks for service providers, the most recent being \$25 per hour of service or 12 hours per service user per week for the \$259 per week (\$13,500 per annum) funding for Community Participation. This means that no Community Participation service user will receive services that are capable of fulfilling the Disability Service Standards (DSS) at all times. For instance, the benchmarks will dictate that a significant component of services will be shared and centre-based according to a set program. This raises issues with DSS's relating to participation and integration into the community; valued status; decision making and choice; individual needs; and, privacy, dignity and confidentiality. It will also impact on services' ability to comply

with the DSS relation to service management, industrial relations and Occupational Health & Safety obligations.

2.3. Community Participation and Transition to Work funding levels are inadequate. Prior to leaving primary school, people with disabilities can access school, out of school hours support services and vacation care at little or no cost. In high school people with a disability no longer have access to subsidised out of school hours support or vacation care. This reduction in support often has a serious impact on family functionality in that carers' fatigue levels rise and their availability for employment is reduced. This results in a reduction in coping abilities and diminished financial independence.

Nevertheless, even at high school, people with disabilities can access up to 30 hours per week of time interacting with people other than their primary support network and gaining education. Anecdotally, most families with a disability can remain functional when their son or daughter can be supported by others to this extent.

Upon completion of high school, families with a disability are faced with the prospect of either no support due to ineligibility for Transition to Work or Community Participation, or if they are eligible, much reduced hours of support when compared with what was available during school years. This phase coincides with the additional burdens of transition to adulthood by their son or daughter with a disability. Again anecdotally, this is often the turning point at which families loose independence and begin to rely more heavily on social supports for their existence. Their quality of life often diminishes to a subsistence level or less. Given their wish, most families would require services on a minimum of 5 days per week for at least 3 hours on each of those days. This would give them a break in their often intense caring roles, or allow them to attend to needs other than those of their son or daughter.

- 2.4. The supplementary funding pool of \$1.4M for the whole of the State is insufficient. This observation is made more relevant when considered from the perspective that base funding levels are inadequate to begin with. To illustrate the point, if the \$1.4M was shared amongst half of the current service users in the State, each would receive less than \$20 per week in supplementary funding. Using DADHC's benchmarks, this amounts to less than one additional hours of support per week.
- 2.5. The cost study being conducted by the University of Wollongong prior to the announcement of the ATLAS/PSO reforms was mysteriously halted before completion. It is expected that the study would have produced results that would have conflicted seriously with the arbitrary benchmarks set by DADHC and the political agenda behind them.
- 2.6. Based on available data, it appears that the DADHC bureaucracy absorbs almost 60% of the funding available to the post school/day support programs for administration and that the value received for this cost is negligible. Data extracted from the Commonwealth, State and Territories Disabilities Agreement (CSTDA) and performance reports on the agreement indicates that in the 2002/3 financial year the Commonwealth and State contributed an average funding in the range of \$36,000 (\$750 per week) to each service user in the target group. The source documentation shows that there is a growth component for subsequent years.

The fact that DADHC is making available just \$259.00 per service user per week (in 2004/5 terms) in the Community Participation program begs a question about what happens to the money that doesn't reach services. This revelation becomes even more alarming when considered in the context that some service providers have not had a visit from an SSDO for up to 5 years.

Almost without exception, once a service user is placed with a service provider, DADHC's involvement ceases other than to provide funding and process acquittals for that funding. This raises a huge question about why DADHC exists in this program area at all. Even if the 60% figure is overstated and DADHC only took 10% of the available funding, the question must be posed about the value it would add to service user outcomes for such a cost.

If the funds made available under the CSTDA were applied primarily to service provision, and not to fuelling an ineffective and inefficient bureaucracy, the debate about the adequacy of funding for direct service provision would not be occurring. It appears that there are adequate funds already in the system. The tragedy is that rather than reduce the cost of bureaucracy, DADHC has chosen make families with disabilities carry the load of its excesses. To add insult to injury, DADHC has unofficially told service providers that administration costs of any more than 25% of the funding provided to services is unacceptable.

- 2.7. Small community based organisations are efficient service providers and they produce a number of economic and social benefits. Views have been expressed by DADHC that small, community based organisations are inefficient and hard to administer (by DADHC). This opinion overlooks the several important facts:
 - 2.7.1.Unlike most large organisations, DADHC for example, community based organisations reflect the true needs of their service users if they did not they would not exist;
 - 2.7.2. Where more than one community based organisation exists within a catchment area, they provide service users with greater choice, and the competition (albeit friendly) between service providers often results in greater innovation and variety in service options;
 - 2.7.3.By their nature community based organisations engage the community in the form of volunteering and donations and this more than offsets the administrative inefficiencies associated with small organisations;
 - 2.7.4.Community based organisations provide an effective means for the integration of people with disabilities with the community;
 - 2.7.5. Large, centrally based organisations are more likely to be driven by political and economic agendas that often overlook local needs and the rights of service stakeholders:
 - 2.7.6.Because community based organisations are more responsive to local need, families with disabilities remain more functional and thus less dependant on more costly forms of social support such as health care, accommodation and respite services; and,
 - 2.7.7.Because community based organisations are more responsive to local need, the quality of life of service stakeholders is enhanced and the broader community is enriched because people with disabilities form a genuine and meaningful part of it.
- 2.8. During the implementation phase of the Community Participation program, some service providers were directed unofficially by DADHC SSDOs' to use funding from other programs because Community Participation funding was not yet available. This direction is in gross violation of the DADHC/service provider funding agreements, and it is a further indicator of poor state of management within DADHC. One service provider that declined to use funds in contravention to its funding agreement was threatened with having their service users transferred to another service.
- 3. The role of advocates, both individual and peak groups in the consultation process.
 - 3.1. The implementation of the changes has been plagued by much chaos, and this alone is proof that the initial consultation process was a failure. It is believed that the following factors contributed to this outcome:
 - 3.1.1.DADHC did not disclose crucial information about funding:
 - 3.1.2.Deliberate or not, the failure to disclose this information points to serious systemic deficiencies within DADHC;

- 3.1.3.DADHC did not apply sufficient skills and resources to the facilitation of the consultative process, and this is evidence by the extent of the reaction by other stakeholders when the changes were announced;
- 3.1.4. The consultative groups associated with the reforms were not adequately representative and this is evidenced by their failure to identify major issues relating to block funding;
- 3.1.5. The logistics and costs of participating in the consultative process were beyond the means of many service providers, and they are generally too under-resourced to participate appropriately had they been given the opportunity;
- 3.1.6.No consultative group, no matter how representative, could be expected to perform effectively without all relevant information about the issues being considered; and,
- 3.1.7. There is a commonly held view that organisations such as ACROD did not take an appropriately assertive advocacy role in the consultative process and subsequent campaign, opting rather to be conciliatory in the face of the completely unrealistic, unreasonable and stubborn position of DADHC.

3.2. People and families with a disability do not have a sufficiently strong political voice and this is evidenced by the following:

- 3.2.1. The Former Minister, the Honourable Carmel Tebbutt and Senior DADHC officers have said that that the change agenda was based on economics and was driven from a Treasury perspective;
- 3.2.2.It is clear from these statements that people and families with disabilities are not represented to the extent required for them to receive consideration based on equity and justice;
- 3.2.3. The lack of political representation is further evidenced by the fact that the politicians and DADHC officials pushed forward with the changes believing that the sector would accept what is being proposed without complaint;
- 3.2.4. The last point demonstrates at best a complete lack of political and bureaucratic awareness of the needs of people and families with disabilities, and at worst, a culture of arrogance that caused decision makers to assume that they could just "steamroll" other stakeholders; and,
- 3.2.5.If people and families with disabilities had a sufficiently strong political voice, politicians and bureaucrats would be more wary about trying to steamroll change.
- 3.3. In the absence of having a political voice, advocates for people and families with disabilities ran a campaign of "interference" against the changes with the objective of bringing awareness to the unjust aspects of what was being forced upon them. As negative as the campaign was it had five major achievements:
 - 3.3.1. The government overturned its decision to include PSO;
 - 3.3.2. Base funding levels for Community Participation were raised from \$9,000 to \$13,500;
 - 3.3.3. The implementation of the changes was delayed;
 - 3.3.4. This inquiry was initiated; and,
 - 3.3.5. Service stakeholders have become more united and aware of the need to be recognised politically, and there is an active movement towards achieving this objective. Politicians should be aware that they will be under considerably more public scrutiny in relation to their support for people and families with disabilities in future.
- 3.4. As the person who occupies the most senior advocacy role for people and families with disabilities in the State, the current Minister for Disabilities has far too many portfolio responsibilities to be properly representative of such a significant group in the community.

- 4. The impact of the exclusion of students enrolled or proposing to enroll in post secondary and higher education from eligibility for assistance under the new programs.
 - 4.1. Experience shows that service providers can often give the support needed to "bridge the gaps" between non-participation and successful participation in further education. In the Hastings people with disabilities already face increased barriers to entry to institutions such as TAFE because of the rigid rules surrounding participation in courses. This results in a low enrolment rate for people with disabilities who are often put off by the lack of encouragement and support they receive from within institutions. Service providers work with service users to enhance the skills needed to overcome these obstacles. Entering a tertiary education institution can be a daunting experience, even for those who do not have a disability. In many cases, it is the "behind the scenes" involvement of service providers that enables participation by service users in further education opportunities and the achievement of great success stories.
- 5. The appropriateness of the assessment methodology used to identify school leaver support needs and to stream school leavers into the new programs.
 - 5.1. Research indicates that the assessment of levels of disability is based on Australian Bureau of Statistics derivations from the World Health Organisation standards and these derivations do not provide sufficient clarity on intellectual disability, particularly in the areas of behavioural and cognitive impairment. People with intellectual disabilities, the target group of Community Participation and Transition to Work Programs, are disadvantaged at the outset because their level of disability is often grossly understated due to the inadequate definition of their levels of disability. Using a local example, one service user who has a drivers' license and regularly drives a car has the same level of funding as another service user whose head is braced to his wheelchair by metal rods and cannot move independently. This shows that before the assessment of school leaver support needs can commence, there needs to be a major overhaul of the national model for the assessment of levels of disability. Refer to the relevant definitions.
 - 5.2. The assessment methodology used to identify school leaver support needs is seriously defective. This conclusion is based on the following observations:
 - 5.2.1. The assessment instrument is administered by organisations whose core business does not involve support for people with an intellectual disability;
 - 5.2.2. The assessment instrument is of questionable value when it comes to its accuracy in reflecting the true level of disability and needs i.e. it provides no proper measure of the level of disability to enable proper assessment of need.
 - 5.2.3. The assessment instrument lacks integrity in that it does not clearly indicate the source of data i.e. whether or not it was the person with the disability or another support person (who may not know the service user well) who provided the information, nor does it verify the accuracy of and such data recorded.

A similar assessment methodology was used in 2002 for ATLAS participants and the process was administered by one of the organisations engaged to conduct the current round. There are numerous examples of inappropriate categorisation of levels of disability in the last round.

- 6. The adequacy of complaints and appeals mechanisms established in relation to the implementation of the new programs, and particularly with respect to assessment decisions.
 - 6.1. There was no transparent or obvious complaints or appeals mechanism for service providers. Service providers have been subjected to threatening and divisive tactics by DADHC. On one occasion when one of the authors' organisations protested in writing about the duress being metered out by DADHC, a senior DADHC officer made verbal contact with the complainant and summarily dismissed the complaint. In another instance, complaints

were made by a service provider to two separate DADHC officers after the service provider was told by DADHC to accept unfunded service users or risk the loss of future funding, The complaint fell on deaf ears.

- 7. Whether appropriate and sustainable further education and vocational training and employment outcomes for people with disability are likely to be achieved as a result of these changes.
 - 7.1. It is believed that in the Hastings Local Government Area, there will be no noticeable improvement in further education and vocational training and employment outcomes for people with disability as a result of the changes. This conclusion is based on the following observations:
 - 7.1.1. There already exists a partnership between service providers and a specialist employment service for people with a disability that provides a balanced blend of support for social and living skills and access to employment;
 - 7.1.2.If the blend of support for social and living skills and access to employment becomes imbalanced, success rates will be adversely affected;
 - 7.1.3.Employment and tertiary educational opportunities are limited for all people in the Hastings area, not just those with disabilities;
 - 7.1.4. The management of relationships with employers of people with disabilities requires high levels of specialised skill to ensure ongoing access to already limited job opportunities;
 - 7.1.5. Any unskillful dealings with such employers will jeopardise ongoing opportunities;
 - 7.1.6. Funding levels for new entrants and existing ATLAS service users will be less, and therefore less support will be available to participants in the Transition to Work program; and,
 - 7.1.7. Due to reduced individual funding levels, people placed in the Community Participation program will have fewer opportunities for individual support when pursuing further education goals, and this will make an already difficult job even harder.