

**Submission
No 93**

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

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Date Received: 07/03/2005

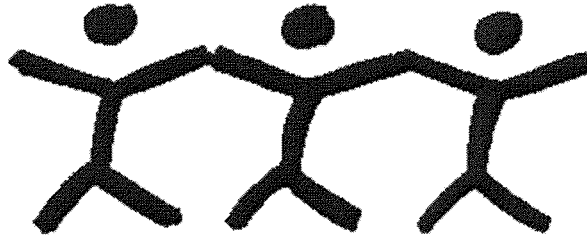
Subject:

Summary

Legislative Council
GENERAL PURPOSE
STANDING COMMITTEES

7 MAR 2005

RECEIVED



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A submission to the
N.S.W. Legislative Council's
General Purpose Standing Committee No.2
for the

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

March 2005

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An Introduction to Fairfield Community Resource Centre

Fairfield Community Resource Centre (FCRC) is an independent non-profit community based organization currently providing programs and services in the Fairfield Local Government Area across five teams: Children's, Community, Employment and Training, Youth and Disability Services.

Vision Statement

FCRC believes in a society where all individuals have opportunities to participate and enhance their quality of life.

Mission Statement

FCRC seeks to assist the community in overcoming barriers to participation by:

- providing quality services and programs which respond directly to community needs
- actively engaging in community development
- advocating on behalf of individuals and groups.

Values and Outcomes

FCRC is committed to putting these values into practice to achieve positive outcomes:

- We aim to empower service users, encouraging independence and inclusion into society.
- We will provide a safe environment which is accessible to everyone, where diversity is promoted, individuals are not discriminated against, and confidentiality is respected.
- We will work in a professional, creative, ethical and pro-active way, engaging in partnerships with other bodies where appropriate.

Strategy

FCRC aims to provide services to the community of south west Sydney that improve financial, social and environmental wellbeing where it is in the best interests of the community that these be provided by FCRC.

FCRC's Disability Services

FCRC's Disability Services team operates the Post School Options (PSO) program and, until the reforms came into effect in 2005, also operated the Adult Training and Learning and Support (ATLAS) program.

FCRC successfully tendered to operate the Transition to Work (TW) program and the Community Participation (CP) program following the reforms.

FCRC addresses the Inquiry's Terms of Reference:

1. The program structure and policy framework, including eligibility criteria, for Transition to Work and Community Participation Programs.

Out of twenty-four service users in the two new programs, FCRC has been provided with funding for eight Transition to Work participants as a result of decisions made based on the first round of preferences.

Slow decision-making process

The second round of preferences is yet to be determined. The decision-making process has been extremely slow, and this is very obviously affecting not only service providers' capacity to plan and structure training under the new programs, but also the service users' families, who are placed in the difficult and stressful ordeal of not knowing what their children's future will be, nor how to plan around it themselves. Furthermore, the slowness of DADHC's response is also deeply affecting the cognitive ability of service users. The longer they remain out of programs, the more rapidly any skills they may have attained under the ATLAS program deteriorate, undoing much productive effort on their part and on the part of the service providers.

FCRC has been provided with no information about why this process is taking such a long time. No progress reports have been provided by DADHC, which compounds the confusion and anxiety for all concerned who await DADHC's decisions.

Confusion over eligibility criteria

The policy framework for the new programs contains no information on the specific criteria constituting the high support needs of a service user. The onus has been on the service user to provide documentation supporting a family's claims that their child has high support needs. This has been a frustrating process for FCRC and the families concerned who all feel as though they are working in the dark with DADHC on this most important issue.

Three new people have already been allotted a place within FCRC's disability services. As yet, FCRC has still not received any information about the medical condition and background of the three new service users, nor have their assessments been provided to FCRC. This makes it extremely difficult for FCRC's disability workers to know of any known potential behavioural problems that could arise in the course of these users' participation in our services. Not only does it make client-centred service delivery in accordance with DADHC's specifications difficult to plan, but it also means that the users are not being given the correct consideration due to them. Workers are left to find out about their conditions based on trial and error, which is simply not good enough, but which is the only option left to them when information from DADHC has proved to be so difficult to obtain.

Poor management of service users' records

The issue of DADHC's seeming incapacity to manage the maintenance of service users' records is one that continually arises. FCRC was recently allocated a client for the Transition to Work program who, as it turned out, was blind. It is extremely difficult to conceive that DADHC apparently had no record of the client's blindness. However, it would seem that this was the case, as DADHC, when contacted, were clearly unaware of this and had no corresponding record of the user's condition.

In the past, FCRC has encountered numerous instances where service users' details do not change on DADHC correspondence, even though DADHC would have been informed of these changes by FCRC. This is particularly so with regard to funding variations. In some cases, participants have transferred from one of FCRC's services to another service. DADHC has been informed in writing of any transferral from FCRC's services that has occurred in the past and yet, the names of those participants whose transferral has long come into effect still appear on FCRC's funding agreement with DADHC, despite correspondence from FCRC informing DADHC of the changed circumstances.

Insufficient DADHC case management

Another issue of significant concern is the lack of sufficient and supportive case management provided to service users by DADHC. The stress on parents of managing often severely difficult behavioural problems has not been relieved by the case management provided by DADHC. It is frequently the situation that families in these circumstances are given a behaviour management plan by DADHC's case workers, and yet do not receive any training whatsoever on the implementation of this plan.

The obvious lack of support that families are receiving in this regard is reflected in the fact that, instead of contacting their DADHC case manager, parents and carers often contact Gail Katronis, FCRC's disability services co-ordinator, for this type of support, when it should not fall into our co-ordinator's role to pick up the slack in DADHC's service provision, nor to lobby for this essential service on behalf of families who quite often feel completely neglected by the system imposed by DADHC.

2. The adequacy and appropriateness of funding arrangements for the new programs.

Previously, individual funding was available to school leavers entering the ATLAS program. Under the new arrangements, block funding has been established for school leavers entering Transition to Work and Community Participation.

Discriminatory consequences of block funding

FCRC would like to stress that block funding causes great problems for service users exiting programs who may later find it necessary to return to a program. Without their own individual funding package available, service users are subject to a system that is too inflexible to sustain their needs. Without having the freedom to enter and exit the programs with their own transferable funding, service users are heavily reliant on there being a funded place available in a service accessible to them, so that they are not forced to travel exorbitant distances in order to be part of a program. If there are

no funded places available within reach of their local area, the families of service users, already under significant strain in Fairfield due to the high costs of medical and other expenses, may be forced to bear the costs and disruption of relocation in order to be able to give their disabled family member the opportunity to access the program and valuable training.

The consequences of this will be very serious for all families wishing to participate in the programs and raise significant concerns about access and equity under the new funding arrangements.

Furthermore, under block funding arrangements, it is left to the discretion of the disability service provider to make decisions as to the quantity of care provided for service users. Previously, under individual funding arrangements, service providers were required to spend the money allocated to each individual directly on that individual's skills development. The change in these funding arrangements brings about two undesirable situations, both equally unfair to service users.

The first is that the pressure on participants and service providers to produce employment outcomes will no doubt mean that more funded days are provided to Transition to Work participants than to Community Participation participants, who are less likely to gain employment. This will create discrimination against those in the Community Participation program.

The second situation anticipated by FCRC is that those with low support needs will miss out on receiving the same amount of funding being spent on their skills development by service providers through the program, due to the fact that their needs will not be so urgent on a quotidian basis. More funding is required to provide adequate service to those with high support needs, whose intensive needs simply cannot be ignored. Long term, however, this discrepancy, necessary under the reforms, will have the negative effect of reducing the capacity for those with low support needs to be provided with the attention and the stimulation necessary to effective skills development. The block funding arrangements will have the unintentional but discriminatory outcome of punishing participants with low support needs, simply because of the unsustainable way in which providers are expected to deliver services as a result of the funding cuts and the block funding arrangements.

The situation is in both of the above cases highly inequitable and, unfortunately, often unavoidable for disability service providers who still aim, in spite of the difficult circumstances, to provide a client-centred service of a standard that meets that outlined in the Disability Services Act.

All service providers have been informed that there is a 'funding pool' available from DADHC for those service users with high support needs. As yet, even following our attempts to inquire about this funding pool, FCRC has been provided with no further information as to the details of how to apply for this funding and what kind of funding is actually available. It is now March and service users, some with high support needs, have already commenced participation in the programs. Still, no information has been forthcoming from DADHC.

Forced reduction in staff

If DADHC expects service providers to continue to deliver services to the same number of participants as before, even with reduced staff as a result of the funding cuts, then the assumption could be made that DADHC is encouraging service providers to breach their occupational health and safety obligations under the Disability Services Act. If DADHC is not prepared to make allowances for the fact that service providers need to be able to offer adequate duty of care to clients, then essentially DADHC is funding organizations to contravene the Act.

The bottom line of the reduction in funding is that disability service providers have been forced to reduce staff in order to accommodate program participants for the number of days per week necessary to their skills development. However, this has also meant that service providers are put in the difficult situation of maintaining duty of care with reduced staff. What this inevitably means is that the provider is forced to reduce the number of participants that it can sustain, thereby leading to a reduction in the numbers of places locally available to young people with a disability.

For FCRC, this has meant carefully juggling the amount of days offered to program participants in order to be able to retain the same number of staff and to thus provide the same level of care over forty-nine weeks of the year. By doing so, FCRC has been conscious of meeting families' expectations of the quality of care received by the participants. On reduced days, however, there is the high likelihood that skills developed by program participants during their time at school will deteriorate rapidly following their entry into the programs. This is due to no fault of the disability workers nor service providers, but rather is a situation forced on everyone concerned by DADHC's funding inadequacies.

Lack of funded respite services

FCRC has recently experienced great frustration in dealing with DADHC concerning FCRC's plans to offer both programs for forty-nine weeks of the year, with the same amount of days provided, within FCRC's designated budget and at no extra cost to DADHC. DADHC has responded to FCRC's plans by stating that it wants programs to be provided for forty-eight weeks of the year only, based on the mistaken assumption that this will mean FCRC can offer the programs for more hours each week than it has otherwise planned. DADHC has brooked no negotiation of these terms on the part of FCRC, despite the fact that FCRC has clearly stated that its intention to offer the programs for forty-nine weeks will not affect the amount of days per week it intends to offer both programs throughout the year.

FCRC's reasoning behind offering the programs for forty-nine weeks is that these terms of provision reduce significantly the pressure on working parents to find respite for their disabled family members during the school holidays, a time of the year when respite is most unavailable. FCRC is attempting to manage both programs with a client-centered focus but on significantly reduced funding that has affected from the outset the number of days per week service providers are able to offer programs to participants. It should be clear to DADHC that the issue is not how much service providers are prepared to accommodate funding cuts within their already limited budgets, but rather the obvious lack of respite that is provided to these members of the community in dire need of its availability.

FCRC does not consider reduced funding for these programs to be sustainable if DADHC is not prepared to provide for a corresponding increase in group homes and respite for young people, and thus take the pressure off families and service providers. Of course, if disability service providers were funded adequately enough to be able to offer clients both programs at five days per week for forty-nine weeks of the year, then this would automatically reduce the pressure on inadequate respite services and families' attempts to access these.

FCRC has already encountered some very tragic situations as a result of the pressure placed on parents to manage without adequate DADHC case management support and respite services. One parent recently resorted to abandoning her child, who has severe behavioural problems, at the Department of Community Services in a last ditch effort to get a group home for her loved one. Another parent experienced the worrying consequences of a lack of respite services for her daughter. A place became available for her at a respite service in Wetherill Park which had been blocking beds that would otherwise be available to young people in the area with a disability. One such male client, who was living long term in the respite service, had been in jail for serious offences. The thought of leaving her daughter in this type of situation filled this particular mother with dread, and as a consequence, she decided to keep her daughter with her, despite the fact that her daughter's challenging behaviours were becoming extremely difficult for her to cope with alone.

The pressure placed on parents to bear cuts to the amount of days that disability service providers can offer for program participants is immense, and particularly in the Fairfield LGA where low income and high unemployment are ongoing problems and are among the highest rates in the state. Cuts to days inevitably mean that parents unable to afford external assistance will be forced to give up work to look after their children, leading to further problems of low income and unemployment for these families. The effect is negative for both parent and child. The parent cannot be expected to fulfil the role of a teacher, and it is cruel to force a situation where the young person must remain at home without access to adequate social interaction. Either way, this will lead to huge barriers for these families who will suffer social isolation as a result of their exclusion from services and employment opportunities.

3. The role of advocates, both individual and peak groups, in the consultation process.

Lack of open consultation

As a disability services provider with an intimate knowledge of community needs and operating in one of the most disadvantaged Local Government Areas in NSW, it is unfortunate that FCRC was not directly consulted by DADHC throughout the process of the development of the reforms. In fact, there seemed to be no consultation with any of the disability service providers in the area after the reforms process began to get underway. It would seem that these decisions, of such wide impact in the community and bearing such potentially devastating consequences, were made behind closed doors.

At a DADHC state forum held in the middle of 2004, reforms were discussed for the very first time. The figure of \$9000 funding per client in Community Participation was casually raised by DADHC representatives, much to the shock of disability service providers who were present at the forum. It is FCRC's belief that even before the announcement of a consultation process to address ATLAS reform, DADHC had already established the funding figure that they then promoted once announcement of the reforms was underway. FCRC sees this as unethical and perceives DADHC's commitment to consultation to be, at best, superficial.

Pressure on lobby groups to accept cuts

FCRC finds it astonishing that ACROD, the National Industry Association for Disability Services, openly supported the decision concerning block funding, when it is FCRC's experience, from participation in regional forums and those held by other lobby groups such as Action for People with a Disability, that most service providers are opposed to block funding arrangements for the detrimental effect this will have on service provision to clients. ACROD is funded by DADHC to advise on decisions that will affect disability service providers, not to support those decisions when most providers are opposed to them. It is FCRC's understanding that ACROD was perhaps pressured to support block funding on the condition that if it did not, funding for Community Participation would not be increased from \$9000 to \$13 500 per client.

It is also FCRC's opinion that DADHC deliberately pitched funding for Community Participation at a ridiculously low level, so that it could later announce the funding increase to \$13 500 and thereby reduce considerably the criticism it would otherwise receive for cutting program funding to the extent that it has. We are not alone in this assessment, as our participation in regional and metropolitan forums reveals this to be the perception of other organizations as well.

4. The impact of the exclusion of students enrolled or proposing to enrol in post secondary and higher education from eligibility for assistance under the new programs.

FCRC has no information to offer the Inquiry on this particular issue, due to the fact that our concern as a disability service provider is focused on our existing participants' and their families' experiences of the system and our own difficulty operating under the reforms.

5. The appropriateness of the assessment methodology used to identify school leaver support needs and to stream school leavers into the new programs.

Use of out-dated, inaccurate assessments

It is of the greatest concern to FCRC that assessment for school leavers' entry into the new programs has been based on assessments made previously for entry into ATLAS, which are now out of date. In the case of many service users, medical conditions can decline over time. It would seem, incredibly, that DADHC is unaware of this frequent occurrence. FCRC would like to make it very clear that service users' needs change over time. What might have once been an appropriate program for one user, based on

an old assessment, may now be entirely inappropriate, if a new assessment were to be made of the user's condition.

An example of an inaccurate assessment for entry into the two new programs can be found in the case of two participants in FCRC's former ATLAS program, Dean and Vikesh.

Dean is quite capable in many ways – he can conduct a conversation and travels on public transport by himself. FCRC believes that, given the opportunity, he might feasibly be able to enter the workforce. However, according to an assessment made of Dean by Commonwealth Rehabilitation Services (CRS) to determine which program is appropriate for his needs, Dean was placed in Community Participation. FCRC is most concerned that if Dean should remain in this program, his already low self-esteem will be worsened by not having the chance to further develop his skills and his work potential.

Vikesh is a service user with relatively high support needs – he is not able to travel on public transport by himself, and cannot maintain a task he is given unless he is closely observed and actively encouraged. FCRC believes it to be unlikely that Vikesh will ever gain permanent employment in the workforce. However, incredibly, Vikesh was assessed as being eligible for the Transition to Work program.

FCRC as well as the two families concerned find it difficult and disheartening to understand how such assessment of these two young men could be made, given the circumstances particular to each.

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.

FCRC has been provided with no information about the complaints and appeals process supposedly available to service users' families and to service providers.

FCRC has a positive relationship with Mary Shalhoub, the local representative for DADHC in the metropolitan south-west. However, it is clear that DADHC employees are also given no information about the complaints and appeals mechanisms, the reasoning behind the decisions made based on assessments, and the funding pools widely publicized by DADHC.

7. Whether appropriate and sustainable further education and vocational training and employment outcomes for people with a disability are likely to be achieved as a result of these changes.

Funding cuts, not reforms

There is an over-riding sense at FCRC and in the wider community that nothing has really changed for the better as a result of the ATLAS reforms. Funding has been reduced, not increased, and the need to increase the skills of staff employed to deliver services has not been addressed at all in the climate of reduced funding. If young people are to have their employment skills adequately developed, then disability service providers need to receive adequate funding in order to be able to employ staff specialized in the area of employment skills development, or to be able to train their existing staff in this important and much-needed area. As it is, young people with a disability leave school where they have had the benefit of qualified special education teachers, and arrive in a program where staff are no doubt dedicated, but largely unskilled in delivering employment skills training to disabled people.

Lack of employment opportunities

At the heart of the debate as to whether young people with a disability will be likely to achieve appropriate and sustainable employment outcomes is the undeniable fact that the Federal Government is not providing enough employment opportunities for those with a disability willing and potentially able to enter the workforce. This issue was not addressed nor negotiated throughout the process of supposed reform of disability programs. Instead, it would seem that funding cuts were dressed up in the guise of reforms.

Moreover, the two-tiered system established by DADHC, in which one program is skills-based and the other is community-based is highly discriminatory. It is FCRC's strong belief that those allocated to the Community Participation program also have the right to a skills-based program. What the funding cuts have ultimately achieved is a limitation on the capacity of service providers to accommodate skills-based training for all users, not just some. Community Participation participants have equivalent needs to Transition to Work participants, these including access to skills development as well as to participation in the community.

Violation of human rights

FCRC is deeply concerned that these reforms are a violation of the basic human rights of young people with a disability, in particular, of the right to fully develop as a human being. It is society's and the government's obligation to ensure that all young people with a disability have access to participation in the community, to development of their employable skills, to opportunities in the workforce, but also to stimulating social contact and enjoyable, varied activities, in short, to the same opportunities as any young person. Under the reforms, these rights are seriously discouraged.

Of great concern again to FCRC is the emphasis by DADHC on the future employment outcomes of program participants. It is a reality that many of the participants will not be able to achieve lasting employment, despite providers' best

intentions of working towards this ultimate goal. Parents also fear that if their children are unable to achieve employment, then they will be forced out of the system altogether, especially if the government fails to adequately fund service providers to deliver Community Participation with enough places to supply demand. If employment is simply going to be out of the question for some, these young people should still be equally valued in the system, and should still receive funding adequate to developing their social skills. People with a disability are not optional human beings, and should not be treated as such under a two-tiered system which punishes those less capable in terms of future employment with cuts to their funding.

It is a fact that the positions allocated to disabled people in the current workforce are low paid, and that the work these people are expected to carry out is extremely repetitive. Sometimes work merely contributes further to the low self esteem issues already borne by young people with an intellectual disability. It is also a fact that those people born with a severe intellectual disability usually have the mental attitude of a 0-5 year old child. Given that our society would not tolerate children in the 0-5 year old age group being forced to work, indeed children of any age, it seems punitive and discriminatory in the extreme that DADHC bases the level of its funding to disability service users on their capacity to achieve employment outcomes.

Grim future for disability programs

In considering the future of disability service provision, FCRC is fearful of the consequences of greater numbers of young people coming through the disability system, and of the precedent DADHC has now set by continuously cutting, not increasing, funding over the years that services have been on offer to these young people.

The impact of funding cuts will not just be noticeable in the short term, but will have significant long term impact on families and the communities who support them. Families arrange their lives around places in disability services. The effect that reduced days of service will have on parents' and carers' employment options could be severe, and as DADHC case management continues to fail to deliver, parents will be left to bear the full brunt of their children's challenging behaviours, often the only mode of expression for their feelings that they have available to them, especially when service provision is so inadequately funded that they miss out on the social interaction and outlets that they would otherwise be able to access.

FCRC's Recommendations

FCRC recommends:

- **that the two-tiered program structure be abolished as discriminatory**
- **that all service users, irrespective of their support needs and their individual employment goals, be funded individually at levels of between \$20 000 and \$25 000 in order that they may all attend programs for the full five days of the week and all have access to skills development and community participation with skilled and fully trained specialized staff**
- **that DADHC maintain accurate service user records, up-to-date assessments of service users, and adequate and attentive case management support for families**
- **that disability service providers be included in an open, accountable consultation process for any future reforms and that they be informed of the complaints and appeals process from the outset**
- **that assessment methodology be reviewed and monitored so that families may be assured of the appropriateness of DADHC's decisions**
- **that any future reforms be not centred on funding cuts based on the low percentage of program participants' employment outcomes, but that they address the greater social issues of why this percentage should be so low and the quantity of employment opportunities available within the community for school leavers with a disability**
- **that the Anti-Discrimination Act, the Disability Services Act and International Human Rights Instruments be considered closely in any future reform of disability programs and services.**

FCRC would like to extend its appreciation to the General Purpose Standing Committee No. 2 for the invitation to voice its concerns and to offer its recommendations to Parliament on the implementation, direction and consequences of these recent reforms.

Should you require further information, please contact **Dennis Skender, Acting Disability Services Manager** at FCRC.

This submission was written by Angela Morsley, FCRC's Policy Officer.