Submission
No 82

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

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Subject:

Summary

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Legislative Council
GENERAL PURPOSE
STANDING COMMITTEES
- 7 MAR 2005
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General Purpose Standing Committee No.2
Parliament House
Macquarie Street
Sydney, NSW 2000

Friday, 4 March 2005

Dear Madam, Sir;

Please find enclosed our submission in relation to your inquiry into changes to post school programs for young adults with disability.

As you can see from our submission we have focussed our attention on the issues as they apply to young adults from a non- English speaking background with disability.

If there are any further questions or if we can be of assistance to your inquiry, please do not hesitate to contact me.

Yours sincerely

Barbel Winter
Executive Director

Submission to General Purpose Standing Committee No. 2

Inquiry into changes to the Post School Programs for young adults with disability

The focus of this submission is the impact of the changes on young adults from a non-English speaking background with disability.

About MDAA and our expertise

MDAA is the peak advocacy body for people from a non-English speaking background (NESB) with disability in NSW. We provide a range of advocacy and other services to people from a NESB with disability and their families and we aim to support the human services sector (including government and non-government services) to provide culturally competent services to our constituency.

We provide individual advocacy services to over 400 people per year. MDAA consumers live across NSW with all types of disability from all NESB backgrounds. In 2003-2004 we provided individual advocacy to approximately 75 children and young people aged between 0 and 19 with all types of disability from many different ethnic background. Together with them and their parents we dealt with 50 matters related directly to education, including transition from education.

In addition, we have just completed original research with parents of children in the NSW education sector with the aim of increasing knowledge about the issues facing young adults with disability. We will submit this research, currently in its first phase, to the DET futures consultations.

The figures

Figures on ethnicity

In NSW, there are 1.155 million young people between **5 and 17 years** of age. Of these, **16.6%** (191,886) speak a language other than English (LOTE) at home and 7.5% were born overseas (ABS 2001, Population and Housing Census). This is consistent with the CRC statistics that in 2001, **15.5%** (913,6400) of people who identify themselves as poor or non-English speakers and speak a language other than English at home are aged between **0-12 years** (CRC Table 2.7 Languages spoken at home by persons who speak English not well or not at all – NSW 2001 Census). In 2003-2004 196,651 full time students enrolled in primary and secondary schools in NSW were from a NESB (DET Annual Report 2004, p.181)

Figures on Disability

The latest disability data (ABS 2003) identifies that 10% of all children aged **5-14 years** have a disability, with 7.5% of all children in that age group having some schooling or employment restrictions (ABS Table 6. All persons disability status by age and living arrangements 2004, pp. 20-21)

The DET Disability Action Plan 2004 - 2006 reports that '...the number of students with disabilities, more than 16,000 are enrolled in regular schools and supported by integration funding in excess of $72 million in 2003 (DET, Disability Action Plan 2004 – 2006, p.17)

Figures on ethnicity and disability

Using MDAA's definition of NESB which includes second generation Australians, people from a NESB with disability make up about 5% of the total population of NSW, or about 25% of all people with disability (NSW population = 6,326,579 with 5% of that total being people from a NESB with disability = 314,335) (based on ABS, Disability, Ageing and Carers: 1998)

As there are no indicators which suggest that the rate of disability among children from a NESB is higher or lower than their ESB counterparts, we can extrapolate that 10% of all children who speak a language other than English at home (LOTE) have a disability (19,188) and that of all LOTE children 7.5% (14,395) have some school or employment restrictions (NSW Commission for Children and Young People. (2003): Kids Stats).

DET mid year figures for 2003 suggest that students from a NESB make up **26.2%** of the total school population while they account for **30.4%** of the school population enrolled in SSP and Support classes (DET Annual Report 2004) .

Another relevant figure available is the percentage of students from a NESB with disability in the VET sector, with a clear trend of reduced access rates across Australia (from 12.5% in 1995 to 10.1% in 2000) (Productivity Commission Report, Review of the DDA 2004)

What we don't know .....

The Productivity Commission's Review of the Disability Discrimination Act 1992 shows that across Australia the enrolment of students with disability is increasing in the non-government school sector with just fewer than 20% of students with disability enrolled in these schools in 2002. However MDAA has not been able to gather statistical information on the number of students from a NESB with disability enrolled in non-government schools at the State level.

No figures are available indicating clearly the percentage of students from a NESB with disability in integrated, regular classrooms. As DET figures indicate that NESB students make up over 25% of the total school population, 25% or over 4,000 students of the 16,000+ students receiving integration funding in regular classrooms (DET, Disability Action Plan 2004 – 2006,, p.17) should be from a NESB.

Statistical data published by DET for 2003, show that students from a NESB account for 26.2% of the total school enrolment. Students from a NESB with disability make up 32.5% of the total enrolment in Schools for Specific Purposes (SSP) and 24.7% of total enrolment in Support Units, or 30.4% of the total enrolment in SSP and Support classes

The DET Ethnic Affairs Priorities Statement Report 2003 gave figures that showed a 4.35% and 3.22% increase in the enrolment of students from language backgrounds other than English over the years 2001–2002 and 2002–2003. These figures are reflected in the DET statistics for full-time enrolment from 1999 to 2003 If the increasing enrolment figures for these students is an ongoing trend we can extrapolate that, as students from a NESB with disability currently represent approximately a quarter to a third of the students in support units or SSP, and by inference a similar percentage of the students with disability or learning difficulties in regular classrooms, they make up a significant proportion of the student population.

Another viewpoint may be that students from a NESB with disability are over-represented in SSP and Support classes and under-represented in integrated, regular classrooms.

To clarify this issue more detailed research and data collection need to be undertaken.

Either way this group of students by sheer weight of numbers deserve a strong focus from the education systems. Strategic planning must consider the delivery of services to support this group of students. The services for students with disability and students from a NESB must intersect and be transferable across the diversity of ethnicity and ability.

Number of young adults from a NESB with disability in post school programs

MDAA has no access to any data concerning service utilisation rates for young adults from a NESB with disability in post school programs. We are uncertain that the Department of Ageing, Disability and Home Care (DADHC) has the data available and we urge the committee to seek such data.

In the absence of any data about post school programs little other data is available:

- The Productivity Commission's report into Government Services 2004 reports that the proportion of NESB users of accommodation support services is 0.2%.
- The latest Commonwealth Snapshot data for employment services suggests that 6.3% of all service users were born in a non- English speaking country (FACS Disability Services Census 2002)
- In his evidence to the NSW Upper House Parliamentary Inquiry the then DADHC Deputy Director Robert Griew reported that only 3% of all disability services users are from a NESB (Legislative Council, Standing Committee on Social Issues, Report 28)

MDAA estimates that in general, the access rate for people from a NESB with disability to disability services is approximately 5%, which means at a minimum 3 out of 4 people from a NESB with disability miss out on disability services despite being eligible.

In relation to post school programs, we estimate that the access rate is somewhat higher than 5%, especially following efforts targeting young school leavers from a NESB in 2003 (see below).

MDAA estimates that at best service utilisation rates of young people from a NESB with disability in post school programs are 10%. This means that at least one in every two young people with disability misses out on those services simply because of their race.

Key Issues of young adults from a NESB with disability in relation to post school programs

The lack of equitable access is the key issue facing young people with disability from a NESB in relation to any post school program. There are myriad reasons why access rates are that low, but on a systemic level they reflect the system's lack of cultural competence to respond to community diversity and provide services to all within the target group.

In our recent interim report "All I want is what's best for my child" (MDAA 2005), what will happen after school was one of the concerns of the parents interviewed. Much of the experiences and concerns of parents of students from a NESB with disability, about what happens after school, tend to be defined by the level of support the child needs. For those with low support needs, difficulties relate to accessing further training and employment. Parents of students with high support needs were mainly concerned about the care options and availability and security of funding.

For a number of students with mild or moderate intellectual disability or with low level support needs for a physical disability, access to further training and employment were the main concern. Parents wanted to know what was available and how their child could get a job or the required training. Some families from a NESB believe their children are receiving an education that will give them options similar to those available to their children without disability. They do not understand that if the child attends a Support Unit or SSP they are receiving a modified or differentiated curriculum, and while they might receive their School Certificate or Higher School Certificate, they will not be able to participate in most tertiary education. Students and their families need to know what services and supports are available to them after they complete their secondary schooling.

Parents reported that their child had difficulties accessing support services that the NSW TAFE system advertises. One problem was getting and maintaining apprenticeships. When students did find an apprenticeship they experienced exploitation or discovered that they could not physically complete the daily tasks. When parents or students approached TAFE for support to explain to employers the student's situation, staff were difficult to contact, and despite the use of interpreters, they could not resolve the problems.

Francesca worked hard at school and got her HSC. She wanted to be a hairdresser so she completed a year at TAFE and finally got an apprenticeship through the Spanish community. But the proprietor didn't teach her anything. She washed dishes and was always looking after the grandchildren. After 3 months the proprietor said she hadn't learnt to do anything and was always tired, so they sacked her. As Francesca has epilepsy she does get tired, and when she tried to get the TAFE to talk to the employer, they said they couldn't do anything about the situation. Because she hasn't been able to get another apprenticeship she had to stop going to TAFE and now she has to do something else.

Families of students with severe intellectual disabilities or multiple disabilities, who have high support needs, including health, hygiene, mobility and communication, reported great anxiety about their child's future. Some parents we interviewed were aware of recent changes to DADHC programs for school-leavers. These parents were very worried about their child's future. These concerns are magnified when language and cultural differences make communication difficult. The process and practice of ever changing government policy are bewildering and the students appear to be at risk of losing services and support.

'I've never used any services like Respite Care because I knew Alex would be picked up at 8:45 and arrive home at 3:30. I've pushed to keep him in school as long as possible by insisting he did 'Pathways' for his HSC. Now I don't know what I'll do because with the cuts in the PSO/ATLAS funding nobody, not even DADHC, seem to know or be able to offer advice. I could be faced with caring for a 120kg, 20 year old who has to have his nappy changed regularly. I just don't think I can do it 24/7. Just physically let alone looking after his 4 siblings. I love the education system. I was smart enough to understand that the education system would fill the first 20 years of my son's life. I don't know what will happen in the future'.

Some parents were untroubled by the prospect of school ending. When asked what they expected their child would do in the future after leaving school, some responded that they expected the school to help them, while others had no idea.

In one discussion with a group of mothers of pre-school and primary aged children we asked about this. The conversation began with the researcher talking about her own son who has learning difficulties and by the age of 21 had managed to complete two years at University. This caused the mothers to ask a lot of questions. They were mostly interested in hearing what support he had accessed on his way through school and now at University. They asked if their children would have access to the exam readers and writers he had used. Could their children go to TAFE and use those qualifications to apply for university entry? What type of support did he get at university? None of the mothers had any idea that these kinds of support may be available to their children.

This conversation highlighted the difference between the experience of parents of a student from a NESB with disability and that of a parent of a student from an ESB with disability. The researcher is from an ESB and has participated in the education and disability sectors. All parents of students with disability need to be advised of all the options and services available for their child to maximise their learning capacity. For families from a NESB this information must be delivered in an appropriate way. Culturally competent staff with experience and understanding of the education, health and disability service sectors ought to provide these explanations

The previous programs

MDAA together with several other agencies participated in a DADHC working group to propose changes to the PSO/ATLAS program to achieve better outcomes. In fact one of the main concerns with that program was that it did not demonstrate good outcomes. It is important to point out that Day programs also play an integral part in the delivery of post school programs, with many service providers delivering both day programs and PSO/ATLAS programs. In 2002 MDAA provided a submission to the DADHC reviewers of the Day Program. That review was either never completed or never made public by DADHC. Neither one of those programs delivered equitable services to young people with disability.

Yet in 2003 young people from a NESB were identified as a target group and anecdotal evidence suggests that service utilisation rates increased. We recommended to DADHC at the time that some more research ought to be undertaken to investigate the effectiveness or otherwise of the targeted approach in order to make recommendations for future initiatives aimed to achieve greater racial equity.

The Changes and how they may or may not impact on young adults with disability

Like several other agencies MDAA was advising DADHC, as a member of a PSO/ATLAS working group, about how to change the system to make it more effective for young adults with disability. At the time we spent considerable energy and time assisting DADHC to develop a program that can better meet the needs of young adults with disability, especially those from a NESB. We had been somewhat encouraged by the priority given to young people from a NESB (discussed above) and we were hopeful that some of the lessons learned through that process and some of the benefits gained could be built into a revised version. Being closely involved with what we believed to be a process of change for a program that clearly needed to be changed, we like others were surprised and disappointed by the way the Government went about abolishing the program and introducing a new program. To our knowledge there was NO prior consultation with any of the agencies involved in the DADHC working group. We believe that this action and the way the Government went about it is reminiscent of the advocacy and information services 'reform' which we understand is now generally regarded as a prime example of how not to deal with community agencies and services affecting the lives of people with disability.

While we absolutely agree with the Government that the previous PSO/ATLAS program needed serious reform, and we welcome the Government's commitment to create some certainty by providing ongoing funding, we assume that the changes were introduced much more for fiscal reasons than concern for the needs of young people with disability.

Specifically, we are concerned that the Government's decision did not include any specific changes that attempt to increase program utilisation rates for young adults from a NESB. We are also yet to be convinced that the changes introduced will lead to an increase in the employment rates or improve outcomes for people with disability and people from a non-English speaking background (NESB) with disability in particular.

Alfredo is a pianist who has performed at many events such as weddings, community organisation events, RSLs and other clubs. He gives concerts regularly and has made some money from his art. His grandmother supports him often and sometime she adds her amazing voice to his piano playing. Alfredo, who is blind and has autism, has been assessed as only being eligible for the Community Participation program. His talents have counted for nothing in the assessment despite his apparent abilities. Alfredo's grandma wants him to develop his piano skills further, and practice his piano daily. At the Community Participation program there is only a tiny children's keyboard, so Alfredo is trying to practise on that. As a result he is getting increasingly frustrated, which he expresses the only way he knows how, by getting angry.

The then Minister, Carmel Tebbutt, stated in a letter to the Sydney Morning Herald (11 August 2004) "The NSW Government is fully committed to improving outcomes for people with a disability". At the time, we wrote to the Minister with a set of questions that remain unanswered. These questions included:

- What measures has the Department put in place to ensure that the changes will definitely result in improved outcomes for people with disability, and people from a NESB with disability in particular, in Transition to Work (TTW) and Community Participation (CP) programs?
- What mechanisms will the Government put in place to ensure equity of outcome for people from a NESB with disability?
- How did the EOIs identify the ability of service providers to meet the cultural and linguistic needs of people with disability from a NESB? In particular, how will these needs be met with the limited funding available in both programs? Will additional funding be made available for these needs? Does the Department have criteria against which to assess the tender documents from service providers to ensure that best practice or proven training models/ programs are delivered, or specific changes introduced, in TTW programs to ensure higher than 3% transition rates to open or suported employment?
- Why has access to TTW been restricted to school leavers only? Why is this opportunity not available to young adults who may not have known about ATLAS when at school or whose skills or life circumstances have changed and who now wish to gain employment?

- Why is there such lack of emphasis on skill development in the CP program? How will this ensure improved outcomes?

At this stage it is difficult for us to see the clear impacts the changes have had on young people from a NESB with disability, but given the changes we argue that it will be even harder for people from a NESB with disability to access appropriate services and gain the necessary skills and opportunities to lead meaningful lives and contribute to the community. The exclusion from skills based, employment focused programs for anyone except school leavers is of concern specifically for recent migrants. There is no or little opportunity for skill development in Community Participation programs.

Hannah has three daughters, including Susannah who has a disability. Susannah needs high levels of personal care and Hannah does much of that work, including lifting her every day. Hannah has a job which requires her to work shifts. She has to keep the job because the family has a mortgage. In the past year Susannah accessed a PSO program; it was good and Susannah learnt new skills and she enjoyed going to the program. Hannah wants Susannah to be involved with other people, learn new things and get out and be part of the community. With all the changes afoot Hannah is worried that there will not only be a cut to the number of hours that Susannah can access the program, but also a reduction in the quality of the program, with less money being available for staff, outings, one-to-one work, etc.

We believe that employment rates will not increase as no specific changes have been introduced in the new Transition to Work program to ensure this. Reduced funding will also provide services with another reason to argue that it is too difficult to meet the cultural and linguistic needs of people from a NESB with disability. Life will not improve for people from a NESB with disability as no specific changes have been introduced in the new programs to ensure this.

We believe that the implementation of 'reforms' will result in poorer quality services, fewer hours of service delivery and a move to 'group care'. It will also be difficult for people to choose and move between different services in an area.

Conclusion

To conclude, MDAA continues to argue that any new model is only worth introducing if it:

- Focuses on skill development for all participants.
- Ensures adequate funding to meet the individual learning and support needs for all people with disability, including people from a NESB with disability.
- Encourages transition to work and participation in society at all ages.
- Provides funding that is individualised, portable and equitable.

We urge the Committee to view the changes introduced in the light of the above points.

In relation to people from a NESB with disability, we urge to Committee to make strong comments and recommendations about the racist nature of the NSW disability services system and its inability to meet the needs of a significant proportion of its target group.

We urge the Committee to be guided by the Standing Committee on Social Issues, who in their report (Legislative Council, Standing Committee on Social Issues, Report 28) made the following recommendations in relation to people from a NESB with disability:

"The Department of Ageing, Disability and Home Care should, in consultation with representative groups, establish Departmental targets for equitable service access by people from culturally and linguistically diverse backgrounds.

- Targets should be established for vacancy management, service growth within existing programs and in new programs
- Performance against the targets should be monitored and reported upon in the Department's annual report, and
- An implementation plan should be developed that outlines the specific steps that will be taken to meet the targets.

The Department of Ageing, Disability and Home Care should adopt a culturally competent approach to disability services which includes:

- The development of explicit NESB access strategies as an essential and ongoing component of all its programs and services
- A systematic approach to consultation with culturally diverse groups in order to inform policy and program development and implementation
- The implementation of mechanisms such as service guidelines, performance measurements and monitoring systems to ensure that funded service providers deliver culturally inclusive disability services.

The Department of Ageing, Disability and Home Care should adequately resource the services it funds to undertake translations and utilize interpreting services."