

**Submission
No 122**

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

Organisation:

Name: Dr Michele Meltzer

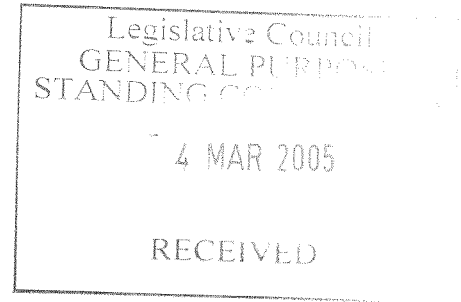
Telephone:

Date Received: 04/03/2005

Subject:

Summary

From: "Ariella ..."
To: <gpscno2@parliament.nsw.gov.au>
Date: Fri, Mar 4, 2005 12:40 pm
Subject: school leavers with a disability



4.3.05

To: Director,
General Purpose Standing Committee number 2

Re: Post School programmes for Young Adults with a Disability

To Whom It May Concern:

I am writing to express my deep concern about the changes to the post school programmes for young adults with a disability, and the disastrous changes this will mean for our family.

Our family consists of five persons, namely myself, my husband Philip, and my three children Maia (18), Ariella (18) and Max (9). My daughter Maia has a very severe disability, consisting of cerebral palsy (severe spastic quadriplegia), as well as a C1/C2 spinal injury. She is completely dependent, in that she cannot make any voluntary movements at all. She is not able to move her wheelchair, feed, dress, or help herself in any way. She is however bright and sociable. She can speak, though her speech is dysarthric, and this is the way that she communicates to others how she would like them to assist her.

Currently Maia is in year 12 at the Support Unit of Sydney Secondary College, Blackwattle Bay campus. She attends school full time, and enjoys the intellectual stimulation, social interaction, educational content, structure and care afforded her by the staff at the Support Unit. She looks forward to going to school every day. She is transported to and from school by special transport. On weekends and holidays, she misses school, as the family can never assist and stimulate her full-time, in the manner that school does. On weekends, the family receives 4 hours of individual respite care. School holidays are always a problem without structured activities, and with the need for additional paid carers.

Next year, her twin sister plans to travel overseas and study at university, expanding her experience and contacts. However, the contrast with what the new year holds for Maia could not be more extreme, as her world is shrinking and becoming less and less stimulating.

Under the new "post school" guidelines, she will apparently receive enough funding for a mere one-and-a-half to two days per week of a "community participation" day programme. The other five to five-and-a-half days a week are the family's responsibility, and it is difficult to imagine how she might spend this time. It seems as if the government's expectation is that she should assume the lifestyle of an elderly retiree at the age of 18!

My husband works long and irregular hours in the entertainment industry, and will not be available to act as an unpaid carer. I currently work three

days per week as a Career Medical Officer in a community mental health service, an area of public health currently experiencing severe understaffing. Working in the public sector as I do, the remuneration is not overly generous. Currently my income goes towards our household budget. I should point out here, that this budget includes hundreds of dollars per week in disability related additional costs, that the average Australian would not need to pay.

Next year, when my daughter Maia leaves school, I will need to choose between severely reducing my work hours and staying with her five days a week; or continuing to work, but paying in excess of \$155 per day to "buy" extra days of care. In my case, after tax, I would break even, but not contribute to the household budget any longer. However, many Australians would not be able to even consider this option. Both of these options are not ideal. If I were to stay with my daughter five days a week, I cannot imagine what we would do together every day. If I were to "buy" extra days of care, I will not be able to contribute to our budget.

Additionally, both of these options leave her with very little in the way of intellectual stimulation. I have looked into the option of my daughter attending a part-time TAFE course. However, as she is fully dependent in her care, she requires a personal carer. TAFE have informed me that they cannot provide this, and funding for it would need to come out of the miserly allocation for the one-and-a-half to two days care per week that she will receive. The course that she is interested in is in the area of welfare and disability services. It is possible that she might be able to work in the future as a consumer advocate, but unless she tries, we will never know. This area is one in which she has insider knowledge and strong opinions, and I believe she might be able to make a valuable contribution to society were she given the opportunity. However, under the current system, she will not be able to try.

Also, I gather that under the new "block funding" arrangements for "community participation" programmes, it is not possible to divide the money into separate components as required. This would mean that she would be unable to attend both a day programme and a TAFE course.

It seems to me that programmes for school leavers should be assessed and funded on a needs basis. In my daughter's case, I feel that the grossly inadequate funding for her high support needs, has created a situation where the government has educated her to year 12, and now are forcing her to "retire" at age 18, without having any opportunity to use her education. When I compare her shrinking world to her twin sister's expanding one, the only possible conclusion that I can come to is that this constitutes discrimination on the basis of disability, and is in breach of the Anti-Discrimination Act.

This is a clear-cut matter of social justice. Australia is an affluent country, and to treat its citizens in this manner is simply unacceptable.

I invite the minister to attend my daughter's support unit, and explain to the bright, active, and eager year 12 students and their parents, what exactly they are supposed to do in their five "free" days a week after leaving school.

Yours Sincerely,

Dr Michele Meltzer
parent