

Submission
No 88

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

Organisation:

Name: Mr & Miss Greg & Tess Ricketson

Telephone:

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Subject:

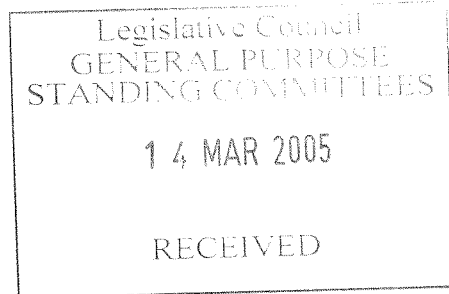
Summary

Greg & Tess Ricketson

You can contact us at

9th March, 2005

Parliament of NSW,
Legislative Council,
General Purpose Standing Committee No 2,
Parliament House,
Macquarie Street,
Sydney , 2000



RE : INQUIRY INTO CHANGES TO POST SCHOOL PROGRAMS FOR YOUNG ADULTS WITH A DISABILITY

I am the father of TESS, a young adult , now 19, catagorised throughout her life as having "moderate intellectual disability" . I would like to put to the Committee my views on the 7 points of reference.

I would like to think these are also Tess' views, but she is unable to write them herself.

And I would also like to say that I / we would be happy to discuss these issues directly with the Committee, or Representatives of the Committee.

BACKGROUND AND OVERVIEW

To paint a quick background, Tess currently lives un Hornsby with her mother , brother [22], and sister [17] who is in final year in High School. I see Tess regularly each fortnight, and during holidays.

The "living locations" for Tess' immediate family for the past 13 years in the school system, have been largely dictated by the accessibility to appropriate special schooling facilities for Tess. This priority has not always sat comfortably with other family preferences, access to support networks, and work requirements, and there have always been very real practical restrictions imposed on myself, Tess' mother and her family as a result.

In planning for Tess' future after school, we understandably relied on the ATLAS policy framework, and had looked forward to putting together a diverse and flexible range of developmental activities, with less rigid restrictions on where Tess and her family could live, and her access to me.

Those plans have been completely shattered by the introduction of the two new policy frameworks, and there has been six nightmarish months of stress and anxiety in trying to re-assess what is best for Tess' future. No firm solutions have yet emerged, as it seems simply that the new policy frameworks have been put together with little regard to her longer term practical development needs, or her family support structures.

There have been many years of carefully personalised nurturing of Tess in her special school, concentrating on her very specific skills development needs. The new policy guidelines effectively puts an immediate stop to such personalised programs, and my greatest fear is that a lot of the development milestones that have been achieved at school will go backwards.

If there is a simple "overview" comment for this letter, it is for Government to honestly listen to all the issues that are raised with the Committee, give them some sense of priority, address them, embrace them, and come up with policies that enshrine respect and understanding and observation of the simple human rights of these most wonderful but vulnerable members of our society.

And in the process of enshrining respect and understanding for "clients" [can the Committee consider banning that word ?] such as Tess, to look carefully at the support structures for carers that are just so completely limited : and give the carers their due as well.

My comments regarding the specific Terms of Reference follow :

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

The overall structure and policy framework of both programs is fundamentally flawed at its conceptual base.

While the programs acknowledge the need to provide a targeted support structure, it sets up an extremely narrow "eligibility categorisation" into two quite distinct program streams that simply do not recognise the complexities of the individual circumstances faced by each of these young adults.

In any particular group to be assessed at a particular "snapshot time", there will be a relatively small proportion only that fit neatly and obviously into one or other of the two program categories. By far the larger proportion will fall in a huge grey area in between the neat and obvious fits.

The reason is painfully simple : each individual young adult with a disability has his / her own degrees of disability [whether physical or intellectual, or a combination of both], different stages of personal physical and emotional development, different capacities of life skills [whether these be personal hygiene issues, the ability to communicate, to dress, to cook, to travel, to understand money, etc], different capacity to sustain concentration for extended periods, different degrees of confidence and self esteem, different behavioural aspects, different degrees of mental health and stability [which can sometimes vary hugely month by month depending upon the vast array of almost experimental medical treatments with drugs], and on the list can go.

Added to these enormous variations of "degree" is an endless series of combinations that defy any clear "categorisation", and then add that even those endless combinations are dynamic and vary very significantly over time : an "eligibility snapshot" one particular month, or quarter, or six-monthly, or annually, could reveal quite different circumstances, and lead to quite different "eligibility criteria".

My own experience with Tess is that all these various factors can evolve and change very quickly. Over any particular time frame, she may advance significantly in some skill or behavioural areas, but at the same time drop back in others. In another time frame, some skills she has had and maintained successfully for years can temporarily just disappear, only to reappear again the next month.

Self esteem and behaviour seems to go up and down in direct relation to the drugs she is prescribed. The very high social skills ability she has had all her life can mysteriously desert her for a week, a month....and then return just as strong overnight. There is no logical answer to the way this all works.

And yet the policy framework adopted for the two new programs would have us believe that there are logical answers, that those answers can be fully assessed at an arbitrary snapshot time, and that a logical criteria can be applied that would then "lock" Tess into one of the two "group" programs for an arbitrary two year time frame.

This has several fundamental flaws.

First, it denies well documented past histories as to how Tess has developed through her school years. Not only her family, but I am sure also her teachers and Medical Practitioners, would love to know just how this policy framework can provide such answers so readily when they have been scratching their heads, mystified by Tess, for many years now.

Second, it denies Tess any sense of individuality, with her own specific developmental needs, by imposing an "across the board" assessment criteria which, at very best is arbitrary, and at worst, discriminatory.

Tess is very much in the high proportion "grey" range discussed above. It is simply unfair and inhumane, to force Tess, and young adults like her, into programs with such limited eligibility ranges.

Third, the new programs, by transferring funding eligibility - payment from being to Tess as an individual, to now being to the service provider, severely restricts the possibility of tailoring an individualised support program that not only recognises personal development needs, but also allows for a wider range of activity and stimulation as her development evolves.

Fourth, by shifting funding allocation from the individual to the service provider, the new programs make it impossible for Tess to have any flexibility in attending a combination of centres and / or workplaces in different places around Sydney [as was possible under the ATLAS arrangements]. The programs therefore directly limit the range of activities, and the consequent varied skills development and social stimulation.

Fifth, by definition from the third and fourth points, it makes it virtually impossible for families with divorced parents [the majority for families of young adults with disabilities], to share living arrangements when the programs are "locked" into one specific locality.

The sixth point flows from the fifth. The programs, with limited service providers and intake periods, in effect prevent carers from moving, whether for work or personal or support reasons. This is totally inequitable and unfair to carers who already face the most difficult of circumstances.

If all those aspects aren't enough, my final point is that the inflexibility of the programs act completely contrary to the interest and rights of Tess as an individual to continue her development.

In any particular year, I may spend some several months, sometimes longer, out of Australia developing or working on projects. I would love to be able to have Tess with me for some of those times. She would be culturally stimulated, she could do limited amounts of work in and around the office , [which she thoroughly enjoys doing], she would have a wide social stimulation, and she and her mother could have a break from each other which could only be healthy, and a relief for her mother.

From what I have read of the programs, such an arrangement would be impossible , regardless of it being hugely positive for Tess' development.

In summary, I find it difficult to comprehend just how programs such as these can have been introduced that almost actively attack, rather than support, the simple human rights of vulnerable young adults and their families and carers.

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

There is only one simple answer to this : completely inadequate. The new funding levels are significantly lower than the previous ATLAS arrangements, which themselves had remained largely stagnant over a period of years.

The service providers have made it very clear that the level of funding is simply not going to allow the same degree of attention to personalised programs. In many cases, the low funding levels will reduce some of the service providers to being glorified "child minders".

And the low level of funding has seen the number of "days" available reduced in most instances from 5 to 3. This will have a dramatic impact on the well being of the young adults, and their carers.

What on earth is meant to be happening on the other days ? It all but locks carers out of work possibilities, it increases the financial and emotional strains on families, and dangerously diminishes the amount of social interaction that is so important for ongoing development.

There is already a high degree of mental illness amongst young adults with disabilities : this is likely to increase as a result of the reduced times and the inability of service providers to deliver personalised programs.

As regards "appropriateness", I have already commented above as to the extensive ramifications of now making the funding available to the service provider, rather than to the individual. This restricts the range of activities that can be tailored to personalised needs, and also has a dramatic impact on carers who remain "locked in" to a particular facility.

Even IF the funding were to be retained as being to the service provider, at the very least, further funding needs to be allocated to increase the number of facilities and providers to allow greater program flexibility, and to diminish crippling transport issues.

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

I can't really comment with any authority, but from everything I have read, it would appear that the consultation process was completely inadequate.

Certainly from a family perspective, the lack of clear answers to critical questions over the past six months has been truly appalling. And remains so.

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.

As discussed above, the programs are conceptually flawed in attempting to "categorise" each individual into narrow streams. It is simply impossible to do so.

Flexible support funding should be available to cover a myriad of further individualised development programs, and should be available across a wide variation of activities : from attendance at service provider facilities, to casual work attendance and trials, to attending part time post-secondary courses if appropriate for skills development.....on the list can go.

It makes no policy sense to "exclude" any activity that furthers the development of the young adult after leaving the school system, and particularly if that activity is intentionally aimed at increasing the possibility of he / she obtaining some vocational training to assist in finding work.

These are young adults with special needs, with variable outcomes. "Development" simply doesn't stop at the arbitrary school leaving age. Sometimes the "development" will work, sometimes not....or perhaps not this semester at a TAFE college or whatever....But the opportunity must be there for development to continue, to try things out, to test capabilities, to regroup if something doesn't work out, and try something else.

This is where the whole issue of "funding to the individual" comes back in : there has to be the flexibility to continue development in this manner : and no activity, including post-secondary courses, should be excluded.

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

Completely inappropriate, but best left for comment by professionals. Personally, I simply don't understand how these assessments are being made. There seems little connection with reality : in the case of Tess and her school classmates, the assessment procedures were all over the place, and often inappropriate.

I think again this gets back to the "grey area" and the complexities commented on above. There is no simple and reliable assessment method, and the attempt to do so is fraught with problems.

Particularly if the policy framework allows for only two assessment criteria that ignores the majority in the grey area.

The adequacy of complaints and appeals mechanisms established in relation to the implementation of the new programs, and particularly with respect to assessment decisions.

In short, completely inadequate, to a point of arrogance, and a complete lack of compassion to the very people, and their families, that the programs are supposed to be helping.

As commented on above, there can be very very significant development changes over fairly short periods of time. What might be a fair and reasonable assessment at a particular time could be completely inappropriate three, six, or twelve months later.

So back to my overriding comment of the programs needing flexibility, not this rigid assessment process that "locks" in for two years.

At the very least, assessments should be more dynamic.

As to an appeals mechanism....exactly what mechanism ? It is still completely unclear just what the process is, or will be.

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.

As commented on above, the new programs, through their low funding and inflexibility, are likely to have negative, not positive, outcomes.

A young adult like Tess, and I would say hundreds like her, needs support that can be tailored to her very specific skills development needs. She needs variation of activities , social interaction, further professional help with some skills areas.

She needs to try some on the job training in flexible workplaces [that I and colleagues like me could occasionally provide]. It may be appropriate to try a subject or two in the future at a TAFE to see how her concentration goes.

Above all, she needs to have her own voice in these development options.

I do not see these programs allowing her to have a voice as an individual, but merely to be a part of an underfunded group.

I fail to see how the outcomes can be positive in these circumstances.

As will be very clear, I, and my family, are stressed, and angered about pretty well all aspects of these new programs. They seem to have been introduced without any regard whatsoever to the practical realities of the very people (and their carers) they are meant to be aimed at.


The only way these support policies will work is if the focus returns to the fundamental rights and needs of the individual to continued flexible nurturing and development after leaving the school system.

An arbitrary assessment and categorisation into two limited groups of "those that can work" and those that "can't" is a heartless and doomed exercise that consigns these vulnerable individuals, and their carers, to a life without compassion and hope.

Is that what the policy framework is meant to do ?

Thank you for your time,

Regards

A handwritten signature in black ink, appearing to read 'Greg Ricketson', with a long horizontal flourish extending to the right.

Greg Ricketson, for Tess