

**Submission
No 6**

INQUIRY INTO POST SCHOOL DISABILITY PROGRAMS

Organisation:

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Date Received: 01/03/2005

Subject:

Summary

Legislative Council
GENERAL PURPOSE
STANDING COMMITTEES

- 1 MAR 2005

RECEIVED

27-02-05

To the General Purpose Standing Committee No. 2 Inquiry,

I am writing to your committee as an extremely concerned and distressed parent of a young adult, currently in the A.T.L.A.S program. At the moment my son, Nathan is attending a quality, five day a week program and absolutely loves this time. I am fully aware that any program requires evaluation and through that evaluation process the positives are kept and the areas which require adjusting, are done so, keeping in mind the needs of the individuals.

There are two main areas in the new post school program, entitled 'Transition to Work' and 'Community Participation'. I have grave concerns about the eligibility criteria applied to the 'Transition To Work' program and the time frame in which the participants are suppose to have reached the 'ready to work' goal. Questions have to be asked.

Is two years an adequate time frame to apply to this category?

Have we got a clear definition of work ready?

If a young adult is capable of working after the designated period then is there an appropriate job available?

Is there something in place that provides support for placing our young adults in available positions?

I firmly believe that the answer to these questions is no!

My son has been classified at Transition to Work in the A.T.L.A.S. program. Nathan is legally blind, has cerebral palsy, is right hemi-paretic – and is intellectually delayed.

There is absolutely no way that Nathan will ever be 'work ready' in two years. Nathan's classification has been questioned by absolutely everyone who has contact with him. Very careful consideration needs to be given when 'slotting' a child into a category. This decision should include the parents and professionals who are currently involved with the young adult.

Every person has the right to have high expectations held about him or her. Some people require longer than others and everyone needs developmental, skills based programs and support. There needs to be greater flexibility in the time frames allocated and between the 2 program classifications in the new Post School programs.

Some of our young adults are only capable of working for 1 or 2 days per week. Where does that leave them for the rest of the week? Provision needs to be made for these sorts of situations.

When a child is considered to be work ready and there is no job available, what happens then? This question was put to the then, Minister for Disability Services, Carmel Tebbutt by Ms Sylvia Hale. The Hon. Carmel Tebbutt replied that she could not make commitments with regard to the Commonwealth Government programs and availability of jobs. At the same time she did not say that those who were considered 'work ready'

and did not have a job to go to would not be forced to leave the program. Further to this, when I attended the DADHC information session, the same question was asked by parents of people on the PSO program. These parents had received a letter from the department stating that their child would be forced to leave the program if jobs are unavailable and they were considered 'work ready'. The reply was that the State Government would inform the Federal Government of the situation. This is appalling!

No matter which program, it is absolutely essential that a 5 day, quality, individualised program should be provided for these young adults in accordance with the Disability Act.

The funding provided for these programs is inadequate and the type of funding is unacceptable!

Currently, each young person has individualized funding. While I accept that this is harder to administer than block funding, it is extremely important to have individualised funding to optimise individual programs as rightly required by the state disabilities services law. The decision to go to block funding removes the right of choice to our young adults. If you move to a different suburb or want to change to a different service provider, the funding is not portable. I am absolutely amazed that anyone with a basic level of intelligence feels that this is acceptable. The minister of our church has a multiply handicapped child and they have just moved to another parish. Ministers generally move to a new parish every 5 to 8 years. This will certainly be an unacceptable extra stress in their lives.

Then there is the equity issue. Why is individualised funding acceptable for PSO participants but not for our children. Why are PSO participants funded at an acceptable level and my son and other young adults at an unacceptable, lower level?

The Hon. Carmel Tebbutt announced the retention of the PSO funding on the John Laws show, 13th August 2004. During this interview she stated that the PSO group "tended to have higher support needs". This is a load of rubbish! The children leaving school after a particular date did not have some miracle cure, which resulted in lesser needs than the children leaving school on a previous date. Generally speaking, the students leaving school from one year to another will be similar.

In the media release dated 2nd August 2004 the Hon Carmel Tebbut stated that: "The reforms are not intended to result in a reduction of hours for clients. Our focus is on improving employment outcomes and providing longer term certainty to young people – not reducing access to programs."

How can Ms Tebbutt possibly expect the same amount of hours and quality programs for less money? Nathan will be absolutely devastated when can't attend his 'work' five days a week. It is disgraceful that the program, which is supposed to assist disabled people into work and training, ends up condemning them to boredom with little or no hope. When my son moves to Community Participation we can expect only 2 ½ days per week of program with our Service Provider. This is abominable! It will not only have a devastating effect on Nathan but also the rest of our family. I will probably have to resign

my job as a teacher to care for Nathan on the days he will be unable to attend the program. Without my wage this will place our family in financial difficulty and increase the stress factor in our household. Our eldest child is currently in her fourth year of study in a non-HECS based course. If I lose my job I have serious doubts that she will be able to complete the five-year course in which she is currently achieving Distinctions and High Distinctions. We are still yet to fully educate our youngest daughter who is currently in Year 8 at high school. Our wish is that **all** of our children can have opportunities to reach their potential and take their rightful and productive place in society. Nathan will be very bored at home and will certainly regress and lose many of the skills he has gained throughout the past fourteen months. He will not be able to reach his full potential at home. Apart from anything else, I love my job and have completed several other courses to further benefit the students I am teaching. The most recent of which is training to be a Reading Recovery teacher, this is my second year of training. If I leave another teacher will have to be trained at the Government's expense. It is a wonderful program and I particularly enjoy working with the children and seeing many wonderful results.

The reduction in funding is an economically unsound decision. In our case, the Government will be losing the taxes from a full-time wage, will have to foot the expense of training another teacher in one of the positions I will leave. As well as this my husband and I fully intended on being self – funded retirees – this will definitely be for a much shorter period of time if I have to give up my job.

The people living in supported accommodation will also have their daily program cut and the service provider will have to provide extra staff to care for them. Alternately many service providers may choose to have the supported accommodation people take up positions in the day care / Community Participation program as it would be economically viable to do so.

What about the families that have young adults with high support needs or challenging behaviours? They are already emotionally and physically exhausted and many are only just 'keeping their heads above water' because, at the moment, they are given some time to themselves when their child attends their program. Please remember that the majority of families who have a child with a disability are single parent families. For those of you who are parents. Can you remember the worst times when your children were young and sick? You were able to survive because, usually, this is only for a short period of time in your life. – A light at the end of the tunnel! We don't have a light at the end of a tunnel. Some of these parents have to get up through the night and change the sleeping position of their young adult, tube feed them, dress and bath them, change adult nappies and put up with extremely stressful behaviour. Will these people go under?

We all have lost sleep over the loss of days in the program and have even shed many tears. Our whole family is being affected.

During the time since the changes to the A.T.L.A.S. program were announced we have been very fortunate with the support provided by Flintwood Disability Services, our Service Provider. They have been very honest and have provided us with up to-date reports and details. We are also fortunate to have a parent of a girl in the PSO program

that is a member of N.C.O.S.S. She has kept us informed of everything that she was able to throughout the time. We have attended many parent evenings, DADHC information sessions and many other appropriate meetings so that we were able to make informed decisions. The service providers were not invited to the DADHC information session and I was absolutely amazed to find out that the service providers had been accused of 'rabble rousing'. I am certainly capable of getting extremely angry all by myself when the Government makes outrageous decisions that affect my son's life. This is an insult to our intelligence! To be told that the service providers provoked our anger.

What has really distressed us was the fact that the changes were made without consulting with the consumers. How can any effective changes be made when the service users and their families are not included in the consultation process?

When trying to register complaints and find out any further information using the phone numbers provided, only standard responses were given which were exactly the same as what was written in the letters.

When Nathan was classified at Transition to Work, the school's transition teacher registered her concern and asked to have it changed. I personally rang at least 4 times until I found the correct person and I was informed that the request for reassessment has to come from the service provider. Our service provider also put in a written request for reassessment, in October, after giving Nathan a reasonable amount of time in the program. To this day nothing has been done. I have not even received acknowledgement from the department that they have received a reassessment request.

To provide an effective program that meets the needs and educational outcomes of an individual with a disability, the program needs to be an adequately funded, quality programs that operates for 5 days per week, not just a baby-sitting service. Nathan's and other school leavers funding needs to be at the same level of the PSO people.

I am a very concerned, outraged parent who finds it difficult to imagine that a Government can be so callous as to target one of the most vulnerable groups in our society.

Could I please have a copy of the findings from the inquiry.

Thank you for your co-operation.

Yours sincerely,

Lynne Gould