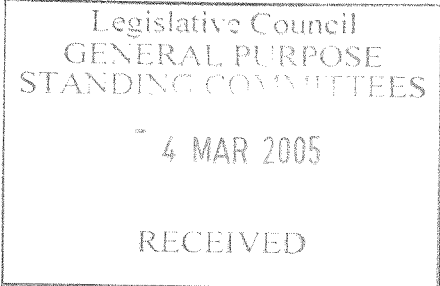


From: "Nell Brown"
To: <gpscno2@parliament.nsw.gov.au>
Date: Fri, Mar 4, 2005 4:01 pm
Subject: Upper House Standing Committee No 2



*I have re-submitted this as I received no confirmation of arrival of the original

*I think that all families/carers whose young adults attend these programs should have been given the opportunity to respond. Only those "in the loop" will be aware of this standing committee.

DADHC has a list of all participants and their mailing list should have been made available to the committee, for an accurate assessment of the effects of these funding cuts on peoples lives.

Att General Purpose Standing Committee No 2,
 Legislative Council,
 Parliament House,
 Macquarie Street,
 Sydney, 2000.

We welcome the focus of NSW on issues of disabilities; furthermore we welcome the NSW government's initiative to bring about improvements in outcomes through legislation and regulation. It is however of great concern that the "reforms" to the Atlas/ PSO programs, have done nothing but given the lowest amount of funding to those with the highest levels of disability and therefore the most expensive support needs.

These "reforms" have denied these citizens the right to participate in the community as equal citizens and are denied support for inclusion in the community, due to the high person/carer ratio that is required. They were already inadequately serviced, and poorly funded in the past.

These cuts to program funding came very soon after the findings of the Coronial Inquest into the death of Diana Dawes's son. The inquest found the government had been remiss in its duty of care for not making sure adequate supports were in place to assist families who are struggling with the day to day pressures of the high support needs of their disabled children.

Perhaps the most obvious question is this - why with this hanging over the NSW governments head, the NSW government felt the answer was to slash vital funding levels, to increase pressure on families/carers, when it is patently obvious that the possible ramifications were most likely to propel tragedy, not prevent it?

I have friends whose young adults has been left with two days of support care, their livelihoods have been compromised, their children who are already an enormous emotional and physical drain are requiring even more help and support from families.

It is apparent to me as a carer that the government of NSW is creating a crisis whose magnitude is yet to be felt, however the repercussions are obvious and will be thrust upon the family yet again. The action of the NSW government is not only insensitive to the needs of the disabled and their families but retrograde in that the NSW government will have to spend scarce community resources to "fix" or undo the damage to a particularly vulnerable and ignored segment of the NSW community.

People's lives are in the process of imploding.

I think one of the major questions for this committee is how can these programs continue to offer quality-enhancing, life supporting inclusion when in 10 years the funding has not gone up with the CPI.

The Atlas program was brought in as a way of cutting the original costs of the PSO funding, it was renamed Atlas, regurgitated, but in essence the same, but with less allocations per head of funds. We now have an even greater reduction of costs than for the same programs 6 years on.

I applied through the school for the entry of my daughter to attend an Atlas

program for 2005 in April 2004. I was told we would be notified in Sept about her placement. In August I was informed about the governments "reforms".

Our entire families lives were thrown into the air. We were told that we would have an answer in September as to what was happening.

I actually was informed as to my daughters being placed in the "community participation" program in November. Our treatment has been very shabby; these "reforms" should have been delayed, not raced through in haste. They were never about quality; they were only about the lowest possible costs.

Within the frame of these cost cuts I have been fortunate; once I understood that Tess was to be placed in "community participation" I harassed, bullied, abused and got my way. I never appealed in writing; I was told there was no appeal process except for those who had been denied any funding at all. (The minister had told us at parliament house that we could appeal, she was to later renege). I just screamed and yelled and made such a bloody nuisance of myself to the point where everyone recognised my voice if they were to unfortunately be the one to answer the phone.

My daughter was funded this year for the "community participation" program, which would have allowed her a three day program- that is with a great deal of fundraising, to allow for what I think is the best program of its kind that there is.

This in fact is the correct "named" program for her; it will be many years until she is work ready, if ever, BUT I know she needs more assistance than those who would possibly be trained enough to be dumped from the program. There was no way I was going to take whatever they were to throw our way. How could I?

I was fighting for my daughters future, there was no way that I was going to have a government department decide that her life, or my families lives do not have as much worth or value as perhaps anothers, with lower support needs.

A few days before Christmas I received a phone call from DADHC informing me that miracles do exist; my daughter had been reclassified as being suitable for "transition to work" which would give her the added day. The old squeaky wheel theory.

I attended many DADHC meetings; the level of anger was palpable.

The last meeting I attended was designed to intimidate parent/carers. They had 12 people from DADHC sitting around a horseshoe table at the Gordon council chambers.

They had DADHC people give 15-minute speeches on how terrific it all was, "the audience, a lot of very distressed, frustrated and in the main, incredibly angry families" were allowed 5 minutes question/answers and then they refused any further questions. The answers were long and drawn out, so as to avoid many questions, they were unable to answer any questions about the Atlas programs, as they themselves didn't know the answers. Once "question time" was over, they refused to listen to further questions. I left. It seemed so designed to intimidate, to curb free speech. My experience is indicative of the top down approach employed by bureaucrats who consistently fail to listen to legitimate concerns.

Of greater insult to us as family members of disabled people is that bureaucrats fail to engage with families and the disabled with a view to creating individualised responses that meet the needs of the individual with the disability. The energy, creativity and knowledge of the family/care of the person with the disability are ignored.

Top down solutions are doomed to fail because they do not include or involve those for whom the service is designed in the first instance, to ascertain the need and the dreams of the individual with the disability.

If the person with the disability cannot articulate their needs and their dreams there are processes that can be put into place to do this. The most significant starting point is to begin with a meaningful discussion with the family members. This is not new. It has been tried successfully in other

states of Australia and overseas. The outcomes have been successful. All too often the solutions that have been agreed to have been LESS COSTLY TO THE STATE.

The following week I attended a meeting at the Dougherty Centre where no one from DADHC came, even though the minister had promised to attend. The government, thankfully (in retrospect) cancelled at 4.30 that day; people came from all over Sydney. From this meeting this Standing Committee Inquiry was promised.

The reason for this was simple. They still had no answers, this was policy on the run and it was failing to meet the guidelines as little forward-planning, thought, consultation or care had gone into the process. It was about grabbing a figure out of the ether and trying to force service providers to come up with packages to meet that arbitrary figure.

As this committee would be well aware, the original "arbitrary" figure was compromised as there was no way possible that those pegged for "community participation", even those who only had an intellectual disability, let alone those with physical as well as intellectual disabilities were going to get more than 2 days with the original figure of \$9,000, after all they were the ones with the highest support and funding needs. The government realised that there would literally be blood on the streets if they persevered with that figure.

Tess's program does not include people with acute/severe intellectual disability.

It is these people who have been thrown on the disability "garbage" heap. They are the people whose needs are greatest, who if not allowed adequate stimulation are going to be seriously compromised. Their carers, already exhausted and teetering on the edge of living any quality of life, virtually on the edge of despair and sanity, have been left behind to implode. With the amount of money available to these people, given the high cost of support, are now funded for 2 days. We all should be appalled, horrified and deeply ashamed.

Tess currently attends 6 hours a day for 4 days per week. If she weren't given "transition to work" she would only be attending 6 hours a day 3 days a week.

Her program is brilliant, not because of the government, but because those who run it are amazing women with a great deal of training and foresight who have a life passion to teach and train disabled adults to become the best that they can.

It might have been possible for Tess to attend another service that allowed five days for "transition to work", but I had to weigh up whether I could settle for a "baby sitting service" or one that would perhaps give her quality and therefore possibilities to extend herself to achieve the most with her life. I know that they are already struggling with this figure for her four days.

In the program we have chosen, the young people are doing the same things together for either program, whether it be "transition to work" or "community

participation". The difference being that some have an extra day for honing up and developing skills that will see some possibly being able to maintain the paid employment level of 6 hours a week. These skills are also vital to the ones who do not have the extra day. They will be missing out and any chance they would have had to further their skills.

With disability, lost time is a disaster, these people are already struggling, the added burden of not enough stimuli can have permanent all-of-life ramifications.

A lot of young adults that are "successfully" transitioned to work will eventually fail in employment; they will be left at home, forgotten and alone. This is the NSW government's effort to pass costs onto the Federal government.

The risk of these needs not being met outweighs the possible benefits to the state. They are playing a brutal game with vulnerable peoples lives.

A two-year training program to become "work ready" for most of these young people is a joke. My daughter at 19 has the emotional maturity of a 10 year old.

It will be many years of support and training for her to reach an emotional maturity that will be appropriate for work. This does not mean that it will not happen, perhaps in 5 years something will "click" and the changes will skyrocket ahead.

Without an extremely high level of activity and training this will not happen, she will either regress or stagnate.

We cannot view the "social abilities" of these young people on a normal age-line; their milestones are met on an individual basis.

Something very important for this committee to remember is that ALL of the people in this program have high support needs. They on the whole, during the entire educational process, have never been able to integrate successfully into society. They are part of the very tiny percentage of people born with fairly acute intellectual and/or severe physical impairments.

Those with mild disabilities have already been denied access to these programs.

Over the break between leaving school and starting her new life (7weeks), the deterioration of my daughter has been acute. She has become more withdrawn, prefers to be alone with her family and her social skills have taken a backward step. This to me shows how important the social function of these programs is to the emotional stability of the participants.

I am a single parent, as so many carers are. We live in borderline poverty as it is, and I have to work. I HAD two part-time jobs, I had no choice but to leave Tess at home over Christmas whilst I worked, we cannot eat, nor pay the bills and the rent if I do not.

As it is I have had to give up one of my jobs as Tess is now home every Friday and really is not "safe" to leave at home alone, except for very short periods. After 2 years if Tess hasn't "transitioned to work" she will instead be "transitioned to community participation". This will mean at the current funding levels two years on, that Tess will only have funding for 2-3 days a week. (most likely two, it is only borderline viable presently for three)

Beyond the enormous social, mental health ramifications to Tess's well being it will also see me unable to work at all!

If the NSW government does not want to fund these programs adequately and would prefer us to stay at home caring, perhaps the NSW government should be obliged to offer us grants equal to a good, quality "living wage". Then perhaps we will have the financial resources to allow for quality daily living and care, for assistance with our young adults needs.

I have no support at all except for this service. I live away from my support networks (I had to move for Tess's schooling); I have another daughter still at high school.

The lack of portability with block funding means that even when my youngest leaves school I will not be able to return to my support networks, as I cannot take my daughters funding with us.

The lack of choice in my future life due to the inflexibility of this is extremely frightening.

I rent a house in the northern suburbs of Sydney, I can see a time looming when I will no longer be able to afford to live here. What happens to us then?

What happens if I'm offered employment elsewhere and have the possibility of stepping out of the poverty trap. I would have to choose which trap is going to destroy our lives the most, poverty or emotional /social disintegration of my daughter.

The less funded these programs are the greater the level of mental health problems that will evolve. NSW already has a mental health crisis; these cuts are guaranteed to add to them. (It would seem that the NSW government would be willing to spend \$60,000 per year on my daughter if they could jail her instead) Many young people with intellectual disabilities also develop a mental illness.

The government spends 1.4 billion dollars on DADHC services, so why the 10 million dollar cost cuts to the most vital of their services. These programs currently cost around 66 million dollars out of that vast budget, and in dollar terms are the best value.

If the cuts to DADHC's budget are needed, why not to the vast, ever growing costs of the bureaucratic nightmare, which I believe, is where the bulk of the costs are spent.

I have ploughed through the DADHC budget, it is impossible to understand and to breakdown. The amount of people with high support needs is actually not very high.

The figures are iffy. They say they service an enormous amount of people, the bulk of whom only receive over 55 cards, or even very few hours, if any of service annually, but if they are on the books they are included in the tally, to inflate the figures.

In my daughters life we have used DADHC's services for approximately 5 years, and very little at that. She would be on their customer tally for about 13 years. I do not trust DADHC's ability to keep her safe, so I prefer not use their services.

DADHC services go to people who scream the loudest, or the people who have a good relationship with their caseworker. Level of disability is not a necessary requirement. Often the easiest clients receive the most services.

This Inquiry should perhaps be broadened to really look in depth into where the money goes, and then perhaps we would not be in the current mess.

It should take into consideration carer depression, which is endemic.

We already have the most difficult lives of any group in this country; our sense of loneliness and depression is statistically undeniable.

I believe the government thought that they would get away with treating us in this

manner, as their research, (they always research) would have shown just how vulnerable we are as a group. Our lives are not our own. Our load is so large. Where would we find the energy necessary to fight? It is apparent to me that the government is adding to our woes by their move to shift responsibility of care onto families.

I think they forgot to build in the fact that we also have the most to lose. We already live on the edge of any quality of life; we cannot allow it to be worse. All it would leave is an enormous, overwhelming possibility for tragedy.

Where do you go when your support network makes your life more difficult, rather than assisting?

Integration and de-institutionalisation was the most humane road to travel, but not when governments think of it as avenues for cost cutting, penny pinching avoidance and tossing away their duty of care.

If it were to become untenable for me to look after Tess, she would cost the NSW government around \$250,000- \$350,000 per year (unless they were to use the preferred option of jail).

I think that they have been getting a bargain!

I think we are being taken for granted. Our contribution needs to be recognised as an indispensable element for the care of the most vulnerable in our community.

Many families will not have the time or ability to write a response to this inquiry. I would not like you to think it is apathy. Their lives are not their own, even more so now, with the cost cutting to vital services.

I thank you for your willingness to have this inquiry and hope that it may help define the future of disability care for those with high support needs.

I would be happy to appear in person to add to, or clarify the submission

before you and answer questions from the committee.

Nell Brown

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CC: