

MC 21/8/08

Sharon

I've never driven a car but I know the theory of driving because I've read books written by experts. I am now going to tell all car drivers how to drive.

How can people with no experience make decisions about a carer's needs? Any politician or organisation who does make these decisions should get some training otherwise how can they know what they are talking about? Thus every politician whose portfolio is in disabilities, every senior manager in DADHC will now have two weeks 'work experience'. Not a long time when you consider those who have it for a life time. They will look after a high needs intellectually disabled child – and go to work – for two weeks. They will remain upbeat and patient whilst constantly overseeing that child. There will be no let up and every part of their lives at home will be filled with changing nappies even though the child is well past nappy stage; it will be filled with getting up through the night, administering medicine and taking time off work to take the child to a constant flow of medical appointments. There will be no social life because no babysitter could cope. They will find it difficult to leave the house because of the child's unpredictable screaming fits. They will have interrupted sleep, perhaps some nights none at all. They'll get help though. Respite is at hand! It's all been thought out. A stranger will call in to their house once during that fortnight for an overnight stay. They will set up a bed for that stranger and that stranger will sit at their table during the evening meal. But they will be grateful because this is what DADHC has deemed 'respite' and they will be told they are the lucky ones because not everyone can get such assistance. If they are very lucky, a stranger may also turn up at their door for two hours during that fortnight to give them even more respite. Now they truly have nothing to complain about. They have all the breaks in the world needed to cope with their situation.

We had to relinquish our daughter who is forecast to die around her 12th birthday to DoCS in order to get respite. Out of home care for children under 12 does not exist. The fact that she may well be dead by then is of no consequence. We should feel ashamed of even thinking of putting her in out of home care at her age! The lack of understanding by those making decisions is disgraceful. We love our child. She was adopted and it took us years to have her. Being forced to relinquish a soul that you love is a horrifying experience that no loving parent should ever have to endure. But what person can cope with an unrelenting draining situation where you are basically told to get on with it? The lack of respite in my mind actually fosters child abuse. Not physical abuse, hopefully, but mental abuse. What parent has the energy to stay patient and upbeat when a

child – through no fault of its own – is like fingers scraping down a chalk board to that parent? These are the things that people just don't want to hear and some, who are in such situations, are ashamed to say for fear of public opinion. Yet if I have felt this then I must believe that many others have felt this too.

Our child has a deteriorating brain condition. This condition causes severe sleep and behavioural disorders. It will get much, much worse, we are told. We sought to have out of home care during the week so we could cope on the weekends. Our only option was to relinquish her to DoCS we were told by DADHC. Unable to cope and simply without any choice we had to do this. DoCS placed our daughter in Newcastle at a cost of \$11,000 per week to the state. All this because there is neither foresight nor planning in terms of proper out of home care facilities. What we could do with a small portion of that money would be miraculous but the State doesn't have provision for that so we are told. So only crisis care is available. It's not even available in Sydney. Where on earth is the planning?

This is not an unusual story according to the Wood Inquiry. Our story is indicative of many. Our daughter is still - after 8 months - living in Newcastle. We had to fight through the media and shadow ministers to get DADHC to take responsibility. They now have done so but are pursuing a shared care foster family situation. There is a shortage of foster families. We don't feel a foster family could cope – even if one can be sought. Thus she may remain in Newcastle for years. We love this child. She is adopted from China, a process that took years to complete. The events that we have been through just so we could get proper respite to deal with her needs are shameful. We see her every weekend but to have her removed to Newcastle was the last thing we wanted. It is a disgrace. Not just for the parents who are on their last legs (if they remain together) but for the child. How can a child flourish when their parents are at their wits' end and thin on patience - not to mention the siblings. What carers like us need is not band-aid solutions for respite, we need out of home care – and we need it now!

So you want to find out how best to care for carers? Two weeks work experience in the 'field' for every manager and politician that makes decisions. I can tell you now you'd have no more need for inquiries because you'd soon find out what you need to know.