

RASAID



WINDS OF CHANGE – Letter to Eddie Bartnik – 13th March 2009

Dear Eddie Bartnik

I was lucky to have a trip to India recently. Unfortunately, I have to travel by myself because unlike other couples, my husband and I cannot get away together. However, single is better than not going. Driving along the highway in Rajasthan is a fascinating experience. Camels are the favourite mode of transport, followed by little four-stroke auto-rickshaws with twenty-odd people hanging out the doorways. Legs are used a lot, too, both for pedalling push bikes and for walking and it is amazing to watch the women with flowing robes balancing their possessions on their heads as they walk along. Then in the middle of the desert, we came to a large billboard. "Save the environment - CARPOOL" it admonished anyone who cared to read it.

I am not going to be impertinent and ask you if you designed that billboard, because I know you didn't. I am going to suggest that your seminar is about as relevant to the great majority of people with a disability as a sign about carpooling is to the Indians. To spell it out, if you don't have a car, it is not possible to pool it, and if you don't have any funding, individualized or not, then you don't have many life choices.

Let's face it, if you were to have a seminar about health when 97% of the population had no access to the health system you would be held up to ridicule. If you were to have a conference (almost certainly on the gold coast) about education when only 3% of our children could attend a school, you would be laughed out of town. And yet that is what we have in disability. 97% of all people with an intellectual disability in this state live at home with their parents, and many of them are way past the stage in life that it is age-appropriate for them to do so. Tens of thousands of them languish at home with ageing parents and there is no plan to provide a place for any one of them.

These are Australia's unwanted citizens, regarded generally as a burden on society, an embarrassment or their families' responsibility. They have, however, spawned a great and growing industry, the disability industry. In the service sector (that is, servicing the tiny minority), the research sector and the advocacy sector, the Australian disability industry emulates that of other developed countries. If you were to drop in on any conference or seminar around the country, you would hear all the right words: integration, inclusion, equality, choice, "person-centred planning". Perhaps more than any other, you will hear the word "valued". You will be led to believe that disabled people in Australia are valued, that their opinions are valued, their relationships are valued and that they can make a valuable contribution to society. You will come away impressed with the first-world service delivery that appears to be happening in this country, particularly if you fail to catch the passing reference to "unmet need" which will be said sotto voce.

There was always disparity between the reality and the rhetoric, but now it is becoming a chasm. Let's look at some of the rhetoric:

"New ways of supporting people to make their own life choices". The many disabled people that I know have never known any old ways of making choices.

"Increased range of community living options". This sounds like the government department. If there is

none and you make one, that constitutes "increase", "growth" "improvement" and "expansion".
"Focus on individualized funding". You can focus all you like, but this country has no intention of providing funding.

"The move from programs to people" I know about the people but what would the programs be that you mention?

"Person centred planning" We are awash with plans and have been for years, but without the means to bring them to fruition.

Now, to get back to India. If you were to have a disabled child in India or any other third world country, you could expect to look after that child until you die and then hope that a family member would continue to care after you were gone. But, hey, that's what happens in Australia! There are differences, however. We have a service sector which provides for the lucky few, which serves to underline what the many are not receiving. We have an advocacy sector which - well, what is it that the advocacy sector does? And we have the research sector, which turns out learned papers about integration, inclusion, choice - oh yes, and resilience - how we can make those caring families more resilient, when the families that I know could write the book about the subject - if only they had the time.

And now we have a further 10 million for disability research. Isn't that what the disabled people of this country really need! I am sure the sigh of relief was audible in your department.

It goes without saying that as a lifelong carer who is now in the fourth decade of caring, I do not have \$132 to attend your seminar. One of the many reasons that we have no services is that carers like myself have no voice, no union and no representation. This is not an accident - it is that way by design. This is my voice and I wish it to be heard. I ask you to read my email at your seminar. I doubt that you will do so, in which case I will say to you: carry on with the delusion of a civil society, a caring society, a modern first world society. To give you one more metaphor: you are debating the advantages of butter over margarine, but we don't even have the bread to put them on.

Yours Sincerely

Estelle Shields