24/4/2011

We support and encourage the Commission in their effort to forge a sorely-needed National Disability and Injury Insurance Scheme.

“No-one chooses to be disabled. Any of us can become so at any time”. For Example, our daughter’s problems began immediately following triple antigen immunisation. We did not waste time and resources trying to sue anyone. We have born the cost and distress silently for 29 yrs. We are still firm advocates for universal immunisation, knowing that two or three random casualties (we know of three from that year alone) are the price to be paid for the life-saving protection of tens of thousands of children. BUT, having drawn that short straw, surely our daughter is owed support by the rest of society-at-large which avoided illness thanks to the triple antigen vaccination.

In formulating this Scheme I sincerely hope that the Government will,
i) ease up on the paranoid suspicion that generates requirements for people with disabilities, or their parents, to jump repetitively through justification hoops. I can see no motivation to defraud Disability Insurance (unlike unemployment benefits, perhaps). **Our requests are for things that only the genuinely disabled could conceivably want**. Able-bodied, sound-minded people do not want to scam some adult nappies, or ask for someone to be sent around to wake them up and watch them take their medication, or beg for someone to manage their money for them, or plot to steal a joy ride in a maxitaxi.

ii) Recognise that folks with some very serious disabilities can have an intermittent clear day, a happier week, an easier month or even a better year. It doesn’t mean “oh well, that’s all right then.” It is a very is a bumpy ride.

iii) Regognise that there would be very few parents whose disabled child’s needs are not their top priority.

Background:

Our Daughter L, (29yrs) has:

1) A porencephalic cyst, causing spastic hemiplegia with some very troublesome orthopaedic sequelae, and an intellectual, and hence educational deficit.
2) Intractable temporal lobe epilepsy generating psychiatric problems including spontaneous rage, hallucinations and delusions, (even a phantom pregnancy).
   Medications required for the epilepsy have, of themselves, caused more psychiatric problems including a different form of hallucination, aggression, paranoia and disordered thinking, and, demotivation, drowsiness, catastrophic though temporary weight gain, and even a 2 month hospitalisation in a catatonic state. She has also suffered a fractured hip consequent to osteoporosis caused by medications and disuse.

We, her parents and sole carers are aged 63 and 75yrs respectively.
We moved from our family home to a duplex in order to give her some independence and yet be available to help her when needed, immediately, day or night.

Key points in the outlined plan that we wish to emphasise from our personal experience are.

1) **The notion of the Client/Guardian directing the use of allocated funds, is paramount.**

Two simple examples

A) We looked into the concept of the Testamentary Trust, which seemed like a good idea. Over our lifetime, we have paid several hundred thousand dollars in tax. We would have been willing, (and have paid less tax) to set a good amount of our income aside for a Trust to help L have some life after we are dead. But as things stand, it is not at all satisfactory to us. Tax dollars are dissipated on layers of beaurocracy to dream up services that L personally may not need, but disallow ones she does. **The Testamentary Trust consistently allows employing but not purchasing. The clients/family must have the discretion to choose what will be most helpful to them in their individual circumstances.**. eg L does not drive, but neither does she at this stage need to employ a driver, or apply for a CAP package which includes a driver However, when she has had a seizure, or is exhausted, upset, frightened, lost, or mentally/physically ill, she sure could use a taxi on the spot. Foot note:

Even now, we do not feel we can access taxi vouchers (and therefore taxis) without perjuring ourselves. The criteria state clearly that if she is physically able to stagger onto a bus, she is not eligible. (In their wisdom they have included "not even at night". Most people with disabilities are far too vulnerable to use public transport safely after dark even, if they can struggle on, during the day.

B) Our LAC advised us that there was some sudden "spare" money that could be applied for, to purchase certain things that would help L to live independently. What we craved at that time was a satisfactory intercom arrangement to summon us from next door (often several times per night) when she was about to have a seizure. (For two whole years, either parent slept at her unit). However, we were told that the money could not be used for that, but it could be used for home alterations to the actual house, like a sliding door, for which we had no need.

If we were ever granted some funding from an insurance scheme we would definitely take it in the cashed out form, to tailor help to our own situation.(See opening remark about normal parents having no higher priority than their disabled child's needs

2) **360,000 people to receive funding would be the same old tip of the iceberg.**

A) Our daughter, whist trying to "get a life" after a big deterioration ending in 2 months of being totally "out of it" in SCGH, was refused CAP funding for 'community access,'- not just refused, but put in the "don't bother to apply again" box. Less than 30 out of about 240 people were funded it in that batch of applications.

B) Many friends suggest, as we are getting older and are not immortal, that L (who wants to live away from us) could go to a Group Home. Our LAC states categorically she would not be eligible. i.e. Don't even think about it!

The queue is obviously very, very long!

3 **Even if money is granted to employ, there is not always the skilled/appropriate manpower on the specificly mandated agency's books**

We need to source help anywhere we can.

Eg, i) On one of the occasions when our daughter was psychotic, she was physically assaulting us when we tried to administer her antiepileptic medication. We paid a subsidised amount for some good short term help from Silver Chain nurses, whom L would not assault. However, SC curtailed the trained nurse services and we were redirected to their non-nursing, home-care services. After 5 days with no help, the only worker they could find to wake this halucinating and sexually fixated girl in her

dark bedroom at 7am was a newly-arrived man. Nice gentleman or not, we were not happy to risk him becoming embroiled in L's perseverating delusional sexual fantasies. There were no female workers available.
Eg.ii) When L was discharged after insertion of pin and plate in her hip she was granted a couple of hours of home help. It was at the time of the last resources boom and PHCS had no staff available. A fairly simple elderly woman was co-opted from the aged care sector to manage this very difficult client, and we ended up letting her go…

4. **Sustainable funding, interstate portability and freedom from political interference**. This group of points are, I would have thought, axiomatic, and we are very glad they will be addressed.

5. **Injury Insurance**. No-fault injury insurance is also long overdue. The public, private and social cost of the current adversarial way of funding the accidentally injured is absurd. We all know how it doesn't work to anyone's betterment. It only funnels the funds to courts and legal and medical providers, and prolongs the state of limbo for the client.
Over-the-top fear of being sued, has lead to the mind-numbing prohibition of almost anything that might be a bit of harmless healthy fun, eg. jumping off the Cottesloe pylon, banned after generations of use, after a desperate attempt to sue the Council for an unrelated no-fault accident in the surf). Eg. A friend was forced to remove a simple child's swing from a tree on his street-verge.(Nedlands) Is it any wonder our young people end up bored and alienated.

Summary.

We wish to heartily congratulate those who have initiated this proposal and encourage the commission in its deliberations
We submit that the Commission is pointing in the right direction with the concept of no fault universal disability insurance.