INITIAL SUBMISSION TO NDIS APRIL 2010

I am a mother of two adult sons with intellectual disability. They are vastly different in their need and level of disability. Therefore the issues with both of them are entirely different.

There is always the problem of what happens when I am not longer around. My husband and I are the youngest of our families and we have no other children. The son with the least level of disability is more vulnerable in these circumstances as he has a certain ability for independence but still needs varying degrees of guidance. He currently works in a disability enterprise but at the moment there is nowhere for people like him to go when they are of retirement age and the funding is not tied to him but to his place in the Disability Enterprise service. Funding should be available or his support dollars should be transportable with him to where ever he goes. People are prohibited from retirement because there is no provision for some day stimulation or activity which keeps them functioning at their optimum level. My son lives alone but other people such as he, live in group homes and there is no day time staff to care for them if they don't go to work and no funding forthcoming as currently funding comes out of different buckets.

My other son is profoundly intellectually disabled with no speech and no personal skills, he has epilepsy and requires care 24/7 to maintain a home for him and take care of all his hygiene needs etc. and monitor his seizures and administer his medications. He has a level of funding for this which has become increasingly insufficient and his carers have no respite and lately have been on stress leave and my levels of stress have risen accordingly as I thought my husband and I had set him up in a situation which would not require us to be forever present and we could die in peace knowing that his care would be there without our propping it up and finding extra funds to take care of some other costs involved and having to support his carers when they are in need of respite.

The way funding is allocated is a joke. Submissions are sent in and if you are about to die or divorce or have a breakdown you might get considered. I'm sure that this is what you are trying to alleviate with this NDIS but it needs to be set up properly or it will go the same way the medical system has gone under Medicare and end up still very short of funds.

Funding for People with Disability should be done on a whole of life basis not piecemeal as and when the need arises depending on which level of Government handles which area of funding. At the moment the idea of Commonwealth only funding employment and people not being to move to alternatives to employment or retirement or from one to another on a daily basis without being told they are double dipping, is ridiculous. A lifetime plan should be put in place and funding accrued or calculated over the period fore seen as the person's lifetime bearing in mind that people are living much longer.

Proper planning is needed for aged care and other therapies which may become necessary at any time during a person’s life. The funding could be allocated to the person as soon as the disability is diagnosed and allowed to attract interest which would set things up for when it is really needed. However this should not prevent a top up if it proves to be insufficient as needs change and costs of care and living are constantly going up while the supposed CPI increases in funding is not sufficient to cover this.

I am registering my interest in the process as it unfolds and would like the opportunity to attend any public meetings and to submit further as the process unfolds. I am about to escape my situation by going overseas for a couple of months but would you continue to send information as and when it comes available so that I can keep up with developments and remain informed when I return.

Yours faithfully

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