SUBMISSION TO PRODUCTIVITY COMMISSION

Disability Care and Support

This submission is telling my story to relay the devastating impact that unsupported disability has had on my family over a period of 28 years. I hope to lend weight to the introduction of a National Disability Insurance scheme so that similar stories will not be repeated. With such a scheme there should be appropriate and guaranteed help available, from the government of the day into the future. This should include people with a mild intellectual disability.

Three years ago I privately sought and funded a diagnosis of Aspergers Syndrome, for my youngest son, who also suffers from a mild intellectual disability, epilepsy and IBS. After many years of struggle and despair, I had finally got an explanation.

Thirty years ago my marriage to a young farmer which I now suspect has undiagnosed Aspergers Syndrome, produced three children, a daughter and two sons. The son’s both inherited the Asperger’s syndrome. The older one remains undiagnosed; though I am sure he has it. With above average IQ, he had challenging behaviour and left school early, falling into trouble and developing a marijuana addiction. He now receives unemployment benefits. The younger son still lives with me and receives a DSP. Both our sons are now in their late 20’s, jobless and with low self esteem and depression. Our daughter escaped the Asperger’s but has developed Crohns disease. She luckily maintains a good job and somehow survived the family problems.

There is an obvious genetic link and the risk of this happening to a family is impossible to calculate. However the effect on the quality of our lives has been enormous.

The difficulties of this 28 year journey involved financial loss, divorce, addictions, domestic violence and social isolation, depression, deteriorating physical and mental health and joblessness. My repeated failures to rejoin the workforce have been due to my caring responsibilities and the stress I have suffered. There is an untold story here.

Over this time, our dairy farm was lost to the bank, our extended family relationships fell away and my husband and I divorced and now live in separate states. I have a court order for disability Child Support payments for the younger son, which the father resents and consistently defaults on.

He rarely visits his children and counselling and/or diagnosis is actively avoided by both the father and therefore by the older son, despite my attempts to make this happen.

For many years, my sons' teachers saw me as being an overprotective mother and all behavioural problems were sourced within the family. There was no help, living in an isolated area, with little knowledge back then, of Asperger's syndrome. This was especially hard for me as a trained teacher and working in various schools as a relief teacher. Three times in the last decade I have unsuccessfully attempted University study to upgrade my skills, so I could work again, but always this created more problems as I was not focusing on my sons.

The shameful neglect of the disability sector which has saved Government money has used Carers and their loved ones to bear the shocking burden. I found myself totally unsupported and have been reduced to a state of poverty. I have worked long and hard, living on a Carer's pension at 24cents/hr since the 1990's, though this has recently risen slightly. This has been both gruelling and insulting, considering the massive toll wrought on my health and wellbeing, and the enormous challenges and losses faced by my family over this time. Trying to navigate an endless array of Government bodies and agencies with little communication flowing between them, hence lost opportunities, has added to our emotional and financial stress.

The social isolation we endured over the last two decades has been unbelievably harrowing during the tumultuous teens and beyond. This was particularly difficult with my older son after our divorce, when he became physically violent and repeated restraining orders were taken out. This stopped when I left the State for a few months, becoming homeless at the same time. He now lives a fairly reclusive life and has lost his licence. He is still ‘in denial’ and refuses to ask for help. Subsequently he stays on long term unemployment lacking the independent financial/ social /emotional support that he needs. We have a better relationship now, though I worry what would happen if Centrelink cut his already meagre payments.

Discrimination and bullying both in the schools and the wider community found me defending both my son’s over their formative years. My younger son’s integrity was defended in court in 2000 using Anti-Discrimination law. I also have Power of Attorney for him, though he can still sign a contract. The introduction of a National Disability Insurance scheme should help foster more tolerance and legal protection, promoting a more inclusive attitude towards those with a disability.

My younger son suffers memory loss due to his epilepsy. He is vulnerable and has extra needs which are ongoing and costly. Recently he has received SIPS funding from the State Govt to support his job pathway, which must be resubmitted each year and is uncertain. Obtaining this has been a struggle, battling against discrimination towards his attendance at the TAFE Art School. He is also on a waiting list for a much contested Independent Support Package, which he desperately needs. He has recently been accepted into the Commonwealth PHAMS program and has become the recipient of a Companion card and participates in supported workplace training as part of his SIPS package. This has all been very positive for him over the past 12 months; however I worry that his funding will not be ongoing and that there is no long-term lifetime plan in place for him. I also have concerns that he would be excluded from help from a disability insurance scheme, as he is not regarded as severely or profoundly disabled.

Self directed Government funds from a disability insurance scheme would be more desirable for my son's future wellbeing, provided he qualifies under expanded guidelines. His future housing needs should be addressed from this scheme as well. He has expressed the wish to move out on his own and this would be a positive step for him, though he would need much support to achieve this successfully. I have started to access Respite and in-home help for him, though he is reluctant to participate. However, both my son and I would both be disadvantaged financially if we lived separately, under the current guidelines.

Ten years ago I could rent a decent house whilst receiving the Carer's pension, but prices have tripled in that time. I have moved 7 times in the last decade, including two times when I was homeless with my son and reliant on emergency flats. The effect of this transience on my family stability has been indescribable. I have felt like a refugee in my own country, never staying in one place for more than two years. I have either lost or had to sell most of my possessions just to survive. This is due to my state of poverty brought about by government neglect of the disability sector.

Ageing and vulnerability increase my concerns for my sons as I have little chance of acquiring a well paid job now. This means I cannot provide for them as I would like to, plus I have no assets or superannuation to pass onto them to secure their accommodation into the future. When I go, there will be no person to replace the daily support they receive from me and no place for them to go. My younger son's extra expenses are currently paid for from child support funds. When his father stops working there will be no other income stream to supplement our son’s pension and meet his extra needs. The recent increase in pensions has been helpful, though not enough to meet all of his needs.

It is my firm belief, that if there had been similar funding to the proposed insurance scheme when my sons were still in their infancy, the negative and profound impacts of their disabilities would have been greatly reduced and they would have more productive lives now. Such a scheme may also have lent support to our marriage and family ties, reducing the financial strain and improving the health, quality of life and job outcomes for us all.

There are generations of people with disabilities, their Carers and their families who have suffered unnecessarily due to shameful government neglect and lack of adequate funding. An expanded insurance scheme should help redress this, provided it is broader in its eligibility criteria. Such a scheme would foster more hope through Government policy, establishing equal rights for those struggling with disability in their lives.