

10th June 2008

The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Submission to the Senate Committee Inquiry – Special Disability Trust.

My wife and I have a son born with Cerebral Palsy. Richard is now 38 years old. He has nerve damage down both sides of his body. The nerve damage has left him with no feeling to the left side of his face leading to a lack of control of his tongue, a severe speech affliction and a saliva dribble problem.

His left arm has a turned elbow and a lack of control to his left hand which also has no fine motor movement.

He walks with a slight gait because of the damage in both his left and right legs.

He also has a co ordination problem and finds it difficult to focus his eyes at times.

Richard has a driving licence and can use the mechanics of a vehicle very well but chooses not to drive because he has trouble judging distances and the speed of other vehicles, especially those coming towards him.

Richard has had a disability support pension since age 16 and has worked in a sheltered workshop (Good Samaritans Industries) since he was 18 years of age. Over that time he has undergone computer studies and is computer literate. He has completed an elementary course at TAFE in engineering, is a competent welder but unfortunately can no longer perform that duty at work as his disability has in the past put him at risk of serious injury.

Richard does not drink alcohol or smoke, is fearlessly independent and lives in his own small duplex unit. In 1995 he decided that he wanted to move out of the family home, so his mother and I investigated what was available. Despite eventually being offered a place in a group dwelling, Richard wanted his own place, to live as his brothers and sister lived, and opted for a low income Homewest Access Loan available in Western Australia though the State Government.

His mother and I subsidized Richard into the Access Housing loan and the repayments of the balance are taken automatically from his Centrelink disability pension.

He can catch public transport but if he gets off at the wrong stop is disorientated. With the coaching of the Disability Services Commission he can do his own shopping, which he now does mostly over the internet, prepare simple meals and do his own laundry.

While this all sounds good, it has placed a huge burden on my wife and myself. We have to maintain the property, both financially and manually, do all his ironing and most of the cleaning as Richard although trying very hard, sometimes cannot remember what needs to be done.

He cannot trim his finger nails. Has difficulty doing up buttons and trying his shoe laces
Has difficulty showering.

We spend many hours each week making sure that Richard's life is functioning properly and supporting him financially as after paying his home loan, private health insurance, dental health and medical bills and just every day survival, he does not have much money left over.

We have never applied for or received a carer's allowance, nor, other than his home loan and a small amount of input from the Disability Services Commission, received monetary or other assistance from any Government body.

We are prepared to support our son as long as it takes and as long as we are around. What really frightens us that we do not know who will take care of him when we are gone. His siblings, whilst very supportive have their own families to care for and could not offer the necessary time required.

The special disability trust which we would have set up in our will, could have been a perfect vehicle for providing for Richard's future needs, but unfortunately, he would not qualify because we do not receive a carer's allowance and he lives in his own home.

The limitations of the Trust in its present form means it could not be used to maintain his dwelling, home cleaning, pay for his medical needs nor help give him a quality of life.

We find it very difficult to understand why the Trust allows a limit of \$500,000. Disabled people living in institutions, hostels or group dwellings would have had place funding yet the Trust restricts to use of the money to accommodation purposes. What are they going to spend the money on? We believe that families are not taking up the Special Disability Trust because the money put in these Trusts would become "Dead Money".

Whilst Richard is permanently disabled and disadvantaged just as much as most other disabled members of the community it looks like he has fallen through the cracks in the system because he has struggled to make a life for himself.

Obviously there must be many others in our country whose position is the same as Richard and in its present form the Special Disability Trust offers no advantage what so ever. To have an effective impact on the disabled community the Trust needs to have a far broader scope to allow better utilization of the money.

It also needs to have a less bureaucratic application system. Richard has had a disabled support pension for 22 years yet under the current system he would have had to submit

doctors and health service reports to verify his affliction. What? Has he suddenly found a miracle cure for cerebral palsy. People with disabled offsprings really are sick and tired of having their permanently disabled sons and daughters continually being assessed.

I am sure that all the disabled community will welcome the Community Affairs Committee inquiry, and only hope that it will deliver more realistic benefits to those living with a disability so that the mum and dads can rest a little easier knowing that after they are gone, there is a system in place that will allow their disadvantaged children to enjoy the quality of life that they deserve.

Yours sincerely

Colin F. West