

**Submission
No 36**

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

Name: Mr Martin Boers

Date received: 5/08/2010

We have a 6-year old child with Muscular Dystrophy. She cannot walk, stand, or roll over. As well as requiring a wheelchair to mobilise, our daughter requires essential therapeutic equipment along with regular speech, physio and occupational therapies. Without these, our daughter's condition will deteriorate more quickly, making it less likely that she will be able to attend mainstream school, more likely that she will require extended periods in hospital, and more likely that she will die earlier than she otherwise would.

We are constantly amazed at the lack of basic equipment and services available from the NSW and Australian governments, not just to our daughter, but to all the families with disabled children that we read about on www.australiansmadashell.com.au. Even if you ignore the obvious ethical questions, it just makes basic economic sense to for the government to help keep people out of hospital. What possible explanation can there be for this lack of both compassion and financial common sense?

What about Enable NSW? They recently refused our request for a "Stander", a piece of therapeutic equipment that has been clinically proven to help children with physical conditions like our daughter's. Based on Enable's response to our application, we would have had more luck applying for a hang-glider for our daughter. Enable NSW is a failure. With nowhere else to go, we were forced to apply for funding from Variety. While the people who are involved in charities like Variety are wonderful, the fact that charities need to fill this gap in government services is shameful. My friends overseas thought that we lived in The Lucky Country, but they had to think again when they heard about the disgraceful treatment of our daughter by the people in this government.

It is clear from our experience that the Department of Ageing, Disability and Home Care (ADHC), and the other government departments who passed the buck when we contacted them, is completely ineffective in the delivery of disability services. Disability services need to be completely restructured. The proposed National Disability Insurance Scheme would be a good start. In both the federal and state elections, my vote (and the votes of all my family and friends) will be going to the candidate that supports the NDIS.