

MATTHEW DRURY

Petition

MR R.F. JOHNSON (Hillarys) [3.29 pm]: I present a petition couched in the following terms -

To the Honourable the Speaker and Members of the Legislative Assembly of the Parliament of Western Australia in Parliament assembled.

We, the undersigned, bring to your attention the situation of Matthew Drury and his family.

Matthew is a seventeen year old young man who was born with Tuberous Sclerosis. He lives at home with his parents and his older brother in the suburb of Duncraig.

That is in my electorate. The petition continues -

Tuberous Sclerosis is a syndrome characterised by epilepsy, skin lesions and developmental delay.

Matthew started his seizures at the age of two months. Because of the very early onset of his seizures the doctors indicated a poor prognosis for him.

Matthew has a most gorgeous smile and is dearly loved by those who know him. He has just had a growth spurt and now stands over six feet tall. He attends an Educational Support School during the day.

Matthew is totally dependent on his family for all his personal needs, including feeding, dressing, bathing and toileting. He has no speech and very limited fine and gross motor skills. He is able to walk but has no sense of danger. He therefore requires constant supervision, at all times.

Despite a cocktail of four different anticonvulsant drugs three times a day Matthew's epilepsy remains severe and uncontrolled. He has had several broken bones and teeth as a result of his seizures. He now has to wear a helmet to protect him from fracturing his skull.

Matthew's care falls mainly to his mother, as his father works long hours and occasionally has to work away from home. His brother is a university student and has a part time job. With the ongoing and increasing pressure of trying to meet Matthew's needs, as well as those of the rest of the family, Matthew's mother came very close to a physical and mental collapse. The family received some much appreciated Intensive Family Support funding for additional assistance.

Matthew's family have reached the point where they need accommodation support for him. While the decision to apply for this has been made with anguish, the family realises that it is the only option for them. They have applied SEVEN times, and been rejected SEVEN times. Each rejection is a devastating blow. The family wonders if they will have to completely collapse before they receive the help they urgently need.

Now we ask that the Legislative Assembly give urgent attention to:

The provision of the accommodation support services needed by the estimated 300 people with disabilities and their families in Western Australia currently unable to access the accommodation support they need.

The provision of the respite services needed by the estimated 950 people with disabilities and their families in Western Australia currently unable to access the respite they need.

The provision of the "Post School Option" services needed by the estimated 800 people with disabilities in Western Australia currently unable to access the support they need to engage in activities during the day.

The petition bears four signatures and I certify that it conforms to the standing orders of the Legislative Assembly.

The DEPUTY SPEAKER: I direct that the petition be brought to the Table of the House.

[See petition No 92.]