

By way of background I am the father of a 25 year old man with severe disabilities (Cerebral palsy, epilepsy, scoliosis, developmental delay, cortically blind). We live in Perth WA and my son stays at home for 4 nights a week and is in respite for 3 nights. He receives post schools options funding to attend Rocky Bay Monday to Friday. In addition we receive IFS and FFS funding to pay for in-home-respite. We have been applying for funding for long-term care but have to date been unsuccessful.

The key points I wish to make are as follows:

1. With regard to the provision long-term care the system in WA does not tell caregivers when or if you will be funded. It just rates your need. We have been applying unsuccessfully for six years and all we know is that we have "high needs". We need an indication of when we will be funded so we can plan our lives. Even if we don't like the advice given at least we can plan our lives accordingly. We need some certainty.
2. The eligibility for services must be national and not state by state, and most importantly, the provision of services must be transferable from state to state. About 8 years ago we moved from VIC to WA and it took as nearly a year to get services fully operational. The perceived hassle of moving our son again prevents us from considering moving to another state now.
3. I see no reason why the provision of services should vary from state to state. There may be geographic reasons why the services in a city should vary from those in a regional town, but this is a common problem in all states.
4. The selection criteria must not be so negative. We like to be positive about all our children. Why should we have to be so negative about our disabled children in order to ensure that their needs are met.
5. Currently I control the spending of the IFS and FFS funding. I employ the caregivers and pay them. This system is empowering and works well.

I am happy for my submission to be made public.

Many thanks,

*Paul Smale*

WA