

Personal Story

16 August 2010

I am the mother of a 13 year old with Rett Syndrome. My daughter does not speak or walk, is incontinent and has uncontrolled epilepsy. She needs me or another carer to look after her every need.

I love having her at home while she is school age but I do not want to be taking care of her in our home for the rest of my life. I would like to have my daughter set up in a home with one or a few other children like her by the time she is 21.

We are relatively well off and could afford to buy the property for her to live in but, notwithstanding our financial situation, we could not afford the ongoing care costs for her to live out of the family home for the rest of her life.

I propose that a combination of the following should be considered under a national care and support scheme to assist in the funding of supported accommodation for people with disabilities:

- Subject to scaled means-testing, a once-off payment by families for the right of the disabled person to occupy a residence, as per the retirement village payment of an incoming contribution.
- Subject to scaled means-testing, an ongoing rental to supplement any pension available to the resident, as per the daily supplement required to be paid by the residents in Nursing Homes.
- An option to become involved in additional activities subject to payment of a small additional fee.
- Permitting parents to access their superannuation funds to cover the establishment costs of the residence.
- Subject to means-testing, payment of a percentage of care costs on a deferred and in-advance basis at the time of death of the last parent to survive. This is akin to the deferred payment due in most retirement villages when a resident leaves or dies. The concept needs to be modified of course in the case of people with disabilities due to the fact that their lifespan is so much longer than people in retirement villages and, commonly, they have no assets to liquidate on their death.
- There should be incentives for parents encouraging them to donate their homes if they would be suitable as a Group Home, especially, as is likely to be the case, if the house has been modified so it is suitable for a person with physical disabilities.
- Tax-deductibility of payments into a Special Disability Trust would encourage parents to plan for their child's future if they were financially able to do so.

Also, of paramount importance is the right to choose from a range of accommodation models without the current stigma attached to cluster living arrangements.