

RASAID



NO PLACE FOR OUR LOVED ONES TO GO

There is a great and growing crisis in Australia that few people know about and even less are talking about, says Sydney mother and working carer Estelle Shields.

“There is nowhere in the ‘lucky country’ for its citizens with severe dependent disabilities to go – except staying at home with their parents,” said Estelle, mother to 32-year-old Daniel, who has high support needs and a severe intellectual disability.

“When those parents grow old and sick, there is still nowhere for their adult children to go. It is these people, not the Indigenous peoples or the refugees, who are our most vulnerable and needy citizens – but they are somehow below the radar, not even on the agenda.

“Around the developed world, governments have come to terms with this issue and have taken responsibility for their citizens with an intellectual disability. Here in Australia, we trail far behind other first world countries. The solution that our governments are suggesting, that is, that we pass our disabled adult children on to their siblings, is a third world one and unworthy of this wealthy nation.

“You have probably heard an expectant parent say that he or she has no preference about the gender of the child, as long as the baby is ‘OK’. But what happens to those parents who randomly receive into their hearts and homes the child who is ‘not OK’?

“The average Australian believes that things are improving for disabled people, because they see wheelchair-accessible buildings and transport. The reality is that waiting lists for early intervention are longer than they have ever been, disability education is in crisis and the costs involved in raising a disabled child are often crippling.

“Divorce rates are doubled in families with a disabled child and respite services are stretched to breaking. Parents of a disabled child work far harder than other parents but when they reach retirement age, they are told there is nowhere for their family member to go and they must keep caring. They have not earned a retirement and their person has not earned the right to leave home and gain independence from them.

“There is a disability system in each state but it is beyond the capacity of the states to deliver what is needed. Currently, the disability system in NSW is boasting extra funding under Stronger Together. But they are meeting the need of only approximately seven per cent of the families that apply for supported accommodation.

“Imagine the outrage in our society if we had an education system or a health system that could meet the need of only seven per cent of the population. Yet this is what we have in the disability sector and very few people mention it.

“Where does this leave the parent carers? We are faced with caring until death or dementia. Our sons and daughters often wish to live with their peer group instead of being stuck at home with ageing parents.

The only way of achieving supported accommodation through our disability department is to abandon our beloved son or daughter at its door. When we have devoted our lives to providing for the every need of our person for decades, how can we then relinquish that person at the door of a department that has no place for him or her?

“This is how the disability system works in Australia: it is dependent on the fact that we love our sons and daughters too much to relinquish them. Yet in our state last year, 65 families who were pushed to the edge did just this. I know one of these families and the trauma and anguish that they suffered was just too much. It is unconscionable that our society can let this happen.

“How did we get to this situation? Earlier generations had places for their disabled sons and daughters to go. Some of these places were highly inappropriate but many were family instigated and family run and were caring village-style residences. They have all been branded with the label of ‘institution’ and closed, but very little has been done to replace them. A report released recently says that for many years people with disabilities found themselves shut in, but now they find themselves shut out - shut out of the way of life the rest of us take for granted.

“There is no economic imperative to provide supported accommodation. People with an intellectual disability are perceived as valueless people. My son earns \$1.50 per hour from his supported employment provider while I am paid \$50 per week carer’s allowance. This is our economic worth. Ageing carers are too old to resume employment, if they were ever able to work at all, so providing accommodation will not get them back to the workforce. Supported accommodation comes at a large cost to governments while family carers are cheap – almost free, in fact. So our governments give us a carer’s bonus of \$600 per year and an ageing parent carer’s respite package amounting to one week per year. They are patting us on the head and telling us to carry on!

“The outcomes from the lack of supported accommodation are frightening. I am seeing older and older carers, even into their nineties. They are afraid to die and leave their son or daughter unprovided for. Even when they become ill, there is great difficulty finding emergency respite. I am seeing anxious siblings who have families of their own and mortgages concerned that their careers and whole way of life may be compromised if they have to take on the care of their disabled sibling.

“I see an increase in mental health issues in people with an intellectual disability and wonder if they perceive that no provision is being made for their future and that an earthquake is coming their way. When it comes, it is cruel and sweeping. In the same moment, the person with a disability, that person with the cognitive ability of a small child, loses their primary carer, the only home ever known and the familiar locality. Because no gradual transition out of home and into supported accommodation has been possible, the wrench is total and it is inhumane.

“The family pet has a better chance of finding a loving home in the local area than the person with a disability. This is not a future scenario: we have seen it played out over and over again in our community. Carers are dying while still caring. We have to do better than this!

“Not one to sit on my hands, I joined with a group of other local families in my area to achieve what we all so desperately want for our sons and daughters. Our group is called RASAIID, which stands for Ryde Area Supported Accommodation for Intellectually Disabled. If a family is lucky enough to be included in the seven percent who do get accommodation, it will invariably be far removed from the local community. Our dream is to make a cluster residential setting here in the local area. We have seen our people grow up together over decades and witnessed how much they enjoy each other’s company. We want to make an intentional community with a pioneering model that will set a precedent for housing people with an intellectual disability and be emulated across the country. To this end, we have spent six years garnering support for our project from politicians and bureaucrats. Today, after years of assurances and promises, we are as far from achieving our dream as we ever were. In a climate of economic crisis, people with a disability are the last in line.

“Carers are well known for playing down their needs and seeing others as worse off. I do the same. I consider myself one of the lucky carers. I trained as a high school music teacher and while I could not go to work after I had my son, I have been able to carve out another career teaching piano from home while being here for him. I have had a wonderfully supportive husband, who now, upon leaving work, wonders why he cannot have the sort of retirement he hoped to have, the one he sees his mates having.

“My son, Daniel, has a significant disability. He has the cognitive age of a three or four-year-old and needs a lot of assistance with his daily living. Yet he is strong and well, active and happy, a valued member of the team at his workplace, a loyal friend and an integral part of our family. Everything he has achieved over the years has come with great effort and this qualifies him to be called an 'Aussie Battler'. At the age of 32, he has earned the right to leave home and we have earned the right to retire.

“There are thousands like us and we look to our governments to provide what we must have. We are told that as Australia ages, there are measures in place to accommodate the needs of the changing demographics. We, the carers, are also ageing, and there are no plans in place for our precious sons and daughters - no place for them to go when we are not here.”

Estelle Shields