

RASAID



A MOTHER'S LAMENT FOR DISABLED CARE

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Imagine if you woke up one morning and your teenage body no longer worked. Something has ruptured in your brain and you can't move your legs, arms or hands. Overnight, you have become paralysed. The basic daily necessities - eating, drinking, going to the toilet - are done for you.

This happened to a friend of my son, who is himself disabled. People can be disabled for many reasons: strokes, acquired brain injury or, like my son, born with a condition such as cerebral palsy.

As Victoria's Public Advocate, Colleen Pearce, revealed last month, the state system for care of people with disabilities is scandalous, racked by inadequate services and chronic accommodation shortages: about 2500 disabled people are unable to get supported accommodation.

The lack of supported accommodation is so severe that worn-out family carers, desperate for a placement for their loved one, abandon their highly dependent relatives, forcing the Department of Human Services to find them somewhere to live. In Australia today, abandonment is one of the only ways to get supported accommodation.

I was forced to do this 12 years ago when my son was 16.

He moved into a community residential unit (CRU), a six-bedroom house run by a not-for-profit organisation. He shares his home with five other wheelchair-bound adults, and is cared for by support staff.

A few years ago, I could sleep at night because my son's house was staffed by dedicated permanent carers. But most have since left. This could have had something to do with working in a largely unsupported environment, or the lousy wages - disability support workers earn about \$20 an hour.

My son and his housemates now cope with a merry-go-round of casual agency staff, most of whom are strangers to them. This causes them anguish - people who have difficulty communicating their needs will become extremely frustrated when continually confronted with strangers. The disability organisation claims it is difficult to attract or retain permanent staff; hardly surprising when they're paid little more than burger-flippers.

Why is there a lack of quality care and accommodation for people with disabilities in Victoria? In the 1980s, governments adopted the ideology of deinstitutionalisation, whereby people with disabilities would live in CRUs - stand-alone houses in suburban streets - rather than congregate care, as in old-style institutions. They were to be "normalised".

Community integration began as an understandable and necessary reaction to institutionalisation. But the pendulum swung rapidly towards wholesale community integration that became an equally indiscriminate orthodoxy, whereby no matter how severely intellectually or physically disabled a person was, they would be housed under the one-size-fits-all, care in the community policy.

Many families were worried: might this expensive option mean fewer accommodation places? We argued that a lot of CRUs would have to be built to provide adequate housing and a lot of staff paid to work in them. Where, we asked, was the money going to come from to pay for it all? We were ignored. Families were not clamouring for a return to institutions. Many, like me, saw the sense of cluster housing, like a mini-retirement village comprising six to eight houses on one site, which operate beautifully and cost-effectively in countries such as Britain and the Netherlands.

I wept when I toured a cluster in Manchester: villas dotted around a lively community centre - which meant a social life for residents - safe pathways to traverse. There was no huge staff turnover, and more staff on site meant if a bad apple worked there, they were less likely to have the opportunity to maltreat residents.

Families' pleas for the option of cluster housing have long been ignored in Victoria, stranding our loved ones - those, that is, who could get any accommodation at all - in suburban streets.

Today, these so-called community utopias in the suburbs are riddled with problems.

Aside from the staffing crisis and the constant fear of abuse from unsupervised casual staff, isolation is one of the biggest issues: marooned in suburban enclaves, largely ignored in their "community", the loneliness of people like my son and his housemates is heart-wrenching.

While federal and state governments allocate billions of dollars of taxpayers' money each year for disability services, and charities raise millions more, after the money is filtered down through layers of bureaucracy and divided among a maze of service providers, not a great deal remains for actual services.

Eighty per cent of my son's disability support pension is swallowed up in board and lodging. On top of this, he pays \$60 a week for a maxi-taxi to take him to his day training program and more than \$3000 a year to attend that day training program.

I think about why governments continue to disregard cluster housing as an accommodation option and persist in a blanket care of CRUs when after two decades this clearly does not work for everyone.

Cluster housing means that shared facilities would be cheaper to run; more on-site staff means residents are less likely to endure abuse; and residents can enjoy a social life with their peers.

Of course, none of this may affect you. But you never know when it might. My son's friend, who woke up one day paralysed, once kicked footballs in winter, and batted centuries on a cricket pitch in summer.

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