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THE DISABLED NEED LOVE. NOT SOME IDEOLOGICAL UTOPIA

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Forcing people with a disability into the "community" can be heartless and thoughtless, writes Sandy Guy.

Mary Pearson and I live worlds apart - me in Ballarat and she in central London. Mary's former husband is a lord, mine a concreter. Yet on the same day in 1980 our lives changed forever. On opposite sides of the world, we both gave birth to babies with disabilities.

Our stories are similar: the grief suffered on the day of diagnosis, the day-to-day battle to cope, the heartbreaking search for appropriate educational placements for our children, the impossible stress on a marriage. Both our marriages ended when our special children were six years old.

A placement was eventually found for Mary's daughter at a sheltered village community outside London. My son began his education at a specialist school in Melbourne with respite facilities.

We were happy with our choices, and congratulated the health systems of our respective countries that seemed to take into account the wishes of parents in the care of their disabled sons and daughters. For a few days a week we were able to live like everyone else.

But we lived in a fool's paradise. It was during these years that the ideology of "normalisation" was gaining a vice-like grip on government policy. Proponents of deinstitutionalisation demanded that all people with a disability, regardless of the severity of their disability, move into suburban houses in the community. They were to be "normalised".

There is no doubt that large institutions were unsatisfactory. Community integration began as an understandable and necessary reaction to institutionalisation. But the pendulum swung very quickly towards wholesale community integration, and now there is an equally indiscriminate orthodoxy according to which every person with a disability is deemed better off in the community.

In Victoria today this means that people with disabilities are, along with prisoners, the only members of our society forced to live in a certain, prescribed way.

Unlike Mary's daughter, who today lives happily in a small village community for people with disabilities outside London, my son lives in a Community Residential Unit (CRU) in Melbourne that he shares with five housemates, all with severe disabilities.

Because he lives in Victoria, my son has no other option - unlike most non-disabled members of society who may choose to live in a retirement village, commune or community of some type.

Although the house is roomy and bright and staff do their best to make it homey, it can be a depressing place. Isolation is one of the biggest complaints from residents. In the five years my son has lived at the CRU, not one neighbour has visited the house. At no time have my son or his housemates been invited to any event in the neighbourhood. They are ignored in this "community", apart from the occasional complaint regarding staff cars parking in the street.

Just getting from one place to another is a logistical nightmare. For example, if my son wants to visit his best friend who lives several streets away - in compliance with policy, a staff member must load him and his wheelchair into a van, drive across five streets, unload him, and repeat the performance a few hours later. And this is only if a bus, shared between several houses, is available.

He is no longer able to go to swimming, which he loves, due to staff shortages and similar problems getting there - unlike Mary's daughter whose community has a pool on-site.

My son and his housemates cope with a merry-go-round of staff, but it causes them great anguish. Unlike Mary's daughter's home, my son's CRU has a high staff turnover.

Are we happy with this so-called community utopia? No we are not. I have lost count of the times I have been asked by the young adults living in the CRU: "Why can't our friends live in the same street?"

But families who have witnessed these glaring problems in some aspects of the community care ideology, and battled for the rights for their sons and daughters for years, have largely been ignored. They stand by helplessly as hard-fought-for facilities and land are sold to developers, who then erect town houses for the well-to-do (clearly, some forms of social segregation are acceptable).

It is the lack of consultation and disregard for the wishes of families in the decisions surrounding their intellectually disabled loved ones that has brought Mary and me - and thousands of families from around the world - together.

It is time to understand that families are not clamouring for a return to institutions. But we reject those ridiculous definitions of "institution" such as houses with more than six bedrooms or houses situated next door to each other. If other people can choose to live as a community, then why can't my son live in cluster-style accommodation with other young people with disabilities if he wants to? This reeks to me of discrimination.

From opposite sides of the globe, Mary and I have continued to battle for the rights of our children, whose choices we believe should be respected. All people with disabilities have the right to a life of happiness and dignity in an environment best suited to their needs - not one demanded by theorists.

Politicians and bureaucrats, often making decisions affecting the lives of thousands of people with disabilities, come and go. Yet those who presume to make these decisions regarding our children forget one very important point: we love them, they don't.

Sandy Guy is a Ballarat writer.