

Disability advocates ignoring what's best for disabled



by [The Angry Cripple](#)

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Sue O'Reilly, who has guest written today's column on The Angry Cripple is a freelance journalist and the mother of a 21-year-old son with cerebral palsy. She co-founded [Australians Mad as Hell](#) last year with Fiona Porter to campaign for an NDIS and established a charity called [Fighting Chance](#) to help people with disabilities pay for essential therapy services.

The president of South Australia's Council on Intellectual Disabilities recently stated that all people with disabilities have 'a right to live in an ordinary home in an ordinary street'.



Photo: Justin Lloyd.

But what if some people with disabilities don't want to live in 'an ordinary house in an ordinary street'?

What if they want to live in something like the manicured villages that have sprung up everywhere for people over 55, or an apartment complex with 24/7 care facilities?

Do many disability rights advocates defend this choice as a ‘right’? No - they start jumping up and down about ‘re-institutionalisation’.

While most of us, with financial consideration, can choose whether we live in a house, an apartment, a caravan or boat, it is only people with severe dependent disabilities, it seems, who get to have no actual choice whatsoever.

Why is that? Because for the past 40-odd years, many disability advocates have insisted that stand-alone small group houses in suburban streets are the only acceptable alternative to old congregate institutions.

There are, it seems, no other possible options anyone might consider.

Yet ‘ordinary’ Australians are not restricted just one ideologically acceptable housing option - and aren’t we all now supposed to be aspiring for people with disabilities to live an ‘ordinary’ life?

When world-wide moves towards deinstitutionalisation began in the late 1970s, the sole alternative held up as the ‘right way to go’ was to move all people with dependent disabilities into small group houses in the community; into ‘ordinary houses in ordinary streets’.

But since then, important lessons have emerged, one of which is that institutionalisation is not so much about *where* a person lives as *how*.

If ‘institutionalisation’ is fundamentally about others making decisions about what a person does each day - what time you get up, what time you go to bed, what times you are allowed to eat, and so on – then a person with severe disabilities can be just as institutionalised in a small group home in an suburban street as in any prison block.

If you can’t physically get out and about by yourself, don’t drive, can’t work, don’t have speech and have few or no family or friends to socialise with out in the community, are you necessarily going to be happy in a house in a street that’s empty during the day because everyone else is off working or at school or whatever?

Clearly, this debate needs to move on, away from where people with disabilities live and on to how they live.

Another lesson that should have been learned by now is that some lowly-paid support workers employed to look after four or five severely disabled people in an ‘ordinary house’ can actually be indifferent, lazy or even sadistic.

If you have a severe intellectual or physical disability, how do you defend yourself?

To whom do you complain? A [recent investigation by The New York Times](#) found: ‘Nearly 40 years after New York emptied its scandal-ridden warehouses for the developmentally disabled, the far-flung network of small group homes that replaced them operates with scant oversight and few consequences for employees who abuse the vulnerable population. Employees who raped, sexually abused, beat or taunted residents were rarely fired even after repeated offences, and in many cases simply transferred to other group homes.’

I sent this article to a friend who works for a State Disabilities Department as a group home manager, and who is in constant despair about how impossible it is to do anything about lazy, abusive or sadistic staff because of trade union muscle.

He initially assumed this article was from an Australian newspaper, not an American one - as well it could have been.

The extreme vulnerability and defencelessness of Australians with disabilities living in small group homes in ordinary streets has been documented over and over again.

But do we hear the (mainly salaried, professional, often non-disabled themselves) disability rights advocates ever expressing outrage about abuse and mistreatment of entirely vulnerable people in government-funded small group homes? Not that I'm aware of.

And why not? Well, for two reasons, I'd suggest. Firstly, because their salaries are almost always paid by the same government departments that run these small group homes and secondly, because when reality challenges an ideological position to which people are bound hand and foot, their only option is to ignore reality.

Many salaried rights advocates squawk 'institutionalisation' as soon as anyone dares suggest any alternative to the 'ordinary house in an ordinary street' model.

But do they really know or care what actually might be going on in these 'ordinary houses'?

When the dynamic Brisbane-based organisation Youngcare built a superb 16-bed apartment complex for people under the age of 55 who'd previously been dumped in aged care nursing homes, guess how many disability rights ideologues reacted?

Youngcare had, however, raised the entire \$12 million or so needed for construction and fit-out themselves, and so were able to tell the ideologues where to stick their entirely abstract rhetoric.

- **Life on two wheels:** [The Angry Cripple](#)