

Harrowing choice put a loving mother to the test

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Reporter: Louise Hall

Forced to the brink ... Anita Cain had to abandon her son Niall, 15, to get help, but then fought to retain her parental rights!

Exhausted and depressed after devoting her life to caring for her severely disabled son Niall, Anita Cain took him to a respite centre - and left him there.

Abandoning him to the state's welfare system 3 years ago was the only way the single mother could get the support she needed.

A rare genetic condition means Niall is deaf, blind in one eye and developmentally delayed, but Ms Cain's pleas for a permanent placement in supported accommodation were rejected until she relinquished day-to-day responsibility for him to the Department of Community Services.

"I only got one weekend every two months respite all I wanted was more regular, longer breaks, but they wouldn't find anywhere for Niall to go unless I officially abandoned him," she said.

In NSW 32 children were given up to the Department of Community Services in the two years to June and this could worsen, with the state's only boarding school for severely disabled children facing closure.

Last week, Vanessa Browne met department officials and told them she would have to abandon her son Alex, 15, if Kingsdene Special School at Telopea shuts its residential program.

The Anglicare Council, chaired by the Anglican Archbishop, Dr Peter Jensen, is meeting today to decide the fate of the school, which is hundreds of thousands of dollars in debt due to a shortfall in Federal Government funding.

Alex has Sotos syndrome, a rare genetic disorder characterised by excessive physical growth during infancy. He is 195 centimetres tall, doesn't speak and has the intellectual capacity of a five-year-old.

Ms Browne, who cares for him on weekends, would have to give up her job if he was home full-time, cutting off her income.

"I want to avoid 'DOCS dumping' but that's what we are being forced to do," she said.

The Wood inquiry into child protection last year was scathing of a system that forced parents into the "terrible dilemma of either reporting their child to DOCS for being at risk of harm or abandoning them in respite or hospital".

Niall, also 15, is now thriving in a group home run by Life Without Barriers in Matraville. Ms Cain, a lawyer, fought the department to maintain her parental rights.

However, DOCS tells other parents they will be extinguishing their right to make most decisions about their child and Mary Lou Carter, the secretary of the political party Carers Alliance, says governments exploit parents' feelings of guilt and shame.

She believes shared care, such as special schools where students board during the week and go home to their families on weekends and holidays, is ideal.

But the Department of Ageing, Disability and Home Care prefers family-based care - by biological parents, adopted or foster parents. Special approval must be given for a group home placement, and then only if such a placement exists.

"It goes back to the ideological view that to have children in such an environment is institutionalising them," Mrs Carter said.

A spokesman for the Minister for Disability Services, Paul Lynch, said: " Our priority is to work towards the best possible outcome for the child or young person and their family.

"This includes working with families to overcome barriers that they may have had in providing day-to-day care."

LISA Comment: Battling Bloody-minded Bureaucracy and DIY culture is all too common for families across Australia with a family member with a disability. If bureaucracy spent but a fraction of the energy and resources they chew-up on negativity and avoidance, on being positive and pro active, there would be far fewer stories like this one.

Parents who have lovingly cared for their son or daughter with high support needs, are suddenly told they are nobodies when their son or daughter becomes 18 years of age. Parents are, on the stroke of midnight, no longer are legal parents! Yet their family member still has the same needs!

In Victoria, parents have to battle the Victorian Civil & Administrative Tribunal (VCAT) to continue to be legal parents - plenary guardians. VCAT argues, in the extreme, Section 22(1)(c) of the Guardian and Administration Act.

This section says, "Is the person in need of a guardian". VCAT will argue every-which-way against basic common sense, that a person with high support needs does not need a whole of life guardian, a plenary guardian - parents to continue to be legal parents.

The extremely bureaucratic VCAT considers its doing a great job, as it can boast there are very few Plenary Guardians in Victoria.

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