

<http://www.smh.com.au/news/national/carers-cry-for-the-eternal-children/2007/06/15/1181414542354.html>

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Ageing parents of disabled children are desperate for help.

writes **Mark Metherell**.

'John is now 30, we are now 60. Nothing much has changed. We still provide the transport, do his washing, ironing, meal preparation, wipe the bottom, wipe the nose, wipe the face, cut up the food, clean up after and love him very much.

"But now we are really afraid, afraid of what will happen when we are dead. Who will care if he does not clean his teeth, if he wears old, unmatching clothes, and who will cover him up when it's cold at night?"

These words of an anonymous NSW couple reflect the desperation gripping thousands of families confronted by the clash of ageing and disability. Their numbers are rising along with their anxiety. Despite Australia's affluence, a squabble between state and federal governments over funding offers no comfort....

The plight of families such as the Marmonts and the Allens is, if anything, becoming more common. There are 23,800 Australians with serious disabilities needing accommodation or respite care who go without, according to the latest estimates by the Australian Institute of Health and Welfare.

The institute says that figure is conservative but it also represents a near-doubling of such cases since the last survey in 2001.

But those figures conceal the real level of need, according to the peak sector group National Disability Services.

If Australians with disabilities were to be treated on the same basis as elderly Australians, the number of beds provided by government would need to more than double; at present 49 out of every 1000 people with a

severe or profound disability get government-financed beds. That compares with the federally financed benchmark of 113 nursing home beds per 1000 Australians aged over 70.

After years of neglect in NSW, the Lemna Government last year pledged to put \$1.3 billion over five years into disability services under its Stronger Together plan.

This has a hollow ring to parents such as Katrina Clark, a former lawyer who has done her own research into unmet need in NSW and estimates the state needs 20,000 beds - four times the current number, and many more than the 1400 additional places promised by the State Government.

This week the *Herald* asked the NSW Minister for Disability Services, Kristina Keneally, what the level of unmet need for disability accommodation in NSW was. Keneally would not give a figure, instead referring the *Herald* to the detailed plans set out in Stronger Together. She described the document as "the most comprehensive plan, the most detailed plan ... in Australian history".

But the plan does not detail unmet need for disability accommodation.

"It seems staggering they don't know the level of need," says Clark, the founder of Taskforce Independence, a community umbrella group on disability.

Across Sydney, grassroots groups are forming to press for much more than what they believe Stronger Together is offering. One is the Sutherland Shire Disability Accommodation Group, which in less than six months has registered 150 families pushing for a place for their ageing children.

Its president, Judy Foord, says the problem with Stronger Together is that most of the places will be taken up by those accommodated inappropriately in the jails, those blocking beds designed for respite care and others in foster care.

"There are no new places for the children of us ordinary people," Foord says....

So, how is it that in a nation where the Government proclaims a \$10.6 billion surplus, thousands of families can be left like this? The question is even more frustrating when it is considered that the Federal Government says it accepts Australia's disability effort is a

"disgrace" and says it is prepared to spend whatever it takes to expand accommodation. But Canberra's offer comes with a big condition - in essence, a radical overhaul by the states of the way they manage disability care and accommodation.

The Federal Government is offering a below-inflation increase in its 20 per cent contribution to existing services but a potentially much larger boost for new services, dollar for dollar, aimed at dealing with the widespread unmet need for disability accommodation. The crunch is the federal demand on states to make improvements in four areas, including much greater accountability on how states spend the money, introducing a consistent measure of need, independent quality audits and improved services for indigenous people.

"I think we have treated our disabled over a long period of time in a disgraceful manner and I am determined to see that attitude change," says the federal Families and Community Services Minister, Mal Brough.

The lack of accountability or transparency in disability services meant that "neither the Government, nor the [service] sector nor most particularly the parents have any confidence as to additional services or where they are going to meet unmet need and how we are going to address this growing issue".

Brough says NSW's \$1.3 billion commitment "is not going to touch the sides" without transparency, accountability and external validation. Brough's demands have infuriated the states, which say correctly that in recent years while they have increased their spending, the Federal Government's share has declined.

Keneally says Brough's refusal to match the NSW commitment because it was not new was "penalising" NSW.

The federal-state quarrel incenses people like Mary Lou Carter, an advocate on disability who is leading a Carers' Alliance campaign for a NSW Senate seat. "This system is so fraught with blame-shifting. While the duck-shoving goes on, people's lives are fraying at the edges and falling apart."