

Printed October 06, 2007 12:05am AEST

## Carers for disabled plan protest on PM's doorstep

Adam Cresswell, Health editor | October 06, 2007

### **CARERS are stepping up pressure on both sides of politics for a big increase in the availability of long-term accommodation for people with severe disabilities.**

Campaigners are planning a second sit-in at John Howard's campaign office in Eastwood, part of his Bennelong electorate, on October 17, after a previous one at his Gladesville office last week attracted some 60 protesters.

Katrina Clark, one of the co-ordinators of last week's action, said while the subsequent announcements from Howard and Opposition leader Kevin Rudd on improved autism services were welcome, they did not change the focus of her campaign.

"Autism is a huge issue, but it (the Government's plan) doesn't help at all the lack of long-term supported accommodation," she told Weekend Health this week.

Howard this week announced a \$190 million five-year program to tackle autism, comprising \$20 million for new Medicare-funded services to diagnose autism spectrum disorders and provide early-intervention treatment; and \$116 million over five years for new early-intervention services, including up to 200 new autism-specific playgroups by 2012 and one-on-one or tailored group programs for up to 4000 eligible children.

The Government's plan will also provide \$20,000 for eligible services over two years for 1200 severely affected children, and \$30 million over five years for new training and support for parents and carers to learn intervention techniques.

The Labor opposition was accused of trying to hijack the Government's announcement by announcing the same morning proposals for a network of six autism centres across the country to assist in the provision of intensive autism-related services.

After the first sit-in, Clark -- president of the Association for Children with a Disability in NSW -- said the issue at the centre of the protest was the share of funding provided by the federal Government towards the Commonwealth, State and Territory Disability Agreement (CSTDA), under which long-term supported accommodation was provided.

"In July this year they recognised there's a crisis in accommodation," Clark said. "But they are only targeting (disabled) people in the community who are still living with their parents and are over 40. If you're over 40 your parents have probably got one foot in the grave. That still leaves a huge gaping hole for people aged 20 to 40, who have to rely on funding under the CSTDA."

Under that agreement, she said the federal Government had been providing about 20 per cent of the funding. However, in some states including NSW, that share had recently slipped -- to about 16 per cent in the case of NSW -- because the states have begun putting more money in.

The agreement expired on June 30 and a new one is still under negotiation.

"The Commonwealth has no new funds on the table -- they are not even going to keep up with inflation," Clark said. "What we need is a huge injection of funds -- we don't care if the Commonwealth or the states provide the services, but it has to be attended to."

"We need permanent accommodation for people so severely disabled that they can't look after themselves. You just can't imagine the burden every day of looking after your (disabled) child in the family home. You are talking about grandparents looking after a 30-year-old son who weighs 80kg ... they are still full-time carers for an 80kg-equivalent of a six-year-old child."

MaryLou Carter is secretary of a newly registered political party called the Carers' Alliance, and its number one Senate candidate in NSW. She was at last week's demonstration: "We are seeking a Senate seat, because without a political voice, carers will continue to be put on the back burner, boiling over and no-one doing any mopping

up. There are always so many other decisions and politicians ignore us because they can, and do."

Carter has a severely intellectually disabled 16-year-old son, who has had his disability since birth.

"When he was three, four and five, I didn't have any idea of what was waiting for me, and what would be my fate," she says. "I started my own business, but for the last 16 years I have not been able to be part of that business. This is the story of so many people."

Clark says there are about 17,000 long-term accommodation places in Australia. If Australia had as many places per head of population as Norway and Sweden -- where there are no waiting lists for such accommodation -- then Australia would have something like 60,000 places, she says. "We have to get up to 20,000 around the country, but that will still only be one-third of what we truly need."

Protesters at last week's demonstration did not actually sit down en masse inside John Howard's office, but instead trooped in one by one to pass their concerns and complaint to one of the Prime Minister's staff. Clark said they had a "very polite reception".

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