

Home alone

Parents of children with disabilities are increasingly frustrated at their often lonely and unsupported struggle to raise their families, prompting several federal MPs to speak out in the House of Representatives. PETER COTTON REPORTS.

Photos: Paul Beutel



Peter Edwards and his son Nathaniel.

PAUL NEVILLE describes his meeting late last year with a group of parents of disabled children as a 'Road to Damascus' experience which left him in tears and made him determined to champion their cause.

"I've never come away from a meeting so disturbed," says Mr Neville, the Member for Hinkler (Qld). "I cried that night, but now it troubles me that I might create an expectation that I can't fulfil and that's why I'm moving cautiously. I want to build this thing, rather than go all out and fail. I'm determined to help these people."

Earlier this year, Paul Neville took his first big step as an advocate for parent carers when he raised their plight in the House of Representatives during private members business.

He moved that the House recognise the role of parents who raise profoundly disabled children and acknowledge the

challenges they face when seeking respite care and funding for special services and equipment. He called for a comprehensive reassessment of these parents' eligibility for disability payments and he also called for an examination of respite services available to parents of disabled children.

To back his motion, Mr Neville presented some searing examples. One couple he met late last year never goes out socially because their daughter suffers from such an extreme behavioral disorder that she's often enraged and uncontrollable. The girl has put her head through a glass window and performs other acts of self-harm.

"A respected pediatrician described her as one of the most severe cases he'd seen," says Paul Neville, "however, the Centrelink forms have no category for her or her disability and so her parents don't qualify for a disability benefit.

"If you tick the box [on a benefits application form] that asks whether your

child has a respiratory problem, you almost automatically get an allowance. But if your child's kicking in the walls at home, spreading food around the kitchen, if he needs two parents to change his nappy and if he chucks faeces all over the house, you're not eligible for any Commonwealth benefit."

Mr Neville says the next time a minister with any responsibility for this area of policy comes to his Queensland electorate, he'll assemble the same group of parents who had such an impact on him last year and have them meet that minister. And he doesn't rule out organising a similar meeting for the Prime Minister.

"I've had the Prime Minister in my electorate a number of times in the past few years and if he comes again soon I'd like him to meet some of these families," says Mr Neville.

Given that the special needs of these families are so obvious and easily established, why is it that their plight hasn't been addressed? According to the Member for Shortland (NSW), Jill Hall, families caring for profoundly disabled children are so focused on day-to-day survival that they have no energy to lobby government on their own behalf.

"It's the squeaky wheel that gets the grease, and these people just don't have the time or energy to make the necessary noise," says Ms Hall. "If you have a new born baby, it's a very demanding time. The demands on parents with a disabled child are similar to that, but for them the demands never stop. And mixed in with it, they're involved in an enormous grieving process for their disabled child. They're in a terrible situation."

As for the lack of respite care available to these parents, the Member for Gilmore (NSW), Joanna Gash, says the 70 disabled children she knows of

in her electorate have access to only five respite beds.

“Those beds are full all the time and one or two of them are always occupied by the same children because they’re so severely disabled that they have nowhere else to go,” says Mrs Gash. “Some nursing homes provide beds for respite, but those places are not suitable for children.”

Mrs Gash, who supported Paul Neville’s motion in the House, says the provision

of respite care for disabled children is a state responsibility. She says parents of disabled children should pressure the states to fund more respite care beds.

“[Paul Neville’s motion] will give [the Minister for Family and Community Services] Senator Kay Patterson a little more ammunition when she talks to her counterparts in the states to ask where they spend the money allocated to them by the federal government for respite care,” says Mrs Gash.

But Jill Hall, who also supported Paul Neville’s motion, sees no point in arguing over who’s responsible for alleviating the plight of these families. “The best outcome for families of children with disabilities would be if all levels of government worked together for a solution,” says Ms Hall.

“It’s no use pointing the finger and trying to shift blame for the terrible life these people have. There are things both levels of government can do to make their lives easier than it is now. A good outcome will only be achieved if we work together.”

For his part, the Member for Franklin (Tas), Harry Quick, says there’s a role for local government in addressing the special needs of carer parents.

“Part of the rates you pay to local government go to an ambulance levy, a water levy and a fire levy,” says Mr Quick. “Why not institute a community service levy so that if you have a child with a disability, you can access respite care and other community assistance. I think the Commonwealth and the states should look at working through local government so that these families don’t miss out.”

The Member for Chisholm (Vic), Anna Burke, is particularly concerned for the ageing parents of children with disabilities. “These are people in their 70s



Above: Michael Mulvena and his son Timothy. Below: Francis Dolinski (standing) with his daughter Helen and Paul Neville, the Member for Hinkler.



"I think the Commonwealth and the states should look at working through local government so that these families don't miss out."

and 80s who have a disabled child at home who’s 30–something and who’s totally dependent on them. They’re still managing, but the time will come when they won’t,” says Ms Burke.

“These older people live in fear of what will happen to their children when they die—that there’ll be no one to look after them, or worse, that they’ll end up in a dilapidated boarding house being preyed upon by some of society’s nasties. It’s just another reason why all levels of government need to be serious about this issue and put some money into it.”

As for younger parents of disabled children, says Ms Burke, they want to stay in the workforce but can’t, especially

Continued page 24 ►

Younger parents of disabled children want to stay in the workforce but can't because there's no respite care.

after their child has finished school, because there's no respite care.

"The school system copes quite well with disabled students," she says, "but once they reach 18, they still need 24 hour care. I recently met with a group of parents whose children will soon leave a very supportive school environment and they're considering quitting their jobs because there's nowhere that caters for their children during working hours."

Ms Burke says that as well as resolving the argument over who pays to help these families, the Commonwealth and state governments must also address problems caused by the de-institutionalisation of Australian society over the past couple of decades.

"There's now a mindset that institutional care for disabled people is no good and that everything has to be done in the community," she says. "While I generally support that notion, there are some people who will never make it in the community, who have to be supported 24 hours a day, seven days a week."

"We need a range of options available to help these people. Some may be best cared for in an institution. Others may be best living in community housing. And some may be best at home, with appropriate support. There are various models we could look at. It's just a matter of where the money comes from."

Paul Neville believes that the de-institutionalisation of Australian society has gone too far. "Years ago, profoundly disabled kids were in institutions and that allowed their parents some quality of life," he says. "Now most of them are managed at home with a degree of government support, but I think that neither the states nor the Commonwealth government are aware of the depth of the problem that's been created by de-institutionalisation."

"It's not that they're avoiding the issue or denying that it exists. It's just that these kids are seldom seen," says

Mr Neville. "The de-institutionalisation of our society has made it a matter of 'out of sight, out of mind'. The pendulum has swung too far and needs to swing back to some form of institutionalisation that brings a greater amount of respite."

"The bottom line is that we need to find a bucket of money to pay for it and a lot of these things fall over because there's no coordination between the state and federal levels."

Paul Neville says he enjoys the support of his Coalition colleagues in his campaign on behalf of carer parents. "When I spoke about this in the party room," he says, "the Prime Minister and the Treasurer were both nodding their heads and that gave me some incentive to think that we might be able to get things changed."

The Member for Cowper (NSW), Luke Hartsuyker, supported Mr Neville's motion in the House and agrees that the criteria for carer parents applying for benefits should be re-assessed.

"There are quite a number of people who are excluded by the current criteria and, as legislators, we need to look at that," says Mr Hartsuyker, "because the criteria don't reflect the workload of these parents."

"I've discussed this with the minister and raised it in the parliament because it's a matter of concern in the community and the time is now right for us to look at giving greater support to these families, without whom these children would have to go into more formal care at great cost to the taxpayer."

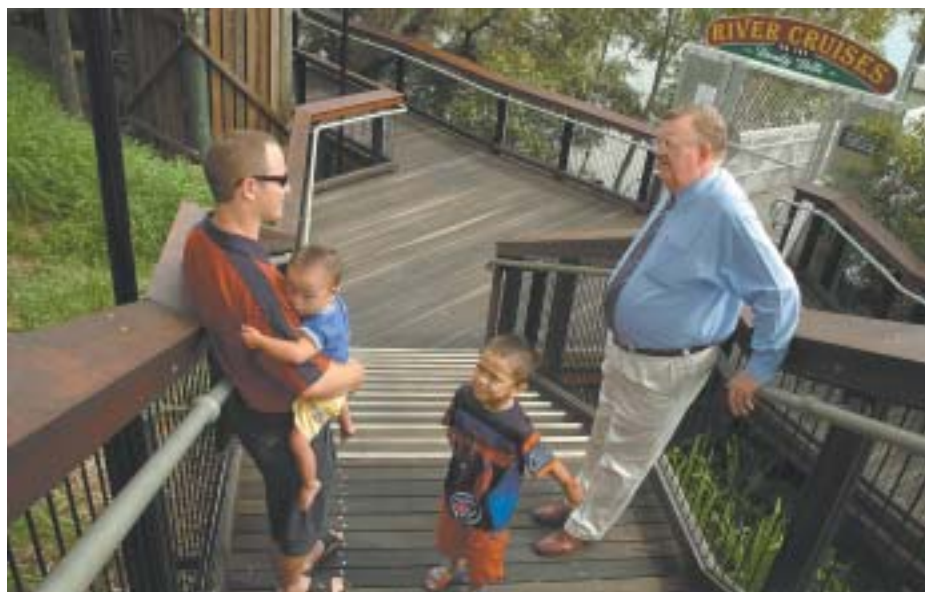
"Respite is vital because if carers break down, they can't look after their children. However, an increase in respite services doesn't necessarily mean more bricks and mortar. If we look at the service delivery model, we may find we can deliver help in the family home. But whichever way you go, respite is expensive and the federal government is focused on supporting carers, as seen in the most recent budget."

Anna Burke says most parents of disabled children don't want applause for dealing with their extraordinary circumstances. "They want to be understood," she says. "They want people to comprehend what they have to deal with, physically, mentally and financially, day in and day out. They say they accept that their children are their responsibility, but they expect some help along the way."

"If you're an engaged member of parliament, you've come across a lot of these parents. You've had them in your office, they've written to you and rung you up. You've dealt with their issues."

"We got to the stage with aged care a few years ago where there was a line drawn in the sand and a decision was made in the parliament to deal with it. I think that's where we are now as we consider how to support the carers of disabled children. So instead of continuing to play the blame game and the cost shifting game, we need to put our heads together and solve it. As for how we fund that solution, there's only one bucket of money and it has to pay for everything." ■

Peter Cotton is a freelance journalist from Canberra.



Julian Bond with his sons Lachlan and Jaden, and Member for Hinkler Paul Neville.