



Sue Corrigan at home in Sydney with her son Shane, 19.



# The STRUGGLE FOR CARE

Let down by politicians, burnt out from battling an impossibly unwieldy system, the parent carers of Australia's disabled have reached breaking point, writes *Sue Corrigan*.

>> PHOTOGRAPHY ADAM KNOTT

I

n a large town in country NSW, three weeks before last Christmas, a mother is preparing breakfast for her severely intellectually disabled 22-year-old son. The young man doesn't know it, because he has the mental age of a toddler, but his mother is planning to drive him to his day activity centre after she has finished feeding him, and then abandon him there. Exhausted, severely depressed and suffering health problems, this woman has reached her personal breaking point.

Later that same morning, she will pack her son's belongings and hand them to state government officials who, forewarned of her decision, have no choice but to take the boy to an emergency respite centre, 100km away, while they search for more permanent accommodation in a group house closer to home. Today, more than three months later, they are still looking. Speaking to *The Weekend Australian Magazine* only on condition of anonymity, the 49-year-old mother says that when she told her GP of her plans, he said he often strongly advised other carers in similar positions to do exactly the same thing.

But the vast majority of the thousands of Australians now caring full-time for an adult family member with a severe physical or intellectual disability could never bring themselves to do that. Despite coping with double the average national levels of poverty, marriage breakdown, depression and ill health, most carers somehow manage,

decade after decade, to soldier on. They don't have much choice. Although abandonment of a vulnerable, highly dependent adult son, daughter or other close relative is now the only way to access supported, out-of-home accommodation in many parts of Australia, for most carers this is not an acceptable option.

If it were, governments would have a crisis of almost inconceivable proportions on their hands. Of more than 700,000 Australians under the age of 65 officially classified as having severe or profound disabilities, only 33,000 – fewer than 5 per cent – receive some form of government-funded accommodation support. Waiting lists for assistance are now so long that most states have simply abolished them. While many people with severe disabilities are adults living in their own homes, or are children living with parents, more than 55,000 still living with co-resident parent carers are over the age of 34.

A single group home place costs taxpayers up to \$130,000 a year. If round-the-clock care is needed, as it often is, three shifts of care workers are employed every day, seven days a week. By contrast, caring for someone you love, more or less by yourself, week in, week out, usually means you qualify for a carer's allowance of just \$50 a week. There is also a carer "payment" of up to \$278 a week, but it is actually a very strictly means-tested pension, payable in full only to those people with virtually no other source of income.

Carers get lots of pats on the back, and are accustomed to being praised, usually by politicians, as “selfless” and “unsung heroes”. What politicians don’t tend to point out is that these people are Australia’s last line of defence against a truly nightmare prospect. Without them, hospitals, police stations, temporary respite centres and government offices – all places where distraught parents have been forced to abandon their disabled offspring – would be overwhelmed.

But with an entire generation of parent carers now heading into their 60s and 70s, even 80s, it is starting to dawn on government officials that this scenario could yet eventuate. The carers belonging to what could be called the Betrayed Generation are beginning not just to burn out, but to die out – and as a result, 30 years of cost-cutting, inertia and broken promises to people with severe disabilities and their families may just be coming to an end.

**W**HEN STATE GOVERNMENT ministers and senior officials decided, in the early ’80s, to close the often gruesome institutions in which disabled people were locked away, commonly from early childhood, they promised to establish small group homes in suburban streets, staffed around the clock, for all those adults too disabled to live independently. Parents were assured that if or when they could no longer care for a severely disabled adult son or daughter at home, high quality, community-based houses would be there to take over.

As it happens, I know only too well about those promises. As press secretary to Laurie Brereton, the then state government health minister who began the process of “deinstitutionalisation” in NSW, I wrote many of the media releases and speeches trumpeting how wonderful it would all be. At the time, governments around the world were moving to replace institutions with alternative, home and community-based services.

The mass closure of psychiatric hospitals as part of the same reformist philosophy was always far more questionable and problematic. For psychiatric patients, “care in the community” was all too often a euphemism for “dumped in the streets”.

But who could argue with the closure of nightmarish places such as Melbourne’s St Nicholas Hospital, exposed by Anne McDonald and Rosemary Crossley in their famous book *Annie’s Coming Out?* Disabled from birth with cerebral palsy, McDonald was incarcerated in 1964, aged just three, along with hundreds of other children in a place reminiscent of Romania’s communist-era orphanages.

“St Nicholas was the state garbage bin,” McDonald wrote. “Very young children were taken into permanent

care. If they were disfigured, distorted or disturbed, then the world should not have to see or acknowledge them. You knew that you had failed to measure up to the standard expected of babies. You were expected to die.”

Constantly assuring people with disabilities and their families that such institutions were to be replaced by far better services, I never imagined that one day these promises might directly affect me. I knew no one with a disabled child, and the possibility that my journalist husband, David O’Reilly, and I might have one didn’t enter my head.

But in 1989, our third child was born 10 weeks prematurely. While in neonatal intensive care, Shane was infected by the hospital-borne MRSA bug, developed septicemia and had more or less haemorrhaged to death before doctors and nurses belatedly

get even the most basic equipment, the fight to get your child included in a local preschool, the fight to find a school that meets your child’s needs and the fight for vital ongoing therapy.

All this effort means you then face a huge battle to find the time to focus on any other children you may have, to stay afloat financially and, if it hasn’t already broken up, to maintain a marriage battered by grief, anger, despair and rabid exhaustion.

When Shane was five, however, David and I stumbled upon an easy way out, and we took it. We’d considered the one hour of physiotherapy every six weeks that was available in Canberra, and the dumping-ground “special” school, where paralysed children were left lying on the floor for an hour every day while the teachers had their lunch, and where Shane would have been put

where so often parents are told, yes, they may well need something urgently and, good news, they do indeed qualify to get it ... except sorry, there’s no money to fund it. It’s not perfect by any means, but the English system is so much better than Australia’s essentially because four landmark acts of parliament – all introduced, by the way, as private members’ bills – give people with disabilities and their families the legal right to whatever they are assessed as needing. No such legal rights exist in Australia.

In England, of course, there are no state parliaments or state bureaucracies to complicate and confuse matters. Health, welfare and education policies are all set at one, national level, with funds then directly distributed to local government authorities to spend locally. Taxes are higher, but the welfare system is far more comprehensive as a result. And with a much higher population density than Australia’s, there is also more scope for diversity, innovation and specialised services, rather than the one-size-fits-all, take-it-or-leave-it approach to service provision here.

Because Shane’s primary school offered a high quality, intensive therapy system known as Conductive Education (then virtually unheard of in Australia), he developed none of the physical contractures and deformities which children with his form of cerebral palsy inevitably develop in Australia, such as malformed hips and twisted spines and feet. Contrary to the doctors’ predictions, he acquired speech and can operate an electric wheelchair. Such skills make a huge difference in the lives of physically disabled children who, like Shane, are bright and smart and very switched on.

After primary school, we wanted Shane to attend a world-class residential secondary school which, because it catered so well for children with his type of disabilities, our local authority readily agreed to pay for. For Shane, boarding Monday to Friday meant access to a teenage social life he otherwise would not have had. For David and me, it meant the precious gift of time to spend with our other children, to work and to rest. David was able to complete a PhD in political science. I could work full-time for a Fleet Street newspaper.

And then, in mid-2006, David collapsed with what turned out to be advanced bowel cancer. He died, just three months later, aged 55.

Although the thought of having to start battling all over again for decent care and services for my son was frightening, life in England had become too lonely to stay on. Discussing my decision to return home with friends here caring for severely disabled children, as well as with other Australian “disability exiles” in England, it was less than reassuring that all of them, without exception, told me I was mad.



Sue’s husband David with their children (from left) Laura, Shane and Jordy, in 1992.

rushed to his aid, pumped out the blood flooding into his lungs and put him on life support. Ten weeks later, they handed me a screaming bundle and cheerily waved goodbye.

Eight months after that, a doctor finally broke the news to us that the reason why Shane was screaming in pain for around 20 hours every day was because he had sustained severe brain damage that had left him with spastic quadriplegic cerebral palsy. The doctor explained that this meant he would never walk, stand or sit unaided, was highly unlikely to have speech, and would be lucky to be able to operate the controls of an electric wheelchair.

Our battle – like that faced by thousands of dazed parents before and since – had begun. Starting with the fight to get adequate early intervention services, we discovered that the battle continues with the fight to get a few hours of respite each week, the fight to

in a room labelled The Immobiles (seriously), and we left the country.

David had been national political reporter for *The Bulletin* but we decided to leave our jobs, families, friends and the house we’d built and move to England so Shane could attend a genuinely special school we’d heard about, with daily therapy and teaching programs tailored specifically to children with cerebral palsy. Although extremely hard in many ways, leaving was far easier than staying. It felt like we were being driven into exile from our own country, but it also felt like we’d escaped.

In England we discovered that a well planned and adequately resourced disability support system doesn’t have to be a pipedream. There is no exhausting fight for vital equipment or services. If you’re assessed as needing something, it is provided, usually immediately – unlike in Australia,

IN THE YEAR SINCE OUR RETURN, Shane and I have encountered nothing but kindness and support from the many dedicated teachers, therapists and respite care workers, among numerous other people, who devote their lives to helping people with disabilities and their families. Shane and I have been blessed by their compassion. But they work within what is, with too few exceptions, a deeply dysfunctional and inequitable system. Federal and state governments allocate billions of dollars of taxpayers' money each year for disability services, and charities raise millions more, but after that money has trickled down through layer after layer of bureaucracy, red tape and administration costs, then been divided among a splintered maze of service providers, not a great deal remains for actual service provision.

Because government health and welfare agencies are under no obligation to provide anything once their budget runs out (often just a few months into a financial year), there is no incentive, as there is in England, to design the most efficient system possible to make sure the money goes far enough.

When Shane needed an electric wheelchair in England, our local cottage hospital supplied it. The chair was basic but it did the job perfectly well, and best of all, it was all organised within a

## SEVERE RATIONING AND LONG WAITING LISTS, REGARDLESS OF NEED, ARE NOT FEATURES OF A PROPERLY FUNCTIONING, EQUITABLE SYSTEM

month. Here, we've been told the same process could take up to four years.

A friend in Wollongong, NSW, needs an electric hoist to help lift her disabled, 60kg son in and out of bed, on and off the toilet, and so on. But she is not permitted to apply for funding (from the state health department) until an occupational therapist (from the disability department) writes a report. The waiting time for a therapist is 18 months.

If a parent can't wait, because of severe back pain for instance, officials consider it entirely acceptable to say, "Well, you'll just have to pay for a

private therapist and buy a hoist yourself." But a hoist costs around \$3000. The electric bed I had to buy for Shane, because I couldn't wait two years for it to be funded, cost \$2000. The wheelchair-accessible car I had to buy, because they are not funded at all here (unlike in England), cost \$60,000. None of this is even tax-deductible. Full-time carers who cannot work at all because of their responsibilities, or who have very limited income for the same reason, either just have to go without, or beg for help from a charity. Severe rationing and long waiting lists, regardless of need, are not features of a properly functioning, equitable system.

There are myriad other examples of families forced to wait years for "early" intervention and other vital therapy services, essential equipment and respite. Above all else, though, the issue haunting Australian carers is the failure of governments to fulfil their promises to provide supported, out-of-home accommodation.

LAST APRIL, A WISP OF A WOMAN called Catherine Murray stood up at a federal cabinet community meeting in western Sydney and in a few heartfelt, eloquent sentences articulated the very deepest fears and anxieties of carers around the nation. Murray rose

not to complain about having to provide round-the-clock care for her profoundly disabled son, Jonathon, then a 24-year-old man with the mental age of a six-month-old baby, but to describe her despair at the absence of alternative accommodation for him once she could no longer go on.

"I find it unconscionable that I would have to surrender my child, abandon him in the hospital, if it all got too much for me," she told Prime Minister Kevin Rudd and his ministers. "Cradle to grave is a big ask – a really, really big ask. I struggle to hang on to my dignity, because I object to begging. I really do object to begging. [But] if anything happened to me, where would my son go? That's what keeps me awake at three in the morning."

As Murray was only too aware, even the death of a carer does not ensure a place in a group home will be allocated to the disabled person left behind. Instead, government officials twist the arms of any brother, sister or other relative who can be found, suggesting they take over "just until we find something". Years later, the substitute carer can still be waiting.

Mary Lou Carter, one of the founders of the national political party Carers Alliance, recounts that she was approached by a 71-year-old woman

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who, dying of cancer, was frantic with worry about what would happen to her 39-year-old intellectually disabled son.

“On her behalf, I wrote to federal and state ministers and her MPs, pleading for some compassion so she could at least die with peace of mind,” says Carter, herself the mother of an 18-year-old son, Nicholas, who has a severe intellectual disability. “But she died a year ago in terrible anguish, still not knowing what was to happen.” Because no relatives could be found to take him in, a place was finally found about a month after her death.

“The disability support system in this country is entirely crisis-driven,” Carter says. “Governments rely on most parents never being able to bring themselves to abandon their children. Deep parental love and a sense of duty are being deliberately exploited solely in order to save money, which, in a country as wealthy as Australia, is profoundly shocking. But even the most devoted and self-sacrificing of parents can’t keep on caring if they’re dead.”

In Catherine Murray’s case, she has at least been spared ongoing anxiety, but only because her beloved son, around whom her world revolved, died in January, aged 25. Touchingly, she received a handwritten condolence note from Mr Rudd, who shortly after the community meeting announced an extra \$100 million for accommodation services, crediting Murray’s words as the reason for his ad hoc decision.

But, as politicians and policy-makers are increasingly coming to realise, there is little point pouring more and more money into a bucket if that bucket is full of gaping holes. Former deputy prime minister Brian Howe is one of a number of influential social policy analysts who believe the time has come for a “paradigm shift” in Australia’s disability services system; for fundamental, systemic reform. Based at Melbourne University’s Centre for Public Policy, Professor Howe says that with a plethora of federal, state and community agencies involved in service delivery, “the frustration of people with disabilities and families is that they’re never able to get their hands on who is responsible”.

“A great deal of money gets wasted and fails to reach the people it is intended to help if a system is badly designed,” he says. “The focus needs to turn from providing extra money to that of systemic change, aimed at eliminating the enormous inequities and unmet need that now exists.”

“With many carers ageing and no longer able or willing to bear so much of the burden alone, that level of unmet need is a sleeping giant. The closure of institutions from the 1980s coincided with the onset of economic rationalism and constrained budgets, so that governments failed to invest in creating the good, integrated model of community services they’d promised.

“We need to move from thinking about disability services as welfare to thinking about them as social investment. We also need to introduce a national, compulsory, no-fault insurance scheme to cover the costs that arise as a result of long-term disability, on a well-planned, fair and equitable basis.”

Normally, this would be the point at which any article on the subject of Australia’s disability services ground to a mournful halt. Around four years ago, however, Brian Howe presented his insurance scheme idea to a Disability Housing Trust meeting in Melbourne, and one of the people there that day was Bruce Bonyhady, a former federal Treasury officer turned banker, businessman and philanthropist, and chairman of Victoria’s largest disability community organisation, Yooralla.

With two sons born with cerebral palsy, Bonyhady and his wife Rae know all about, as he puts it, “the stress on families that results from having to fight on 16 fronts at once to get some service that’s not even adequate”. Bonyhady realised while listening to Howe that a national disability insurance scheme was the answer – the obvious, visionary answer.

**A**S HE SITS IN THE KITCHEN of his Melbourne home, Bonyhady says that, according to virtually every indicator, Australia’s disability system is “broken and failing”, despite billions of dollars in funding each year. “The question is whether you keep applying Band-Aids, or whether you go for fundamental systemic reform,” he says.

“Disability can affect any family, anywhere, at any time. Many people may assume this issue has nothing to do with them, but nobody is invulnerable. Your perfectly healthy teenage son can fall off his skateboard and be permanently brain-damaged. You can dive into the surf, break your spine and be left quadriplegic. You or a loved one can be felled by a stroke, or develop multiple sclerosis, or your child may be born with autism, or an intellectual disability, Down syndrome or cerebral palsy.

“The possibility of disability somehow touching our lives is a risk we all face, more or less every day. Why not enable people to insure against that risk, through a national, no-fault disability insurance scheme?”

“If you’re left disabled after any sort of motor vehicle accident, you’re now fully covered in most parts of Australia for all your rehabilitation and equipment costs, funded by a levy on registration certificates. Similar schemes are in place to cover workplace accidents. But if you’re born with autism, say, or break your neck in a fall, you’re not covered in any way for the lifetime costs of care. We need to move from an insurance and compensation

system based on cause to one based on need. To be as efficient, cost-effective and equitable as possible, that system needs to be compulsory and it needs to be national.”

Now heavily involved in the sensitive task of persuading federal government ministers of the merits of this proposal, Bonyhady and other supporters decline to discuss details of how such a scheme might work. Finalising those details would take a lot of time and effort. Virtually every major disability service organisation in Australia has endorsed the proposal. The final report of last year's 2020 Summit in Canberra recommended its adoption, and it is understood that Kevin Rudd confided to several delegates that he regarded it as one of the gathering's most compelling recommendations.

With the Federal Government due to unveil the draft of Australia's first National Disability Strategy later this year, could a landmark social and economic reform, ranking in importance alongside the introduction of Medicare and compulsory superannuation, be in the offing? Certainly, momentum for radical reform seems to be building. The federal Parliamentary Secretary for Disabilities, Bill Shorten, recently described Australia's treatment of people with disabilities as “a disgrace ...



The system is crisis-driven, says Mary Lou Carter (with son Nicholas, 18). “Governments rely on most parents never being able to bring themselves to abandon their children.”

the most significant public policy failure”. Around the same time, the head of NSW's Department of Ageing, Disability and Home Care, Brendan O'Reilly, called for “a tax levy on all Australians, similar to Medicare, to fund lifelong care of people with severe disabilities”. In essence, that is precisely what Bruce Bonyhady is proposing.

Bonyhady is quietly confident that even if the notion of ensuring social justice for Australia's most vulnerable citizens fails to move governments, hard-edged economic realities must, sooner or later, force change. He says the dire shortfall in funds to meet even existing levels of need in the disability field is not dissimilar to the crisis confronting governments in the 1980s, when millions of ageing Australians with no retirement savings were heading towards a poverty-stricken old age. The Hawke government solved that problem by boldly introducing a compulsory national superannuation scheme that is, today, the envy of the world.

“In one leap, a compulsory national disability insurance scheme would transform an almost hopeless situation, bringing a sense of security and hope where there is now only despair. So, really, the question is no longer why. It has become simply when, how and – most importantly of all – why not?”

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