

2010 Clare Stevenson Memorial Lecture

By Sue O'Reilly

Distinguished guests, ladies and gentlemen –

Thank you so much to the board of Carers NSW for doing me the great honour of inviting me to deliver this year's Clare Stevenson lecture. Everything I have read about Clare Stevenson since being asked to give this memorial lecture demonstrates she was a remarkable woman, ahead of her time, with steely strength of character and deep compassion. Carers everywhere in Australia owe her a great debt.

The term "carer" is, of course, a very general descriptor, covering a broad spectrum of activities. You can be a carer for one hour a day, or round the clock. You can be a carer for a few years, or for decades. When Clare Stevenson and others such as Averil Fink first established what was to become Carers NSW, the overwhelming issue of the day was the situation facing those struggling to care at home for the frail aged. Some 35 to 40 years on, I would contend we have seen major improvements in this area of social need, not least because of the tireless advocacy work and lobbying of organisations such as Carers NSW, other State branches and Carers Australia.

Over time, however, another critical area of social need involving carers has been gradually developing as a result of the policies of successive federal and State governments; and that is the now-desperate plight of ageing parents given no option but to provide lifetime care for sons and daughters with severe physical and/or intellectual disabilities.

Ever since I was invited to give this memorial lecture, I have been mulling over what to say about this particular issue. I have had much difficulty deciding what, among the myriad of difficulties facing lifetime carers in Australia I should actually focus on - and that hasn't already been said, 10,000 times before.

The essential problem is, I think, that there is in the end just too much to say. In fundamental design terms, Australia's disability care and support system is pretty much a complete shambles, and the suffering caused as a result to people with people with severe to profound disabilities, who are the main victims of that shambles, and the people who love them – their parents and other close family members – is almost beyond summation.

Something is very wrong in Australia. There is a societal blindness and lack of concern or awareness about what people with severe to profound disabilities need to function in society that poisons the lives of many affected by disability. I realise this is a wild generalisation, but as a society, I believe the majority of Australians don't want to know about that aspect of human existence that is disability, and people with disability.

I know this happened in many other countries as well, but we need to remember that up until only 25 or so years ago, Australians with disabilities as young as two or three were simply made to vanish, locked away in horrific places like Melbourne's St Nicholas's Hospital or NSW's Peat Island where, as Annie McDonald wrote in the book *Annie's Coming Out*: "If you were disfigured, distorted or disturbed, then the world should not have to see or acknowledge you. You knew that you had failed to measure up to the standard expected of babies. You were expected to die."

We need to think about why it is that Australia's immigration system still to this day instantly and ruthlessly bars anyone with a disability from settlement in this country. I was deeply ashamed of my country when a South African woman told me 15 years or so ago how when she, her husband and seven children were in the process of migrating to Australia she made the mistake, the day before they were due to leave, of going into an Australian consulate office with her youngest daughter, who has cerebral palsy. She said an Australian official pointed at her seven-year-old daughter and said, in effect: "What's that?" And then, after she explained it was her daughter who had cerebral palsy, how he upbraided her for not revealing on the application forms that she had a disabled daughter, telling her the family would never have been granted settlement visas if consulate officials had realised – and how, their visas were then revoked, leaving them completely stranded! This woman told me this story in the car park of a specialist school in the south of England which offered a level of help and support for her daughter and my son unheard of in this country. She was very grateful in the end how things how turned out.

We seem in Australia to have a revulsion about disability, and people with anything more than the mildest disabilities, which I simply never encountered in 12 years living in the UK. We seem as a "polity", to use Tony Abbott's word, to profoundly begrudge any help or assistance whatsoever for those who most need it, which again, I simply never encountered in the UK. There, the more help from society a person (and their family) genuinely needs, the more they get. More or less automatically and unquestioningly. Here, the absolute opposite is the case. And it's not just different in the UK, or other European countries. A friend of mine who has a son with physical disabilities told me she was really worried when she posted from Sydney to New York by her employers. She assumed that in New York, as in America generally, people with disabilities would be even lower down the social and public funding pecking order than in Australia. Instead, to her amazement, she found a publicly funded system that bent over backwards to make sure her young son got all the educational and therapy support he needed, in a streamlined, well co-ordinated and effective way. And all completely free of charge.

If anything is ever to change in Australia, then we have to understand and realise that we have the worst disability care and support system in the western world. Infinitely worse than New Zealand. Infinitely worse than the UK, or Canada, or Israel, or anywhere really except the world's poorest and most backwards countries.

Yet we think we are so superior. We think, as Julia Gillard kept saying *ad nauseam* in the recent election campaign that we live “in the best country in the world”. And if we are able-bodied and the people we love are all able-bodied, well then, yes, perhaps we do. If we swim or run fast or throw a javelin or are a pole-vaulter, well yes, perhaps we do.

But if we are severely physically or intellectually disabled, or if we love someone who is, then we live in a hell-hole.

Bill Shorten recognised this, and had the rare guts and courage for an Australian politician whose party was in power to say so. Many people are cynical about his motives, but I am not one of them. I believe that as federal parliamentary secretary for disabilities, Shorten was genuinely shocked and appalled by what he discovered when he lifted up the rocks under which Australians with disabilities and their families cower in this country and saw the truth of our lives. His one-time Liberal counterpart, now Shadow Minister for Disabilities, Senator Mitch Fifield, said a similar thing when he noted recently:

“I was shocked. I thought, like most people, that you pay your taxes and you have the right to be helped. This is Australia, after all.”

Yes, Mitch, this is indeed Australia, after all.

This is a country where Australian Olympic Committee head John Coates can be given 15 prime time minutes to whinge on 60 Minutes about how we are “at risk” of dropping from fourth to fifth or whatever it was on the Olympic gold medals table unless the federal government immediately gives him several hundred extra million dollars and where, just a few days later, he is given it.

Yet was 60 Minutes interested in covering disability in the lead-up to the last federal election, and the desperate plight of literally millions of Australians in this wealthy, advanced western country? Well, I for one tried for months, and got nowhere. As a nation, we seem obsessed with the fit and the young and the healthy. We are interested only in winners, with our complacent, smug, self-satisfied “she’ll be right, mate” attitudes. We were told by Deakin University’s School of Psychology several years ago now, in research commissioned by Carers Australia, that full-time carers have the lowest collective wellbeing score of any group in Australia yet investigated. More than one-third were found to be severely to extremely severely depressed. More than half live in poverty. Carers are twice as likely as people in general to experience chronic pain.

But do we care? Enough, at any rate, to attempt to do anything structurally, systemically meaningful about this situation? The answer, to date at least, has been - no, we do not.

Except that is not quite right. I accept I am being overly negative here. Some Australians care. There are politicians from all parties and journalists and academics and policy-makers and business people who do understand, and who do care. There are organisations and

charities and government bureaucrats who do understand, and do care. But nothing is really going to change, I would suggest – nothing – until and unless we begin to understand, here in this complacent country in which we live, how vilely and callously we treat people with severe disabilities and their family carers, and engage in some robust soul-searching as to why that might be so.

Is it our convict roots? Is it that in the early days of white settlement, only the strongest and fittest could survive in what the author and art critic Robert Hughes called “the fatal shore”? Is that being disabled doesn’t fit with our more recent image of ourselves as “The Lucky Country?”

Whatever the reasons, some sort of national soul-searching is, I would suggest, an absolutely essential pre-requisite if we are to have any hope whatsoever of seeing the sort of transformational reforms encapsulated in the proposals for a National Disability Insurance Scheme introduced. We need the sort of national soul-searching that went on after the revelations about the impact on tens of thousands of indigenous Australians of children being snatched from their parents; the Stolen Generations.

Without this sort of public exposure and debate, how is the broader Australian public ever to be convinced of the need for billions of dollars in additional funding for disability care and support services unless it first grasps – and acknowledges - the extent of the physical, emotional and psychological suffering caused to people with severe disabilities and their full-time, lifelong carers by the existing system?

That, I think, is what Bill Shorten grasped, and what he was getting at when he actually drew a parallel by describing Australia’s treatment of people with disabilities and their families as “a public policy failure on a par with the nation’s past treatment of its indigenous people”. It’s what, very hearteningly, Mitch Fifield has also grasped, and publicly acknowledged. In an article in the Australian newspaper a few months ago he said: “If you are an Australian with a disability, you have a pretty frayed patchwork of support. And the support that you get is determined not by your need but by how you acquired your disability. It’s a bit of a lottery and in most cases you face a Soviet-style system of rationing.”

Apart from it being a lot more than a “bit” of a lottery, and apart from this comparison being rather harsh on the Soviets, I’d agree completely with Senator Fifield’s assessment.

As the author of the article, Angela Shanahan, also observed: “Surely we can do better than a do-it-yourself approach, which comes down to stumbling on some service that may make or break your own mental health.”

A disability care and support system should do what it says on the tin: provide care and support. Yet in Australia, we have a care and support system which actually seems to go out of its way to make what is already a very stressful, difficult and distressing situation for its

most vulnerable citizens even more stressful, difficult and distressing. Why is this so? How did this happen? And what can be done about it?

We are, I believe, very fortunate indeed that proposals for a transformational National Disability Insurance Scheme, or NDIS, have now emerged, thanks to visionaries like Brian Howe and Bruce Bonyhady, and that thanks to astonishingly broad political and community support, these proposals have progressed to the stage of an in-depth feasibility study by the Productivity Commission.

This inquiry – thank God - is not just another hand-wringing exercise by well-intentioned but toothless federal parliamentary committees, of which we carers and people with disabilities have now endured way too many.

The Commission is a high-powered, economics-based organisation whose *raison d'être* is to consider sweeping structural change and reform, and that is most certainly is now required with Australia's disability system, rather than any more bandaid solutions which leave fundamental systemic and structural problems unaddressed.

Again, many people are cynical about the process now underway; again, I am not one of them. Call me Pollyanna, but I believe there are a number of reasons for justifiable optimism and real hope now.

To begin with, I truly believe we may have reached that all-important tipping point with disability services in Australia; the point at which things get **so** bad, and are clearly and undeniably so bad, that real, significant, meaningful change becomes an imperative; the point at which there is far more momentum behind change, however, difficult, than for the seemingly easier option of just maintaining the status quo. That's how and why Medicare came into being, despite massive opposition at the time. That's how, and why, our world-class compulsory superannuation scheme came into being.

The possibility that something similar may be about to happen with the disability system in this country is demonstrated by many things, among them the overwhelming number of submissions received by the Productivity Commission - the most, in fact, in its history – and by the fact that the overwhelming majority of these submissions are not just supportive of an NDIS in general terms, but also in the details of how it should be structured, how it should work and what its primary goals and objectives should be.

Another reason for justifiable optimism, I believe, is how widely it is now understood that this country's dysfunctional disability system is not just an abomination in social justice terms but - even worse in many respects- represents economic lunacy. It is lunacy, for instance, not to invest in good quality, intensive early intervention services that help minimise the long-term degree and nature of many disabilities. It is lunacy not to invest in

good quality therapy and vital equipment, provided in a timely and efficient manner, so as to reduce the impact, if not prevent altogether, contractures, deformities and other preventable physical problems developing among people with disabilities and carers alike, such as broken backs.

It is lunacy not to invest in good quality education and training supports that maximise the employment prospects of a person with a disability. It is lunacy not to invest in making all buildings and public transport accessible, so that people in wheelchairs for example can get to work. It is lunacy to subject families to so much emotional, psychological, physical and financial pressure that marriages and families break down at twice the rate experienced in the broader community. It is lunacy to subject carers to so much pressure that the majority of us are suffering mental health problems and can get through each day only with the help of anti-depressants and Valium. And it is lunacy not to invest in good quality respite and other support services which would enable tens of thousands of currently full-time carers, many of us tertiary-educated, to work, pay taxes and build up some superannuation for our old age, rather than condemn us as at present to poverty-stricken dependence on carers pensions as our only or chief source of income.

As Bruce Bonyhady has put it, is it lunacy for Australian governments to spend as much money as they currently do on disability care and support services for such poor outcomes; for such absolutely pathetic results. It is far better, and more sensible, to spend more money doing something properly than it is to spend a lesser amount doing something really badly. Penny-pinching can be an idiotically false economy.

Another reason for optimism, I believe, is that the very process of talking about and reflecting on a reform as sweeping as an NDIS has helped open the floodgates to a relatively new way of thinking – in Australia at any rate - which is absolutely vital if people with disabilities and their families are to have any chance at all of a better life; and that is the move towards individualised, self-directed funding, controlled by people with disabilities themselves, wherever possible and appropriate, and by their families.

One of the chief reasons why the current system here is so dysfunctional is because of the bureaucratic and administrative rigidities which have plagued it, for decades. A support system based almost entirely on block funding to bureaucrats, non-government service providers and charities to then decide what services they will provide to individuals, and how, and where, and when, is a grossly old-fashioned, outdated one. It is a system based on the assumption that people with disabilities are too disabled, and/or their families too helpless or ignorant or stupid, to work out for themselves what will best suit their own particular individual needs, and then have the wherewithal to go organise it.

It is a deeply paternalistic approach, and one which contributes hugely to the stresses on, and suffering of, people with disabilities and families. And while it may have been defensible

in the 1940s or 50s, it is clearly indefensible in this day and age, when many parents of children with disabilities, for instance, are highly educated professionals perfectly capable of deciding which form of therapy suits their own child, or which method of education, or respite, or whatever it may be.

The move to individualised, self-directed funding will not be an easy one in Australia, and will not happen overnight, given that service providers are entitled to some time and space to adjust, but it IS going to happen, because - it's a worldwide trend; it saves a vast amount of money by eliminating layers and layers of middlemen administrators and bureaucrats; it is in keeping with all the current rhetoric about consumer choice and the human rights of people with disabilities; and it makes basic common sense.

Another reason for optimism, ironically enough perhaps, lies in grim demographic realities. Since the closure of institutions from the mid-1980s on, Australia's cheapskate disability support system has to a considerable degree been based on exploiting the love and sense of duty which parents feel for their adult sons and daughters with severe to profound disabilities.

When governments began closing these institutions, here as elsewhere around the world, they promised to replace them with an extensive network of small, group houses in the community for those people with severe to profound disabilities who needed 24-hour care and support. Because small group houses lacked the economies of scale available in large institutions, however, they turned out to be expensive to run. So there came a point in Australia, as elsewhere, where governments had to decide whether they were actually willing to put their money where their noble-sounding words were. Were they willing to commit the substantial additional funding that was going to be required to ensure that adults with severe to profound disabilities could live in the community, with a far better quality of life than could previously be offered by institutions?

In countries like the UK, the answer, by and large, was yes. Substantial government funding was provided to create a nationwide network of good quality, supported accommodation options, available to anyone with a severe to profound disability once they reached adulthood. And by adulthood, by the way, I mean from 18 years of age.

The answer in Australia, however, was no.

At some point, governments here decided that the best option – best because apart from any other consideration, it was far and away the cheapest – the best option was to “encourage” families of children with severe to profound disabilities to continue housing and caring for them, for decades into adulthood, in the family home.

I put “encourage” in quotation marks because ordinarily, that word implies at least some degree of free choice.

But of course, in the absence of any alternative, there is actually little if any free choice involved and family carers have had progressively less choice and say in the matter in Australia over recent decades.

The result is that the situation in Australia today is that families are expected to continue to house and care, around the clock, for a family member with a severe to profound disability for decades. If one parent dies, the other must carry on alone. When the second parent dies, the next generation, the brothers and sisters of people with severe to profound disabilities, are expected to take over.

The economic rationale behind such a policy is obvious. A place in a group house for a person needing 24/7 care and support costs governments around \$3,000 a week, or \$150,000 a year, whereas a place in the family home costs governments a fraction of that sum. In place of all the staff required to cover three shifts a day, seven days a week – a total of 21 shifts – you simply leave it to families to work out amongst themselves how to cover all those “shifts”, so to speak. The result is often one primary carer – usually a mother – covering something like 120 hours or more of the 168 hours in a week. And in return, this primary carer only has to be paid, at an absolute maximum, the pension known as Carer Payment of some \$300 a week.

The only fly in this ointment, however, at least as far as government policymakers are concerned, is the prospect that many family-based primary care givers are likely, at some point in a 40- or 50-year time span, to go: “Um, hold on a minute....”

So, one can just picture the bureaucrats pondering: - how to get around any disgustingly selfish reluctance some primary caregivers may feel about the prospect of spending 40, 50 even 60-plus years caring around the clock for a family member with a severe to profound disability?

One answer they have come up with is to make it very clear to family caregivers that actually, there is no acceptable alternative option for a family member for whom that caregiver is likely to feel deep love and a profound sense of personal responsibility. Sure, you can simply refuse to go on, but if you do, that means you will literally have to decide to abandon your son or daughter, or brother or sister, or whatever the close relationship may be, in a hospital or temporary respite centre, from which you can be assured your son or daughter or brother or sister will be shuffled around, moved from one temporary centre to another for what could well be years.

That’s the stick end of this particular carrot-and-stick approach. The carrot end is to heap praise on caregivers; to laud them as “the angels and saints of our society”, as federal Opposition leader Tony Abbott put it recently. To keep assuring carers what heroes we are. To fund carers’ organisations to offer carers lots of solicitous advice and encouragement so as to demonstrate how much, as a society, we “value” and “appreciate” carers. To stage

annual Carers' Weeks, for precisely the same purpose, at which carers get to have a free lunch. To hand out awards and plaques and certificates to "Carers of the Year", including to children as young as seven and eight. To fund academics to do research into how to "promote resilience" among carers. To fund counsellors to go around to carers' houses – many of whom are absolutely distraught - where they are able to suggest "coping mechanisms" like "play soothing music in your car as you drive around", as one such counsellor helpfully suggested to me.

Anything – anything – to stave off having to fund independent living options and care outside the family home for adults with severe to profound disabilities, as other wealthy developed nations such as the UK do.

This policy approach over the past 20 years or so has now got our society to the point where even a carer diagnosed with cancer of the spine is unable to find a supported accommodation place for her 30-something, 80kg severely physically disabled son, as is the case with one sole-parent mother I know. Even a carer diagnosed with multiple sclerosis is unable to find a supported accommodation place for her profoundly physically and intellectually disabled 20-something daughter outside the family home, as is the case with another woman I know.

Even carers in their 80s and 90s are unable to find supported accommodation placements for sons and daughters in their 40s and 50s with severe and multiple disabilities. As is the case with all of us, the one remaining shred of hope left is that their disabled sons or daughters will die before they do.

What can one possibly say in response to such a catastrophic situation for any wealthy country to find itself facing, except perhaps: "What a triumph of social policy this has all turned out to be, politicians and government bureaucrats everywhere. A bit of money well spent, a lot of money well saved. Well done, and congratulations."

There's just one slight problem, however, which is that this policy approach has left Australia, and Australian taxpayers, sitting on a demographic time bomb.

Because where family care-givers differ from "angels and saints" is that angels and saints are immortal. Family care-givers, however, are not. Disgracefully selfish I realise, but sooner or later, we die. As one mother put it, in an article I wrote for the Weekend Australian Magazine last year about this social and economic time bomb: "Even the most dedicated and selfless carer can't go on providing round-the-clock care if they are dead."

Sure, there's often the option of guilt-stricken siblings to fall back on. But what if there are no siblings, or the siblings say no?

At present in Australia, we have tens of thousands of adults with severe to profound disabilities living in their family home with parent carers heading into their 70s, 80s and

even 90s, and with no independent accommodation infrastructure in place to take those adults when their ageing parents completely physically collapse and/or die.

As a result of at least two decades of severe underfunding and head-in-the-sand governmental neglect, the cost of rectifying this yawning, generational hole in the nation's social support fabric is now absolutely astronomic. Furthermore, how and why did all those involved in framing disability policy in this country, including all the many organisations funded by governments to advocate for and represent the interests of people with disabilities, and of families and carers, allow this disgraceful, socially catastrophic situation to develop, without sounding far more of an alarm?

And that is a necessary question to ask, I believe, because until and unless we work out why things have gone so wrong over the past 30 or so years, we will struggle to come up with anything approaching feasible solutions.

One of the core problems, in my view, is that governments set the lead, and when governments are extremely determined not to fund anywhere near enough supported accommodation places, or indeed even not fund any additional new places at all, it takes a hell of a lot of courage for any organisation which is reliant itself on government funding for its survival to protest; to speak out.

The public silence of the major disability service providers over the last decade or so has been quite appalling, I'd suggest. And ultimately self-defeating, as I think they have now realised. The disability rights lobby is also loath to acknowledge the need for any form of accommodation for adults with disabilities staffed by paid support workers. The theory is that ALL adults, no matter what type or degree of disability they have, should just live in their own home in the community, like everyone else - even if that means in practise 40- and 50-year-olds with very severe disabilities continuing to live in their aged parents' homes. Pushed, the rights lobbyists will reluctantly agree to a group home model - but only on condition that there are no more than five beds in that home. Anything more than five, and it becomes by their definition an "institution". Why five is the magic number, I'm not sure. But these days at least, five is definitely the magic number.

This sort of rigid right-on correctness is beyond infuriating to those of us parents who have decades of lived experience of disability, from a carer's perspective at least.

Recently, my Mad as Hell co-founder, Fiona Porter, and I were invited to speak at a public forum, sharing the stage with one of Australia's most prominent disability rights advocates, Rhonda Galbally. Rhonda is an extremely intelligent, articulate, impressive woman. She is very highly educated, has served with distinction on numerous government panels and boards and so on representing people with disabilities, and is a very successful businesswoman. She also has mobility problems as a result of childhood polio.

Rhonda said it was terrible that over the past 20 years or so, carers had managed to “hijack” and derail the disability rights movement by making it “all about them”. She said that when she watched TV documentaries or read newspaper and magazine articles about the plight of ageing carers – 75-year-old parents, for instance, struggling to care at home for severely disabled adult sons and daughters in their 40s and 50s – that this sort of depiction of people with disabilities as “a burden” made her feel “like killing myself”.

Well, while I’m sorry that watching footage of a 75-yr-old drag an adult son with disabilities up two flights of stairs for a shower makes Rhonda feel like killing herself, I actually feel a lot sorrier for the 75-yr-old, and indeed his son. I far prefer Bill Shorten’s analysis, which is that Australia’s treatment of its most severely disabled citizens and their families over the past 30 or so years has been a cruel and terrible public policy failure, and is “a disgrace”.

It’s a shame that reality doesn’t match the theory, but the stark reality is this: that there are tens of thousands of Australian adults with severe to profound disabilities whose round-the-clock care and support needs mean they are never going to be able to live independently and “normally”, just like everyone else. And furthermore the cruel, cheapskate solution to this problem to date – to simply dump the problem on a generation of parents, safely tucked away behind the closed doors of family homes, out of sight and out of mind – will not keep being an option, because that generation of parents is now getting old; those parents are dying.

So what, as I asked earlier, is going to happen? How can this looming social and fiscal catastrophe even begin to be addressed?

To begin with, it’s clear that the problem is now so large, only visionary, highly innovative and extremely creative, flexible ways of thinking about it offer any prospect of success. The ideologues need to understand that the best way to ensure the human rights they claim to be fighting for is to enable and empower individuals to start thinking about solutions that fit their own particular needs, depending on individual circumstances.

It is a very welcome development that so many people now acknowledge the fact that Australia’s cruelly rationed, crisis-driven disability care and support system as currently constituted has to be swept away, and replaced by some form of streamlined, more securely funded national disability support system, based on the bedrock principles of legal entitlement to services for those assessed as eligible, and far more individualised, self-directed funding.

That’s an essential first step, and we can all only hope and pray that the Productivity Commission will come up with proposals so coherent and compelling when it reports next July that the federal government will have no choice but to act. And that if it doesn’t, that all hell will break loose.

The next step will be for Australia, as a wealthy, supposedly civilised and caring society, to acknowledge that expecting individuals to care round the clock for decades for family members with severe to profound disabilities until death is utterly unacceptable, and utterly unconscionable.

As a society, we no longer expect people to care around the clock for aged family members with intensive support needs and medical conditions. As a society, we have acknowledged that this is unreasonable and unjust, which is why governments now fund tens of thousands of aged care nursing home beds. Middle-aged sons and daughters are no longer expected to drop everything, give up their jobs and careers and lives, and spend even a few years washing and dressing and feeding and lifting and caring for frail aged parents round the clock, night and day, day after day after day – let alone decades.

Yet for some reason, we continue to think this is an entirely acceptable ask for the middle-aged and elderly parents of adult sons and daughters with severe dependent disabilities in their 30s, 40s and 50s.

I would propose that as a society, we set an absolute time limit on how long individuals are expected to be full-time, round the clock carers, and I'd propose that this be something like 30 years.

In the UK, as mentioned, this time limit is in effect 18 years. Once children with severe to profound disabilities turn 18, the UK accepts that these now young adult should have the choice of moving into independent, out-of-home accommodation, with whatever level of support is necessary. Of course, people don't have to take up this choice. Many people choose to remain in the family home, at least until they are in, say, their late 20s or whatever. Many parents or other family carers choose to continue providing care and support in the family home. Fine. The crucial point of course is however that it's a personal choice.

In Australia, as a starting point, I propose we make 30 the legal entitlement age for the statutory provision – or the offer at least - of a supported accommodation placement outside the family home.

By the time a person with a severe disability reaches 30, his or her parents are into, or heading into, their 60s. The chances are overwhelmingly high that by that time, the parental carer or carers will be chronically exhausted. As all the data and research studies around the place show, the chances are overwhelmingly high that the parents' marriage will have broken up, and that the remaining primary caregiver will be in poor health, will be suffering from severe depression and will be living in poverty.

In my case, my son Shane, who has severe spastic quadriplegic cerebral palsy, is only just 21. My husband and I had the benefit of 12 years living in the UK, where all the basic services and supports we needed, entirely unlike Australia, were provided, quickly, smoothly and

efficiently and without the endless nightmare struggles and battles that exists here. We had the benefit of six years of our son attending a weekly boarding school, meaning that apart from 17 weeks of school holidays, I only had to cope with severely disrupted sleep three nights a week, not seven.

How do the other mothers and fathers around me, who have been forced to endure this country's shambolic and dysfunctional disability support system ever since the birth of their severely disabled sons or daughters two, three, four decades ago – how do they cope? How do they stay sane? How do they keep going?

I have no idea.

And in particular, how do people keep going when there is no end in sight? When death is the only release in prospect, as is now the case in this benighted country?

I have no idea.

And why do so many parents stifle so much of their suffering? Why do they not howl and scream their endless pain and despair so much more loudly than most of them now do, in this benighted country?

Well, partly, it's because it is our children we are talking about here and our love for and devotion to them supersedes every other emotion we may feel. If a 30- or 40-year-old son or daughter still needs as much care and attention as a six-month-old baby, and there's no external support structure in place, then we give it. But in addition, I'd suggest, we have also allowed ourselves to be cowed into silence and acquiescence by the disability rights ideologues, who tell us that if we even dare to suggest that our adult sons and daughters are "a burden", we are selfish pigs, a disgrace to the human race, and make them feel like "killing themselves".

We are also cowed into silence and acquiescence by those ideologues who, at the very mention of the need for a wider, more flexible range of supported accommodation options, start screaming "institutionalisation", "institutionalisation" to anyone who will listen.

Well I, for one, believe it is time for parents to start saying that yes, caring around the clock for decades for an adult who needs as much care and attention as a six-month-old baby IS a burden, actually. That, heading into our 60s and 70s and 80s, we are actually entitled to some rest. That heading into our 60s and 70s and 80s, it is NOT too much to ask that there be options available so that our adult sons and daughters can move out of home – like - guess what? - happens "normally".

It's high time, I would suggest, that parents of adults with severe to profound disabilities start standing up and saying this: **that actually, carers like us have human rights too, guys.** That we are no longer going to put up with being patted on the head and told what heroes and saints and angels we are; that we are not interested in any more band-aids; that we are

not interested in governments introducing meaningless Carer Recognition bills with long lists of platitudinous statements about what we “should” be entitled to – but aren’t.

We want sweeping, transformational reform of Australia’s long-term disability care and support system. Nothing less. We want a genuine say in and control over how the money ostensibly allocated for our sons’ and daughters’ benefit gets spent, particularly when they are under 18; and we want supported accommodation, out of the family home, to be made available for our sons and daughters when they are adults.

I am happy to keep looking after my son for as long as humanly possible. At 21, he needs help and assistance around the clock. He can do nothing for himself physically, and is very vulnerable. But when he turns 30, in nine years’ time, I will be 65 years old. There’s a limit to what any one human being can actually do, and I suspect that by that time, I will have reached it.

In nine years’ time, I can but hope and pray, Australia will have a long-term disability care and system in place that will allow me, and thousands of parents like me, the luxury of at least dying in peace, knowing our sons and daughters have somewhere to live when we are gone.

In nine years’ time, I can but hope and pray, there will not only be small, isolated group homes plonked in the middle of lonely suburban streets, because that is the only model the disability rights ideologues will countenance as “normal”, but also small, purpose-built communities and villages where people with severe disabilities, if they so wish, can choose to live together, with inbuilt social and recreational facilities.

This is not “institutionalisation”, as the zealots claim. This is just giving people with disabilities precisely the same sort of communal environment in which thousands of our senior citizens now freely choose to live. Does anyone go around squawking that the retirement villages that have sprung up all around Australia, with their heated indoor swimming pools and gardens and communal facilities are “institutions”? Of course not.

When you have the money, these villages are deemed a “lifestyle choice”. But when you don’t have the money, because you are a person or the parent of a person with a severe disability, and you need government funding to help establish such a village, suddenly the ideologues get to be involved, telling us that yes, they advocate choice, but only as long as it is a choice they deem “appropriate”?

The only way to blow such people out of the way is to provide people with disabilities and their families with the option of individualised, self-managed funding, so that individuals get to choose what they, on the basis of their own lived personal experience, know to be the best options for them.

With the proposals for an NDIS now on the table, Australia has the opportunity to move from the worst disability care and support system in the developed world to one of the very best. It can't, and it won't, happen overnight. But if it is to happen at all, then we need our political leaders to stand up, as Bill Shorten and Mitch Fifield and a number of others have now done, and tell the truth. We need service providers to stand up, as a number are now beginning to do, and tell the truth. We need the disability rights ideologues to start showing a little more humility and stop being so bossy and authoritarian, telling the rest of us what is right for us.

And most of all, we need all those Australians whose lives are now so grievously affected by Australia's dysfunctional disability support system to stand up and make it crystal clear: We are mad as hell. We are not going to take it anymore. And there are millions of us.

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