

SUBMISSION TO NATIONAL CARER STRATEGY

THE BENIGHTED NATION

THE SYSTEM

Carers are supposed to be supported by a system and the system that carers of people with a disability operates within is the disability support system. At the outset of this submission, I would like to restate the word that has often been used to describe Australia's disability support system. It is a disgrace. Any discussion of the rights or entitlements of carers who are dependent upon the Australian disability support system is a sham and a travesty. Before you can think of a strategy to enhance the lives of this group of carers, you must firstly fix the disability system. To do otherwise is a classic case of putting the cart before the horse.

We have in this country tens of thousands of families crying out for services that do not exist or that exist for only a few. We have young families who wait for months and years for essential therapies for newly diagnosed children. We have parents who need to rejoin the workforce but who cannot access before- or after-school care. We have physically disabled children who wait so long for aids and wheelchairs that they have outgrown them on arrival and long lists of families trying to gain respite. And we have my group of carers, the ageing parent carers, who have looked after their son or daughter for decades and who cannot access supported accommodation because there is none.

To discover the cause of this great but largely unspoken area of social neglect it is necessary to search the soul of our nation. Why do Australians have such scant regard for people with a disability? Is it that we are such a young country, only a few generations from our convict past and not yet fully civilized? Is it that we adulate our sporting heroes and think ourselves healthy, outdoor people so that people with disability do not fit the image we have of ourselves? Is it that we are so smug in our certainty that we are the best country in the world that we cannot conceive of anything as bad as our disability system? Or is it just that we are caught up in a world of economic rationalism, where we look at what it would cost to properly care for all our people with disability and how cheaply the lifelong carers do it?

Someone with a severe intellectual disability like my son would cost between two and three thousand dollars per week to care for. It is not as if he will ever get "better" or productive in the sense that he will pay tax. He is viewed as a drain on the economy and as such, it is considered that such a "value-less" person is best cared for by the family. The family carer is paid fifty-three dollars per week allowance plus a six hundred dollar bonus once per year. If there is no other income, then the family carer will receive the pension of around three hundred dollars per week plus a few allowances. There will be supports, such as a day program and a few hours of respite and this is considered a cost-effective way of running a disability support service. However, while maintaining this economically justifiable mentality, there are other issues with which to contend.

One is the growing issue of disability rights. Having signed the United Nations Convention, this country is supposed to deliver to people like my son the right to choices, community participation, valued status and all the rest. Then there is a social equity issue which dictates that no one group is supposed to be denied access to the common good. There is also the embarrassing comparison with similar countries, which allows us to see in this shrinking globe how poorly we measure against every other developed nation in our treatment of our disabled citizens. And there is also another looming reality in the cheapskate disability system that our country boasts: the "informal" freely-given family care has a use-by date on it. The parent carers are ageing and even as I write, are dying. The siblings are not stepping forward, despite coercion in some quarters, and it would appear that the nation may have to begin to provide for its own disabled citizens.

Our problems may be traced back to 1993 when a Commonwealth-State agreement gave responsibility for supported accommodation to the states. It is abundantly clear that the states, despite the best of intentions, do not have the capacity to fund this sector except for a fraction of the need. We look to our federal government, the collector of the bulk of our taxes, for the services that we need. We get, instead, an announcement of \$5.8 billion for the whole country for the next five years. The main reason for the appalling state of the disability sector is its lack of money. Disability needs a budget similar to the aged care budget and if we valued our people with disability the way we should, it would have one. The secondary reason for the poverty of the system is that the inadequate funding is then filtered through so many bureaucracies and held so little to account that it often does not reach the intended recipients.

In some developed countries, supported accommodation is made available at the ratio of 30 places per ten thousand. Using this formula, our country is some fifty thousand places short. Every day, I hear another horror story about a family in crisis and unable to access a long term residential placement. There is literally no place for our loved ones to go in this, the lucky country. Here in New South Wales, we are coming to the end of Stronger Together 1. We hear much about the improvement this extra funding has made, but here on the ground, we know it has been negligible. Within my extensive group of carers, I know of four families who have gained supported accommodation in the past four years. Two of them did so through relinquishing their family member. Our impossibly under-resourced disability agency is charged with devolving large residential units, taking in children leaving the care of child protection, relocating people from corrective services and unblocking respite beds. The only places for people like my son, who are considered a low priority, are made available after the last remaining parent has died or become too ill to carry on. This is the reality with which we live.

In response to this situation, a group of twenty families in my area formed RASAIID - Ryde Area Supported Accommodation for Intellectually Disabled. It has been our goal to create a cluster residential model for our intellectually disabled sons and daughters in the local community. For more than six years we have lobbied, rattled cages, gained media attention, attended scores of meetings and received overwhelming support for what we are doing from politicians and bureaucrats. However, we cannot get our project off the ground because we always come back to this one stumbling block: we are not the most needy families in the state (because we are still alive) so we therefore cannot be a priority for funding. We are unable to do anything to plan for the futures of our adult children.

We are encouraged to live in hope of an improved system. I have been hearing hopeful statements that boast "new, improved, expanded, enlarged, innovative" services for decades. More recently they will promise all of the above plus be "person-centred, inclusive, and individualized". At the moment we are anticipating Stronger Together 2 and the National Disability Insurance Scheme. However, the need of my family and so many others is not in the future. It is right now. Our disability agency is currently meeting four per cent (4%) of the requests for immediate and urgent supported accommodation. We have a calamity of monstrous proportions right here, right now, and it is going to be alleviated only with federal government funding that is sufficient to meet the degree of need.

I hope it can be seen that any discussion of carers rights, entitlements, options, choices or quality of life is redundant and clearly a nonsense in this climate of non - provision for people with a disability and their caring families.

THE SILENCE

How has this appalling situation been permitted to develop? Around the country we have a plethora of disability advocates, carers organizations, peak bodies, academics and planning divisions in government departments. Why have alarm bells not been sounding for years as the population ages and nothing, but nothing has been done to provide for the future needs of our disabled sons and daughters? It is as though governments have been caught unawares. Puzzled statements about disabled people living longer are made, as though they now have the temerity to outlive their carers.

The people who are paid to advise the government are funded by the government. Afraid to bite the hand

that feeds them, they say, not too loudly, that there is still a level of unmet need in the disability sector. Instead of crying from the rooftops about the demographic time bomb that this country is sitting upon, they obsequiously congratulate government for any small crumb thrown the way of the disability sector.

Take, for example, the 150 new places announced as an election promise by our prime minister and referred to in your discussion paper. Imagine, if you will, a situation wherein fifty thousand children were unable to avail themselves of an education in this country and in which our government made 150 new school places available. There would be outrage and an early election. Imagine a situation wherein fifty thousand sick people could not access hospital care and in which our government made 150 new beds available. There would be civil unrest. Yet this is what we have in the disability sector but there is no one to say so. Our paid spokespersons stand in line to welcome the new places and to congratulate our government on its latest initiative. There is no-one to say that our government is derelict in its duty of care for its disabled citizens and that the provision of 150 places is a disgraceful abnegation of responsibility to the most needy people in the country. Surely you do not expect us to accept that 150 places across the nation qualifies as a "reform" and an "innovation", as you state in your paper?

We, the carers of people with a disability, have no voice, no union, no association, no representation and no influence. We are not silent but we are silenced. The disability industry chugs along without us, although we are doing 95% of the care and accommodation for this nation's people with disability. We are told that Carers Australia represents us. Carers Australia represents all carers. The mainstream carers, who are those people looking after an ailing spouse or ageing parent at the end of life, are in the great majority. Their issues are totally different from ours. They care for a relatively short time and will outlive the person they care for. Our great need is to transition our person into supported accommodation and supervise that transition. Yet Carers Australia is funded to keep the carers caring for as long as possible. Therein is the inherent conflict of interest such that Carers Australia cannot possibly speak for us. We have been demanding grass roots regional carers representation for many years but because you do not wish to hear us, we do not receive that for which we ask.

Our sons and daughters who have an intellectual disability also have no voice. They are spoken for by career lobbyists who are either people with disabilities but not a cognitive one or professionals with no lived experience of intellectual disability. By being represented in a whole of disability framework, the people with intellectual disability always miss out because they cannot speak for themselves. So they are dictated to by the disability zealots, who have all the power and influence and who tell us what to do and how to live. They tell us it is wrong to regard our family member as a "burden" and that we have hijacked the disability rights movement and made it "all about us". They tell us that it is wrong to want anything "special" for our person and that they should be treated just like everyone else.

The corollary from this is that as long as people with disability are situated "in the community" in a house like everyone else's, they are "socially included" and are doing fine. The few hundred that remain in large residential units attract much activism while the thousands that live at home with ageing parents are considered to be fulfilling the terms of the social inclusion rhetoric. No matter that the freedom of choice of people like my son amounts to a decision over which television channel to watch and which breakfast cereal to eat. No matter that his choice, which he has clearly stated for more than a decade, has been to leave home as his siblings have done. No matter that he is isolated and lonely living in an age-inappropriate situation. It is time that we all woke up and understood what it is that social inclusion has come to mean: it is a euphemism for leaving disabled adults in their parents' home for life, an excuse for placing the onus of care squarely in the court of the family.

It is not that I do not support social inclusion. Of course I do - in fact, I would like a little of it for myself. However, there is a moment coming in the life of my son and all the thousands like him when he will lose his primary carer, the only home he has ever known and almost certainly, his familiar community. (Crisis driven placements may be anywhere in the state). At a time in his life that he will be grieving and bewildered, my son will be uprooted and traumatized because I have not been able to supervise his gradual transition to supported accommodation. Imagine, if you will, being permanently removed from your family, your home and your community and being unable to read, write, drive or make contact in any way. How would you cope with this upheaval? Now multiply your response many times for the

circumstance of a person with intellectual disability who, by definition, has greatly reduced adaptive capacities. The only possible conclusion is that it is an inhumane and uncaring society that can allow such a thing to happen. When placed alongside the overwhelming need for urgent supported accommodation to avert this human tragedy, the need for social inclusion seems to pale to insignificance.

If ageing parent carers are nothing more than a footnote in the discourse around caring and people with an intellectual disability have no voice at all, it can be well understood how the plight of our families has been left unrecognised. Of course, governments know and have known for decades of our need and have wilfully decided to fund only a small fraction of the number of supported accommodation places needed in this country. The groundswell of public opinion required to reverse this trend and to force the supply of the correct number of places is not forthcoming. This is because people with a disability are just not high in the public consciousness of our country. We do not have the sense of collective responsibility that I find in many other countries. Or perhaps it is simply that Australians are so used to governments providing that they cannot imagine a sector in which single-digit supply is applied to overwhelming demand. The usual response of people meeting myself and my son for the first time is the presumption that I must be caring for him by choice and purposely not availing myself of the services of the local group home. We do not have high profile leadership and powerful spokespersons telling the wider community of the crisis within the disability sector.

We do not have to look far to find the reason for the lack of community awareness of our grave predicament. Here is our peak body, National Disability Services, advocating on our behalf:

For many carers of people with disability, the most important recognition of their role and contribution will come from acknowledgement that their role is not theirs alone - they want to be informed about options and assured that access to formal support services for the person they care for will be available when required.....And they need assurance that should there come a time when they require additional assistance, or find themselves unable to continue to provide everyday care, additional support will be available for them and their son or daughter.(Submission to Productivity Commission Inquiry into Caring for Older Australians)

The premise that this statement is based upon is that support services should be available only at a time when ageing parent carers find themselves unable to provide daily care. It is accepted and acceptable within this discourse that parents should continue to provide care while they are able to do so, unto death. The trauma of upheaval described above for the person with disability is accepted as due process. Where is the call for legislated entitlement to services? Where is the call for an age whereupon the statutory provision of accommodation must be made? Where is there a demand for population based benchmark funding of disability services as in aged care? Where is there the offer to bring political pressure and organize resistance if recommendations are not fulfilled? They are not to be found within the discourse of our mealy-mouthed advocates.

These are the voices which speak for us. How can we gain recognition by government of our overwhelming need when we cannot gain recognition within the disability and carer agencies funded to give us a voice? These agencies are funded by government and are really an arm of government. For more than a century, the tradition in this country by people who have failed to have needs met and rights fulfilled has been to strike. But carers cannot strike for two reasons: firstly, we cannot jeopardize the welfare of the people for whom we care and secondly, we have, by design, representatives who answer to government and who will never rock the boat. So we remain, your captive, unpaid workforce, engineered to be hidden, dispersed and silenced.

I attended a consultation session relating to the proposed Carers Strategy. Before the meeting proper had commenced, the existence of my group of carers was denied in the welcoming address given by a representative of Carers Australia who suggested that the strategy will enable carers to access employment or return to it. When I challenged this, I was told that the needs of my group of carers are best represented by disability advocates, to whom the mainstream carers do not have access. When I asked which they would be, I was told NDS. Shortly after this, on a separate occasion, I met a senior representative from NDS who told me that its role was to advocate for the service providers and that the

issues of my group of carers are best dealt with by Carers Australia. I think this is called passing the buck. It also underscores the reality that, in fact, no one represents the cohort of desperately needy ageing parent carers.

If you need confirmation of the invisibility of my group of carers, you need only look at your own response form to this call for submissions. *How long have you been caring?* we are asked. We may tick the box for less than 1 year, for 1 to 5 years, for 5 to 10 years or over 10 years. Where, may I ask, is the box for 10 to 15 years or for 15 to 20 years? Were you not able to conceive of the need for a box for 20 to 25 years? Clearly the person employed to design the survey has no idea that there are carers who devote whole lifetimes to the task of caring. The person who did the proofreading was also unaware of the need to have a box for 25 to 30 years and another for 30 to 35 years. I will soon require the box that you forgot to include for more than 35 years, while some of my ageing carer colleagues would tick the box for over 50 years if their eyesight permitted. You see, we are hidden under a stone out here, forgotten, unrepresented and silenced!

THE STRATEGY

You are no doubt thinking that I am outside the terms of reference of your enquiry and that I should be discussing your five goals. This is because you have missed the most important consideration for my group of carers. At the top of the list for ageing parent carers is the need for choice. Caring should always and forever be a freely given and freely chosen occupation. It has been so for decades for my group of carers but it has now ceased to be so. We choose to care no longer but we are trapped in a spiral with our dependent person and the only way out is through death or relinquishment. Few of us can face this latter option because it means abandoning the person to whom we have devoted our lives and whom we love with a fierce protectiveness. So we are stuck in situation that we no longer choose, exploited by our love for our vulnerable person.

Recognition is a huge issue for us, because if we cannot gain acknowledgement of our needs within the groups funded to represent us, how can we hope for recognition at a policy or funding level? It is recognition of our need to retire and transition our person that is the issue for us. In a different sense, recognition of our role as carers within the wider community is not an issue for my group of carers. We are used to being figuratively patted on the head and called "unsung heroes" and the like. We are easily recognised in our neighbourhoods. You see us, elderly mothers and fathers holding the hand of our middle-aged son or daughter in the supermarket or crossing the street. Our recognition often comes in the form of the pitying stance or the averted eye. We are too old to be mistaken for paid disability workers so we are seen for what we are: ageing and aged parents whose offspring have failed to fly.

We are too old to return to work, if we ever did work, so this goal does not apply to my group of carers. Many of us sacrificed careers to care for our children, before the days of after-school care or respite. Some of us found ways to work a few hours around the care needs of our person. Many of us have subsisted on pensions for a lifetime and most of us are without superannuation in our retirement.

The need for information is not a high priority for my group of carers. We are an educated group, with good networks and access to internet and email. We communicate with parents and disability agencies across the country and around the world, which is how we know that this country has the worst disability service in the developed world. Take, for example, the support system in the United Kingdom. From age 18 to 25, transition training is funded to specialist providers. At 25 years, the person with a disability has legislated entitlement to an accommodation service. The only ageing parent carers in the UK are those who have chosen to be so.

Similarly, the need for training in how to best care for our person is irrelevant for my carers. We are the experts in our field and we train others in how to care for our person. This is why we are so anxious to obtain supported accommodation, in order to pass on our wealth of experience and expertise to the people who will be caring for our son or daughter when we are not here.

My group of carers suffers from chronic depression and exhaustion. Any discussion of health and wellbeing for them can only be met with the derision it deserves. It is not only the impact of being totally responsible for the care needs of another human being for decade upon decade. It is not only the denial of a basic human need that dictates it is necessary for us all to have something to look forward to. It is also the fear and dread of the future for the person we care for. Because we have been unable to plan for our person, we live with the knowledge that our illness or death will cause an avalanche of despair and suffering for him or her.

I watch my fellow carers work through a process that starts with hope of a placement, usually encouraged by deliberately misleading assurances of a case worker, which brings the promise of a life after caring and some peace of mind. This gives way to doubt as no placement eventuates and the realization sets in that there may well be no life after caring and no peace of mind. Then a sort of moribund fatalism takes hold, as an awareness of society's abandonment sets in and despair takes over. The researcher comes to interview these older, older parent carers and announces that they are doing just fine. They are not. They have fought for services all their lives and now they have given up. They are too old to adapt to change and too tired to contemplate it. This is what awaits us all and makes any discussion of health and wellbeing superfluous.

I recognize the voice of one of these carers in your discussion paper:

We find it difficult to stay balanced and healthy or be positive and objective, to enjoy retirement together like ordinary Australians.

Yes, indeed! How do we stay positive with no end in sight? It is difficult to stay healthy while covering three shifts every day. It is hard to stay objective while feeling marginalized and forgotten. And retirement - what is that?

Your five goals have little or no application in the lives of my group of carers. There is only one strategy we wish to see. It is an EXIT STRATEGY.

The recognition that we require is a recognition that it is utterly unacceptable and unconscionable to expect parents to care around the clock for decades without any end in sight. Other Australians may choose to care or not to care for an aged or ailing family member. If they choose to care, they may put their hand up at any time and state that their person's care needs are now beyond their capacity to meet. This is why we have an aged care system which has more than two hundred thousand funded places and which grows every day to meet demand. We require you to recognise that our group of carers should have the same rights and the same choices as our fellow carers, that is, the right to choose to care and the right to choose when not to care.

Recently, the Report from the Inquiry into the Services Provided by ADHC has been released. In the preamble, it says:

There must be processes established to prevent carers from reaching breaking point before being eligible to receive support. We are deeply concerned by the stress and fear experienced by many carers whose attempts to plan for the future of their children have not been well supported by ADHC. We are disappointed that access to supported accommodation is largely provided in response to crisis and emergency rather than in a planned way. A system that requires its families to reach breaking point before providing adequate support and services is unacceptable.

This is the sort of statement I have been reading for the past two decades. We are awash with enquiries, conferences, round-tables and the like, recommendations are forthcoming and heads are nodded. But nothing ever gets done! At the federal level, disability does not even merit a Minister and we gained a Parliamentary Secretary this time as an afterthought. There is no commitment to the care and support of this nation's disabled people, no planned infrastructure or trained workforce. While the problem is brushed aside as a state issue, we carers go on and on and on.

Our predicament has been described as *velvet violence*. I like this term because it depicts the gloved hand that entraps us. We are caring for a person whom we love and whom we cannot abandon to a government department that has no places. We have given our lives to keep our person safe and well and happy and we cannot walk away. Both we and our person need a passage through which to move onto the next stage in life but because none exists, we are prisoners together. Both we and our person are denied a timely and age-appropriate transition and you, our government, are our jailer and the exploiter of our love for our person. You are the perpetrator of the velvet violence.

We must have thousands of extra supported accommodation places immediately. Our federal government must accept at least some responsibility for the care and support of its disabled citizens. We cannot wait for an NDIS which will ensure that our circumstances are not visited upon the next generation of caring families. We cannot count on Stronger Together 2 because it will have to stretch too far. Even John Howard, after a decade of proclaiming that *the families are the best providers*, was made to understand the crisis and undertook to take responsibility for people with disability who were over 40. Even this promise, far too late in his term and their lives, has not been taken up by the present government.

You are placed at the helm of a great social welfare crisis, a veritable tsunami of unmet human need. We must have a national conversation around the responsibility for the care and support of our disabled population. Australians must be told that social injustice and discrimination are issues not only for refugees or the indigenous. We must ask if we can afford national broadband before we have provided for the disabled members of our society or while we still have parent carers in their seventies, eighties and nineties. It is time for us, the carers, to be placed on the national agenda and for acknowledgment to be made of the fact that we, too, have rights. We must have the right to retire and the right to die in peace. Any carer strategy that does not deliver these inalienable rights is in itself merely lip service and tokenism.

It is time for Australia, the benighted nation, to wake up and switch on the light.

Estelle Shields