

# RASAID



## THE RIGHT HAND AND THE LEFT HAND

In New South Wales, the Minister for Disability is also the Minister for Ageing. While the states are not responsible for aged care, they administer areas like Seniors Card and Seniors Week. As Minister for Ageing, Paul Lynch, the current Minister, is advised by MACA, the Minister's Advisory Committee on Ageing. On its website, MACA states that "policy advice and administrative support are provided by secretariat staff based in the Office for Ageing in the NSW Department of Ageing, Disability and Home Care." In other words, MACA operates from the same office as other DADHC employees; it is in fact a subgroup within the department.

MACA has a vision statement:

A fair go, a fair share, a fair say, for older people in New South Wales.

MACA has a Positive Ageing Statement:

Growing older has its rewards and challenges. We can age well when we have the opportunity, support and encouragement to live our lives according to our desires and capacities.

MACA has its principles, which are listed on its website as follows:

Older people have the right to

- Participate in all aspects of community life
- Have their views recognised and valued in Government decision making
- Respect for the diversity of their experiences, views, living circumstances and cultural background
- Equitable access to services, facilities and programs
- Dignity, independence and choice

We can imagine a small group of public servants within the office of DADHC writing these statements and principles while possibly in the same office, in a different section, another group of workers compose a document called *Guidelines for the Support Co-ordination Program for Older Parent Carers*. We are fortunate in this era of transparency that we can approach our disability department's website and access such documents. Under No 2.2 you will see:

The objectives of the Support Co-ordination Program are to identify, engage and support older parent carers of a son or daughter with a disability to maintain their caring role FOR AS LONG AS POSSIBLE.

We can now assume that it is official policy that parents who gave birth to a disabled child decades ago are expected to continue in their caring role for an indefinite term, for as long as there is breath in their

bodies, FOR AS LONG AS POSSIBLE. You will notice that the *Guidelines* do not suggest that parents should maintain their caring role until age-appropriate supported accommodation is found for their adult children. It does not suggest that they should maintain their caring role until local and responsive residential care is provided by their department. It does not suggest that there is an age after which it is no longer appropriate for them to be still caring, nor does it suggest there is an age after which it is inappropriate for disabled adults to be living at home with ageing parent carers. It does not suggest that there is any way in which ageing parents may terminate their caring role if they so choose. It just underlines the fact that these parents are expected to continue to care interminably, FOR AS LONG AS POSSIBLE.

Imagine these two groups of bureaucrats chatting together over coffee in the office of DADHC. We can presume that they do not discuss their work with each other or they would realize that the statements that each has written are mutually exclusive. They would see that it is not possible to reconcile these two conflicting testimonies that have both emanated from the same department, if not the same office.

They would see, for instance, that it is impossible to claim that ageing parent carers are given a *fair go* when they cannot do the things that their peer group takes for granted. It is clear that there is no *fair go* in a system without entitlement to service, but only deemed priority within limited resources. It is obvious that they are not given a *fair share* of the public purse when comparable developed countries have taken responsibility for their own disabled citizens by legislating entitlement and do not require their aged citizens to care for their disabled ones. It is clear that they are not given a *fair say* or any say at all, because parent carers in this state have no representation, no advocacy, no union, no peak body and no collective voice with which to express their sense of abandonment and betrayal by their governments.

Ageing parent carers know all about the *challenges* of growing older but are yet to taste the *rewards*. They agree that *we can age well when we have the opportunity, support and encouragement to live our lives according to our desires and capacities*. Ageing parent carers, however, do not have the opportunities of mainstream Australians because they must remain in their caring role FOR AS LONG AS POSSIBLE. They are on the giving rather than the receiving end of *support* as they continue to nurture and assist their adult children. Any support they receive is designed to prop them up so that they will continue to care FOR AS LONG AS POSSIBLE. They do not have the *capacity to live our lives according to our desires* because they are locked into a role that they have fulfilled for decades and wish at this stage in their lives to be relieved of. They wish this for themselves and also for their sons and daughters, who need to achieve independence in their adulthood.

Older people may have a right to *participate in all aspects of community life* but ageing parent carers find their participation severely restricted with the caring demands of their disabled sons and daughters to be attended to. Invariably, they are required to be home at 3.00pm almost every day of their lives which has a way of confining community involvement and any out of home activity. Older people may have a right to *dignity*, but I can assure you that there is nothing dignified about parents in their late sixties, seventies or even older, struggling to care for their severely disabled offspring. Older people may have a right to *independence* but clearly ageing carers have no rights in this area and neither does the person that is being cared for. Older people in this state may have *choice* but ageing carers have only two: to continue to care FOR AS LONG AS POSSIBLE or to abandon their beloved person to a government department that has no places. This is the Clayton's *choice* of an ageing parent carer. Their fellow carers, those who care for an ageing parent or an ailing spouse, have the right to choose how long they will care because an aged care system makes places available for their family member. The state disability system currently meets the needs of just seven per cent of demand; the remaining majority are cared for by parents, who are often not just ageing but aged.

There is widespread community ignorance of this great social inequity in our midst. It is understandable that public servants from another government department could write bold and far-reaching statements on the rights of ageing Australians. However, that such statements should come from the very department that denies these same rights to its stakeholders is unforgivable, irresponsible and just plain insensitive. I demand that these two groups of bureaucrats be introduced to each other. I demand that the contradictory nature of their statements be pointed out to them. DADHC is not so large a department that

its right hand should not know what its left hand is doing. I further demand that acknowledgment be made that there is one group of Australians to whom these rights do not apply and therefore that amendments and exclusion clauses be added to the abovementioned documents.

The next time I refer to the MACA website, I will expect to see a Vision Statement that says:

A fair go, a fair share, a fair say, for older people in New South Wales (this statement does not apply to ageing parent carers)

I will expect to see the Positive Ageing Statement modified to read:

Growing older has its rewards and challenges. We can all age well when we have the opportunity, support and encouragement to live our lives according to our desires and capacities. (Ageing parent carers, who are giving and not receiving support, and who are without opportunity, are therefore excluded from this statement)

I will also expect to see a footnote after the list of principles that reads:

Older parent carers, who are required to continue to care for disabled sons and daughters until the end of their lives, are necessarily unable to be included in the application of these principles.

I will require these changes to be left in place until such time as DADHC is able to amend the *Guidelines for the Support Co-ordination Program for Older Parent Carers* document so that it reads:

The objectives of the Support Co-ordination Program are to identify, engage and support older parent carers of a son or daughter with a disability to maintain their caring role UNTIL THE SON OR DAUGHTER HAS TURNED TWENTY-FIVE, AT WHICH TIME THEIR LEGISLATED ENTITLEMENT TO SERVICE DEMANDS THAT SUPPORTED ACCOMMODATION BE MADE AVAILABLE TO THEM.

By this time, there will be no need for Guidelines, because there will be no Support Co-ordination Program for Older Parent Carers, because that person, the older parent carer, will no longer exist in this country. We will then be able to remove the exclusion statements and parentheses from MACA's statements because these fine principles will apply to all.

**Estelle Shields**