



Dear Sir/Madam,

RE: INQUIRY INTO EFFECTIVENESS OF CSTDA

"DO YOU CARE THAT WE CARE?"

I write as the parent and primary carer of a 29 year old man who has a severe intellectual disability. My son is at the stage in life where his peer group is leaving home or has already done so. He would dearly love to live with people his own age and is lonely and isolated at home. My husband and I are at the stage in life where our peer group is retiring, relocating, downsizing, travelling, enjoying the next phase in their lives. Having worked all our lives, raised four sons and cared for our disabled son for almost three decades, we would like to think that these options are available to us.

The reality is that at 60, we are relatively young in the age spectrum of carers. There are parents who are twenty or even thirty years older than us and who are still caring for their middle-aged sons and daughters. The only way to become eligible for an accommodation service from NSW Disability Department (DADHC) is to be in crisis or homeless. We are not single, "ageing" or disadvantaged, our son does not have challenging behaviours or high support needs. In the scheme of things we are on the lowest priority level. We have been told (unofficially) from DADHC that the only way that we would ever receive a service from them is to relinquish care. This means that we would have to "dump" our son and walk away. This is an abomination and something that no parent should be required to do.

Under the present system, a placement is made available for the disabled person only when the primary carer dies or collapses. This means that a vulnerable person with the mental capacity of a young child loses at the same time the only home he has ever known and his carer, usually his mother. The thought of this huge upheaval is terrifying for parents and most live in the state of anxiety wondering "what will happen to my child after I'm gone?" For the disabled persons, the grief and loss is so great that they may never fully adjust. A humane system would see a gradual transition away from home at a stage in life appropriate for the disabled person and the parents, allowing consultation with all involved parties and better outcomes all around.

I would like to see the disability sector benchmarked, so that a certain number of supported accommodation places are made available each year, in proportion to the ageing of the carers' population. I would also like to see a recommended age, possibly 30 or 35 for the disabled person or 65 for the primary carer, whereupon the family was offered (but not compelled to accept) an appropriate residential setting for their family member. I do not think that this is beyond the capacity of a country such as ours, with its billions of dollars surplus each year. However, it is certainly beyond the capacity of the state governments. The recent commitment of a billion dollars over five years by the NSW premier will go some way to redressing the shortfall. However, we know that there is such a backlog of urgent and desperate cases that families such as ours will not qualify for an accommodation package in this funding round.

This is why we ask in this review of the Commonwealth State Territories Disability Agreement that the Federal Government be requested to contribute towards the accommodation of its disabled citizens. Across our great nation, certain rights are taken for granted: the right to leave home, the

right to an enjoyable retirement, the right to die in peace knowing provision has been made for one's dependents. These rights are currently denied our family and thousands like ours.

If you have a disabled child in Australia today, you care for that child from its cradle to your grave. Lifelong caring is quite different from caring for an ailing or rehabilitating family member, or an ageing parent. That caring is for a limited time only, after which the carer gets back his or her life. Lifelong caring often brings sacrifices in careers, in social lives, in freedom of movement, in asset building and superannuation. My husband and I have been fortunate that we have both been able to work part time around the needs of our son. However, we share with many fellow carers when we express a heartfelt belief that our lives have been greatly restricted, are yet to be lived, that we are running out of time fast and that THIRTY YEARS IS ENOUGH!

The circuit breaker for our family and thousands like us is respite. For the first half of our son's life it was not a word that we knew, but now it has become the means of a short holiday or a break to replenish our resources. However, because the supported accommodation services are in such crisis, the respite beds are being used as permanent beds. When a family goes into crisis, a disabled person is put into a respite bed that would have otherwise been used to prevent another family from going into crisis. We are told that as many as 30% of all respite beds across the state are "blocked". As I write it is now eight months since we have had any respite. This is because our local respite cottage had a bed blocked for more than five months by a physically and sexually abusive person with whom we would not leave our son. This person has now been removed and we are looking forward to a short break later this month.

A source of much frustration around respite is the comparison with the aged cared sector and their entitlements. It seems that the carers of a person over 65 are entitled to and in regular receipt of 63 days respite per annum. Hostels and nursing homes are built with respite beds included and I hear of families having six and seven week holidays overseas. In the disability world, our carers, who are lifelong carers, think they are lucky if they receive one weekend per month, and many are offered only one weekend in three months. This huge discrepancy is because aged care is funded by the Commonwealth and disability accommodation and respite by the State.

Another problem is with the funding granted us by the Commonwealth through the Carers Respite Centres. While this will fund centre-based respite for the aged, it assists our carers only with in-home respite. Overwhelmingly, our need is for holiday-length centre-based respite. We wish to lock our doors and go away for a period like other Australians. Also, our sons and daughters must have the experience of another residential setting to prepare them for their eventual move from home. While in-home respite is appropriate for an aged or infirm person, it is not what our carers want. We have been saying this for years but we are not heard. Repeatedly, we are handed what is known as "flexible respite options", a few hours of in-home or out-of-home recreational respite. However, DADHC assures me that when my son turns 65, I too will be eligible for 63 days - I just have to live into my 90's.

This country is lagging behind other developed nations in its delivery of disability services. The group home model is a good one, but can we afford it? The drop-in support model is leaving many disabled persons with inadequate support and isolation. While our advocates insist upon these models, they do not always represent the views of the families or the best interests of the disabled population. 97% of disabled people in New South Wales are being cared for at home by a family member. The lucky 3% use 45% of DADHC's budget. Something has to change, and it needs to be both the accommodation model and the Commonwealth's approach to funding it.



Estelle Shields

Committee Secretary
Community Affairs Committee
Department of the Senate
P O Box 6100
Parliament House
Canberra ACT 2600



Dear Sir/Madam

Re: INQUIRY INTO LIFE WORK BALANCE

'DO YOU CARE THAT WE CARE?'

I write as the parent and primary carer of a 29 year old man who has a severe intellectual disability. My son is at the stage in life where his peer group is leaving home or has already done so. He would dearly love to live with people his own age and is lonely and isolated at home. My husband and I are at the stage in life where our peer group is retiring, relocating, downsizing, travelling, enjoying the next phase in their lives. Having worked all our lives, raised four sons and cared for our disabled son for almost three decades, we would like to think that these options would be available to us.

The reality is that at 60, we are relatively young in the age spectrum of carers. There are parents who are twenty and even thirty years older than us and who are still caring for their middle-aged sons and daughters. The only way to become eligible for an accommodation service from NSW Disability Department (DADHC) is to be in crisis or homeless. We are not single, "ageing"(!) or disadvantaged, our son does not have challenging behaviours or high support needs. In the scheme of things, we are on the lowest priority level. We have been told (unofficially) from DADHC that the only way we would ever receive a service from them is to relinquish care. This means that we would have to "dump" our son and walk away. This is an abomination and something that no parent should be required to do.

Under the present system, a placement is made available for the disabled person only when the primary carer dies or collapses. This means that a vulnerable person with the mental capacity of a young child loses at the same time the only home he has ever known and his carer, usually his mother. The thought of this huge upheaval is terrifying for parents and most live in a state of anxiety wondering "what will happen to my child after I'm gone?" For the disabled person, the grief and loss is so great that they may never fully adjust. A humane system would see a gradual transition away from home at a stage in life appropriate for the disabled person and the parents, allowing consultation with all involved parties and better outcomes all around.

I would like to see the disability sector benchmarked, so that a certain number of new supported accommodation places are made available each year, in proportion to the ageing carers' population. I would also like to see a recommended age, possibly 30 or 35 for the disabled person or 65 for the primary carer, whereupon the family was offered (but not compelled to accept) an appropriate residential setting for their family member. I do not think that this is beyond the capacity of a country such as ours, with its billions of dollars surplus each year. However, it seems to be beyond the capacity of the state governments, who are charged under the CSTDA with providing accommodation for our disabled citizens. The recent commitment of a billion dollars over five years by the NSW premier will go some way to redressing the shortfall. However, we know that there is such a backlog of urgent and desperate cases that families such as ours will not qualify for an accommodation package in this funding round.

If you have a disabled child in Australia today, you care for that child from its cradle to your grave.

Lifelong caring is quite different from caring for an ailing or rehabilitating family member, or an ageing parent. That caring is for a limited time only, after which the carer gets back his or her life. Lifelong caring often brings sacrifices in careers, in social lives, in freedom of movement, in asset building and provision for one's retirement. My husband and I have been fortunate in that we have both been able to work part time around the needs of our son. However, we share with many fellow carers when we express a heartfelt belief that our lives have been greatly restricted, are yet to be lived, that we are running out of time fast and that THIRTY YEARS IS ENOUGH.

The circuit breaker for our family and thousands like us is respite. For the first half of our son's life it was not a word that we knew, but now it has become the means of a short holiday or a break to replenish our resources. However, because the supported accommodation services are in such crisis, the respite beds are being used as permanent beds. When a family goes into crisis, a disabled person is put into a respite bed that would have otherwise been used to prevent another family from going into crisis. We are told that as many as 30% of all respite beds across the state are "blocked". As I write, it is now nine months since we have had any respite. This is because our local respite cottage had a bed blocked for more than five months by a physically and sexually abusive person with whom we would not leave our son. This person has now been removed and we are looking forward to a short break next month.

A source of much frustration around respite is the comparison with the aged care sector and their entitlements. It seems that the carers of a person who is over the age of 65 are entitled to and in regular receipt of up to 63 days respite per annum. Aged care hostels and nursing homes are built with respite beds included and I hear of families having six and seven week overseas holidays while their family member is in respite. In the disability world, our carers, who are lifelong carers, think they are lucky if they receive one weekend per month, and many are offered one weekend in three months. This huge discrepancy is because aged care is funded by the Commonwealth and disability accommodation and respite by the State.

A further problem with respite is the form in which it is delivered. Overwhelmingly, the need for our carers is holiday-length centre-based respite. While a few hours of in-home or out-of-home respite may be appropriate for an aged or infirm person, our sons and daughters must have the experience of another residential setting to prepare them for their eventual move from home. Our carers have the need to lock their doors and go away for holidays like other Australians. We have been saying this for years but we are not heard. Repeatedly we are handed what is known as "flexible respite options", which turns out to be a few hours of in-home or out-of-home recreational respite. However, DADHC assures me that when my son turns 65, I too will be eligible for 63 days - I just have to live into my 90's!

As you consider issues around life work balance, please consider the plight of this nation's lifelong carers, for whom there has been too much work and too little life. Do you wonder that we feel abandoned and exploited by our governments? We have saved the community millions by caring for our son ourselves, and it has been our pleasure and privilege to do so. But now we find our reward for doing so is an expectation that we will continue in this role indefinitely. Our country is lagging behind other developed nations in its delivery of disability services. In NSW, only 3% of disabled people have an accommodation service. In the life work equation, most Australians would expect that if you work all your life, you would earn an enjoyable retirement and be able to make provision for your children after you are gone. In the world of disability, this does not apply. There would seem to be something of an imbalance here.



Estelle Shields