

RASAIID



REPORT ENQUIRY INTO BETTER SUPPORT FOR CARERS

If you made a submission to the Enquiry into Better Support for Carers and mentioned, as I know many of you did, the total lack of supported accommodation for adults with a disability in this country, you will be disappointed with the report which has been released today. This great and growing social catastrophe is "outside the terms of reference" of the enquiry. We have thousands of older parent carers in our society who are getting older every day and who are frantic about what will happen to their son or daughter with a disability upon their death. But it seems that this issue fits into the box "disability services" and not into the box "support for carers". Why did we take the time to make a submission if our voices go unheard?

The only support that carers need after forty or fifty years of caring 24/7 is the right to see their family member settled in an appropriate residential setting. The fact that there is one such place for every twenty persons needing it is a national disgrace and a blight on our society. That this great deficit in our service provision goes unmentioned and is "outside the terms of reference" of the enquiry leaves me speechless. What better support could a lifetime carer receive than the knowledge that one day, the tour of duty will be over and the feet can be put up, with the understanding that the disabled son or daughter is safe and secure in a new home? Around the developed world, governments assume responsibility for their disabled citizens and provide accommodation and support for them. Australia lags far behind other comparable countries and there are no plans to address the shortfall.

Currently, carers are growing old and dying without ever seeing their disabled person settled. We have three choices: we can "dump" our son or daughter at the door of a government department that has no place for them, we can pass them on to the next generation and expect their sibling or other extended family member to continue caring after we are gone, or we can look after them into our dotage and try not to think about it. I find all these options totally unacceptable. The report acknowledges that carers need choice. However, the right to choose to care no longer is clearly not one of the options. We are calling for the humane transition of our son or daughter into supported accommodation while we are still around to ease the way and supervise the relocation.

There were 1300 submissions to this enquiry, 1200 of them from individual carers. The Senators were surprised at the large number, saying that an average enquiry expects about two or three hundred. They were at a loss to explain the number. Could it be that we welcome any chance to speak because we have no voice, no representation and no say in any forum that discusses us or makes decisions about us? Could it be that we are so desperate and forgotten that we will jump at any opportunity to get our message across?

With best wishes to all my fellow carers

Estelle Shields

Lifelong Carer of Daniel Shields