

# RASAIID



## **RASAIID RALLY 2009 – Speech by Estelle Shield**

'I have some questions for Paul Lynch, Nathan Rees, Kevin Rudd and anyone else who wants to listen. I want to know why it has to be so hard. You would think that it is difficult enough to raise a disabled child without having to take to the streets in search of basic services for that child. My son was in a stroller when I first marched up Macquarie St, and here we are, thirty years later, still begging and demanding services which do not exist. Why Minister? Imagine the outcry if we had a service sector that provided education for just 3 percent of our children, or a health system that could look after only 5 percent of the population. Yet this is what we have in disability, and who is talking about it?

My next question is what is it about disability in this country that is so different from other countries? What we are asking for, supported accommodation for our sons and daughters that is responsive, appropriate and local is delivered around the developed world by governments. In many cases, it is the legislated entitlement of their disabled citizens. In the UK, for instance, services are funded to provide transition training for people between the ages of 18 and 25, at which time they are all routinely offered an accommodation service. Compare that with NSW, where our government just passed a motion of self-congratulations on providing aged parent carers with three hours of respite per week. You see how far we are behind other comparable countries.

My next question to our Minister is this: what exactly would you have us do with our sons and daughters? By providing one place for every twenty people, you have ordained that there is nowhere in this state for our loved ones to go except to stay home with us. The only way to access this one place is to abandon to a government department the son or daughter to whom we have devoted our lives. Our person will almost certainly be placed a long way from this area, and forced to live with people who may not be compatible and whom they have never met before. For those of us who cannot bear that option, the only other choice is to keep them home with us until we get taken to the nursing home or funeral home, whichever comes first. After that, the siblings or other family members will be faced with the same dilemma, to either care forever or abandon our person. If I had a disabled child in India or Africa, I would be faced with asking another family member to continue to care for my child after I am gone. But, hey, this is the Australian solution to the problem and it is a third world one.

We are some of the families on the receiving end of this neglect and we say it is just not good enough. Our people are true Aussie battlers. Everything they have achieved has come with far more effort and hours than a typical person. They have earned the right to leave home. Many of them have expressed a desire to move out and many have stated that they want to be with their friends. We have worked with them over thousands of hours to make them as independent as they can be so that they can leave home. We worked harder than parents of non-disabled children and on reaching retirement age, we think we have earned the right to retire. We will never retire from our relationship with our kids, or with being part of their lives, just from the everyday care. We are getting older - our oldest member is 87 - and one of our foundation members has died before we could make our dream a reality. We want to be around to settle our kids into their new residence, to support them during the change and to iron out the inevitable bumps. Why should this be too much to ask in the lucky country?

Our vision is quite simple: we want a group of five houses in the local area where our sons and daughters can live. We want them to have their privacy when they want it and to be able to interact with each other when they so desire. Six years ago, when RASAIID was formed, a cluster model would have been unacceptable. However, to its credit, our disability department has listened to the wishes of parents and responded with a wider range of approved models. As yet, they haven't built any, other than for people already within their system, but we believe this is the model most favoured by parents. So we have the potential with RASAIID to be a pioneering project here in Ryde. We believe that our model can offer economies of scale and be cost effective in a way that dispersed group homes cannot, while not at all compromising our people's quality of life. We would like to think that around the country, other groups will form and our model will be copied and improved upon. Maybe this is what our governments are afraid of?

We have worked single-mindedly over the past six years to make our dream come to fruition. We have met with three different disability ministers and received support and encouragement from them all. Before the Ryde bi-election last year, Minister Lynch came here to us to give us a verbal guarantee that RASAIID would happen. When we asked for something in writing, he signed his name in the mid-air and his policy advisor said that we did not need anything in writing - "If the Minister wants it to happen, it will happen" we were told. Well, it is not happening and we are here today to encourage the Minister to make it happen. We are all at the end of our caring careers with a collective 600 years of caring between us. We are all 100% committed to make this project happen, and if we can get no further guarantee of support from our government, we are prepared to relinquish our sons and daughters en masse and with full public scrutiny. But we don't want to do this and we want Paul Lynch to understand that while doing this is not in the best interests of our children, it is not in the best interests of his government, either.

So, whatabout it, Minister?'