

# RASAIID



## **THREE STORIES for BILL SHORTEN – Parliamentary Secretary for Disabilities**

03/03/2009

Dear Bill

I want to tell you three short stories from the world of intellectual disability. It is important that you, as our parliamentary representative, get to hear tales from the coal face.

The first is the story of George and Amanda and their severely disabled son, Graham. This couple were in their late sixties and their son was becoming more difficult to handle. Finally, their long association with the local NGO paid off. They had been part of this community for decades, fund-raising and volunteering in various capacities. It was recognized that their need was urgent and Graham was given a residential placement. Two years later, after seeing their son well settled, George and Amanda moved to the country to retire. They come back regularly to see their son and to support events held by the NGO. They are now in their seventies, glowing with good health and stories about the friendliness of country people, the lack of traffic, how far their retirement dollar goes when a city property can be sold.

George and Amanda were among the last families to gain an accommodation placement when the NGOs had control of their own intake. Now, all placements are subject to vacancy management. This is a policy of single point of entry controlled by the state disability department. Its claim is that it provides a fair and transparent entrance and exit procedure. In reality, it is tearing communities apart, causing disabled people to be housed far from their families, friends and day placements, and causing NGOs to be forced take anyone who is sent to them, whether or not they are a good fit with existing clients. It has meant that NGOs have lost all say in their own destinies and generous parents have lost any reason they may have had to render support. George and Amanda represent the end of an era in the delivery of disability care and accommodation. They also represent an ideal of retirement that is impossible for the most of us.

My second story is of Alf and Enid and their thirty-eight year old daughter, Samantha, who has a moderate intellectual disability and many obsessive behaviours. Alf and Enid are in their early seventies and help to support another chronically ill daughter as well as Enid's elderly mother. Samantha's work placement requires that she travels across the city in a special bus which leaves early in the morning. This means that her parents had to rise at 5.00am on weekdays to get her ready for the day. Totally exhausted, they were both experiencing increasingly poor health and depression. Then, quite unexpectedly, they won the lottery. A place was found for Samantha by DADHC and it is both appropriate and local. This occurred about eight months ago. Alf and Enid look ten years younger. They have energy that we never knew they possessed and Samantha is happy and not nearly so obsessive.

For every Alf and Enid there are twenty other ageing parent carers who will never get an offer of a residential placement. They will go to their graves, exhausted and panic-stricken, not knowing how, where or by whom their beloved son or daughter will be taken care of. This is their reward for a lifetime of devotion and selflessness. They will have had no experience of retirement and no chance to gradually transition their family member into another residential setting. Indeed, in this climate of compassion for the Victorian fire victims, there is no more heart-breaking thought than the grief and bewilderment of a vulnerable disabled person with the cognitive capacity of a small child, losing simultaneously the last remaining parent and the only home ever known.

My final story is of an event that has occurred just this weekend. My good friends, Chas and Rhonda, have relinquished to the care of the department their precious only son, Allan. He is thirty and has a mild intellectual disability, uncontrolled epilepsy and many self-destructive behaviours. His parents, who are in their middle sixties, have looked after him for three decades with the ferocity (as they have hunted down services) and the gentleness of lions. Full-time parenting such as this comes at a price and now they are simply spent - they have nothing more to give. The grief and the guilt they are experiencing is overwhelming but they are as strong in their resolve to give up their son in his own best interests as they were in all their years of caring.

If you were to work in the same position for three decades and do an exemplary job at it, you would perhaps expect some kudos from your peers, some recognition or reward. The reward that Chas and Rhonda will get will be the wrath of a government department and possibly threats. They will be told that they are lacking that most prized commodity: resilience, when in fact they are able to write a book on the subject. They will also receive criticism from some sections of the community, those who believe that it is the lot of parents who have produced a disabled child to care for that person unto death and for the siblings or other family members to continue the care.

One such person is our former Prime Minister, who said just last week that he sees "the family as the most important unit in our society, not only as a source of love and emotional security, but also, quite pragmatically, as mankind's most efficient social welfare system". In other words, we are on our own, which would explain why he chose to let the disability sector remain hopelessly underfunded for twelve years.

We had dared to hope that things may improve under your stewardship. I think you have already discovered that there are no votes in disability. Except for the relatively small proportion of the population which has been touched by disability, Australians basically don't care. They are complacent in the knowledge that "we have the best country in the world" and the suggestion that some areas are not up to scratch sends them into a flurry of defence. I have discovered that the underlying attitude to people with an intellectual disability in this country is that they are not worth much - certainly not the amount that it would take to provide them all with supported accommodation.

And yet that is what we must have. We are all getting older and more afraid. I am sure you are aware of the comment from our departmental head last week. He came out advocating insurance fraud in preference to facing a lifetime of unfunded and un-serviced disability. How can any of us hold up our heads as proud Australians while such a situation exists? If I lived in the United Kingdom or any other of a large number of developed countries, I would not be writing this letter to you. Some years ago my thirty-one year old son would have received a supported accommodation placement. If other countries can do it, why cannot we?

This is an appeal to your sense of social justice and your belief in the fairness of Australian society. The first two stories are tales of how things should be. The third story is one of how things are but must not be. It tells of the only choice of families who live in a society with a service system that will not meet their needs. This is not a matter of choice for your government. We must have at least the hope of supported accommodation for our sons and daughters. We must know that funding has been allocated and that plans are in place. Otherwise you leave us no choice except the one that the family in the third story has made.

I remain

Yours Sincerely

**Estelle Shields**

Lifelong Carer of Daniel Shields

(Names in the stories have been changed)