

Ms Margaret Liveris
Standing Committee on Environment and Public Affairs
GPO Box A11
Perth WA 6837

Dear Ms Liveris

RE: PROPOSED OUTSOURCING of 60% of DSC ACCOMMODATION SERVICES

This letter calls on the Standing Committee on Environment and Public Affairs to launch an inquiry into the transition of accommodation services.

OUR FAMILY

We, Terry and Jo, are the parents of 43-year-old [redacted] who has lived in Disability Services Commission (DSC)-supported accommodation since age 21, just over half his life so far. Currently he lives with two other men at [redacted] Coora Place, Nollamara.

The Person

[redacted] is a sociable, engaging, physically robust individual with a strong personality and great joie de vivre. He appreciates the beauty of nature and of art and music. He likes to be well groomed and well dressed. He has a strong sense of justice and expects fair treatment for himself and others. He swims and surfs well, enjoys cycling, boating and his own version of cricket and other ball games. He is currently working on a large-scale textural painting. Curiosity and an acute sense of humour make people-watching pleasurable for him. Animals and birds are important to him, in particular crows which to him are deliciously comical. He is a good mimic.

Some History

In July 1981 [redacted] was lost for 24 hours from a school camp in the hills near Serpentine. Local aboriginal identity [redacted], with his dog, tracked him and found him soaked, chilled and exhausted. He waved down the Channel 7 helicopter to fly them out. Since this episode [redacted] has an ongoing fascination with aircraft of all kinds.

Difficulties

[redacted] understands speech and body language very well, however his own speech is limited and often indistinct (apraxia). Naturally this causes him great frustration and damages his self-esteem. He becomes very distressed when he cannot make himself understood. All his life bullies have taken advantage of his limited ability to report on them.

[redacted] is subject to episodes of sudden explosive rage the triggers for which are not always evident. Self-harm and property destruction, and sometimes aggression are shown. As a result his activities are restricted. In public he is accompanied by two staff. For transport in his specially modified, dedicated mini-van he is restrained in a harness fixed to anchor points in the van. At his home he may be, as a last resort, placed in seclusion for short periods for the safety of staff and residents. Short-acting calming medication may be used.

Why?

Despite thorough medical, neurological and genetic testing, no cause has been found for [redacted] handicaps. Some delay in milestones first alerted us. Initially a physical impairment eg spasticity was suspected. At age two years a paediatrician identified mild intellectual handicap and referred us to DSC. Secondary causes for his adverse behaviour are frustration with his disabilities. Psychological trauma eg bullying, neglect when away from home is another probable factor.

HEALTH

In an attempt to manage his volatility, [redacted] has since age 15 been prescribed heavy doses of various medications. The side effects have been severe. On two occasions he has suffered medication-related fitting. In 2012 he spent time in hospital with a bowel impaction due to the constipating effects of medication. His cognition and joy in life have been adversely affected. From a well co-ordinated young man he now struggles with postural and balance impairment.

THE CRUNCH

We, Terry and Jo and our daughter did our best but by 1992 we had to face the realisation that we could not cope, and thence made the heart-wrenching decision to place [redacted] in full-time care.

It became too difficult for us to care for him at home, due principally to

- the school routine coming to an end
- the unavailability of any regular day activities or placement for him
- the failure of a part-time placement in sheltered employment
- the need for 24-hour supervision
- his increasingly intense episodes of rage, self-harming and destructive behaviour
- difficulty in accessing suitable respite stays

The loss of his school routine and companions and the lack of any proper alternative damaged [redacted] morale irreparably and his behaviour became much harder to manage.

[redacted] sister was trying to fulfil her university studies, a 5-year Master of Clinical Psychology. Terry was working in the mining and quarrying industries, work which took him to outback Australia and overseas for periods of weeks, at unpredictable intervals. Jo worked full-time at the then State Health Laboratories. She had worked part-time but due to Health Department budget constraints part-time work was no longer available to her. We chose to finance our daughter's, HECS and college fees. Apart from [redacted] disability pension, our earnings were our only income.

DSC ACCOMMODATION 1992 -

We have always kept in close touch with [redacted] and initially we brought him home for weekends and took him for outings and country holidays for some years. Eventually these had to cease as we could not be sure of keeping him safe in the event of an angry episode.

When [redacted] went into residential care in 1992, things were far from ideal. [redacted] was placed in seclusion for prolonged periods. He suffered injuries from breaking glass during seclusion. In 2001 he suffered a head injury when he was attacked by a fellow resident. In 2004 there was an incident

of sexual abuse by a fellow resident, details unclear. We have put enormous energy into advocating for a better deal for

Over time the standard of care at DSC has steadily improved until at present he is in a house staffed exclusively by Level 3 Social Trainers and although there will always be some issues his care has never been better. The system is adequately funded and managed. Most of the staff have a long history with [redacted] and hold valuable historical insights. An important feature is their ability to understand much of [redacted] speech and non-verbal communications. They clearly share a commitment to do their best for him. There is a rapport and mutual affection that have increased over time.

Until the press announcement last October we had begun to feel that we could relax a little and that our boy would be well cared for as inevitably our capabilities diminish.

BOLT FROM THE BLUE

This proposed change defies belief. It came from nowhere with no rationale, no detail, no time frame and no consultation with families or advocates. We are at a loss to divine any valid reason for it, other than blind ideology. It will not save the State significant money. Most outrageous of all, it falsely spruiks the promise of 'choice' while denying the most basic choice, the choice to stay in the DSC setting if they so choose.

A clumsy attempt to sell this policy by linking it to the NDIS does not hold water as long as comprehensive choice is denied.

What has happened to acting with respect, with responsibility, to protecting rights, according dignity to our most vulnerable? Where is their safety, their security? What happened to the moral obligation on government to look after the weakest?

These are people who do not marry, they depend on family contact and the friendship of housemates and staff for their emotional security. Change is very difficult for them to cope with. Yet long-term family-like relationships with housemates and with DSC staff are now under threat. Companions may be separated if placed with different providers. It can take years for trust in new staff to develop.

The corporate knowledge, the painstaking training will be lost forever. Many DSC Social Trainers will leave the service, taking their expertise and experience with them. This is now happening, with two lost from Coora Place already. Seeking employment in an equivalent role in the private sector is not attractive and may not be feasible.

SOME FACTS

The option of seeking accommodation in the non-government sector has always been open; it is not a new avenue of choice. The transfer of services to the non-government sector has been proceeding quietly for many years. People going into residential care for the first time have increasingly been accommodated in the private sector.

There are currently about 500 people in DSC accommodation. Predominantly they are in the older age group, some with no family, others with ageing parents. Of these, around 300 will be expected to choose a non-government provider to care for them. Imagine if you can the anxiety, the insecurity, now taking hold of these people and their loved ones.

For anyone in the remaining 40%, will the standard of DSC service be maintained? Is it even practicable to maintain standards with a reduced bureaucracy supporting the frontline staff?

Why is this group of 300 individuals being targeted? It is not a large number in the scheme of things. Why not maintain the real choice, to live out their lives in peace in a setting of their choice?

WORST CASE

If despite our resistance . . . were to be placed with a private provider we would have great fears. In the hands of inadequately trained staff, given high staff turnover, given a high proportion of staff from non-English-speaking backgrounds, even with the best of intentions we predict catastrophic outcomes. If the initial provider were unable to manage him, in the worst case he would be transferred, perhaps repeatedly, to ever more restrictive settings.

Such a scenario would inevitably result in serious deterioration in . . . physical and mental health, leading to a shortened life span.

For the reasons set out in this letter, we respectfully ask that the Standing Committee on Environment and Public Affairs initiate an inquiry into the proposal to outsource 60% of residential care currently provided by DSC.

Yours sincerely

Terry Donnellan and Jo Donnellan

11 August 2014

cc Ms Eleni Evangel MLA, State Member for Perth