

Submission to Inquiry into Better Support for Carers. House of Representatives Standing Committee on Family, Community Housing and Youth.

AOC 14/7/08

From Peter

Submission No. 759

(Inq into better support for carers)

1. Background

Before I tell you what we would like from our Governments, I will try to let you have a brief look into our lives as carers for a young adult with intellectual and other disabilities.

Richard is 24 years old and is blind, autistic and has epilepsy. He is our foster son and he has been with us since he was 2 1/2 years old. My wife Trish and I are both in our mid sixties and in reasonably good health although the burden of caring for Richard has taken its toll and we have both had treatment for depression.

While caring for Richard can be difficult, in comparison to some, we are lucky. Richard is ambulant and there is no heavy lifting required (except after he has had an epileptic fit). At present Richard sleeps most of the night and apart from his occasional outbursts, his behaviour is usually calm.

We were both professional persons and regard ourselves as capable and able to manage most situations. Over the last few years we have found the going difficult. It is the unrelenting constancy of caring for Richard, and the restrictions on our lives caused by his condition and his sometimes unpredictable behaviour that have severely tested our reserves and ability to cope.

Richard requires assistance with most aspects of his life. He needs help with showering and washing. While he can take himself off to the toilet, he needs help with bottom wiping and invariably doesn't flush the toilet! Richard can eat his meal out of his bowl but needs his food cut up so that it will go on a spoon. He can pour a drink into a glass but that is the limit of his food preparation skills. Richard can dress himself if his clothes are laid out for him. He can't tie up his shoes.

Richard's conversation is very limited. He can make some choices but has difficulty in expressing his wants and requests. His conversation has been more limited of late probably due to the epileptic medication or the medication he is on to moderate his behavioural outbursts. He can't tell us how he is feeling or what effect the medications are having on him. We have to try to infer from his demeanour and behaviour. This can be distressing for us if we detect something is wrong, but can't work out what it is.

It is often very difficult to understand what Richard is saying and what he wants. This often leads to frustration on his part and actions such as tipping over the table, banging the wall with his hand, screaming, tearing his clothes, pinching or grabbing other persons. These outbursts usually last only a few minutes and probably happen every two to three weeks, never the less, they stretch our coping skills to the limit.

We spend a lot of our time trying to anticipate Richard's needs and wants, in order to avoid these difficult behaviours.

Richards attends an adult day centre on Tuesday Thursday and Friday for four hours each day. On the other days Richard stays at home usually sitting in his chair listening to music or

Submission to Inquiry into Better Support for Carers. House of Representatives Standing Committee on Family, Community Housing and Youth.

listening to the television. It is now difficult to get him to go out. Maybe once or twice a week he will want to go to the shop or supermarket to purchase one item and then come home.

Having a bath is one of Richard's great pleasures and he does this at least once a day. Because of his epilepsy we must continually check him while he is in the bath.

Travel with Richard is problematic. If there are unforeseen delays or traffic hold-ups, Richard becomes agitated and will bang the car window with his hand and his head. He has broken the window of the Milparinka bus because it has been delayed in traffic.

Richard's epilepsy requires he must be frequently monitored and cannot be left home by himself. This means that one of us must always remain with Richard and consequently we very rarely go out together.

The only times we go out together is when respite care from the local council has been arranged or when DHS respite is arranged. We are entitled to 12 hours respite care per month, but making effective use of this is difficult. We get four hours care once a month on Wednesday afternoon and though we are entitled to this every 2 weeks this has proved difficult. We also get four hours once a month on Thursday evening (although this only goes to 10:30 PM!). The problem with this respite care is that there are a range of council carers who need to be familiar with Richard's behaviour and needs. Richard gets anxious when we are not present and so he must be forewarned and must know and be comfortable with his carer. There have been some incidents with council carers because they were not familiar with Richard and his habits.

The other problem with in home council respite care is that we must always leave our house! Sometimes you just want to stay at home.

Attendance at any regular scheduled activity or class outside the house by my wife or myself is very difficult to arrange and usually we don't engage in these activities or we have to ask family members to assist.

While we have been very pleased with the care provided to Richard at the DHS Park St/Quick St Respite House, the opportunity for him to stay at this house is limited because the house is used for long-term temporary accommodation of persons with disabilities who are awaiting permanent accommodation. There have been two occasions where arrangements have been cancelled at short notice with consequent disappointment to us and Richard and cancellation of our travel plans. Respite has been offered and taken at another house in Bundoora however this is much further from home and has required us once more to go through the process of familiarisation of Richard with the house and new carers.

Submission to Inquiry into Better Support for Carers. House of Representatives Standing Committee on Family, Community Housing and Youth.

2. Government Support

Richard has been registered with the Victorian DHS Office of Intellectual Disabilities since he was very young and has also been on the accommodation register for several years. Richard has been allocated a DHS case manager who has had a very little contact apart from organising some additional council respite.

We have been informed by his case manager that even if Richard is on the register it will take a very long time for him to get accommodation unless there is a crisis. It seems that the overall DHS approach is driven by response to crisis rather than systematic planning.

As carers we have been told for a long time that we should plan the transition to shared supported accommodation for Richard to enable a smooth transition. We have been very disappointed to find out, when we sought to make these plans, that accommodation was not available. We believe over the years we have been misled by DHS into believing that when the time came accommodation would be available. This now seems not to be the case.

We have been disappointed, but probably not surprised, to read in the Victorian Auditor General's report that the Victorian government has not increased share supported accommodation capacity in the last four years and that DHS "has not accurately quantified future support needs or the associated need for resources". Our experience as carers supports the comments in the report that the DHS approach is reactive and crisis driven.

Submission to Inquiry into Better Support for Carers. House of Representatives Standing Committee on Family, Community Housing and Youth.

3. What we want for Richard and us.

We want to see Richard settled in supported accommodation.

We wanted Richard's move to supported accommodation to be planned so that the anxiety and trauma that such a move will inevitably produce is kept to a minimum.

We want to be involved in assisting Richard with the transition to supported accommodation so that he can feel secure, and the knowledge of his needs and behaviours that we have gained over the years, can be passed on to his new carers.

We don't want Richard to have to go to supported accommodation at short notice because of an emergency or because we are unable to care for him.

We don't want Richard to have to stay for six months in temporary accommodation in a respite house until permanent accommodation can be found.

We don't want to see other carers denied the opportunity for respite as we have been, because the respite house is being used to accommodate homeless persons.

We would like the opportunity to have a rest.

We would like the opportunity to do things together even if it's just go for a walk or a cup of coffee. We would like the opportunity to go for an extended holiday (say 3 weeks) together and not have to worry about whether Richard is settling in and is happy.

We would like to be able to do things without having to always first consider whether Richard will cope.

We would like to be able to make arrangements to go out with out having to depend on other members of family or council carers to look after Richard.

Would like to be able to go to friend's houses and family functions, and leave when we want to, not when Richard has had enough, which it is usually between half to one hour.

We would like more residential respite for Richard, so that we don't have to leave our house to get a break.

Submission to Inquiry into Better Support for Carers. House of Representatives Standing Committee on Family, Community Housing and Youth.

4. What have we want governments to do

We would like to see government policy at the Federal and State level that acknowledges that all persons with intellectual disabilities have a right to state provided accommodation and care in the community from the age of 18.

We would like to see government policy that acknowledges the role of carers but frees them from this responsibility once a person with intellectual disabilities becomes an adult. At present carers save Governments millions of dollars but at a huge cost to the carers in terms of their health and general fulfilment of life. We would like to see government policy that encourages persons with intellectual disabilities to live independent lives.

We would like to see adequate funding provided by the government to build and to staff shared supported accommodation for all persons with a disability who require such accommodation.

We would like to see better pay and conditions for workers in the disability services area so that it can attract and retain high quality employees.

We would like to see improved government planning that anticipates the demand for share supported accommodation and respite, and plans well in advance to meet these needs. This should be relatively easy to do as the numbers are known well in advance of these persons becoming adults.

We would like to see an emergency program in the short-term to overcome the current backlog of share supported accommodation.

We would like to see government funded respite houses used only for respite and not as temporary accommodation for persons waiting for long-term accommodation. This practice reduces the number of respite places available and denies carers the opportunity for a much-needed break.

I would like to take the opportunity to thank you for allowing me to make a submission to your enquiry. I would be pleased to further assist if required. I look forward to your committee making recommendations that improve the life of carers and disabled persons.

Peter

Attachments

1. Letter to Victorian Minister for Community Services 11/06/07
2. Letter to Victorian Minister for Community Services 21/11/07
3. Letter to Victorian Minister for Community Services 30/01/08