

I, Mrs Kathleen Moate of Wodonga, Victoria, am the mother and guardian of my much loved 35 year old son Stephen, born 14 June 1975.

Stephen was diagnosed with Autism at the age of 3. He also has an intellectual disability, no speech, with limited communication using gestures and very basic Makaton signs. He also has many compulsive, obsessive and repetitive behaviours which are a part of Autism.

From birth to the age of 11, Stephen was cared for in the family home by myself and my late husband Paul, together with his only brother Gerard who is almost 18 months his junior.

At the age of 11 years, Stephen became a part time resident at the Mansfield Autistic Centre in Victoria, spending two weeks of every month in Mansfield, and the other two weeks at home where he also attended the Belvoir Developmental School in Wodonga.

From the age of 12 he was a full time resident, only coming home on school holidays and every second or third weekend.

In December 1993 at the age of 18, Stephen was "mainstreamed" due to the Victorian Government decision to decommission mental and physical disability facilities and replace them with mainstream health services.

Stephen came home full time.

My husband and I were both working full time and Stephen's brother was studying his VCE at the time. Stephen did not come home with any funding "attached" to him, so a process began of locating and applying for funding and placements. Stephen received some respite and limited day programs while waiting for a Supported Accommodation Application, made prior to leaving Mansfield, to go through the system. This was a major period of adjustment for Stephen and the entire family.

In April of 2004, Stephen received his first Supported Accommodation placement in a Department of Human Services house and the family was excited that Stephen would be able to move on with the "adult" phase of his life. Our excitement was short lived as this was an inappropriate placement due to incompatibility of residents.

Placement number 2 was a house in Beechworth . Stephen was the first resident and a short time later a second male moved in. All seemed to be going well, until for some reason the Department of Human Services was no longer able to occupy this house and both residents were moved to another departmental house in Beechworth. This disruption to routine, other than being distressing for Stephen and our family, had a very negative impact on the other resident's behaviour patterns and he began having violent outbursts and causing damage to the home. This caused another immediate move.

The next placement was on a temporary basis, but was totally inappropriate. Stephen as a young adult male was placed in a house with 5 elderly disabled women.

The next placement was Wilkinson Drive Wodonga, the house where Stephen resides today. Initially, Stephen was re housed with the same violent resident who was in the house at Beechworth. The same violence issues continued towards Stephen and staff. Stephen wasn't physically harmed, but the psychological effects on his behaviour and safety concerns for him forced us to take Stephen home until other accommodation was found for the other resident.

After 3 weeks disruption to Stephen's routine and that of the family, he went back to Wilkinson Drive, but was the only resident for close to 12 months, during which he went through a very difficult time health wise. As he had begun to suffer from Epilepsy at approximately the age of 16, medication changes altered his personality and learned behaviours caused him to have violent behaviours which he had not exhibited earlier in his life.

After 12 months another resident was moved in and the two, although not very compatible, lived reasonably well for some time. Another two residents were then moved in from Ararat, bringing their funding with them. Prior to their relocation, in order to accommodate 4 residents, the house went through major renovations/modifications and Stephen and the other current resident were moved out during this time to an old Office of Housing property which was very inadequate.

In the late 1990's my husband and I raised various concerns with the Department of Human Services in regard to Stephen. We were concerned about bruising on his body which we noticed when he was home with us on regular weekend monthly visits. We were also receiving information from a staff member that other staff were not caring for the residents as they were required to.

After meetings between ourselves, an advocacy worker and the Department, we felt that nobody in management was listening to us, and so after three years we decided to write to the then Government Minister Christine Campbell who ordered an investigation into the Wilkinson Drive house.

The investigation concluded on 31 July 2000, and it was found that staff had been physically and verbally abusing, and over medicating three of the residents, including Stephen. As a result of the inquiry, 2 staff were dismissed and the other 2 resigned before dismissal.

Since the time of the transfer of the Ararat individuals, there has been a level of conflict between Stephen and one of these individuals. The personalities have not been a good "mix" with the other person unable to tolerate Stephen's repetitive behaviours. Stephen doesn't like to be told what to do and the other is a very strong personality that likes to tell others what they should or should not be doing.

After the inquiry, new staff were appointed and there were great improvements, however 3 to 5 years ago there was a marked increase in violence towards Stephen from the other resident. We started noticing bruising, mainly on his trunk. Sometimes the staff were aware of the incidents which caused the bruises, other times they were not.

On 21 July 2008, Stephen was taken to the Emergency Department at Wodonga Hospital, as the other resident had bitten him on the end of the nose, causing significant injury and pain. The distress of Stephen was obvious from his behaviour when asked about the incident. The presence of the other resident was now having a negative impact on the social and functional progress of Stephen as he was intimidated and stressed and threatened by the situation.

There were incidents of violence toward staff members. Staff profile at the residence was increased to ensure the safety of staff and residents.

In early 2008, my husband and I again approached management in regard to these incidents as the two are clearly incompatible. We also contacted our local Member of Parliament who in turn brought the matter to the Minister's attention, and also brought it up in Parliament. A decision was made to move the other resident to a different residence and this was due to happen in October 2008, but did not eventuate as his mother found that the other residence was not appropriate for him.

On 28 December 2008, my husband Paul was diagnosed with a very large and aggressive brain tumour. After two operations and treatment with chemotherapy and radiation, he unfortunately passed away on 14 May 2009. This caused great stress, and sadness for my family and has been a very difficult time for Stephen as he was very close to his father. Together with staff assistance we managed to get him through this period, but with everything else that has happened in his life he began to have very serious behavioural problems himself.

Stephen has now been a resident at Wilkinson Drive for over 14 years. Today, the housing situation at the residence is still the same, and even though the other resident's behaviour has apparently improved a great deal, although there have still been occasional incidents, the living arrangements are still not suitable for the residents concerned. Stephen is very anxious and his obsessive rituals seem to cause him great distress. He is having problems both at the house and at his day programs. His medication has been changed a lot in the past 12 months, but as yet the right solution has not been found. The medication was changed again in the past week, so all concerned are hoping that this will result in life being easier for Stephen. Due to the increase in medication, Stephen's weight has increased a great deal, and his health is being affected by this and his state of anxiety.

Earlier this year the Department put in a process to determine what would be best for the four residents involved in the house. Apparently some decisions have been made, but I am waiting for a meeting to hear the final outcomes.

The care, safety and happiness of Stephen has always been my main concern, and there have been times where I have seen that the system requires dramatic improvement.

It is obvious that many disruptions are caused by the lack of accommodation and the inability to place residents within an appropriate mix.

Department of Human Services direct care staff work within the restrictions placed on them by both legislation and funding limitations, and the majority do the best job possible. I am always grateful for the care the staff provide at the home for Stephen, but I am also very concerned for the families that have a family member on a waiting list for Supported Accommodation.

There are too many families caring for loved ones when they are elderly themselves, or are physically and mentally not capable of doing so. People feel that they cannot have a life for themselves, or are even afraid of dying as they do not know who will be able to look after their family members.

Over the years I have been to many meetings and conferences, completed questionnaires, and have been promised that conditions for people with disabilities will improve, but time and again when the people who organise these meetings advise that further consultation will be provided, nothing ever changes.

From my personal experience I have found that living with these continuing problems over many years has affected my own health, and I believe that my husband may not have suffered his illness and early death if he had not had this extra stress in his life.

As time has passed since my husband's death, I have attempted to return to the fight for Stephen's right to live in a safe environment. Some of the organisations I have contacted are the Disability Services Commissioner of Victoria, who contacted the Department on my behalf, and the Disability Services Abuse and Neglect Hotline, but no one seems to have any power to change anything.

All Governments, Federal and State need to inject major funding into all areas of Disabilities, to ensure that people with disabilities and families have adequate facilities and staffing available for appropriate placements for those on waiting lists, and for the needs of each person throughout their lifetime.

I believe that there should be a scheme such as the National Disability Insurance Scheme, which has recently been suggested, to provide much needed services for all individuals and families in whatever way they are affected by Disability.