

How life with Jack opened a Premier's eyes

So many parents go through that frustration

by **Henrietta Cook, State Political Reporter, The Age, Saturday, June 8, 2013**

Every night, at exactly five minutes past seven, Denis Napthine's phone rings. His 37 year-old foster son Jack is always on the other end of the line and invariably he asks the same string of questions. "What did you do today?" he asks his dad. And who did he see? And when did he last visit so-and-so?

"He's got a couple of people in his history that he recalls [and asks] when have you seen this family?" the Premier says. "He has an extraordinary memory of people. If he meets anyone once, 20 years later he will remember them."

Jack has severe autism and was at the front of the Premier's mind last month as he choked back tears and signed Victoria up to a full rollout of the national disability insurance scheme.

When he signed the historic agreement, Dr Napthine was also thinking about the "sense of comfort and relief" that people with disabilities and their families would finally experience.

"I have been a parent and a foster parent," he says. "And I have seen the frustrations of trying to get placements and I have seen the trials and tribulations many parents go through."

Dr Napthine and his wife, Peggy, first met Jack when they were in their late 20s and took on the demanding job of being house parents for 10 disabled people in Hamilton.

On their first night in the house they heard tiny footsteps down the hallway about 4am.

It was Jack, then six, who had been abandoned by his mother and left alone after a foster relationship broke down. Seeking comfort, the little boy climbed into the bed and lay down between the couple.

"We were told Jack had a problem relating to people but you could see from that that he was looking to relate to people," the Premier recalls.

Dr Napthine had not entered politics at the time and was working as a vet while Peggy, who is a nurse, spent her days cleaning, cooking and washing for the 10 disabled residents.

At first, Jack did not speak. After some coaching, he began to talk in short, incomplete sentences in the third person.

Dr Naphthine and his wife would gently cup Jack's head in their hands, and lock eyes with him. "We just held him, talked to him one on one and helped him learn to speak," Dr Naphthine recalls.

But they felt he needed more attention and after 18 months decided to leave the house and take Jack with them. They were determined to send him to a mainstream school so he could mix with other children and learn from their behaviour.

Dr Naphthine's voice quivers as he recalls his foster son being turned away from school after school.

"We lasted half an hour at one school, half a day at another and I think we lasted a day at another school."

Eventually, Jack was accepted into a Lutheran school that suited his desire for structure and order- a common characteristic among autistic people and also "a good Germanic trait", according to the Premier.

But when Jack finished primary school the Naphthines hit another hurdle - their school of choice, Hamilton Technical School, would not accept their foster son.

Peggy had to drive two hours to Geelong and stay with a sister during the week just so Jack could go to school and the pair would drive home at weekends.

"So many parents go through that frustration," Dr Naphthine says.

Jack finished his schooling at Portland Secondary College and now lives in a community residential unit in Geelong.

"He has done extraordinarily well. He does a lot of stuff on computers, he loves computers, and he does day programs, he does woodwork."

Jack also loves to paint and one of his artworks hangs proudly on the wall of the Premier's office at 1 Treasury Place. It's the only painting on the white walls and depicts an intricate maze of lights and locks with splashes of blue.

"He will be able to tell you exactly where all those lights are," Dr Naphthine says, pointing to the painting. "He will know whose house it was 20 years ago where he saw that light."

The Napthines have three sons. The Premier says Jack is fortunate to live in supported accommodation and will not see that much change as a result of the NDIS. But others will, he says, particularly those on waiting lists for supported accommodation.

One of the great problems in Victoria is there are people like Jack who are 35 to 50 who are living at home with parents who are now 65 to 80 and 80 plus. The parents are absolutely beside themselves with concern about where their now adult children will live, who will look after them, when they die." He says the NDIS will provide families with accommodation and support.

As well as injecting money into Geelong, he says, basing the headquarters of DisabilityCare Australia in Victoria's second city will ensure senior bureaucrats interact with disabled people.

He defended the Department of Human Services' decision to raise the cost of board and lodging fees for state-run disability accommodation by 50 per cent to consume 75 per cent of the disability pension.

The government says the move, which has angered unions, disability advocates and some families, will ensure fees for state-run disability accommodation is on par with other states and in line with accommodation run by the community sector.

LISA Comment: Although it's good to see Dr Napthine promoting autism on the front page of the Saturday Age, other parents having a family member with disabilities would say his story is just old-hat. They would say, "Been there, done that!"

What most other parents would not say is, they agree with the totally unjustified, out of the blue, 50% increase in Victorian Government group home fees.

Dr Napthine has a massive conflict of interest in his tick-of-approval of this outrageous increase, which can only be described as a tax on people with a disability.

Premier Napthine cannot, and need not allow himself the luxury of a "conscious-vote", as he must be seen to support his government. Whilst, at the same time, having the financial resources to subsidise his son's disability support pension – albeit covertly.

Dr Napthine says residents of group homes, like Jack, will see little benefit from the NDIS. Whereas, they should! Their support service funding should be changed from state government block funding to federal, NDIS, ISP funding. This is to change the service culture from 'charity hand-out' to 'entitlement', where service providers have an obligation to actively show consumers they are providing quality of life care and

support, rather than the current expectation that consumers must prove beyond reasonable doubt they are not.

Group home residents having their support service funded by ISP, rather than block funding, have the financial freedom to move to another service provider, or change their existing service provider. This was one of the major intentions of the Productivity Commission in its endorsement of the NDIS.

Where non-government service providers charge their residents more, or provide less support staff, is a direct result of the DHS providing them with less support service funding than the department provides its own direct care services.

The DHS would allocate, for example, \$128,000pa to provide support services for a resident in on of their group homes. Whereas, a non-government service provider would be allocated just \$100,000pa, for example. This has been a totally unethical situation for many years.

Where Dr Napthine suggests the increase is to provide compatibility with other services, the residents of aged-care are left with very little of their pension, but it is considered they have had a regular life. Whereas, people with intellectual and multiple disabilities, the majority in group homes, have not. And most have not, and never will have a similar, regular, lifestyle most in aged-care have had, even if they are able to do the few things their limited ability will allow.

The severe and unjustified increase in charges will mean the residents of Victorian Government group homes will have a minder care lifestyle similar to those in aged-care who have to live on just their pension with a hostel funding strategy.

The residents of supported accommodation services should not pay more than the actual cost of their daily living in rent and housekeeping, which is what most are currently doing.

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