



# How Jo Moved Out Sue Boyce

**Sue Boyce** is a former Queensland senator and journalist. She's currently Chair of her family's company, Everhard Industries. She has three adult children and five extremely gorgeous granddaughters. Her younger daughter, Joanna, has Down syndrome. Jo and Sue are still working on what self-managing under the NDIS actually looks like.

## How Jo Moved Out

Joanna is a daughter, a sister and sister-in-law, and more interestingly, in her view, an aunt. Most exciting of all, she recently became a WIFE. She's 36 and has Down syndrome.

I've always been very jealous of people who say their child with a disability decided to move out when the older siblings did. Jo has a big brother and sister, but she loathes most change and moving out was never on her agenda.

Plus Jo shared her time—every two weeks or so—between my house and her father's. In retrospect, I realised that this might have been one of the reasons she didn't feel the need to move out—we didn't have time to become as 'irritating' as the parents of young adults are well-known to be.

I first seriously broached the topic of moving out with her when she was 25. One of the biggest problems I encountered was trying to explain the abstract. Jo wanted to know exactly which house with exactly which friends whilst I was talking about 'a' house and as-yet-unknown friends.

So moving out at 25 was an abject failure, but I kept working on her cooking and organising skills. And I was determined when she turned 30 that we were going to DO IT.

My main motivation for wanting Jo to move out was the stories I had heard over the years of people with an intellectual disability left bereft of not only family, but community, when their aged parent died. I still can't forget the horror story of a woman who left her home to a service provider in her Will on the proviso that her 50 plus year old daughter with Down syndrome would continue to live in the house with others. Within two years, the house had been sold and the daughter who had lived alone with her mother within a friendly community she knew very well was moved into a new group home in a new city four hours drive away. Unsurprisingly she developed "behaviour problems"—for which she was medicated! I know that in terms of disability horror stories this is mild, but it's still a horror story to me.

I spent a lot of time in the 1990s looking at how the quality of Jo's life could be protected long-term and what a 'good life' with as much independence as possible looked like. I was initially very motivated by the writings of a Canadian parent and academic Al Etmanski and his early book *A Good Life*. He set up an organisation called Plan Institute. Some have the view that the NDIS funding has superseded the need for such organisations. I don't agree.

We were very lucky that my mother left enough money for a Trust for Jo to buy a house. So when Jo turned 30, I sought approval from Centrelink to set up a Special Disability Trust (SDT) for her. Special Disability Trusts are still one



of Centrelink's best-kept secrets but the information is on the Department of Social Services website. There are a range of benefits including that an SDT can own a home and have about \$680,000 in assets before it affects the beneficiary's eligibility for the pension etc. The SDT can only be used for care and accommodation costs related to the disability, so it could pay for someone to accompany her on a holiday but not her personal costs. Jo already had a discretionary Trust, so I've kept that going.

I had a long list of criteria for Jo's home: not too far from my place, low maintenance, secure, layout that meant a 'supervisor' could live there without being on top of Jo and the 'friend/s', easy access to bus and shops. Jo was fairly reluctant but nevertheless we went house-hunting, so I could turn the abstract 'house' into something she could see. I think we drove real estate agents nuts taking huge amounts of time to 'play act' how she would do things if she lived in each house or unit. Jo became more accepting as she saw how it would play out.

The almost-perfect house became available near me—it's bigger than Jo needed but I thought that was

the least-worst problem we could have. It's solid concrete with very little garden, good security and a downstairs bedroom and bathroom for a housemate.

I'd remembered advice from Dr Tony Attwood years earlier and all the appliances we bought were the same or similar to those she'd been used to using at my place. Jo chose the furniture, with lots of price and colour guidance.

In the meantime I talked to dozens of parents and organisations that shared my values such as CRU, Bespoke Lifestyles, and Community Living Association (CLA).

Jo and I spent six months practising living at the house one or two nights a week, but I still hadn't solved the problem of the "friend" who would occupy the second upstairs bedroom, when Jo solved it herself by telling me her long-term boyfriend Justin would like to move in with her.

So in February 2017, Jo (along with Justin) was finally installed full-time in her own home just down the road from me.

Initially, it was just the two of them with Justin's support worker twice a week but it became obvious pretty quickly that they needed help on a more regular basis with the small things, like the kettle isn't working, and the slightly bigger things, like it's 8pm and we haven't thought about dinner.

There was a lot of parent visiting from me and Justin's parents during that time. To find that extra on-site support, we used a concept from the CLA for 'housemates' who live rent-free in exchange for a certain level of help.

It took a while and several false starts until a friend of a friend expressed interest. The arrangement suited her perfectly because her adult son was very keen to live on his own and this was an affordable way for her to achieve that.

We developed a written agreement with her, based on a template provided

by CLA, which we review annually to see everyone is still happy. She provides evidence of her Blue Card every year and I have worker's compensation and insurance cover for her being there.

Kelly is contracted to be at the house overnight unless she gives us notice, to prepare dinner once a week and some other ad hoc help. She contributes to the cost of utilities.

At first we had some issues with Jo and Justin treating Kelly as the full-time taxi service but she's good at saying "No" and does some driving for them when she has the time. Kelly comes upstairs to use the kitchen and laundry, sometimes reminds them about their jobs, has dinner with them at least once a week, watches some footy matches and helps them choose when they've double or treble-booked themselves. She gets asked about the small...and big things, but they also live separate lives.

In addition to the written agreement, I developed a plain English 'code for the house' so they respected each other's privacy.

Meal prep has been an area that needed some creative thinking. If they prepared their own meals, it would take from the minute they arrived home from work until dinnertime...with supervision needed around cooking times. Instead they currently work with the support worker one day a week to prepare home-cooked meals for two or three nights, Kelly cooks one night a week and they use a meal delivery service for the rest of the week.

Day to day, they are going brilliantly but the COVID shutdown demonstrated how vulnerable they were if the routines changed. Setting them up for Zoom meetings and thinking of things for them to do when work and all sport were cancelled took a lot more parental involvement and organisation.

This has been a great start but there is more to do. The next step I see is finding a person to take over the organisational and financial administration of their home and their activities. Currently the administrative side of having a cleaner, gardener, support workers, house maintenance, travel, bills paid are handled by me and Justin's parents. I'm keen now to explore how these can still be very high quality but not so dependent on us.

### **HOMESHARE – CODE FOR THE HOUSE**

Jo and Justin are very pleased to have KellyB living in their house but they are worried about a few things and they think KellyB might be too.

- KellyB will not go into Jo and Justin's rooms unless they ask her.
- Jo and Justin will not go into KellyB's room unless she asks them.
- KellyB will not talk to other people about Jo's and Justin's private business, unless she thinks they are doing something dangerous. If she thinks they are doing something dangerous, she will tell a parent.
- Jo and Justin will not talk to other people about KellyB's private business.
- KellyB will not tell Jo and Justin what to do, unless they ask for help.
- Jo and Justin will not tell KellyB what to do.
- If Jo and Justin do not like something that KellyB is doing, they will talk to her about it. If that doesn't fix it, they will talk to a parent.
- If KellyB does not like something that Jo and Justin are doing, she will talk to them about it. If that doesn't fix it, she will talk to a parent.
- Jo and Justin will not ask KellyB to do their jobs (dishwasher, bins, laundry and so on) for them. If they need help, they can ask KellyB to show them what to do or to help them decide who to ask.
- KellyB will not ask Jo and Justin to do her jobs for her.