

Hello,

My name is Maureen Morris, Parent of 2 young people now aged 29 and 26



My daughter who is the 26 year old has diagnosis of Autism, Severe LD and a degenerative physical condition call Hereditary Spastic Paraplegia which may mean she will be full time in a wheelchair at some point in her life but currently she is not and only uses her chair when she is tired, going on a long journey or sometimes she uses it in busy places to keep people away from her as she doesn't like crowded places

As you can see I am no longer in the first flush of youth and neither is her father so we always knew that we needed her to be established somewhere safe and secure before we became too infirm to look after her or if something happened to us that meant that she was placed somewhere in a hurry.

We have no close family near-by and her brother is now living in London.

Hardest part was bringing this subject up especially with her father and brother, with her Dad putting his head in the sand and her brother saying she will come and live with me.

But reality needs to be faced and I wanted it to be on my terms for her.

Started the process when she was about 20

The Parent Carer Forum held an event similar to this in Sunderland and we had speakers from the local Social Housing Provider (Gentoo) and Sunderland LA Adult social care but there was not really anyone else around. There were no private providers who had places for young people, they mainly catered for the elderly.

We heard the story of one of our families whose daughter was 34 and living in a shared flat with a woman of 64 that had nothing in common with each other but had been placed together because they both had Downs Syndrome and that was deemed to be enough of a commonality.

I think this event was a bit of a wake-up call for Adult social care and well as the time being right. More private housing providers were coming onto the scene as LA's did not have funds to build properties

Anyway, we put her name on 'the list' - typical of LA speak but was always just referred to as the list, filled in an application form along with her social worker and this was the start of the process for her.

This was a difficult time for her. She doesn't not like change, she was being asked to think of things she didn't want to confront such as the mortality of me and her dad and thus her own and she was being asked to think of things in the abstract. This led to a bit of depression for her but as the process as so long this helped with us being able to talk about things over a long period of time with her.

I had asked what sort of accommodation was available and was told the most common was Core and Cluster houses, there was also community home which just seems to be a fancy name for a care home and a few privately run places.

People moved into the Core House for a period of up to 2 year with a support staff on site while they were helped to become more independent and then moved to an house that was further away with others but no onsite support staff but the Core house staff still supported the young people. They had a bedsit each but shared living room and kitchen. I could not see this working for Caitlin but asked I could see any of these properties so I could get a feel for them. I was told no as they were people's homes - which of course I respected but I did suggest that perhaps a video and pictures could have been available of empty ones, it would help with conversations. This has now been put in place.

Time passed Dad grew more comfortable with the idea - we had several conversations about when you are in your 'own' house with Caitlin, but it was beginning to feel as if it would never happen.

I started to push a little, obviously there is not a list that you progress up, but allocation is based on need and circumstance. So, I felt there was a bit of a dance being done. I had been told about a brand new community based about 6 miles away from where we lived that Sunderland had commissioned places at, but it seemed unlikely that she would be offered a place there. I drove round one day and had a look and it looked lovely. A 24 place community made up of 12 bedsits in a large building and 12 one bedroom bungalows build around the perimeter with staff on site 24/7, CCTV around the place.

A friend of ours had a son who had recently been placed in another place that was privately owned with ensuite bedrooms and communal living and kitchen area. This was commissioned by Sunderland LA and Alex's mum Lesley had just gone through the deputyship process for Alex. I was thinking that I should start this process for Caitlin but was unsure as her needs are complex but she does have mental capacity, if things are explained to her in the appropriate manner. I then got a call from her SW she was being considered for a place a Church View the lovely complex I had surreptitiously visited but she need to have mental capacity to take the tenancy.

She was then offered a provisional place subject to the Carer Provider meeting her and agreeing they could meet her needs

From then to moving in day was about 4 months with Christmas in the middle but she finally moved into her bungalow on 19th February 2018.

I had thought that she would have been better in the big house but the Care Provider thought she would be better in a bungalow, as it was quieter despite being onto the street. The Carer providers said that staff would enter and leave her house via the French doors at the rear of the property if she preferred and also showed her how the front door of her house was visible on the CCTV which is monitored by the staff 24/7.

We were asked not to visit for the first 2 weeks as they had a homesick plan in place and her support was front loaded for the first 6 months to assess what her needs truly were in this new environment.

She has truly thrived, her decision-making skills have improved tremendously with the support of staff and she feels safe. I don't see her every day but I do speak to her every day and I always start with 'have you had a good day?' and the answer is usually 'Yes I have had a wonderful day' so what more could I ask for.