

Our daughter

Ellen

By Alison Doig



a part of the school, and the other children were great with her. However, she was not coming on as we hoped. Her language was stuck at a two to three word level, with a lot of 'echo speech'. Her play was very restricted and she had developed an obsession with one or two toys, especially a plastic fish slice which she would flip constantly. She did not seem to want friends and was in fact often aggressive towards other children, pushing or hitting them if they came too close. We also noticed that she was very sensitive towards certain sounds. Cutlery clattering made her very anxious. She spent increasing amounts of time with her hands over her ears. With hindsight, we should have moved her at the end of Key Stage 1, but neither we nor the school realised the extent of her learning difficulties. At 9 the gap between her and the other children was so wide that inclusion was becoming meaningless and I was tired of pretending that her needs were the same as everyone else's when obviously they weren't.

Ellen, the youngest of our four children, was born on 21 July 1990. The pregnancy and birth were uneventful, and we had no reason to suppose there were any problems, though the midwife did comment that she was 'a bit floppy'. David went home and I waited to be moved up to the ward. Time went on, and Ellen and I were still stuck in our room on the labour ward. I began to feel uneasy. Why were we not being moved?

Then David came back to the hospital with Granny and our other children, then aged 8, 6 and 4. Nurses asked them to wait outside, while David was ushered in followed by the paediatrician. 'Do you know anything about chromosomal disorders?' he asked, and we then found ourselves in the parallel world occupied by parents of disabled children. We could not go to pieces, because there were three children waiting to see their little sister. We had to get on with it.

Fortunately Ellen was healthy (apart from a small congenital cataract in one eye),

and fed well. We had Portage and a playgroup with very supportive staff. She seemed to be coming along well, although we noticed that she was wary of people outside the family, and could be aggressive towards other children. Her play seemed quite repetitive. When she was three we had a major setback. At a routine visit to the doctor about her constant catarrh, I mentioned that she seemed very thirsty. A urine test showed very high sugar levels. Ellen had type 1 diabetes. This seemed terribly unfair: why should she have to cope with this on top of everything else?

Because she was so young she adapted quickly to the routine of insulin injections, and is now on 4-5 a day. Though she is stable, the diabetes is the one of her problems I would get rid of if I could, because it affects everything, and she has never been able to take any responsibility for managing it herself.

Ellen started at our local village primary at 5. Everybody worked hard to make her

We were lucky to live near to an outstanding special school, Glyne Gap in Bexhill, East Sussex. We decided this was the best place for her, and she moved to Glyne Gap when she was just 10. She had become very dependent on her Learning Support Assistant in mainstream, but at Glyne Gap they expect the children to do things for themselves as far as possible, and she started to become more independent. They also noticed straight away that her behaviour patterns were not typical of most children with Downs, and suggested that she be assessed for autism. The assessment confirmed that she did have ASD, and this actually came as a relief because it was much easier to explain her behaviour. We always think of her as an ASD person who happens to have Downs, rather than the other way round.

When she was 16 we were for the first time offered fortnightly respite, at East Sussex Children's Services centre at Sorrel Drive, Eastbourne. To our surprise she adjusted to this pretty much straight away, and they



were great with her, and happy to manage her diabetes.

As Ellen moved into adolescence, her behaviour became more challenging. She finds adapting to change very difficult, and has established a very rigid routine at home, mostly round watching DVDs (Balamory at the moment, over and over again!). She is not usually aggressive, but can lash out if anxious. She doesn't like crowds or loud noises, and if we are out she will often stop and refuse to move. Transitions, like getting out of the car, remain difficult for her. We find that we can work for months on establishing a good behaviour, but a bad one, such as taking clothes off inappropriately, can become fixed very quickly and then takes ages to shift! She develops obsessions readily. She is currently fixated on tissues and carries two large boxes with her everywhere.

Her language has remained quite limited, though she can make her wants known, sometimes quite forcefully, and she has an unerring ear for unsuitable words which she will bring out in places of maximum

embarrassment, such as the doctor's waiting room. She has a variety of rituals around food; although not particularly fussy, she prefers to eat on her own, or at least at a separate table, and will not tolerate noise while eating.

Ellen is now 21. When she first left school, at 19, we opted for a split day placement, 3 days a week at a daycentre run by Adult Social Care, which we thought would stimulate her, and two days in the quieter environment of a centre run by a charity, Autism Sussex, for people with ASD and severe learning difficulty.

It soon became clear that Ellen was not coping with this arrangement. The Social Services daycentre was too big for her, and her behaviour there deteriorated. She began to pull other service users' hair on a regular basis. This is classed as an assault on a vulnerable adult and has to be reported to the police, so we feared she was getting quite a record! In the end they decided they could no longer cope with her, so our social worker arranged for her to be transferred on an emergency

basis to 5 days a week at Autism Sussex with one to one support. To our great relief, this was confirmed as a permanent arrangement, and Ellen is happily settled. She knows all the members of staff by name, and they have a routine of activities for her in the centre and in the community.

Autism Sussex have given Ellen a life, and in doing so have transformed ours. They are very familiar with her kind of behaviour and very good at coping with it. We also have a fortnightly respite arrangement with Adult Social Care, after some initial issues over the diabetes management, and Ellen now looks forward to this (so do we!).

We feel we have been lucky as we have always managed to find the kind of support that Ellen needs. Obviously the future is a worry, particularly at a time when adult social care funding is under pressure.

Although she can be exhausting we want her to live at home with us as long as possible, provided that stimulating day care is in place. She has a great sense of humour and an infectious smile!

