

A Town Like Alice: Episode 11

A Diary by Deborah Berkely

Alice was born in July 2006 and has a rare genetic disorder which causes global developmental delay including learning disability. Deborah has kindly agreed to keep this diary to report on what has happened in their family life so far and to keep us up to date with developments. Deborah, Vince, Alex and Alice are pseudonyms, but all locations are real. To see the previous instalments please go to all previous Issues of IQJ.

November 2010

People and appointments

- Hospital Appointments in last 3 months: orthopaedics
- Child Development Centre (CDC) appointments: family psychotherapist, physiotherapy, orthotics clinic
- New people to meet: OT, vision clinic, paediatrician, audiology clinic
- New people who may not exist: specialist teacher

Clinics to come: orthotics, developmental paediatrician, audiology, vision clinic
Money fed into library photocopier: £4.50 (45 copies)

This month: Alice loses two years, finds a primary school and learns to love her cuddly monkey.

Let's start with the good news. Alice played with her cuddly monkey this morning – he got a welly boot to wear on his head whilst I was changing her clothes. This is a big deal – she has never, so far as I am aware, shown an interest in dressing any of her toys or dolls without 1:1 modelling and encouragement from me or nursery staff. So well done Alice, (even if your styling skills could use some work) and well done Alex for choosing Mr Cuddly Monkey in the toy shop last Christmas.

Now for some hardcore whingeing. I'm in a ranty kind of mood this episode. Tell me. Am I the only person in the world ever to have moved London boroughs (and therefore, children's disability service

providers/school)? Thought not. Then why, oh why, is it so bloody difficult to ensure that Alice's services can be picked up by her new child development team? Or even that her latest statement is cut and pasted into a new document on new borough headed paper, ready for her new school?

I wasn't asking for a miracle – simply that Alice got an appointment to measure her feet for new Piedros. They support her wonky toes just right, but she has grown at least a shoe size since her last orthotics appointment in June, and the Kickers she is wearing as a stop-gap are rubbing her ankles. When I phoned soon after our arrival in our new home, in late August, I made it clear that I wasn't expecting to queue-jump, and that the custom-made insoles still fit (although you can't put them inside Kickers) – merely to get something done about ordering her next pair of shoes as an interim measure.

At first our main problem was that Alice's paperwork hadn't made it to the CDC so they didn't officially know about her. It took eight weeks, a flurry of emails, eight telephone calls, back and forth between our old CDC (who insisted that all referrals had been sent on) and the new (who insisted nothing had been received) and even one visit to our GP (who didn't even know what the orthotics clinic did) to get Alice's case before the complex needs panel, which is the only body that can refer her to the physiotherapy clinic.

Even then, the referral only happened after I had personally photocopied all new copies of the relevant documents and cycled down to the clinic to deliver them into an unmarked letter box. Not knowing if this was indeed the CDC's mailbox, I phoned the next day. 'It was a blue box right by the entrance' I explained to the clinic administrator, who had no idea where you were supposed to deliver mail when the office was closed – she'd never been asked about it before and wasn't even sure that she had ever noticed a letterbox!

New physio, Anna, finally seen last week, agreed that Alice needed boots to replace her hole-ridden and bedraggled Piedros, that her feet were a bit sore-looking from rubbing against her Kickers...but didn't have any spares in stock. And dealing with orthotics wasn't her job. 'Waiting list is six months for new cases' she confessed, explaining that she would argue Alice's case for an upgrade.

'We have already been waiting since moving here in August and are not a new assessment' I pleaded, imagining Alice's feet being unusable by the end of the massive wait. Luckily in the next 48 hours someone with appointment-making powers finally called and offered to squeeze us in '...because we hadn't realised that your daughter's foot problems are caused by a syndrome.' Am not sure what difference that makes, but anyway...phew!!

Getting the SEN statement was even more difficult. Despite being furnished with a complete set of up-to-date paperwork (again hand-delivered by me on my bike), plus our new address in writing and by email, the new LEA sent me a 'final' statement to the wrong address (luckily, with the correct former postcode on it, so the Royal Mail forwarded it to us here) and with the wrong child's name and gender on it.

Looking through the rest of the statement I could see that they had written about Alice, but instead of using the paperwork I gave them, they had cut and pasted her 2008/9 statement. It says things like, 'Alice is not yet using recognisable words but can make baaaa noises when prompted, and associates her high chair with lunch time.' All very relevant when she was 2 years old, but not quite where she is at right now!

Why the fuss? Well, at 2, Alice was less likely to injure herself at school. She was far more timid about her environment and would not have attempted, for example, a climb onto a big climbing frame. Nowadays she has the gross motor skills to use slides, etc, but not the cognitive awareness to slide down a pole safely or step onto a rope ladder. The statement of course did not mention her diagnosis, her current feeding needs, her sociability, her glasses, the problems with her feet, or anything else that makes Alice the person she is today.

Never mind, I thought, I will simply point out the admin errors and all will be well. I ended up having to have an hour-long meeting in which I had to explain all the paperwork and tell them where to cut and paste from her old statement! She (this administrator) couldn't answer some of my basic questions – like whether there was a specialist teacher based in the borough who would come to school to help set the IEPs, as there had been in our old LEA.

I left the SEN team office feeling pretty annoyed – here was someone on a good salary, no doubt, and here I was, using Alice's DLA money to pay a baby-sitter so I could come to her office and sort out her mistakes, to keep my child safe and properly looked after at school. And in case you are reading this and thinking, 'Oh, it was probably some underpaid administrator with far too much work going on', this was a middle-aged woman who had previously worked in a health-related business. She was sweet and friendly but, in my opinion, badly trained, poorly supervised and out of her depth.

Luckily, the new primary school staff (where Alice will start Reception in January) seem to know what they are doing. Vincent had the day off yesterday and took her for a familiarisation session. He said she was at home right away, playing in the home corner, happy to meet the other children and climbing all over the classroom. Much as I despise school uniform, I'm looking forward to seeing her in a little purple school jumper. I don't exactly know how we are going to get there (school is over a mile away, not on a direct bus route and I do not drive) but that will hopefully have been resolved by the next episode of this diary!

By the way, do write and let me know what you think – if you enjoy reading these diaries, or if there is anything you want to hear more (or less) about. Get in touch!

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Contact

If you would like to make contact with Deborah please contact TAC interconnections.