

## NEW WRITING

### *A Town Like Alice* *Episode 4*

#### *A Diary by Deborah Berkeley*

Alice was born in July 2006. 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 IQJ Issues No. 1, 2, 3 and 4.

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#### April 2009

- Hospital Appointments in last 3 months: orthopaedics, medical paediatrician, gastroenterologist, vision clinic.
- Child Development Centre (CDC) appointments: physiotherapist, SALT, Portage, family psychotherapist, occupational therapist, audiologist, vision clinic.
- Specialist teacher.
- Health Professionals: 14 (discharged from paediatrician and gastro clinic).
- Goodbye to: occupational therapist (new job elsewhere) physiotherapist (ditto) medical paediatrician (discharged from clinic).
- Can't say goodbye to: Portage (discharged from home visiting, still attending drop-in).

**Clinics to come:** more audiology, developmental paediatrician.

**This month I'm thinking about: comings, goings and why parents need Portage.**

Whenever I complete the section at the start of these diaries, where I list therapists and appointments, I get a strong visual image of an article I once saw. Appearing in a very learned journal—OK, I admit, it was *Marie Claire*—and titled something like, 'High maintenance women', it featured a slick, smug 30-something, reclining, Odalisque style, on a chaise longue, and surrounded by her 'People': nanny; hairdresser; housekeeper; concierge; personal assistant; personal trainer; personal shopper; personal eyebrow-shaper; personal gardener; personal lady-gardener (I kid you not, there exists in the world of pampered ladies, sought-after bikini-waxers with waiting lists longer than speech therapists). Anyway, you get the picture.

Alice's little chaise longue is surrounded by fewer 'People' than usual at the moment. Just as she was making fantastic progress (can point her finger! Can stack big bricks!) with her new, proactive and energetic physio/OT team, they are off to sparkle elsewhere. Whilst I'll miss them both very much, in some ways their departure was inevitable: uncertain funding priorities mean temporary contracts and/or agency staff, which in turn means therapists who are travelling, between jobs or seeking something

more permanent. Alice will get another OT and another physio after the next half-term, and hopefully won't flounder in the meantime.

We've also said goodbye to Alice's medical paediatrician—despite some ongoing reflux, she is physically well, so there's no real need for her to keep coming back to the hospital—especially now she has transferred to the Child Development Centre for vision clinic and to see the dietitian. Walking away from the hot, stuffy hospital where she was born and spent the first month of her life, I had mixed feelings. Whilst glad not to have to schlep back to the hospital once every three months, I'd grown fond of her quirky, ill-looking consultant; and knew I would miss him. When he told us he was sorry all the tests he'd arranged still couldn't diagnose Alice, and he therefore couldn't make predictions about her degree of future disability, I knew he really cared.

I remember the day I first walked into a drop-in Portage session. Alice was probably about nine months old: I was still in shock. My eyes took in a very special-needsy environment: glasses, hearing-aids, a baby dependent on oxygen being helped to pick-up Rice Krispies, a child of three or so with unintelligible speech, flapping his arms and squealing. I felt tears welling up inside. I'd hated visiting 'normal' drop-ins: feeling impatient with other parents complaining about their perfectly normal babies not doing this or that yet, when in reality they had **No Idea**. This was what I had said I wanted—to meet other families, to learn about ways to stimulate Alice through play whilst on the waiting list for Portage home visits. Could I face the truth—that Alice might be at home, might belong, in the world of special needs? Part of me wanted to grab her and run right out of the door. But someone wanted to introduce herself, and it would have been rude not to listen, so I stayed.

We've never discussed it, but I think Claudia, the Portage worker I met that day, understood exactly what I was going through. The desire to do my best for Alice, coupled with the grief for the way things should have been. In those days, Alice wasn't really able to reach out for anything. Claudia sat us down with some bright orange cellophane paper and within seconds, Alice was scrunching away, her attention captured. As we chatted, I realised that Portage wasn't like the other therapies we were learning about, or the

doctors' appointments, which (at that stage) tended to focus on the things Alice wasn't doing, or that might potentially be wrong. Portage was more about pre-school early education. Alice learned about fun ways to get more out of her immediate environment (like a little chair for her to sit on that supports her back) and I learned about all the things she could already do and the ways I could help her to learn more. For the first time, I started to feel like an active participant in her care rather than a passive witness.

Over the next two years, Portage became a regular fixture of Alice's week—and a highlight of mine in the days when I wasn't out much. OTs, physios and speech therapists came and went but Claudia was always there—a wealth of local knowledge about nurseries and schools and the way Special Needs World worked. Whilst I became my own key worker, co-ordinating Alice's care, sorting out appointments, chasing vanished reports, prodding hospitals for promised follow-up information, she was the one who advised making a claim for DLA\*, getting a Statement, encouraging me to get involved with decision-making, restoring my battered self-confidence as a communicator. Of all Alice's People, she was the one I valued most.

I knew, of course, that once Alice got a Statement, Claudia would play less of a part in her life—she now had a specialist educator, a SENCO and a nursery one-to-one keyworker, after all...but it was still a bit of a shock to learn last month that there would be no more home visiting. OK, so Alice might have moved on, but I'm not sure I have! Who would encourage me, support me and make sure I knew about important things? Luckily we are still allowed to attend the drop-ins. It's funny but that room full of SN children and the expert workers who help them play/learn doesn't look like a scary new world anymore. Thanks to Portage, it feels like home.

More soon...

\* Disability Allowance

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If you would like to make contact with Deborah please contact Interconnections.