

THE POT OF VEGETABLE SOUP
A Disabled Mother's Story
By Simone Baker

I'm sure than anyone who's been a parent for a year-and-a-half or more has been there. That moment when that child, who you thought was so easy to care for, so co-operative and so angelic "turns" or suddenly gets that one step ahead of you... It can be a frightening moment.

It happened to me one day coming out of toddler group. My daughter Lois, then aged 22 months, had up until that moment in time, clung to my hand on the short trip from the car into the community centre and back again, fearful of running off. I had warned her every week, in no uncertain terms to "Stay with Mummy, because there are lots of cars here, and you'll get run over!" She was now too heavy for me to carry, and would struggle out of my arms. Things had been much easier since she had been walking.

But this time was different. I had been guilty of expecting too much of her. How was she expected to know what "being run over by a car" meant? This time, she waited until we were a few steps out of the safety of the hall porch, and then ran off. My disability means that my running capabilities were no match with hers. To cut a long story short, after a lengthy chase (which Lois thoroughly enjoyed) I eventually cornered her, and with the help of a passer-by, grabbed her and wrestled her back to the car.

It is amusing, looking back. But when we were back at home, and Lois was taking her afternoon nap, the reality of the situation hit me. Up until this moment in time, my disability had never been an issue to me in any way. I had worked, lived independently, married – and all of a sudden, my disability meant that I had for the first time, felt out of control of a "normal" situation.

I picked up the telephone, called my local Social services department, and asked them for an assessment. Initially, they seemed unable to understand what I was asking for. It appears that it is normally a GP who asks for an assessment for a client in need. Once it had been established that I was asking for an assessment for myself, the lady on the other end of the 'phone, she said she would need to ask me some questions.

"Can you make yourself a hot drink?" Eh? "Can you prepare a meal for yourself?" I was confused. "Hang on a minute, " I asked her "I just want somebody who can help me out occasionally with my lively toddler.

Someone to help me get her in and out of the car. Someone to assist if I want to take her swimming. I don't need the help. I just want to give my daughter a normal childhood. I want to go out with her, not stay at home because that is where I know I can cope. Why should she miss out because of my inability to do these things without help?"

And then it happened. I was aware of a huge lump rising at the back of my throat, and then the tears were rolling down my cheeks. I began to sob uncontrollably down the telephone.

I hadn't been prepared for this. I don't cry. I don't get emotional. But here I was admitting, for perhaps the first time in my life, that because of my disability I couldn't cope.

Two weeks later, a home care organiser came out to visit me. I joked with friends prior to the visit that it was fortunate that I wasn't the suicidal type. Two weeks is along time when you've reached a low point and are in desperate need of support.

So, the home care organiser arrived. Yes, she thought I would be entitled to some help. Because I was working I might have to pay a contribution to the cost.

She found it difficult to understand that I needed something flexible. I didn't want someone to care for my child. I wanted to continue to do that, but needed help with a few difficult household chores. I didn't always want to be limited to doing my shopping on a certain day of the week. I work from home two days a week, whilst my daughter goes to a childminder. "Can't your husband help you?" she asked. I stopped myself from head-butting her. John is self-employed. He always helped with dressing Lois in the morning, and finished work early to help with teatime and bathing her. He enjoyed this time, and as far as I was concerned, he was already doing more than his share.

The Home Care Organiser explained that mine was an unusual situation. They were geared more to helping young physically disabled people with independent living tasks, or providing personal care to the elderly.

She left somewhat confused as I explained my situation over and over to her. What I needed, I thought, was so simple.

I drew up a weekly schedule, showing what kind of help I needed and when. 10 hours of help spread over the week. Provision for going swimming (if we wanted to), shopping, the toddler group, preparing vegetables, changing the bed. It seemed very straightforward. I sent the schedule off to Social Services with a covering letter in the hope that it might help them.

One week later I received a visit from the manager of the agency that Social Services would be using to provide my help. The manager said she wanted to meet me so that she assigned an appropriate "carer" – someone near my own age and similar in personality. She looked at the schedule I'd drawn up, and said it looked very straightforward. I was feeling confident that the help I needed was now on its way.

She then said that I would have to wait another three weeks until the care package could be set into place. By this time, I had begun to find things a little easier. Just as well, I thought... In the meantime, Social Services sent me a complicated form for completion that would help them to assess my financial situation.

So, three weeks later on a Monday, Maria turned up on my doorstep. I was surprised to see she wore a uniform. How could she accompany us to the toddler group wearing a uniform? People would think I was employing a nanny!

She breezed in. "I'm here to help you look after your baby. Would you like me to take her out for a walk so that you can have a few moments rest?" My heart sunk. Upstairs the bed was ready for changing. The dishwasher needed emptying before I could load the breakfast plates into it.

"Hang on," I said. "You're not here to help me with the baby. You're here to help with other things so that I can look after her." I showed her the schedule that had been drawn up and agreed with Social Services and the Agency. She hadn't seen it before. "Okay," she said, "I'll change the bed" and she raced up the stairs.

I followed her into the bedroom. She was tearing the quilt cover off, and tears were rolling down her cheeks. Crikey, I thought to myself. All I wanted was someone to help me, and here I was consoling a weeping wreck whilst my daughter played happily downstairs. It transpired that this was her first day at work and the previous client had shouted and sworn at her. Not my problem, but consoling her continued to eat into the time she was supposed to be helping me.

She whizzed through the other tasks I assigned to her. Then everything was done. She had only taken three hours out of the five she was working. Of course, my assessment of how long tasks would take, was based on how long they took me. I had no idea of how long it might take anyone else.

She asked whether I wanted some vegetables prepared, and whether I liked soup. She prepared a very large pot of vegetable soup, had a cup of tea, a piece of bread, and then she left. I felt as though a whirlwind had passed through the house.

I called the care agency. Social Services hadn't told me what I would be expected to pay. I wanted to know what the Agency charged - £9.40 an hour. I phoned Social Services. The Home Care Organiser was off sick. "You won't need to pay the whole £9.40" I was told. "The maximum we will charge you is £7.30 an hour". That was still going to work out at £73 a week. I paid my cleaner £24 a week, and the childminder £36 a week. My earnings were £100 a week. I told them that I needed to cancel the arrangement because I couldn't afford to pay the charges. (Note, these are October '98 prices).

So that's how I tested the system, and paid £35 for a pot of very nice vegetable soup that I hadn't even wanted. The system failed me. I've spoken to other parents with disabilities, and it seems the system has failed them too. No provision exists for parents with disabilities. If you're disabled and want children, then struggle or pay for assistance. I count myself lucky. I am fairly capable, have an able-bodied helpful husband, caring family members who live close by, and I do get a break two days a week whilst Lois goes to a childminder. I'm not living in poverty either.

Lois will be at school in another three years. I suppose I can manage until then. And that is what I do. Most days are great. Some days are downright awful. We still go to the toddler group. I refuse to let Lois miss out because the system has failed her mother.

Postscript

In September 2002, Simone began receiving Direct Payments from her Social Services Department, and now employs somebody to help her for 6 hours a week. She says "I wished I had been offered this kind of help four years ago! It would have made things so much easier for me at the time".

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