Case study: John’s story

“My name is John. My partner and I have five children. I have learning difficulties, and so do two of my children. We don’t have any support at home to help us with the kids. My wife won’t allow it. She is terrified of the social workers.

She won’t go and ask them for help, even if we need it. She is terrified that they will judge us for needing help, and decide to take our kids away. She hears other parents talk at the school gates. And she reads it in the papers.

It’s a bit of a struggle as you can imagine.

It was okay until our youngest was born. He has a learning difficulty but it wasn’t diagnosed early. We knew within months, but people wouldn’t listen to us. That’s quite an extra strain. The midwife said to us ‘You’ve had four already, you don’t need anything else from us’.

There is a very good organisation called First Hand. It gives parents a break. We got help from them when we only had four children. When you’ve got five they need to provide two sitters so it costs more so we can’t use them.

It was at this time that I got depressed. I had stopped doing anything in the house and I was worried I was going to start taking out my feelings on the kids. That’s why I walked out. I didn’t go to the Social Work Department for help. You can’t say ‘I’m shouting at my children, I need support’! Not if you have a learning difficulty. That’s asking for trouble.

I was suicidal actually. My G.P. gave me anti-depressants and told me they would help me mentally. He didn’t tell me anything about side effects or how addictive they are. But I’d heard something about them, so I looked into it, and I decided not to take them. I was disappointed though – I felt he’d rather give me drugs than give us the support we needed.

This is how it got to be so bad: everything is harder when you have a learning difficulty. It takes me a day to do things it might take you an hour to do. You can’t get the information you need when you need it. When B (my second child) was in primary school I tried to get the Additional Support for Learning Act on tape. I wanted to know what his rights were. I was told that it would take six months. I gave up because I needed it in two weeks for a transition meeting. He didn’t have a social worker or a key worker, and the meeting was a disaster. So it’s been a battle to get him the right level of support in his school. If you can’t read and write you can’t make a complaint: phone complaints mean nothing – you can’t follow it up a year later and say ‘I phoned to complain a year ago’, because they don’t have it on record.

The different departments are all over town: Education Department, Social Work Department, Children and Families. I see them all to try and get my youngest into a pre-school programme. That was a nightmare – we got him a place but no-one would pay for the transport: Children and Families said it was Education, Education said it was Children and Families, so I would go from one building to another.

That was hard because I had to travel all over town. My memory’s bad and I’m not good at finding my way around. I started making trails in the grass from the bus stop to the offices, so I could find my way back, but the birds started eating the trail! So I tried marking the trees instead.

Continue reading »
Then what happens is they change the structure or move offices, and don’t tell us. Or if they do tell people it’s written somewhere and I can’t read it. So everything takes even longer to sort out.

I spend so much time trying to sort things out for my two kids with learning difficulties that I end up neglecting the other three. It’s not fair on them. But it is draining taking on the system and caring for my family and working.

The schools are another thing on top of that. When our kids started, the schools took no notice of our learning difficulty. Parents’ evenings were a nightmare. Most of the communication with the school is done by letter. The writing is tiny and they don’t make an effort to make the language easy. My wife reads a little bit, so what we do is look for dates and amounts of money, and ignore the rest. So outings and things that need to be paid for, that gets dealt with. But if the letter says swimming classes are starting and you need to bring your swimming costume on such and such a day, they keep missing out on that, and we just remember the next week. Those are small problems compared to all the rest of the stuff. If I let myself get too worked up over things like that I’d get depressed all over again.

The big stuff is making sure the other two get the support they need. Information is really hard to get. Different places tell you different things: The Social Work Department, Citizen’s Advice. And to get anything, you have to tell your story over and over again.

Attitudes of social work, teachers, learning assistants, council staff – they all judge us by our label. You know from their faces when they’re not listening. You can see them writing us off or switching off.

All of that is why I felt like putting an end to it all. I couldn’t see an end to it.

But...I managed to refer myself to a specialist. It took six months but I did it. He helped me a lot. He told me about People First, and through them I met other parents in situations a bit like mine.

I’m feeling better than I was, and I’m back home now. But I won’t pretend we don’t have problems, because we do. We could really do with some support with the kids, but there’s no chance. Asking for support from the same organisation that takes your kids away is always going to be difficult. So we just get on with it.

Fair Deal for Families – Scottish Consortium for Learning Disability 2008