

## **No ordinary life - Sheila Brown, Chief executive, BDF New Life**

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### **Body**

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- Gained wide media coverage of the plight of children with **birth** defects.

I'm far more ordinary than the people you normally interview - I might have an OBE, but I still sweep the stairs.'

This opening gambit from Sheila Brown, chief executive of BDF New Life, illustrates her characteristic modesty - both Brown and the charity are far from ordinary.

New Life, which **funds** research and offers grants to the parents of children with **birth defects, hit** the headlines last week after exposing the chronic underfunding of equipment for disabled children by local authorities and primary care trusts.

The charity had used the Freedom of Information Act to find the combined amount each local authority and PCT in the country spent on disabled children in their catchment areas last year. The findings show that they spent as little as pounds 60 per child, compared with the pounds 20,000 per child that New Life estimates local authorities and PCTs should be spending.

Last week's publication of the findings followed a summer campaign by the charity called It's Not Too Much To Ask. More than 13,000 people have already signed its petition calling for better provision for disabled children.

New Life is a medium-sized charity with an income of pounds 3.1m last year and 130 staff, including one part-time press officer. Despite this, it was featured on Radio 4's Today programme and generated the kind of column inches that bigger charities would struggle to match.

'We tend to get a lot of coverage because we are proactive and quick to respond to opportunities,' says Brown. 'I try to give the media information they are interested in by thinking about what my mum or friends want to hear. I also try to communicate our message in a simple way, so it helps that I'm a simple person.'

Brown's eldest son, Greg, was born with **birth** defects, but it was nine years before he was diagnosed with Noonan Syndrome, a condition associated with congenital heart disease and short stature. The frustration Brown felt at the lack of available support prompted her to **set up** New Life in 1991.

'We did a media search the year before we started,' she says. 'It showed that, although five children with **birth** defects are born every hour, in the whole year the term was used only four times. Articles referred to congenital abnormalities or individual conditions. We realised we had to introduce what was then a new collective term of '**birth** defects'.'

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The term soon entered the medical lexicon and the charity was inundated with calls from concerned parents. This led to the creation of a helpline, which has influenced the charity's direction ever since, as it has adapted to take callers' concerns into account.

Whereas other charities ask donors for unrestricted donations so that they can spend **funds** on priority areas and core costs, Brown is unashamedly proud that 100 per cent of her charity's donations are restricted. This means money can be spent only in ways specified by donors.

'I introduced the policy in 1993 when I received a cheque with a letter from a little boy's mum,' she says. 'This boy had his legs amputated as a baby because of a **birth** defect and had done a sponsored bike ride because he wanted to help children like him. I decided that it would be inappropriate to use the money on administration costs.'

The charity is able to make this pledge because it has a profitable out-of-town clothes shop that pays for such costs, a fact that Brown is less keen to trumpet. Yet she maintains that the system generates committed supporters: 'If we haven't got a service that matches a donor's request, we offer an alternative. Nobody ever asks for their money back - not yet, anyway.'

BROWN CV

1991: Founder and chief executive, BDF New Life

1989: Director, Noonan Syndrome Foundation

1985: Director, Noonan Syndrome Society

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