

THE RIGHT TO FIGHT

In a so-called perfect world of designer homes, and even designer babies, disabled parents face prejudice, disgust and discrimination. **REAL** hears what it's like on the receiving end

You have been married for several years when you discover you are pregnant. Having always dreamed of being a mother, you are naturally full of joy. But everybody else seems to believe your pregnancy is some kind of irresponsible accident. Health workers say, 'Oh dear', and suggest you should have been sterilised. Then the comments from strangers begin: people on the street telling you that your pregnant stomach is disgusting and that you shouldn't be allowed to have children. From the moment your baby is born, even though you are an exemplary parent, people assume you are an incompetent mother. Then, after a desperate struggle, the authorities take your child away from you.

Sound like a crazy nightmare? Shockingly, this scenario is what is happening to many disabled parents – not in the dark ages, but today, in the year 2005.

Disabled Parents Network volunteer and

'born mother' Reesha Armstead, who has cerebral palsy, found that when she became pregnant, she was told off rather than congratulated. No one had ever expected her to become a mother, it seemed, and strangers responded to the sight of her pregnancy with insults and questions on how on earth she had become pregnant. After giving birth, her doctor suggested she was sterilised, saying 'We can't let this happen again, can we?' A social worker told Reesha that her child should be cared for by professionals.

There are just over two million disabled parents in the UK, who, says Victoria Shooter from cerebral palsy charity Scope, face prejudice every day. A staggering recent poll has found that a quarter of the British population do not support disabled people's automatic right to be parents. Specifically, 2% of people think disabled people categorically should not be parents and 23% believe 'it depends'. 'These people who believe 'it depends' are making assumptions on what disabled people can and can't do,' says Victoria. 'No one would consider telling a non-disabled person they shouldn't have children. If two people choose to be parents, it's very natural and personal and they

should be allowed to do just that.' The number of people who do support a disabled person's automatic right to be a parent has risen by 10% since last year, a fact that leads disability charities to hope their anti-disablism message is getting through. Yet legally, although the recent Disability Discrimination Act has improved equality in many aspects of disabled people's lives, British disabled parents still have no specific protection against discrimination and, many say, very little support.

Mother Simone Baker, 43, was motivated to join the Disabled Parents Network after experiencing firsthand with 'horror and shock' how little advice was available during and after her pregnancy in 1996. 'I'm thalidomide impaired so my arms and legs are shorter, and I knew that I wouldn't be able to hold my baby to breastfeed,' she explains. 'My midwife told me that she couldn't tell me how to manage with my particular difficulties, and I was left to find my own solutions to this, and

other problems.' She adds, 'A lot of people assume that disabled people don't even have sex, let alone become parents.'

Simone receives direct payments from social services, which allow her to pay for flexible assistance with time-consuming tasks like chopping vegetables. 'These payments are not automatically offered to disabled parents, but they revolutionise lives by putting parents in control,' she says.

Yet the sad irony is that many disabled parents feel afraid to ask for this kind of basic help from social services, fearing that it will be interpreted as failure to cope and that their children will be taken into care. 'Children's services shouldn't get involved unless there really are signs that a child is being abused or neglected,' states Simone.

Recent research from Sheffield University has found that 40-60% of parents with learning disabilities have their children taken into care. Charities like Mencap believe this disproportionate figure suggests discrimination and are fighting to convince local authorities that parents with learning disabilities can make fantastic parents. ➤

BEING A DISABLED MUM HAS BEEN A GOOD THING FOR MY GIRLS

Lisza Hoyer, 39, a local development worker from Leamington Spa, has Usher Syndrome, which causes deaf-blindness. She and her daughters – Christelle, 23, Kendall, 15, and Chanel, 14 – have a happy, successful home life

I was born 90% deaf. At 13 I started having problems seeing in the dark, and I found out I had Usher Syndrome at 28. If there's no light, I have no sight, so therefore as I lip read, effectively, I also can't hear well.

After my first child, Christelle, was born, my health visitor responded to another health worker's doubts about me by saying that I was a wonderful mother and that I would do fine.

I was a teenage single mum of three, went to college to pass exams, had a part-time job and did voluntary work in the community. Having to deal with my deteriorating sight and hearing, my children and I worked in harmony.

Even at times when I had had enough and wanted to go out on my own, I had to take one of the children with me because I couldn't see or hear. I used to wonder, who was the parent, who was the child!

They keep a tender eye on me – just as I do on them – but they don't overpower me. If I'm in danger walking down the street they immediately help me move, but I'm still the boss.

Now and again my girls get teased because of my white cane. But they are not ashamed of me, and they give as good as they get. I feel my children are much more compassionate, mature and levelheaded compared to many other young people, who can be quite cruel. My children stick up for others at school being unfairly treated, for example.

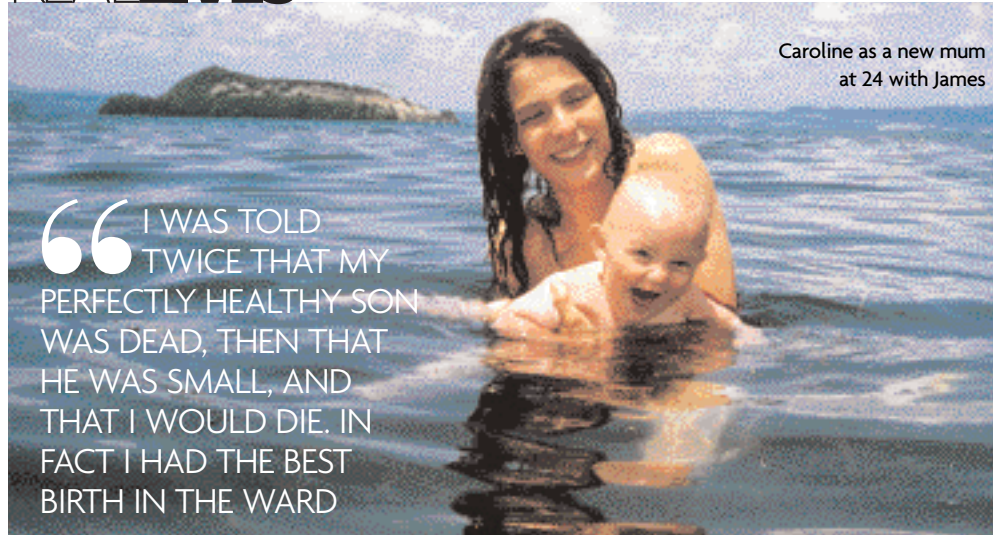
KENDALL SAYS: Having a disabled mum has made me compassionate. I was brought up like any other child, with the same rules and opportunities, I just had to help a lot more. Chanel and I go to Young Carers along with so many others. I have been bullied a lot because of my mum, and it has upset me. But I have been volunteering all my life and it's made me who I am now.

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Lisza surrounded by (left to right) Kendall, Chanel and Christelle. Lisza believes her daughters are more compassionate and mature compared to other children their age

FEATURE Olivia Gordon PHOTOGRAPHS Jass Lall/Jamie Facer – Disability Now/Jason Bridges





“ I WAS TOLD TWICE THAT MY PERFECTLY HEALTHY SON WAS DEAD, THEN THAT HE WAS SMALL, AND THAT I WOULD DIE. IN FACT I HAD THE BEST BIRTH IN THE WARD

Caroline as a new mum at 24 with James

THEY SAID I WAS IRRESPONSIBLE FOR GETTING PREGNANT BECAUSE I'M DISABLED

Caroline Payne, 36, who has cerebral palsy, has brought up her 13-year-old son, James*, as a single mother in London. She works as a secretary at cerebral palsy charity, Scope

The prejudice has come from clinic workers, midwives, health visitors, child-minders, teachers – people who should have known better. When I was pregnant I was told I was irresponsible. I said, 'What do you mean?' I had been living with my partner for seven years. To me, it was normal – you grow up, you get a partner, you have children. I had never questioned it.



Caroline, 36, accused by social services of being a 'bad parent', is more empowered since working at Scope

I said I wanted a water birth but wasn't allowed to in case I had an epileptic fit. Epilepsy is quite common for people with cerebral palsy, but I have never had a fit in my life. No one would listen to me.

During my labour, the hospital staff were very negative. I was told twice that my perfectly healthy son, James was dead, then that he was small, and that I would die. In fact I had the best birth in the ward.

Because of my disability, it was difficult for me to hold my son when he was born, so I held him differently, but I never dropped him. Midwives reported me to social services for child abuse. I have been a great mum, and have never hurt James, but I became scared to touch him at one point, in case I was accused again. I was frightened to ask for any assistance, fearing that they would take James away. During the first two years of his life, social services visited me eight times – each time finding there was no cause for concern.

I was now a single mum, working full-time in the city, and also doing a degree, but if I turned up a little late to collect James from nursery, I'd be accused of neglect instead of commended for outstripping my ability.

Mindless allegations against me continued from James' old school, and a family member who hates

me continued to report me and told James, 'You don't want to grow up like your mother, she's stupid'. Instead of coming to me with concerns, these people told social services, who visited me every six months or so.

The family member took me to court to try to get custody of James, but I won. Even though I gave a copy of the judgement to the school, they still kept ringing the family member – before contacting me – whenever they needed to talk to a parent.

James was bullied at school because of my disability and would run away from lessons. The school said he was running away because I was a bad parent!

James has picked up on people telling him I was a 'bad mother' throughout his childhood and even now, when we have an argument, he behaves violently towards me or runs to complain about me.

Because of all the people telling James I was a bad mum, I was not very strict with him; I just wanted him to love me. He now does not see me as his authority or ultimate carer because of all the mixed messages others have given him.

On one occasion, when he was ten, we had a fight and he tried to strangle me. I pushed him off and I marked him. He ran straight to the family member who rang the police and I was arrested for child abuse. In the end, they let it go but I was left powerless, without any support when he is threatening me. It's almost impossible to get support for your child because nobody wants the responsibility. You give up after a while. Recently working at Scope, I have become more empowered and I get encouragement from my colleagues.

WE BEGGED, 'DON'T TAKE OUR KIDS AWAY, PLEASE, THEY'RE ALL WE'VE GOT.'

In their sitting room filled with children's toys and drawings, Elizabeth*, 44, a housewife, and Tom*, 47, a hospital domestic, from Epping, broke down in tears

We met when we both worked in a factory, and we married 19 years ago. We both have learning disabilities. Our son, Michael*, now 15, was hyperactive and has learning difficulties and took up most of Elizabeth's time. Melissa*, now ten, has no disabilities and was the speaker, a little mum. We would have welcomed a tiny bit of help in looking after Michael, but we'd brought Michael and Melissa up well without any assistance – none had been offered to us.

Social services first got involved in 1999 when our youngest daughter, Sarah*, now six, who has some speech difficulties, was born. The health visitor wasn't sure what to do and we said to her, 'Don't tell social services or we'll never get rid of them.' But she did tell social services and the 'help' we got was vicious and cruel.

Social services were rude and patronising. They came to our home and took the children's clean clothes out of their drawers, threw them on the floor one by one and left them there. Then they said to us, 'You'll have to pick 'em up now and put 'em in the drawers, won't you?' They looked in our cupboards and fridge. Finding half a bottle of wine, they accused Elizabeth of being an alcoholic. Melissa asked another social worker if she would be her friend and she said no. They even said we weren't married. They spoke to us like dirt.

They came week after week. We were having meetings with social services in locked rooms where there were 18 professionals compared to

the two of us. Some of them had never even met us or our children before. We were scared stiff. No one would believe the hostility with which we were treated, the sordid, humiliating accusations. 'They didn't have much food,' would come up in a meeting, and we'd be thinking, 'We just hadn't been shopping yet'. It was degrading, terrifying, very intimidating. You lost all your self-esteem, had no dignity. We didn't even come out like human beings. We came out wanting to go home and commit suicide.

They wanted us to change our lifestyle – the way we played with the children, for example – but they didn't tell us how to change. They were laughing when they gave us their plans. We did everything they wanted us to do. But then they said they were putting all three children on child protection.

They said the children had head-lice chewing their ears, which wasn't true. They said their clothes were grubby and their hair wasn't brushed. But surely, if our children looked like that they wouldn't have had any friends. All the other parents came to us and said, 'It wasn't like that at all. Your children were brilliantly dressed.' We couldn't understand it. We'd hear these claims later in court meetings – no one told us any of these concerns at the time. We were just living our lives, and the children were happy, healthy and clean. They had regular baths. They said we didn't have enough toys, but we have hundreds – our sitting room is full of toys.

For the time being, the children remained living at home and we had no idea they might be taken away. Social services said we had to do a new parenting course. We cried, told the teacher all our problems, opened our hearts. We did three classes and social services said we weren't cooperating. We said, 'What do you mean?' Our children were at risk and we were doing this for them. We had done everything they asked in desperation.

In June last year, we were told to go to London and take verbal reasoning and logic tests. We don't know what that had to do with parenting. When we got home that Friday evening, the phone rang. It was

our solicitor saying we had to go to court on that Monday and the children might be taken away. We panicked, but that last weekend we wanted things to be nice. We took the children on day trips. We didn't want to tell them this was their last weekend at home, which really hurt.

We never spoke in court, and neither did our lawyer. One social worker drew her finger across her throat and said to us, 'You're going down.' We didn't have a chance to make a statement – we didn't even have our own social worker until quite late in the court process. Eventually we were given an advocate from People First, who has been an angel. But we feel the justice system has failed us.

After court that Monday, we were told we weren't to collect the children from school and that they would be going into foster care with two different families. They will be away permanently until they are 18.

“ ONE SOCIAL WORKER DREW HER FINGER ACROSS HER THROAT AND SAID TO US, 'YOU'RE GOING DOWN'

That evening social workers came and collected the kids' clothes. Elizabeth was clutching a purse Melissa had made for her tightly. The purse was a gift from Melissa for Elizabeth for luck and we had put two lucky charms into it one day at the seaside – one for Melissa, one for Elizabeth. But it didn't bring luck. We were begging them, 'Don't take our kids away, please, they're the only thing we've got.' They showed no emotion – they were very cold.

We were only allowed to see the children twice a week for two hours a time. Melissa cried to us at these meetings, saying, 'I want to go home, what have I done wrong?' Later the kids were all adopted by the same family and it's been over a year now since they were taken away. We have only been allowed to meet the people they live with once. All

the children's clothes were still in a bag on top of the wardrobe. We are only allowed to see the children every eight to nine weeks for two hours at a time. We don't see why we aren't allowed to spend at least a day with the five of us together.

It has ripped our hearts out. We just love our kids. We don't know from one day to the next if they are all right. We are missing such a lot of them growing up. We all used to have so much fun. Tom would have Sarah on his shoulders and they would wave when he went to work. We still think they're going to come down the stairs to go to school.

All the precious little moments and cuddles have been taken away. We haven't got anything now. The children don't phone – they are allowed to but we think they are being encouraged to forget us. A social worker once told us openly that they are trying to break the love between us and the children.

It's been like a horror film. We are not allowed to appeal, but we are now taking parenting classes, even though we know what we are being taught already. Tom was bullied at school, and he is still being bullied now. Michael, Melissa and Sarah, if you see this, Mummy and Daddy love you very much and we miss you very much.

*Names have been changed

■ A spokesperson for Essex children and young people's social services says: 'Every child is entitled to have their physical and emotional needs met to allow them the best possible start in life. We have worked with this family for over ten years to support them through difficult times, although the family were not always willing to accept the support offered. It is always our priority to keep families together, but in a very small number of cases this simply isn't possible and since the children have been in foster care they have made good progress.'

USEFUL CONTACTS

The following organisations offer vital services and support to disabled parents and families of disabled parents

- The Disabled Parents Network is a national organisation run by and for disabled parents, offering support, advice and information. Call 0870 241 0450. www.disabledparentsnetwork.org.uk
- Disability, Pregnancy & Parenthood International is a charity which also offers information and advice to disabled parents. Call 0800 018 4730. www.dppi.org.uk
- Scope offers advice and information on disabled rights and fighting disablism. Call 0808 800 3333. www.scope.org.uk

- People First provides state-funded advocacy for parents with learning disabilities. London branch: call 020 7485 6660. www.peoplefirstltd.com
- Learning disability charity Mencap campaigns for disability to be factored out of decisions concerning a person's ability to parent. Call 020 7454 0454. www.mencap.com
- Sense supports people who are deafblind. Call 020 7272 7774. www.sense.org.uk
- Young Carers is a national group supporting under-18s who care for disabled relatives. Call 020 7480 7788. www.youngcarers.net
- General information on the rights of disabled people is available at www.disability.gov.uk and from the Disability Rights Commission at www.drc-gb.org Call 0845 762 2633.

A REAL INSPIRATION...

TANNI GREY-THOMPSON is Britain's most successful wheelchair athlete. The paralympic gold medallist and mother of two-year-old Carys told REAL:

'Being a mother is the most challenging, interesting – and tiring – thing that I have ever done. I don't mind people presuming things about me because I am a wheelchair user, but what sometimes amazes me is that people feel sorry for Carys. They think that because I am disabled she will somehow not be brought up the same as children with 'normal' parents. What keeps me going is something a friend said to me: "You don't need to be the best mother in the world, you just need to be the best mother to Carys." And that, I know I can do.'

