

Parent, carer... victim?

Allegations of fabricating or inducing illness seem to be affecting a worrying number of families of children with autism. Fiona McNeil speaks to parents who have had to endure the distressing experience of being wrongfully accused

Jenny Lockley's son was only a toddler when she began to suspect something wasn't right. He was slow to respond and at first she thought he had hearing problems. When that was ruled out, the idea that the boy might have an ASD began to surface.

Lockley raised the matter with several doctors, but her concerns were dismissed. Exasperated, she took her son to Patricia Howlin, professor of Clinical Child Psychology at the Institute of Psychiatry in London, who immediately diagnosed autism.

"We thought, now we've got the diagnosis we'll be able to access everything we need for him," Lockley explains, "but that was just the start of our problems."


Lockley, who lives in the West Midlands, approached doctors and her son's nursery for help, but was repeatedly brushed off. When she asked her local education authority to assess him with a view to providing extra support when he

started reception, they refused. Bewildered, she asked to see copies of her records and discovered that they stated she had Münchausen syndrome by proxy (see 'The terms', above right) and had 'forced' the specialist to make the autism diagnosis.

"The education department had been spying on me for nearly 18 months. There were descriptions of me pulling up in a car, what I was wearing, what my son was eating," Lockley says. "They even said that I'd starved my son so he would have to be fed through a tube. All of this was started by just one person, but everyone was keen to believe it."

Strangely, social services were never involved. "I asked these people why, if they truly believed I was mistreating my son, they hadn't contacted them, but they couldn't give me an answer," Lockley says. "It was a witch hunt."

Lockley had become another victim of a trend that *Autism Eye*



Terrible loss: at its worst, an accusation of Münchausen syndrome by proxy can end up with children being taken away into care

The terms

● Münchausen syndrome by proxy (MSBP), also known as fabricated or induced illness (FI), is a specific form of child abuse where a parent or carer is believed to be exaggerating or exacerbating a child's problems because of excessive anxiety or for attention or monetary gain. In its worst form it can result in severe injury or death. Experts find it difficult to estimate how many cases occur each year, but it is thought to be rare.

has been noticing with increasing frequency: parents being labelled with FI or Münchausen syndrome by proxy without the proper procedures being followed. The number of stories we hear of parents falling victim to a seemingly casual misdiagnosis could lead an impartial observer to believe that the disorder is far more common than it is thought to be in reality.

In Devon, single mother Mel Rawding has her own story of becoming a victim. Her son and daughter have an ASD and also suffer from Ehlers-Danlos syndrome, a genetic disorder of the body's connective tissue that can affect mobility. The children have formal diagnoses from more than one specialist, but Rawding nevertheless has faced accusations from her local social services department of 'over-exaggerating' their illnesses.

Social services

A number of factors have led to the allegations, she believes. Like Lockley, she had concerns about her son's health when he was a baby, but her GP responded by packing her off to a parenting course. Because she was exhausted from coping with the child's behaviour, the people running the course referred her to social services.

Later, when she took her son to a paediatrician because of his unexplained blackouts, she was told he might have epilepsy, then migraines, but finally heard that there was nothing wrong.

"I lost faith in that doctor and stopped going to him, but a few

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The campaigner: Lisa Blakemore-Brown

Lisa Blakemore-Brown is a practitioner psychologist specialising in autism. She has been campaigning against false accusations of Münchhausen syndrome by proxy and fabricated or induced illness for nearly 20 years.

She first encountered such a case in 1996, when twin girls were sent to her clinic for psychological assessment. Although the reason for this process was supposed to be confidential, before they arrived the practice manager became very excited, saying the mother was "dangerous" and couldn't be in the same room as her children.

"I was suspicious about this. I said, 'Who have you been talking to?'" Blakemore-Brown recalls. "I later learned this was common practice in these cases. There might be a pencilled note passed to someone or a sly nod and a wink. I knew that someone was trying to influence my thinking."

When she met the mother in question, she saw a woman who was clearly exhausted from looking after four kids. The assessment showed that the twins had learning difficulties and were hyperactive. They were also on the autistic spectrum.

"The mum had seen a TV

programme about ADHD and thought, 'That's my kids,'" Blakemore-Brown says. "She'd gone back to the doctors and said, 'You've missed this. I'm going to sue!' That was probably her big mistake."

It turned out the woman was being accused of Münchhausen syndrome by proxy. When she finally went to court, all four of her children were taken away, despite Blakemore-Brown's evidence to the contrary, that of the paediatrician she worked with and the history of the twins' childhood problems and special educational needs. "It was one of the most shocking experiences of my life," she says. "I thought, there is no justice."

Culture of hysteria

To add to her astonishment, while sitting outside the courtroom waiting to go in for the hearing, one of the social workers making the accusations asked the mother to keep an eye on the children (they'd been kept apart from her in a side room until that point).

"If she was so dangerous, why were they letting her sit with her kids?" Blakemore-Brown asks. "They were playing games." Blakemore-Brown speaks of a

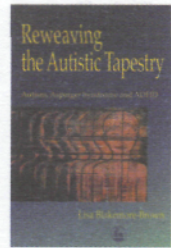
culture of hysteria, where people can make accusations of FII based on very little evidence.

"What is this thing about a hunch?" she questions. "How can you make an accusation that's not backed up by evidence?"

"At the moment, a doctor can have a feeling about a child and contact social services, who then treat it as a referral. But where is the accountability? It's very medieval – a witch hunt."

What is needed, she concludes, is greater understanding of autism, as well as properly conducted investigations.

Blakemore-Brown says she has never seen a genuine case of Münchhausen syndrome by proxy/FII, although she admits she has tended to concentrate on those who have been falsely accused.



Lisa Blakemore-Brown is the author of *Reweaving the Autistic Tapestry*, which studies the links between ADHD and autism spectrum disorders. It is available from Jessica Kingsley Publishers at £22.99

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years later I got a letter out of the blue asking us to go back for an appointment," Rawding says. "We went in to see him and he said, 'Why are you here? I've told you nothing's wrong.' It was bizarre."

Further suspicion was triggered, she believes, by her daughter's idiosyncratic behaviour. Although the girl has tantrums, doesn't make eye-contact and struggles to eat

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anything but sweets, she is able to mimic and appear 'normal' at different times and in front of different people. As a result the school is not convinced she has autism and has asked for a second opinion.

When Rawding arranged for the girl to use a wheelchair after she had dislocated her knees (because of her Ehlers-Danlos syndrome) social services accused her of 'forcing' her daughter into a wheelchair.

Put on anti-depressants

The pressure has been such that Rawding had a breakdown and was put on anti-depressants. "It's terrible. You feel like all the professionals are against you. I began to believe that there really was something wrong with me," she says. "I even went to see a

specialist, Dr David Bickerton (a consultant psychiatrist working within the National Health Service in Devon), who said, 'You definitely do not have Münchhausen's,' but I found it difficult to believe him."

Jan Loxley-Blount runs Parents Protecting Children, a support group for parents of children with an illness or disability who have been wrongly accused of Münchhausen syndrome by proxy or FII. She has been contacted by a number of parents of children with autism who have faced this allegation.

"It's a problem that's growing," she says. "I think there are a number of reasons, but these are just my gut feelings – I have no proof. Firstly, I think it's partly financial. Local authorities are cash-strapped and it's easier to say someone is making a fuss than to give them more resources. >>

There's also a problem in the way cases are looked at. Families are often assessed by psychiatrists trained in Freudian theory, which means they lean towards the outdated 'refrigerator mother' idea. And autism isn't part of their training: Freud had died before Asperger did his research. Psychologists have a better understanding."

Given that some symptoms of autism – lack of eye-contact, withdrawn behaviour and poor communication – can be similar to those of abused children, it's no wonder ill-informed social workers are leaping to the wrong conclusions, Loxley-Blount adds.

Tenacious Aspie mums

Another contributing factor, she strongly believes, is that some mothers of children on the spectrum have autism themselves. This is notoriously tricky to detect in women. Sometimes it is undiagnosed and sometimes the woman has a diagnosis but is frightened to admit to it in case she is judged an unfit mother.

This means that local authorities sometimes misinterpret the mother's behaviour as FII. "Any mother of children with disability or difference fights for diagnosis and resources for her child," Loxley-Blount says, "but the Aspie mum fights with that bit more tenacity and obsessiveness, which is

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misconstrued as her being difficult or inventing illness and disability."

Charlene Kolleyer, who lives in Staffordshire, is the mother of four children, two of whom have a diagnosis of ASD. One child also has Ehlers-Danlos syndrome. She faced accusations of 'over-medicalising' their problems when she made repeated requests to the school for extra support. Her children were placed on the child protection register.

Once she had obtained a diagnosis of Asperger syndrome for herself (at her own expense), her social worker became more sympathetic and her children were taken off the CPR. "This is an absolute nightmare for parents," she says. "The term FII is used far too often. People are looking for a box to tick and if you're pro-active, diligent and anxious, that's the one that fits."

Another Asperger's woman from the south of England, who wishes

to remain anonymous, has been told by her GP that she is 'causing' her daughters' anxiety. The daughters, too, have a diagnosis of Asperger syndrome.

Part of the problem, she says, is that professionals aren't always up to date with the latest information on autism. "It's hard to diagnose in girls and if they can't do it easily they blame the parents. There's also a kind of snobbery with some people," she adds. "They don't want to listen to the parents."

"I feel like it's character assassination," she concludes. "Opinion isn't fact."

“Nothing we did worked”

Lucy Mallows's daughter was difficult from the word go. As a newborn, she screamed if she was passed to other people and she wouldn't go near her father. "Nothing we did worked, but we thought it was our fault because we were new parents," Mallows says.

By the time her daughter was a toddler Mallows was working for Dr Jo Jones, a consultant paediatrician specialising in neurological disorders. Hearing Mallows describe her daughter's behaviour, Dr Jones tentatively suggested a consultation and diagnosed atypical autism with pathological demand avoidance syndrome, in which sufferers avoid the everyday demands made by other people because they have >>

The local authority adviser: Andrew Webb

Andrew Webb is the president of the Association of Directors of Children's Services, a membership organisation for senior management in local authorities in England.

"It's well-documented that FII happens, but it's extremely rare," he says. "I'm not sure whether false accusations are increasing, but it is a problem that's always been around."

Webb says that guidelines from the Department of Health, which were last updated in 2007, state that there are clear procedures to be followed before people can make accusations of FII and that it's not a judgement an individual

should make single-handedly. Initial concerns should be raised gently, with a comment that the parent seems over-concerned, rather than wading in with a full-

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blown label, he advises. The guidelines also suggest, Webb says, that people working with children and families consider all possible explanations for an adult's behaviour before jumping to conclusions.

"For example, there are parents who are naturally anxious and some who might be over-anxious, which gets in the way of good parenting," he explains.

"Then there are parents who might spot the signs of something unusual in their children first. When you think about some of the behaviours of children with autism or Asperger's, this might be the case."



Be cautious: Andrew Webb says that professionals should raise their initial concerns gently rather than wading in with a label



In need of help: it may be a good idea to find someone with good communication skills to represent you when asking for extra support

high anxiety levels when they feel they are not in control. "Before my daughter started school, I went to them and showed them the diagnosis," she says. "I said they probably wouldn't see anything in her because she was unusual, but I gave them lots of information."

Playground gossip

Not long afterwards Mallows, who lives in Gloucestershire, was contacted by social services and her children were put on the child protection register. The reason, it turned out, was nothing more than playground gossip.

"Some parents and teachers had gone out for a bottle of wine and one of the parents started saying that I'd stopped going to playdates and that I was obsessed with getting a diagnosis," she says. "But that wasn't even true because we already had a diagnosis. The

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teacher had gone back to school, taken this as fact and contacted social services."

The problem was worsened, she believes, because her daughter can appear normal at school, leading the teachers to call her a 'model' pupil.

Fortunately, social services were sympathetic, quickly realised

a mistake had been made and took the children off the child protection register. Although the school was criticised because it had failed to follow correct child protection procedures, no apology has been forthcoming.


Although she has a degree in child development and has worked as a nanny, Mallows was so shaken by the experience she came to doubt her own judgement. In addition, feeling criticised by people she thought were her friends, she and her family have decided to move to a different part of the country to make a fresh start.

"It's had a huge effect," she says. "I used to shake on the school run. It really bugs me that no-one's been held to account. And my daughter's still not getting the help she needs at school."

Find an advocate

Monique Blakemore has Asperger syndrome and works as a voluntary advocate for ASD women and their families. "The problems usually start in education, where a mother is trying to obtain support and concerns are raised that she's exaggerating," she explains. "The way it's written up is that it's 'emotional abuse', which is quite bad because the children are supposedly being given the identity of being ill. If the children seem happy, they call it 'future emotional abuse' for something that might never happen."

Blakemore suggests that neurotypical and ASD parents alike find themselves an advocate when approaching local authorities and schools for more help. If you can't find someone trained in this area, take a family friend along to meetings – someone, she emphasises, with good communication skills.

"You won't win if you go into battle with social services," she cautions. "You get some advocates really pushing and acting like a pretend solicitor, but a non-confrontational attitude is best. You've got to give them new knowledge so that they understand. Sometimes the mum also needs to accept that the help she's being offered is OK – you don't need a Rolls-Royce every time." 

CONTACTS

- The National Autistic Society website provides advice on advocacy: www.autism.org.uk; helpline: 0808 800 4104
- Parents Protecting Children: www.parents-protecting-children.org.uk
- Research into the relationship between difficult and uncertain medical diagnoses (including ASDs) and child protection investigations is being developed by Dr Clive Baldwin (baldwin@stu.ca), Professor of Social Work at St Thomas University in Canada, and Jan Loxley-Blount of Parents Protecting Children (see above).