

The fight for an education



Children with special educational needs are being marginalised and excluded as budgets to support them are slashed. *Sharon Hendry* meets the furious parents taking their battle to the High Court



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licia McColl didn't realise her son Kian was autistic until he was five. "I just thought he was a little different," says the mother of three from Farnham, Surrey. "He

was really good at spelling and had lots of energy. He was fanatical about cars and used to flick through the Yellow Pages looking for them. At primary school, the teachers told me he didn't like sand or reading books, but neither do lots of children."

That same year, in 2010, Alicia and Kian's father split up. She moved away and had to put her son into a new school. "The change dysregulated him and he began throwing himself on the floor, throwing chairs and walking out of the classroom," she says.

In 2012, aged 7, he was finally referred to an educational psychologist and a paediatrician. Kian was diagnosed with attention deficit hyperactivity disorder (ADHD) — a neurodevelopmental condition characterised by difficulties in paying attention and controlling behaviour. He was given a special educational needs statement — a legal document that gave him "access to" 20 hours a week of learning support. "But I soon learnt that 'access to' does not mean one-to-one support," Alicia says. "It can just mean there is a teaching assistant in a class of 30 children. It didn't help him in mainstream school at all." She also says her requests for Kian to be formally assessed for autism went unanswered. "He kept being excluded from school. I was being called to collect him when he wasn't 'coping' three times a week on average."

Her voice breaks and she dissolves into tears as she recalls her son's eventual transferral to a "harsh" pupil referral unit for excluded children when he was nine years old. "It was full of desperate children using bad behaviour to communicate a message that they needed help. But the state treats them as delinquents. Kian kept being kicked and hurt by other children and the problems with his behaviour escalated," she says.



Eventually, Alicia paid to have Kian's needs assessed privately and a debilitating range of conditions were diagnosed, including autism, hypermobility, dyspraxia (a neurological disorder causing difficulty in activities requiring movement and co-ordination) and expressive-receptive language disorder (difficulty in using and understanding language), as well as ADHD.

She has since paid for a legal team to challenge the original 20 hours' statutory support provision and won Kian a place in a specialist 50-pupil school that is allowing him to flourish. To fund legal costs, she sold their house and they have had to live in rented accommodation.

Kian is now 14. Earlier this month, he and his mother stood alongside a group of other parents who have taken Surrey county council to the High Court to oppose cuts of £21m from its special educational needs and disabilities (Send) budget — a move they describe as "unlawful" and "unfair".

The proposed cuts threaten vital services for thousands of vulnerable children in Surrey, including home-to-school transport, early years support, post-16 support and one-to-one classroom support. At the time of this article going to press, a

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judge was set to rule on the case imminently.

Alicia, a project manager for the European Medicines Agency who juggles her day job with offering free advocacy to Send parents, describes a "furious special-needs community" rebelling against years of cuts, which she believes have left a generation of vulnerable children ignored and uncared for.

Recent figures reveal that nearly 1.3m children in the UK require additional support to help them participate in state education. But only a little over 250,000 of them had provision that is legally enforceable. For the remainder, the future is bleak. There has been a sharp rise in the number of exclusions from state schools in England — 40 permanent exclusions each day in 2016-17, up from 35 the previous year. Children with Send are seven times more



TAKING A STAND Alicia McColl and her son Kian (second and third from left) at the High Court to oppose Send budget cuts

likely to be excluded. Such "disruptive" but often intelligent youngsters can leave school with no qualifications.

"Support for children in school costs the taxpayer far less than the support they need when they enter the world of unemployment and, for some, criminality," says Alicia, 45. "We represent a new generation of motivated and dedicated parents who are learning the law and simply saying we've had enough of seeing our children treated like second-class citizens. We're not standing for this any

more. The scant provisions on offer are mired in bureaucracy."

She believes the system has created a culture of haves and have-nots. "If you can afford a lawyer, you will eventually beat the system," she says. "But even then, you'll end up with nothing left after years of fighting. I had savings to provide for my children's future, but it has all gone on the fight for Kian's right to an accessible education."

The Surrey parents have been buoyed by a landmark case in Bristol brought before the High Court this summer by similarly outraged parents using legal aid. In August, a judge ruled that Bristol city council had unlawfully slashed its Send budget by £5m and ordered it to reverse the savings. This week, parents in Hackney, east London, are due to go to judicial review to protest 5% spending cuts by Hackney council. ➤➤➤

"It's brutal. Parents are made to feel ashamed"

Former newsreader Tania Tirraoro, 51, from Farnham, Surrey, is one of the UK's foremost campaigners for special educational needs and disabilities (Send). Her website Special Needs Jungle attracts 200,000 visits a month and has 50,000 followers on social

media. Along with her husband, Marco, a City accountant, she fought for years to get their children, Gio, 19, and Luca, 20, appropriate diagnoses and specialist school provision.

"No one in their right mind would enter the current process unless their child

was desperate, because it's brutal," she says. "It is a Kafka-esque nightmare. No one gets back to you, and when they do, it's often with the wrong information. Parents are made to feel ashamed simply for asking what provision their child is entitled to."

Meanwhile, a national parents' group, Send Family Action Group, has launched a crowdfunding campaign to finance a judicial review of the government's entire Send funding policy, which it says has created a national crisis.

In 1978, the moral philosopher and House of Lords crossbencher Baroness Mary Warnock issued a landmark report on special education, sparking legislation that enshrined a policy of inclusion in mainstream schools and changed the vernacular. Harsh terminology such as "mentally defective", "backward", "retarded" and "educationally subnormal" was cast aside and instead children with learning difficulties were identified as having "special educational needs".

The 1981 Education Act later enshrined the report in law and introduced the first system of statutory assessment or "statementing" — a way of formally assessing Send children and providing additional support if deemed necessary. However, the process was regarded as too bureaucratic, so in 2014, the government hurriedly launched a new legal document called an education, health and care plan (EHCP). It was designed to replace statements and combine children's various needs in a single assessment, while raising the age at which they could be entitled to support from 18 to 25.

The parents of many children who have already transitioned from Send statements to EHCPs complain they have been left with lower levels of intervention because of plans that don't sufficiently spell out necessary support. Some children have lost statutory protection entirely and a rushed 2018 transition deadline left an estimated 21,000 children who had not been moved over to EHCPs. Meanwhile, 1m children are making do without plans altogether. Today, Baroness Warnock believes the introduction of EHCPs has had

"Undiagnosed dyslexia is a constant battle"

Molly Cochrane is a 45-year-old Pilates instructor who applied for an education, health and care plan (EHCP) after recognising that her 11-year-old daughter, Lyla, was suffering from the same crippling dyslexia symptoms she experienced as a child.

The mum of two, from north London, says: "In reception, Lyla was struggling to meet all the normal milestones, and by year 1 she needed extra help. It filled

me with dread. Undiagnosed dyslexia is a constant battle. I was continually asking the school to help me get a statement, but was often made to feel neurotic. Eventually, I found a friend who helped me with the application."

Lyla was finally tested at the end of year 5 and diagnosed with severe dyslexia and, later, a sensory processing disorder. An EHCP was issued, but it only gave Lyla access to her existing

teaching assistant — not the specialist learning and school provision she badly needed.

"It was rubbish, but I didn't know any better," Molly says. "I didn't understand what the language meant and I couldn't afford a lawyer. Eventually, I found an amazing parent advocate who helped me launch an appeal against Camden council."

Molly's appeal for a specialist school failed on the grounds that



had to be over 13 with a reading age of six to apply. That is simply unlawful, but parents don't know this. Another LEA told applicants that children with dyslexia were not eligible. Again, untrue and unlawful. Many LEAs say schools must prove they have spent more than £6,000 on a child's special needs before they can be considered. That figure was once ➤➤➤➤

Lyla's needs could be met at a local comprehensive. But the advocate helped her to force the council to provide a more detailed EHCP document. It gave her daughter access to a specialist dyslexia teacher, occupational therapy and speech and language therapy.

Only time will tell if Molly's fight will benefit Lyla. "This has been the most stressful time of my life," she says. "I feel as though I was caught in a web. The only people who can properly fight this system are those with money and connections. It's wrong."

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disastrous consequences for children. "The worst thing, in my view, is that parents have to apply to get a plan for their child, and they may have their application turned down without being given the least idea why."

Andrew Barrowclough, director of HCB Solicitors, in Cardiff, is one of the UK's leading education lawyers who fields hundreds of inquiries from parents lost in what he refers to as the "EHCP maze".

"The process is supposed to involve health and social services, but that almost never happens so it's completely led by education," he says. "That results in the true extent of a child's needs not being taken into account. Local education authorities [LEAs] should be consulting occupational therapists, and in many cases speech and language therapists, to assess language and sensory needs and fine and gross motor skills. However, they often don't have the budget and the NHS waiting lists are too long, so the child's real difficulties get missed and they are denied support."

He says that as a result, "the tribunal system has exploded and is creaking under the weight of appeals. It simply can't find enough judges to hear the cases. A concerning number of children did not

have a school to go to this September because tribunals were being adjourned on a worryingly frequent basis due to a lack of venue or panel availability. Vital learning time will be missed for children already behind in the system."

The escalating volume of Send parents' voices has now reached Westminster, where the education select committee is currently investigating the system. "If you know how to lobby your MP, it's fine," says committee chairman Robert Halfon. "If you are a normal, day-to-day parent who might not know the system, you are at an unfair disadvantage."

Meanwhile, the demand for new EHCPs is on the rise — there were 17% more plans issued nationally during 2016-17 than the previous year. This is largely due to young people now being able to access provisions up to the age of 25, as well as substantial numbers still transferring to the new system. Barrowclough says local authorities are so inundated that they are batting parents away with unlawful tactics.

"An LEA currently has six weeks to respond to a request for an assessment and many are overwhelmed, so they are trying to limit the number of applicants," he says. "I was recently told of an LEA that had adopted a criterion where children allegedly

mentioned in guidelines, but it's not in the statute. It's irrelevant."

Mark Small is a lawyer who sparked outrage in 2016 when he posted a tweet celebrating "a great 'win' which sent some parents into a storm!", after claiming victory in a case on behalf of an LEA against a family seeking Send support for their child. Small was known among parents as "the Terminator" for representing LEAs

"I've had to take loans out on my home and we've never had a holiday." How much has she spent in total? "About £20,000"

before the Send tribunal, an independent appeals process that allows parents and young people to challenge EHCP decisions. He later posted an image of a luxury swimming pool, claiming he was relaxing by it while reading parents' outraged responses to another decision. The director of Baker Small Legal Services, based in Milton Keynes, he was formally rebuked by the Solicitors Regulation Authority and ordered to pay £600 costs.

Now the poacher has turned gamekeeper, helping parents to challenge LEA decisions. Small's unique insight trains a disturbing lens on local government attitudes and tactics. "When I began working for local authorities, it wasn't long before I realised the families of Send children were held in contempt by some of the Send officers and senior managers. 'These families are taking the piss out of the state — go and nail them,' was the unspoken vibe at many of the councils I used to work for," he says.

In 2011, after Small had won 10 Send cases in a row for Cambridgeshire county council, there was a scramble for his services among other LEAs.

"During one year, I calculated that my firm had saved one of our LEA clients £5m. But one of the by-products was that I became hated. I shouldn't have sent those tweets. The process is really awful and, in the end, you become a cynic within it. The one I posted, saying I was by the pool — that wasn't even my pool."

Small says he is now determined to rebuild his reputation through SEN4you, the arm of his firm that now represents parents and children.

"I know of one LEA that is tricking parents by issuing them with something called a MyPlan, which looks like an EHCP but is just conjured up by the council and has no legal status whatsoever. Many of the parents they are dealing with don't know any different," he explains. "Most EHCPs are unlawful ... [they are]

supposed to spell out the support the child is going to get, but I've seen 128-page documents where there is nothing specific, nothing quantified. The reason being that no one wants to pay to deliver it. That's why so many parents end up in the tribunal."

Mum of four Angela Kingston, from Bridlington, Yorkshire, says her battle to get the Send support her children need has cost her her marriage, her job and forced her

to remortgage her home. She grew up in care and says she had a "limited education", but has become a fierce Send advocate while fighting the system on behalf of her autistic son, Curtis, 18, and her daughter, Sienna, 12, who was born with a severe communication and language disorder.

For 16 years, teachers and professionals dismissed Curtis as "naughty", and after

tens of exclusions, one remarked to his desperate mother, "The sooner you accept your son is badly behaved, the better it will be for all of us." Yet Angela fought on and achieved an autism diagnosis and Send statement that granted him specialist support. Sienna, however, has missed out on vital speech and language intervention because the LEA took more than eight months to deliver a relevant EHCP.

"For weeks, I used to do my job as a nursing-home care worker, then stay up all night researching people who could help me understand the statementing process," says Angela, 43, who is now a Send schools governor. "Meanwhile, Curtis's undiagnosed autism meant he was hitting out at other children and unable to focus."

At one point, Angela says Curtis was being "banished to an 'amber room', which was basically a dumping ground for Send children, and he was made to face the wall. At home time, the teachers would hand him over to me. He was never invited to parties."

Eventually, Angela achieved adequate provision for her children. Curtis is now

studying two BTEC qualifications with full-time one-to-one support at a local mainstream college, and Sienna has specialist provision in her local school.

"I had no choice but to educate myself. The system is worse now than it's ever been and I've cried myself to sleep at night," Angela says. "I've had to take loans out on my home and we've never had a holiday. All my money is spent on a Send consultant, fighting to get provision in place for my children."

How much does she think she has spent in total? "A conservative estimate would be £20,000." She referred her case to the local government ombudsman, who recently found in her favour and awarded £300 compensation to each child.

So is there scope for improving the system? The lawyer Mark Small offers a number of suggestions, including providing parents with independent key workers to help them through the process.

And what of Baroness Warnock, whose 1970s vision for Send children's inclusion in society was so full of promise? "What needs to change is that the whole concept of the plan be scrapped and a new start made, which I hope is what the parliamentary select committee will recommend," she says. "It would be wonderful to go back to the days when parents could think of LEAs not as their adversaries, but as their partners in trying to do the best for their children. But as long as the endless financial struggle is constantly covered up, I don't see this change coming about." ■

For advice, visit specialneedsjungle.co.uk



"People don't see autism and ADHD — just bad kids"

Vanessa Bobb, 50, from south London, gave up her career as a videographer to fight for her children's rights. She has been forced to claim benefits and says she is made to feel like a "scrounger" for supporting her children.

After years of trying to get her children's disabilities recognised, her son, Nathaniel, 15, was diagnosed with autism and ADHD in 2008, and now attends a specialist boarding school in Kent. Her daughter, Michaela, 12, was only diagnosed with ADHD last year, and is still awaiting a copy of an appropriate EHCP document. Both her children have experienced numerous exclusions.

"People often don't see special educational needs, they just see bad children," Vanessa says. "For years, my kids have been told they are naughty because I made them that way. I was made to feel as if I was failing my children. Other parents would say, 'My child doesn't do that.' The signs of special needs were there but nobody wanted to see it that way."