



OUTSIDE THE BOX: Twins Hassan (left) and Husayn, 3, undergo 35 hours of intensive ABA therapy a week

Tough love

It is demanding and cruel, say its critics, and the Department of Health won't recognise it. But a high-pressure autism treatment is changing these little boys' lives. *Caroline Scott reports*

Hassan's screams can probably be heard five doors down. The three-year-old's task is simply to put an object in a box. But he doesn't want to do it, and breaks into hysterical sobs choked with tears and snot. Nevertheless, his teacher will battle for however long it takes to get him to complete the task.

Hassan and his twin brother, Husayn, share an autistic spectrum disorder so severe, the world holds little meaning for them. Six months ago, they had no sense of danger; they'd walk into walls, smashing their heads. They'd put their hands into their nappies and eat the contents. They bit, they pulled hair, they lashed out. The hardest thing for their parents, Farooq and Javeria, was that they didn't seem to recognise them over any other adults.

But now, thanks to a radical, expensive and highly controversial tough-love treatment, Farooq says he is meeting his sons properly for the first time. "When we started this journey we just wanted them to be safe," he says. "Now I don't think it's unrealistic to expect them to go to mainstream school."

The boys spend 35 hours a week undergoing Advanced Behavioural Analysis (ABA), a therapy so controversial that it doesn't even appear

»»»

as an option in the national clinical guidelines used by the NHS for treating autism. Its methods fly in the face of current thinking on child-centric learning, and critics label it “cruel”. But parents such as Javeria and Farooq have seen what ABA can achieve, and say Britain’s autistic children are currently getting therapy that is 30 years out of date. A group of these parents are now planning a legal action to challenge the government’s position.

Their voices are finally being heard in one small corner of Britain. This month, The Peartree, a brand new ABA unit attached to the Stanley School in Teddington will open its doors to 18 children aged 5 to 11. Initiated and funded by the London Borough of Richmond, it is the first state-funded ABA nursery in the country. It aims to give children intensive early-years support in the belief most will make sufficient progress to take up a place in mainstream school at 12. Undoubtedly, those parents who can, will move to be near it.

ABA is certainly not for the faint-hearted. Neurotypical children learn through imitation and free play. But autistic children don’t imitate and they don’t play. They prefer intensely ritualistic “stimming” — repetitive

self-stimulating behaviour that can range from rocking and flapping to biting, scratching and more serious self harm. According to ABA principles, if an autistic child is frightened of solid food, you present it to him three times a day. If he doesn’t like noise — and many autistic children don’t — you expose him to a barrage of sound.

ABA devotees see it as simply simply good parenting: Just as you would teach a neurotypical child not to eat with his hands, beat up his sister or shout and swear when other people are talking, so ABA frees autistic children of violent and anti-social behaviours which would otherwise enslave them.

Some practitioners claim that if it is begun early enough — 2½ is not too young to start — and practised intensively, ABA can halt or even reverse a child’s autism. This sounds dangerously close to claiming that autism can be “cured”, and is perhaps why the autism establishment persists in keeping ABA at arm’s length. What is routinely offered to autistic children on the NHS — including music and art therapy — may not be all that effective, but at least it is kind and does not offer false hope.

It’s what Jane McCready the mother of Johnny, a severely autistic 10-year-old, calls

the “Ah, bless” mentality. “We’ve got some wonderful special schools. There’s a lot of playdough and a lot of finger painting. Lovely. But those things are not going to help my son fit into society.”

Those who take an Aspergic view of the condition argue that autistic people should not have to fit in; society should try harder to accept them rather than attempt to change their behaviour. It all depends whether you see autism as a fascinating human quirk or something to be fixed. The question is: by refusing to confront these difficult issues, are we failing autistic children?

Jane is spectacularly and unapologetically un-PC. “I have a low-functioning autistic child, I really think I’m allowed to be. Has he got a special skill? No. Autism is just bloody hard work.” She pours scorn on what she calls “the patronising guff spun around autism”. “We’re so Little England about this, everyone is afraid to say it how it is, and it’s time we caught up with the rest of the world.”

She says it is the thought of her golden-haired toddler at 18 — “Potentially 6ft 5in, 14st and violent” — that informs everything she does. “Without ABA, my beautiful boy would still be non-verbal and punching me in the face when thwarted. Our family would be wrecked and his only hope would be medication and sending him away to some god-forsaken institution, which would have broken all our hearts.”

Jane, previously a marketing manager in the City, says she has fought “like a tiger” to get to where they are now, remortgaging the house and borrowing money to fund a home-ABA programme for two years, then after three years at a mainstream primary, the local authority agreed to part-fund a place at a private ABA school. “We were lucky my husband earns a good salary, but it’s been a huge financial strain.”

At the age of two, Johnny spent most of his day stimming. To demonstrate, Jane jumps up and down and flaps her hands, screeching: “EEeeEEeeEEee!” And when he wasn’t doing that, if he couldn’t hit someone, he was banging his head on the floor.

A speech-and-language therapist who Jane hired at £60 an hour told her Johnny would “probably never talk”. And that, she says, is when she lost it. “Everyone from our local authority told us ABA is too tough, too intense. These are code words for: ‘You’d be the most horrendous, cruel mother to even touch this.’”

After just three weeks of ABA, Johnny, previously “hyperactive to the point of insanity” was able to sit still for a couple of minutes and he’d spoken his first word. “Those who sidestepped his issues, weren’t being kind. If you resort to sign language at three, you are sentencing your child to a life in the special-needs ghetto.”

The options for parents desperate for ABA are pretty limited. Either set up a home programme — unaffordable for most — or face a lengthy legal battle for local authority



“THEY CALL ME MUMMY”: Javeria is amazed by her sons’ progress

CREDIT: HERE PLEASE

OH, BROTHER: Johnny McReady, 10, was told he would never talk. After three weeks of ABA, he'd spoken his first word



“We’re so Little England about this, everyone is afraid to say it how it is, and it’s time we caught up with the rest of the world” Jane McReady

funding for a place at a handful of private ABA schools.

The autism charity Peach believes that taking some of the key elements from the ABA canon and inserting them into state schools’ special-educational-needs programmes would bring about immediate results for autistic children, and save some of the millions that are routinely spent on occupational therapy (there can barely be an autistic child who hasn’t been offered a sensory wobble cushion) and speech-and-language therapy — even though, bizarrely, there is very little evidence for the efficacy of either. Yet the new clinical guidelines on the management and support of children and young people with autism published by National Institute for Health and Care Excellence (Nice) skirts swiftly round ABA.

“In the review of evidence, the Guideline Development Group found no evidence to support ABA, and therefore could not make a recommendation about it,” a spokesman for Nice told *The Sunday Times*.

Which is odd, because ABA is possibly the only comprehensive treatment programme with proven results, supported by research.

Studies in America show that administered intensively — 40 hours a week — half of children who receive ABA as pre-schoolers will go straight into Grade 1, indistinguishable from their peers. The other half make significant gains too, reducing the need for support throughout their school life.

In America, a battle has already been fought and largely won in the law courts over the provision of ABA; 35 US states have now mandated insurance companies to cover ABA therapy. It’s also standard practice in Canada, Italy, the Netherlands and Scandinavia, yet in Britain its use in autism remains poorly understood.

In any case, the current cost to Britain is huge. A report by The Shirley Foundation estimates the national cost of supporting children with autism to be £2.7bn each year. The lifetime cost of supporting Britain’s 700,000 autistic people is now £28bn.

At around £40,000 pounds a year, a place at an ABA school is initially more expensive than mainstream with one-to-one support (£25,000 per year), but much less than the cost of residential (£150,000-£200,000 a year) where the majority of young adults end up

when they’re too big and aggressive to be cared for at home.

For the twins Hassan and Husyan, 35 hours of ABA a week and three hours of supervision from a qualified therapist at £87.50 per hour costs £72,000 a year. Their parents have converted the living room of their modest terraced house in Croydon into a bespoke classroom. Javeria, a teacher until she had her four children, and Farooq, who works for London Transport, are far from wealthy. The couple have taken out loans, borrowed from friends, fundraised and used up money Farooq’s mum was saving for retirement, but they have run out of options. They are now prepared to sell their home. Is it all worth it?

“In a nutshell, 14 months after starting ABA, all negative behaviours have reduced significantly,” says Javeria. “The boys can name all family members, and they are now out of nappies during the day. Most of all, after a year of ABA, they call me ‘Mummy’, and miss me if I am not present. The boys have achieved so much and I am so proud of them. This wouldn’t have been possible without ABA.” ■