



rather than better. “His teacher used to say, ‘If only I could find the starter button.’” At secondary school, homework involved standing next to his mother, Ann, who would say, “Why? What? When?”, then quickly type what he said. “He knew all the answers. But his thinking was, ‘Why are they asking?’ It made no sense to him.”

Peter’s contextual memory is so bad he doesn’t remember this, but Ann, who works full time at a local college, vividly recalls the late-night battles. Peter couldn’t stand the crossing of the boundaries between school and home: “They are two separate entities and I didn’t like the lines being blurred,” he says. Because he didn’t conform, he was labelled unco-operative and lazy. Only his maths teacher seemed to get him. He told his parents: “Peter is Peter. we should encourage him to be himself, not change him.”

But being Peter has not been easy. Asperger’s was not recognised or routinely diagnosed until the early 1990s. Peter says he thought he was going mad. Ann remembers ringing round, trying to get some support for him, and being told it was her problem. She needed to let go. Then, when the Griffins’ youngest child, Stephen, started school, Ann went in to see his teacher and watched aghast as Stephen collected hundreds of rubbers and lined them up under a chair. “I said, ‘Do you think he’s like Peter?’ And his teacher said, ‘I think he’s much worse.’” Stephen’s severe autism

‘THE GAP GOES ON WIDENING. I THINK, “WOO-HOO, ROB WALKED TO THE BUS STOP ON HIS OWN” – BUT OTHER 20-YEAR-OLDS ARE BACKPACKING IN PERU’

was diagnosed at eight, at which point the penny dropped and Peter, then 19, got his diagnosis.

“Michael, our second boy, is what we call neuro-typical,” says Ann. “He was sociable, able, all the things Peter and Stephen weren’t. He was our touchstone. We kept saying, ‘Thank God for Michael, because we know we’re not bad parents.’”

Stephen Griffin is clear-skinned and luminously good-looking, an 18-year-old with the guilelessness of an eight-year-old. His passion is racing cars. He can tell you the name of every Formula One champion back to 1950, yet he doesn’t understand that a bus that takes him one way will also bring him back. The rest of us assume an awful lot about the world, based on knowledge we have gathered and processed. People on the autistic spectrum assume nothing: just because a traffic light turned from red to green last time, it doesn’t mean it will do so again. It makes every step a perilous one.

With his mother’s help, Stephen got a handful of GCSEs – Ann took two weeks off work and together they learnt about the Chinese revolution and the life of plants. But since his statement of special needs ended at 16, he has had no transitional support. Apart from taking an

animal-care course at college – the idea being that through caring for animals, he would learn about taking care of himself – he has been stuck at home, watching racing on TV. He has a normal IQ but is profoundly autistic. If you say, “Would you like to work in a shop?”, he will say “No”, because he has no way of knowing if he’d like it. And anyway, one shop is not the same as another.

Support for Stephen has been patchy and fairly pointless. “I want to help him move towards work,” says Ann. “But the courses available to him seemed designed purely to keep him out of his bedroom for a year.”

Last year, as part of its I Exist campaign, the National Autistic Society (NAS) commissioned the largest-ever UK survey on the experiences of adults with autism and their families. It identified a fundamental problem: nobody – not government nor health authorities nor primary care trusts – knows how many autistic adults there are in England. No wonder, then, that so many don’t have access to the services they need. The National Audit Office, crunching the figures it has on children, estimates that there are half a million people with autistic-spectrum disorders in the UK, of whom around 400,000 are adults, ranging from the mildly affected to those who will need lifelong care. A recent study suggests that autistic adults cost the economy around £25.5 billion a year, 36% of which is

accounted for by lost employment. The government is now committed to developing a national adult-autism strategy, which includes the appointment of a full-time autism specialist within the Department of Health, and training for social and healthcare professionals. Every parent has his or her own professional horror story, from the GP who thought Asperger’s was a childhood syndrome – “Do they think kids magically shed ASD when they’re 18?” asked one parent incredulously – to the social workers who repeatedly lump young adults with ASD (autism-spectrum disorder) together with those who have mental-health or severe learning difficulties.

Dedicated teams within local authorities will now be tasked to ensure that every 14-year-old with a statement has a transition plan. This is a statutory requirement set out in the SEN (special education needs) code of practice, yet at present only 34% of children with ASD have them. The consequences of getting things so badly wrong are huge. Currently, only 15% of adults with ASD are in full-time employment, and they report that their experiences at work are marred by misunderstandings and inadequate support.

Peter Griffin still shares a bedroom with his 25-year-old brother, Christopher. Christopher has a long-term girlfriend, and their older brother



Michael is married. Does Peter see himself married one day? “Oh dear,” he says. “Hmmm. Yes and no.” My questions on this subject are relayed through Ann. Peter is keen to answer, but points out that I’m looking at all this from a neuro-typical point of view. “I’ve never had a girlfriend, so how can I know if I’d like one?” Do you have friends? There is a long pause. “Not really, no. It’s difficult. To develop. To maintain...”

He says working out the basics of social etiquette has been “like learning times tables”. He lacks instinct. It’s just about okay until there’s a nuance in the complex web of communication, and Peter has no idea if something has happened or what. “Before I ask a question, I like to know the answer so I have an idea of what to expect.” I can see how tricky this must be.



Robyn Steward, 22 (left), finds relief from Asperger's in painting

Robbie Petre, 20 (below) is in residential care — but only until he is 21



AUTISM LOWDOWN

Autism is a lifelong developmental disorder that affects how a person communicates and relates to others. It is often referred to as an autism-spectrum disorder (ASD)

The Austrian psychiatrist and physician Leo Kanner described the classic autistic syndrome in a seminal paper in 1943

Autism is estimated to affect more than half a million people in the UK today; about 133,500 of them are under 18

Scientific studies suggest a genetic link: it was recently found that mutations in genes involved in brain connections may increase a child's risk of autism

ASDs appear in 1 in 100 children; of these, 40% wait more than three years for a clear diagnosis, others longer still

Boys are four times more likely than girls to develop autism disorders, which are a lifelong disability

One or, at most, two in 200 people with an ASD — the 'autistic savants' — have an extraordinary talent

"It's just much safer to do nothing rather than risk making a prat of himself," says Ann.

Because no appropriate support exists for Peter, the Griffins are having to define it. After a disastrous year at Leeds University — "He slept all day, played computer games all night and ran up thousands of pounds of debt" — Peter got his degree in astrophysics at the University of Hertfordshire, where he had a "buddy" provided by the Disabled Student Alliance.

Did the physics department all tend towards the, um... "Do you mean, were they all Aspies? Of course they were!" says Peter.

Peter's dad, Laurence, who works in IT — "a very Aspie profession" — acknowledges that a genetic link is likely. "If there were 100 people in a room, one of them would have Asperger's."

"No, no!" says Peter. "You'd never get the Aspie in the room!" They all fall about laughing.

Ann has explored the idea of Peter working as a teaching assistant. He did an eight-week programme with a council-run scheme called Work Solutions. "He was very, very motivated. They said, 'We'll allocate someone to work with you in a few weeks.'" But three months went by and nobody phoned. Peter's mood plummeted. His conclusion was: "I don't know anything is happening, so I'll assume nothing is happening."

Robyn Steward, a 22-year-old with Asperger's and associated difficulties, from dyspraxia to tunnel vision — she lists them for me — has no truck with the idea that "You're autistic, therefore you must be a genius". "At school everyone was expecting Rain Man. Well, I'm rubbish with numbers." Robyn was isolated, stressed and unable to learn because she was bullied all the time. She was 12 when she was told she had Asperger's. "I was sat on my mum's bed. I remember the bedspread..."

Robyn has now learnt to make eye contact, but not to break it. We are eyeball to eyeball for nearly two hours. She has worked hard to understand how neuro-typical people feel: "It's like you have a jar in your head and you have emotional tokens which swoosh round, so you've got a constant flow. With people on the autistic spectrum, the jar gets full really, really quickly and then it explodes and they get scared and they don't know what to do."

When Robyn's jar gets full, she paints. Her tiny kitchen is crammed with paintings, "111 in all", many of them consisting of black swirls with primary-coloured gashes. A particularly dark one was painted after a row with a musician friend, also autistic. "He asked me if I thought he was a genius. I said no. I didn't mean it horribly — I was just being honest. He said, 'Well, you've got an IQ lower than 70 and you'll never get a boyfriend.'"

Robyn has had one neuro-typical and one Aspie boyfriend. "I don't think we feel differently to neuro-typicals. It's just that we're less good at interpreting feelings — ours and other people's." Robyn finds strong feeling — whether hunger, anger or affection — frightening and confusing, and it's mostly this that has scuppered her relationships. Physical problems, she says, can be overcome. "I hate anyone hugging me. But one friend squeezes me gently round the waist while I look away. The biggest problem is finding a connection and maintaining it. "During my teens I was practically a recluse because people were so horrible to me. I didn't learn the things I should have done. Now I'm in my twenties, I find it easier to say, 'I'm not very good at this,' because I know neuro-typicals don't find it easy either."

Robyn's experiences at school were so bad, she says, that "I thought I'd be a homeless drug addict by the time I was 21." She was sent to social-skills classes: "Ate biscuits — pretty useless really." But at college, thanks to a proper transition and



Amy Brosnan, 19, has had no schooling to speak of since diagnosis

society, it's a disability, and it's lifelong."

As a child, Robbie had floor-bashing tantrums that would last for two hours. "The gap between him and other children widened until there came a point where I couldn't pretend everything was okay." "He was diagnosed with dyspraxia at 7 and autism at 11. 'He had one friend who, when Rob was in the middle of a screaming fit, would say, 'D'you want to do some Lego?' Or, when Rob ate with his hands, 'Come on, mate, use your fork.' But that is so rare. In the main, the world has absolutely no patience with people like Robbie."

Robbie is fortunate that he has had an engaged social worker and fantastic care. After he pushed his sister down the stairs, social services listened. "It sounds terrible," says Emma, "but I thank God he can be violent, because it's the only reason we've had the help we have." Since he was 16, Rob has had a 52-week residential placement, currently at Ruskin Mill, a working-farm community in Gloucestershire. Sitting in her south London garden, Emma has no doubt that, for him, the decision has been the right one. "Robbie doesn't need reminding to pay his bills – he needs care."

She sums up the fear and uncertainty of his world very neatly: "I might bring out a cup of tea in a minute or an elephant might drop from the sky. For Robbie, those two things are equally possible. And the gap goes on widening. I think, 'Woo-hoo, Rob walked to the bus stop on his own.' Then you realise other 20-year-olds are backpacking in Peru. But within the context of Rob, he's doing fantastically well. At one point I saw no future for him at all, because I thought he'd kill himself. It is a Greek curse to possess the intelligence to see what you can never have."

Rob can stay where he is until he is 21, and after that the future is uncertain. "My big sorrow," says Emma, "is that it can't go on for life."

Polly Tommey's vision for a supported autistic community would perfectly accommodate Rob, with his "islands of ability surrounded by great abysses of difficulty". Polly, a former actress, formed the Autism Trust two years ago. She publishes *The Autism File*, a forum for parents of children with ASD, and is trying to raise £10m to build the first outreach centre where autistic adults can be supported to work. She talks at 90mph of rolling the idea out nationally and globally: "America is interested. Dubai wants one..."

Calling on the help of friends in advertising, she launched a billboard campaign: "Dear Gordon Brown, I can save you £508m a year. Please call me". It hit the spot: Brown invited her to No 10 to discuss better training in the private sector and the creation of a multi-party autism coalition. ➤➤➤

good learning support, everything went right.

She is now a self-employed mentor for Aspie children, with referrals coming from SENCOs (special needs co-ordinators) and parents. "I get them to draw while we talk, so they don't have to look at me. They often haven't a clue about their own condition. I think, 'How does a kid get to 12 without anyone understanding them?'"

Robyn does a very good job of appearing neuro-typical, yet she is often driven to the edge of reason just trying to get it right. During a spell working for a computer store, customers' imprecision left her so frustrated that she banged

jacket potato.' He keeps me safe from the world."

Robyn says that when we meet again, she won't remember my face, but she has memorised my earrings and shoes. "Life would be easier for people with ASD if others made more of an effort to understand," she says. And it doesn't seem too much to ask, since Robyn has no choice but to spend her life trying to get her head around us.

The Asperger's community, which by its very nature is pretty inflexible, is highly vocal on the subject of inclusion. People with ASD want what the rest of us want: jobs, homes, independence. But the wider community, uneducated in such

SHE WORRIES ABOUT SHOPPING. 'I CAN'T GO INTO WAITROSE. I CAN'T STAND THE SHINY FLOOR.' **ROBYN IS HYPERSENSITIVE TO COLOUR AND TEXTURE**

her head on a wall hard enough to give herself concussion. She needs to know what's coming, what's certain, rather than what might be. She is not an order freak – she quite likes mess – but worries about shopping and food all day. She is hypersensitive to colour and texture. "I can't go into Waitrose – I can't stand the shiny floor." Breakfast has to be two Weetabix lined up, with the milk to exactly the same level. "Sometimes I get so panicky I have to phone my friend Bill [a mentor] to find out what I want for my dinner and he says, 'It sounds as though you'd like a

things, doesn't know if it wants them, and Aspies are divided as to whether they want to put up with us. Part of the problem is that the autistic spectrum is so broad. Emma Cantons, mother of Robbie Petre, a 20-year-old with high-functioning autism, says it ranges from "the man in the office who doesn't mix, and is fixated with balls of elastic bands, to those who will never live independently". Of the group whose slogan is "Autism isn't a disability, it's just a different way of being", she says: "The logic is so delightfully autistic. Trust me – if it stops you fitting into



The Griffin brothers
Peter (left) and Stephen
enjoy a lot of laughs

printed on. Amanda Batten, the NAS's head of policy, says: "We do not underestimate the challenge. We'll keep a very close eye on it and we'll go to court if we have to."

Tribunal-weary parents know that local authorities' quibbling over semantics has become so entrenched in some areas, it could almost be considered policy. Amy Brosnan, an ethereal 19-year-old lodged somewhere between childhood and adulthood, was diagnosed with autism at 11. There was a lot of "holding down" at her first school, which Amy remembers as "all fear and no learning". Since she turned 12, she has been at home; she has had no suitable education at all. And now, her mother, Cathy, believes, she has no future.

Cathy sifts through files of letters, evidence of a systematic failure even to acknowledge Amy's needs. "Local-authority psychologists assess you down. Then, when you get a statement, you fight for every aspect of the provision." Cathy has been to tribunal three times, the last time over a school that Amy could have attended until she was 21. The local education authority vacillated for so long that she lost the place.

Amy, so anxious about my visit that she has barely slept, looks sad and lost. She sits and listens, head on one side, occasionally getting so upset that she has to leave the room. She loves taking photographs, and when I leave she gives me a shot of a landscape that shows real ability, but Cathy believes Amy's confidence and self-esteem are now so low that she will need one-to-one care for the rest of her life. It's a tragedy and makes no financial sense, since the cost to the country of looking after Amy will be far more than that of supporting her properly in the first place. "I really hope the Autism Bill works for the kids who are coming through now, because it's too late for us," says Cathy.

One in three autistic adults suffers mental-health problems, and for each of those, not one but several lives are shattered. So many parents talk of the difficulties in securing a diagnosis, or of getting one — but much too late, when their child has dropped out of college or employment or suffered an emotional breakdown. Janette Robb's 30-year-old son, Danny, was only formally diagnosed two years ago. "My son has spent 75% of the past five years in psychiatric hospitals, much of it due to lack of support within the community."

Rosie Cousins, whose adult son has become addicted to prescription drugs, is filled with fury at the years of botched diagnoses and, ultimately, with grief over what might have been. Her plea is simple: "I love him dearly," she writes. "I don't want his life's journey to be a worthless one." ■

In the Tommeys' bedroom — her husband, Jon, is a clinical nutritionist — four computers compete for space with tumbling piles of files and laundry. E-mails to Polly's dressing room-cum-office go like this: "Dear Polly, I have a 21-year-old son with autism and urgently need advice and help..." She is driven — "We cannot afford to lose these young people to a life without a purpose" — yet is clearly exhausted and often defeated by the number and desperation of the calls she gets. "I don't do this through choice. I cannot ignore the need."

Her own son, Billy, now 13, was so profoundly affected by autism and attendant gut problems that he spent the year between 18 months and 2½ screaming. "He'd bang his head for 12 hours a day." She recalls getting on a train and sitting

One writes: "I hope destiny brings a pill which will wipe us out together..." She tells a ghastly story about a 25-year-old on a nine-month waiting list to see a counsellor, whose anxiety reached tipping point. He put a noose round his neck and hanged himself.

There are pockets of good practice: local authorities in Liverpool, Newham and Oldham have dedicated teams to support autistic adults. And in Sunderland, Paul Shattock has established inspirational residential colleges for autistic adults. "In the right environment — low stress, low sensory stimulation — you've got a chance to make a real difference," he says. ESPA colleges, which take a mix of long-term residential and day students and have a waiting list of hundreds,

'MY SON HAS SPENT 75% OF THE PAST FIVE YEARS IN PSYCHIATRIC HOSPITALS, MUCH OF IT DUE TO LACK OF SUPPORT WITHIN THE COMMUNITY'

between two compartments, crying and crying as people climbed over her. "I was desperate. I know how that feels."

She is realistic about Billy's future. "He has full-blown autism. He will never be independent. People say, 'Oh, Polly, you shouldn't say that.' But it's true. If he lived in the community, he'd be a liability. Not fair on the public. Not fair on Billy. But that doesn't mean he can't lead a useful and productive life with the right support."

The trust's centres will include a residential wing for those who need it, a working farm and a business centre with mentors and PAs. "Autistic people have amazing brains — I haven't met one who can't do something — but aspects of life need to be managed for them." Polly gets calls from grandparents looking after grown-up boys their own children can't cope with, and from weeping mothers who talk of suicide.

have their own charter of rights; paramount is "No decisions about us without us".

Paul points out that there's a lot of money to be made in autism. "Nightclub owners", as he calls them, "buy a house, fit it out and fill it with five or six autistic adults. That's not acceptable. But neither is the other option: the vast majority of autistic young people who end up stuck at home with ageing parents, doing nothing".

The NAS hopes that the national adult autism strategy, due at the end of this year, will "hold local authorities legally responsible for providing support for autistic adults and ensure they have clear routes to diagnosis, assessment and support". Which all sounds marvellous, but a plethora of legislation and statutory guidance already exists that is supposed to do the job. Unless local authorities are held to account, this new guidance may not be worth the paper it's