

My Family and Autism

UK TV documentary : 2003 : dir. Fran Landsman : BBC : 55 min
prod: Fran Landsman : scr: : dir.ph.: Martin Lightening

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Radio Times listing:

“A unique insight into how the world can seem to a child with autism is provided by 14-year old Luke Jackson, who is on a crusade to enhance awareness of his condition. He’s one of four boys, all of whom have autism. For his mother Jacqui, the challenges of caring for her sons include searching for anything which may improve their life: special diet, a research optician and an educational psychologist. Executive Producer Jenny Abbott.”

“Initially this documentary seems to tread familiar ground: a young woman with seven children, four of whom are afflicted by autistic spectrum disorder, lets the cameras into her home to show how the world seems to a child with autism. But this isn’t a triumph over tragedy story, neither does mom Jacqui Jackson use the opportunity to bemoan her lot. Filmed without sensationalism or sentimentality, it’s instead a remarkable insight into one, very special, family’s life.

Fourteen-year old Luke provides much of the footage through his video diary. A very articulate young man, he’s on a mission to make people accept him for what he is. “Different is cool,” he tells the delegates at a

big medical conference before explaining: “Asperger’s Syndrome is a more extreme version of real life. To me the world is full of disorganisation... people talking and making strange, inexplicable expressions.”

His younger brothers are quite a handful: nine-year old Joseph has attention deficit hyperactivity disorder [*sic*], while five-year old Ben, who is Jacqui’s most severely autistic son, has only just learnt to walk and communicate. Jacqui searches relentlessly for anything to improve their life, whether it’s diet to control their behaviour or special glasses to help with their reading problems.

It’s hard to imagine a more loving family [*sic*], and each member accepts the others for the way they are in an ordinary, good-humoured way. The Jacksons are different but, as a family unit, they are an example to us all.”

– Jane Rackham

First broadcast BBC2 July 30 2003. An absorbing and superior fly-on-the-wall piece with no external commentary, it would be interesting enough for what it reveals about autistic behaviour and some surprising techniques for dampening the worst symptoms, but doubly interesting as a video diary from an articulate and good-natured 14-year old with Asperger’s Syndrome – “a sort of forerunner of autism” as he puts it.

Autism disproportionately afflicts male children – no explanation why – and in the Jackson family this gender split is reflected in the extreme: four brothers all with the condition, three

sisters all without it, and, at least so far as the film seemed to imply, the family live largely in those two separate camps: the noisy, messy hyperactive boys and the conventional well-adjusted sisters. Mother Jacqui is a resolutely single parent, and confides to the camera that she more or less drove her ex-husband away by emphatically regarding the kids as her exclusive domain, the two of them leading largely separate lives. We hear no more about him, and he's not mentioned once by Luke or any of the others.

When talking about problems like autism, one has to cleave a wide swathe through the dense foliage of polite language to avoid words such as "normal" – Jacqui herself refers in passing to "parents with *typically-developed* children". There's no real problem with the word "normal", (meaning only "average") except in that it infers the word "abnormal" to anyone who falls outside the boat, and that's a word with inescapable pejorative baggage. I for one am quite happy to be considered abnormal, having little regard for today's standards of "normalcy", but kids are under far more immediate pressures to conform. Luke tells us "I've been bullied a lot in the past and called names like 'freak' and 'geek', but at least at home we can just be ourselves."

"Different is cool" he tells his conference audience, but that rather glib TV soundbite belies the fact that, for any 14-year old, let alone one with his particular impairments, Luke is well in command of the technical terminology for his brothers' conditions, and talks about them with both confidence and insight. So we hear a deal about "early onset conduct disorder" and "attention deficit hyperactivity disorder" and so forth, but also flashes of plain English revelation, both from Luke and his mother, about the subjective autistic world. For example, she has to be careful what idioms she uses in the earshot of Joseph and Ben, because autistic children tend to interpret language ultra-literally. "I'm going to feed your sisters" she tells five-year old Ben, who points out his sisters can quite cope with feeding themselves, so she then has to explain she'll just put the food on a plate and let them eat for themselves.

Ben twirls around the house in nappies still, because autistic children have hyper-sensitive skin. He's also incontinent, with all the attendant miseries for mum, whose bed he shares. Jacqui describes the whole family crawling about on hands and knees one evening, trying to sniff out the location of a stray turd Ben has left somewhere, and then all of them collapsing in laughter when the absurdity of their situation obtruded itself. Joseph meanwhile, a 24-hour ball of manic energy and motion, has a habit of redistributing his brothers' and sisters' possessions and clothing, lifting them and giving them away to people at school. Joseph has no comprehension whatever of private possession, and doesn't so much "steal" these articles as move them arbitrarily to other places. His room is a permanent state of primal chaos, and mum has to keep hunting there whenever articles go missing.

Over all of this Jacqui presides with the patience of a saint, the diligence of a head warder, and the equanimity of an intelligent person who sees beyond the needs of the handicap itself to the challenge of communicating on a different, highly specialised order with four such out-of-the-ordinary sons. Autism, on one level, appears to be a heightened state of sensory awareness – hearing and seeing and smelling the world far more intensely than most of us, which is in itself intriguing, autism as the polar opposite of blindness or deafness. So when she takes Luke and Joseph to see an optical specialist, he achieves quite striking results simply by fitting each of them with different colour-filtered glasses to compensate for the spectrum distortion in their own optical field. Joseph is highly dyslexic, words and letters crawling around on the page for him "like ants" as he describes it, but put him in special red-tinted spectacles and the whole world calms down. Luke, similarly, is agitated by the fluorescent lighting at school, but a pair of green-tinted specs correct for that optical distortion.

An educational psychologist (female, of course) interviews Joseph very closely about how he interprets the way he acts, and the effect of it on those around him, and then plays him a tape of seemingly chaotic sounds, inviting him to count the distinct separate noises. The boy settles to the task with a calmness and intensity Luke has never seen in him before, and clearly can hear patterns in the noise which would baffle most of us. All of this is genuinely

fascinating stuff, so that the film (or Luke and Jacqui) almost single-handedly redefine autism from a mere educational impairment to a uniquely specialised sensory perspective. But this is not to deny the all-too-apparent strains it places on family life, and mother in particular. She still cannot get Ben or Joseph to make direct eye contact when she speaks to them. Luke tells us why this is, and how he worked his own way around it, but it cannot help but cause distress to any parent.

The film is at least as intriguing for the questions it pertinently refuses to address: a family of **seven** children? In this day and age? And the odds against any parent producing four autistic sons in a row (with three perfectly healthy sisters) must be absolutely astronomical, yet we never hear discussed whether this is a genetically transmitted condition or weakness, or any other feasible explanation. Jacqui is midway through her doctoral thesis in forensic psychology, yet she is never asked how one poor woman can possibly cope with all the strains and pressures of such a huge and demanding family, while at the same time fulfilling her commitments to an exacting course of academic study. We see her struggling through the weekly shopping routine with Joseph and Ben in tow, having to meticulously study the ingredient lists for foodstuffs which will exacerbate Jo's hyperactivity, and then hide those foods carefully out of reach, cooking for her kids in rotation – each with their separate dietary needs, attending therapy sessions with Joseph, escorting the whole brood to evening Tai-Kwondo lessons, and on and on. It is exhausting merely to watch the demands of her average day. Only a very exceptional woman could cope. But cope she does.

"Sometimes I feel as if I actually *am* from a different planet" says Luke, who wrote his first book on autism at 13, and has a passion for computers and computer games bordering, in his mother's mind, on obsessionality. His IQ is clearly well above average, autism or no autism, and he's a refreshingly candid and unconceited 14-year old. The RT statement "it's hard to imagine a more loving family" is at the same time obsequious and patronising, but this is certainly a family that commands respect, and a mother shouldering a payload of responsibility far above anything most families ever have to cope with. All families are a kind of zoo, but some of the animals in her zoo are certainly more interesting than the, er, normal. **Recommended.**

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