

INTRODUCTION

The thirteen-year-old author of this book invites you, his reader, to imagine a daily life in which your faculty of speech is taken away. Explaining that you're hungry, or tired, or in pain, is now as beyond your powers as a chat with a friend. I'd like to push the thought-experiment a little further. Now imagine that after you lose your ability to communicate, the editor-in-residence who orders your thoughts walks out without notice. The chances are that you never knew this mind-editor existed but, now that he or she has gone, you realize too late how they allowed your mind to function for all these years. A dam-burst of ideas, memories, impulses and thoughts is cascading over you, unstoppable. Your editor controlled this

flow, diverting the vast majority away, and recommending just a tiny number for your conscious consideration. But now you're on your own.

Now your mind is a room where twenty radios, all tuned to different stations, are blaring out voices and music. The radios have no off-switches or volume controls, the room you're in has no door or window, and relief will come only when you're too exhausted to stay awake. To make matters worse, another hitherto unrecognized editor has just quit without notice – your editor of the senses. Suddenly sensory input from your environment is flooding in too, unfiltered in quality and overwhelming in quantity. Colours and patterns swim and clamour for your attention. The fabric conditioner in your sweater smells as strong as air-freshener fired up your nostrils. Your comfy jeans are now as scratchy as steel wool. Your vestibular and proprioceptive senses are also out of kilter, so the floor keeps tilting like a ferry in heavy seas, and you're no longer sure where your hands and feet are in relation to the rest of you. You can feel the plates of your skull, plus your facial muscles and your jaw: your head feels trapped inside a motorbike helmet three sizes too small which may or may not explain why the air-conditioner is as deafening as an electric drill, but

your father – who’s right here in front of you – sounds as if he’s speaking to you from a cell-phone, on a train going through lots of short tunnels, in fluent Cantonese. You are no longer able to comprehend your mother-tongue, or any tongue: from now on all languages will be foreign languages. Even your sense of time has gone, rendering you unable to distinguish between a minute and an hour, as if you’ve been entombed in an Emily Dickinson poem about eternity, or locked into a time-bending SF film. Poems and films, however, come to an end, whereas this is your new ongoing reality. Autism is a lifelong condition. But even the word ‘autism’ makes no more sense to you now than the word 自閉症 or αυτισμός or ऑटज़िम.

Thanks for sticking to the end, though the real end, for most of us, would involve sedation, and being sectioned, and what happens next it’s better not to speculate. Yet for those people born onto the autistic spectrum, this unedited, unfiltered and scary-as-all-hell reality is home. The functions which genetics bestow on the rest of us – the ‘editors’ – as a birth-right, people with autism must spend their lives learning how to simulate. It is an intellectual and emotional task of Herculean, Sisyphean and Titanic proportions, and if the people with autism who

undertake it aren't heroes, then I don't know what heroism is, never mind that the heroes have no choice. Sentience itself is not so much a fact to be taken for granted, but a brick-by-brick, self-built construct requiring constant maintenance. As if this wasn't a tall enough order, people with autism must survive in an outside world where 'special needs' is playground slang for 'retarded', where meltdowns and panic attacks are viewed as tantrums, where disability allowance claimants are assumed by many to be welfare scroungers, and where British foreign policy can be described as 'autistic' by a French minister. (M. Lellouche apologized later, explaining that he never dreamt that the adjective could have caused offence. I don't doubt it.)

Autism is no cakewalk for the child's parents or carers either, and raising an autistic son or daughter is no job for the fainthearted – in fact, faintheartedness is doomed by the first niggling doubt that there's Something Not Quite Right about your sixteen-month-old. On Diagnosis Day, a child psychologist hands down the verdict with a worn-smooth truism about your son still being the same little guy that he was before this life-redefining news was confirmed. Then you run the gauntlet of other people's reactions: 'It's just so sad'; 'What,

so he's going to be like Dustin Hoffman in *Rain Man*?'; 'I hope you're not going to take this so-called "diagnosis" lying down!'; and my favourite, 'Yes, well, I told my GP where to go stick his MMR jabs.' Your first contacts with most support agencies will put the last nails in the coffin of faintheartedness, and graft onto you a layer of scar-tissue and cynicism as thick as rhino-hide. There are gifted and resourceful people working in autism support, but with depressing regularity government policy appears to be about Band-Aids and fig leaves, and not about realising the potential of children with special needs and helping them become long-term net contributors to society. The scant silver lining is that medical theory is no longer blaming your wife for causing the autism by being a 'Refrigerator Mother' as it did not so long ago (Refrigerator Fathers were unavailable for comment) and that you don't live in a society where people with autism are believed to be witches or devils and get treated accordingly.

Where to turn to next? Books. (You'll have started already, because the first reaction of friends and family desperate to help is to send clippings, web-links and literature, however tangential to your own situation.) Special Needs publishing is a jungle.

Many *How to Help Your Autistic Child* manuals have a doctrinaire spin, with generous helpings of © and ™. They may contain useable ideas, but reading them can feel depressingly like being asked to join a political party or a church. The more academic texts are denser, more cross-referenced and rich in pedagogy and abbreviations. Of course it's good that academics are researching the field, but often the gap between the theory and what's unravelling on your kitchen floor is too wide to bridge.

Another category is the more confessional memoir, usually written by a parent, describing the impact of autism on the family and sometimes the positive effect of an unorthodox treatment. These memoirs are media-friendly and raise the profile of autism in the marketplace of worthy causes, but I found their practical use to be limited, and in fairness they usually aren't written to be useful. Every autistic person exhibits his or her own variation of the condition – autism is more like retina patterns than measles – and the more unorthodox the treatment for one child, the less likely it is to help another (mine, for example).

A fourth category of autism book is the 'autism autobiography' written by insiders on the autistic

spectrum, the most famous example being *Thinking in Pictures* by Temple Grandin. For sure, these books are often illuminating, but almost by definition they tend to be written by adults who are already sorted, and they couldn't help me where I needed help most: to understand why my three-year-old was banging his head against the floor; or flapping his fingers in front of his eyes at high speed; or suffering from skin so sensitive that he couldn't sit or lie down; or howling with grief for forty-five minutes when the *Pingu* DVD was too scratched for the DVD player to read it. My reading provided theories, angles, anecdotes and guesses about these challenges, but without reasons all I could do was look on, helplessly.

One day my wife received a remarkable book she had ordered from Japan called *The Reason I Jump*. Its author, Naoki Higashida, was born in 1992 and was still in junior high-school when the book was published. Naoki's autism is severe enough to make spoken communication pretty much impossible, even now. But thanks to an ambitious teacher and his own persistence, he learnt to spell out words directly onto an alphabet grid. A Japanese alphabet grid is a table of the basic forty Japanese hiragana letters, and its English counterpart is a copy of the

QWERTY keyboard, drawn onto a card and laminated. Naoki communicates by pointing to the letters on these grids to spell out whole words, which a helper at his side then transcribes. These words build up into sentences, paragraphs and entire books. 'Extras' around the side of the grids include numbers, punctuation, and the words 'Finished', 'Yes' and 'No'. (Although Naoki can also write and blog directly onto a computer via its keyboard, he finds the lower-tech alphabet grid a 'steadier hand-rail' as it offers fewer distractions and helps him to focus.) Even in primary school this method enabled him to communicate with others, and compose poems and story books, but it was his explanations about why children with autism do what they do that were, literally, the answers that we had been waiting for. Composed by a writer still with one foot in childhood, and whose autism was at least as challenging and life-altering as our son's, *The Reason I Jump* was a revelatory godsend. It felt as if, for the first time, our own son was talking to us about what was happening inside his head, through Naoki's words.

The book goes much further than providing information, however: it offers up proof that locked inside the helpless-seeming autistic body is

a mind as curious, subtle and complex as yours, as mine, as anyone's. During the 24/7 grind of being a carer, it's all too easy to forget the fact that the person you're doing so much for is, and is obliged to be, more resourceful than you in many respects. As the months turn into years 'forgetting' can become 'disbelieving', and this lack of faith makes both the carer and the cared-for vulnerable to negativities. Naoki Higashida's gift is to restore faith: by demonstrating intellectual acuity and spiritual curiosity; by analysis of his environment and his condition; and by a puckish sense of humour and a drive to write fiction. We're not talking signs or hints of these mental propensities: they're already here, in the book which (I hope) you're about to read.

If that weren't enough, *The Reason I Jump* unwittingly discredits the doomiest item of received wisdom about autism – that people with autism are anti-social loners who lack empathy with others. Naoki Higashida reiterates repeatedly that no, he values the company of other people very much. But because communication is so fraught with problems, a person with autism tends to end up alone in a corner, where people then see him or her and think, *aha, classic sign of autism, that*. Similarly,

if people with autism are oblivious to other people's feelings, how could Naoki testify that the most unendurable aspect of autism is the knowledge that he makes other people stressed out and depressed? How could he write a story (entitled *I'm Right Here* and included at the end of the book) boasting characters who display a range of emotions and a plot designed to tweak the tear-glands? Like all storytelling mammals, Naoki is anticipating his audience's emotions and manipulating them. That is empathy. The conclusion is that both emotional poverty and an aversion to company are not *symptoms* of autism but *consequences* of autism, its harsh lockdown on self-expression and society's near-pristine ignorance about what's happening inside autistic heads.

For me, all the above is transformative, life-enhancing knowledge. When you know that your kid wants to speak with you, when you know that he's taking in his surroundings every bit as attentively as your non-autistic daughter, whatever the evidence to the contrary, then you can be ten times more patient, willing, understanding and communicative; and ten times better able to help his development. It is no exaggeration to say that *The Reason I Jump* allowed me to round a corner in our

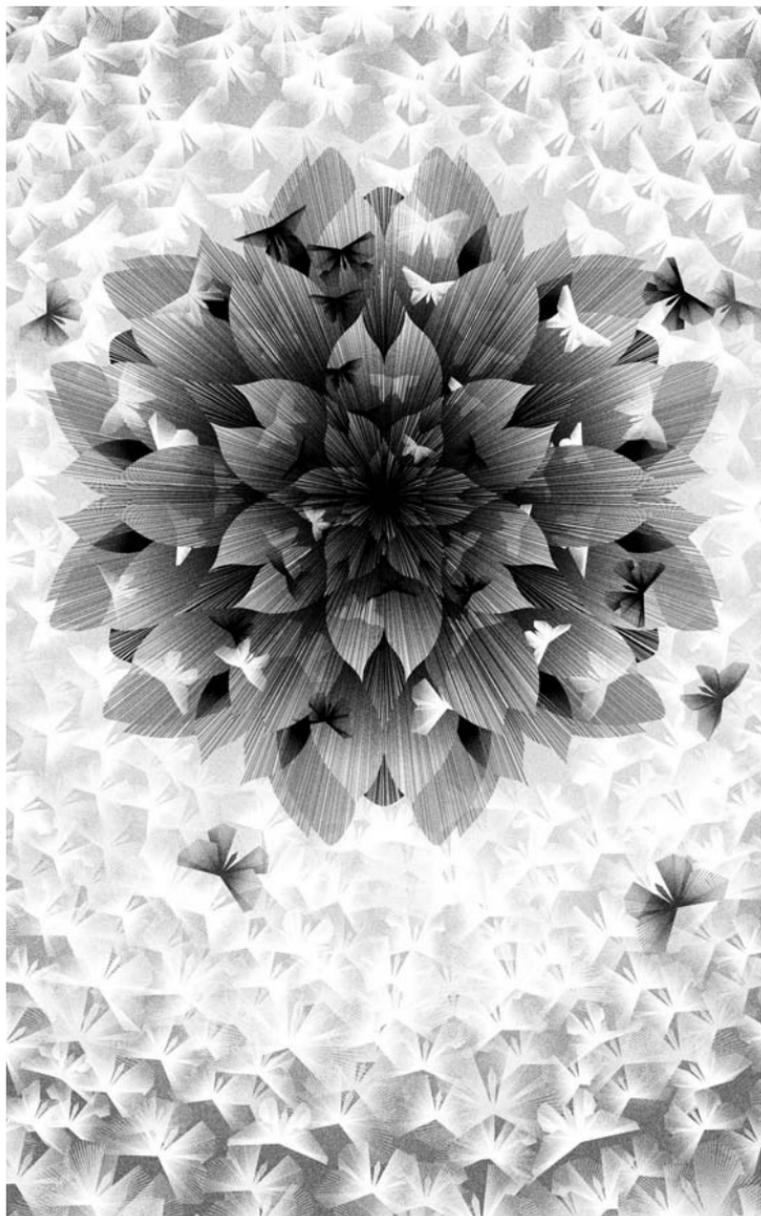
relationship with our son. Naoki Higashida's writing administered the kick I needed to stop feeling sorry for myself, and start thinking how much tougher life was for my son, and what I could do to make it less tough. Virtuous spirals are as wonderful in special needs parenting as anywhere else: your expectations for your child are raised; your stamina to get through the rocky patches is strengthened; and your child senses this, and responds. My wife began to work on an informal translation of Naoki's book into English so that our son's other carers and tutors could read it, as well as a few friends who also have sons and daughters with autism in our corner of Ireland. But after discovering through web groups that other expat Japanese mothers of children with autism were frustrated by the lack of a translation into English, we began to wonder if there might not be a much wider audience for Naoki Higashida. This English translation of *The Reason I Jump* is the result.

The author is not a guru, and if the answers to a few of the questions may seem a little sparse, remember he was only thirteen when he wrote them. Even when he can't provide a short, straight answer – such as to the question 'Why do you like lining up your toys so obsessively?' – what he has to

say is still worthwhile. Naoki Higashida has continued to write, keeps a nearly daily blog, has become well known in autism advocacy circles, and been featured regularly in the Japanese *Big Issue*. He says that he aspires to be a writer, but it's obvious to me that he already is one – an honest, modest, thoughtful writer, who has won over enormous odds and transported first-hand knowledge from the severely autistic mind into the wider world; a process as taxing for him as, say, the act of carrying water in cupped palms across a bustling Times Square or Piccadilly Circus would be to you or me. The three characters used for the word 'autism' in Japanese signify 'self', 'shut' and 'illness'. My imagination converts these characters into a prisoner locked up and forgotten inside a solitary confinement cell waiting for someone, anyone, to realise he or she is in there. *The Reason I Jump* knocks out a brick in the wall.

David Mitchell
Ireland, 2013

THE REASON I JUMP



PREFACE

When I was small, I didn't even know that I was a kid with special needs. How did I find out? By other people telling me that I was different from everyone else, and that this was a problem. True enough. It was very hard for me to act like a normal person, and even now I still can't 'do' a real conversation. I have no problem reading books aloud and singing, but as soon as I try to speak with someone, my words just vanish. Sure, sometimes I manage a few words – but even these can come out the complete opposite to what I want to say! I can't respond appropriately when I'm told to do something, and whenever I get nervous I run off from wherever I happen to be. So even a straightforward activity like shopping

can be really challenging if I'm tackling it on my own.

So *why* can't I do these things? During my frustrating, miserable, helpless days, I've started imagining what it would be like if everyone was autistic. If autism was regarded simply as a personality type, things would be so much easier and happier for us than they are now. For sure, there are bad times when we cause a lot of hassle for other people, but what we really want is to be able to look towards a brighter future.

Thanks to training I've had with Ms Suzuki at Hagukumi School, and my mum, I've learnt a method of communication via writing. Now I can even write on my computer. Problem is, many children with autism don't have the means to express themselves, and often even their own parents don't have a clue what they might be thinking. So my big hope is that I can help a bit by explaining, in my own way, what's going on in the minds of people with autism. I also hope that, by reading this book, you might become a better friend of someone with autism.

You can't judge a person by their looks. But once you know the other person's inner self, both of you can be that much closer. From your point of view, the world of autism must look like a deeply mysterious place. So please, spare a little time to listen to what I have to say.

And have a nice trip through our world.

Naoki Higashida
Japan, 2006

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Q1 HOW ARE YOU WRITING THESE SENTENCES?

The Alphabet Grid is a method of non-vocal communication. You might think that speech is the only way to get your points and intentions across, but there is another way to say what you want without using the vocal nervous system. At first I never dreamt I could make it work, but now I'm well able to express my true self using only a computer and an alphabet grid.

This was an incredible feeling! Not being able to talk means not being able to share what you're feeling and thinking. It's like being a doll spending your whole life in isolation, without dreams and without hopes. Sure, it took a long time before I

could finally start communicating via written text on my own, but on that first day when my mum supported my writing hand in hers, I began to acquire a new way of interacting with others.

Then, to allow more independent communication, Mum invented the alphabet grid. The alphabet grid makes it possible to form my words by simply pointing to their letters, instead of having to write them out one by one. This also lets me anchor my words, words that would otherwise flutter off as soon as I tried to speak them.

Often, while I was learning this method, I'd feel utterly beaten. But finally, I arrived at the point where I could indicate the letters by myself. What kept me hammering away at it was the thought that to live my life as a human being, nothing is more important than being able to express myself. So for me, the alphabet grid isn't just about putting together sentences: it's about getting across to other people what I want and need them to understand.

Q2 WHY DO PEOPLE WITH AUTISM TALK SO LOUDLY AND WEIRDLY?

People often tell me that when I'm talking to myself my voice is really loud, even though I still can't say what I need to, and even though my voice at other times is way too soft. This is one of those things I can't control. It really gets me down. Why can't I fix it?

When I'm talking in a weird voice, I'm not doing it on purpose. Sure, there are some times when I find the sound of my own voice comforting, when I'll use familiar words or easy-to-say phrases. But the voice I can't control is different. This one blurts out, not because I want it to: it's more like a reflex.

A reflex reacting to what? To what I've just seen, in some cases, or to some old memories. When my weird voice gets triggered, it's almost impossible to hold it back – and if I try, it actually hurts, almost as if I'm strangling my own throat.

I'd be okay with my weird voice on my own, but I'm aware that it bothers other people. How often have the strange sounds coming out of my mouth embarrassed me nearly to death? Honest, I want to be nice and calm and quiet too! But even if we're ordered to keep our mouths shut or to be quiet we simply don't know how. Our voices are like our breathing, I feel, just coming out of our mouths, unconsciously.