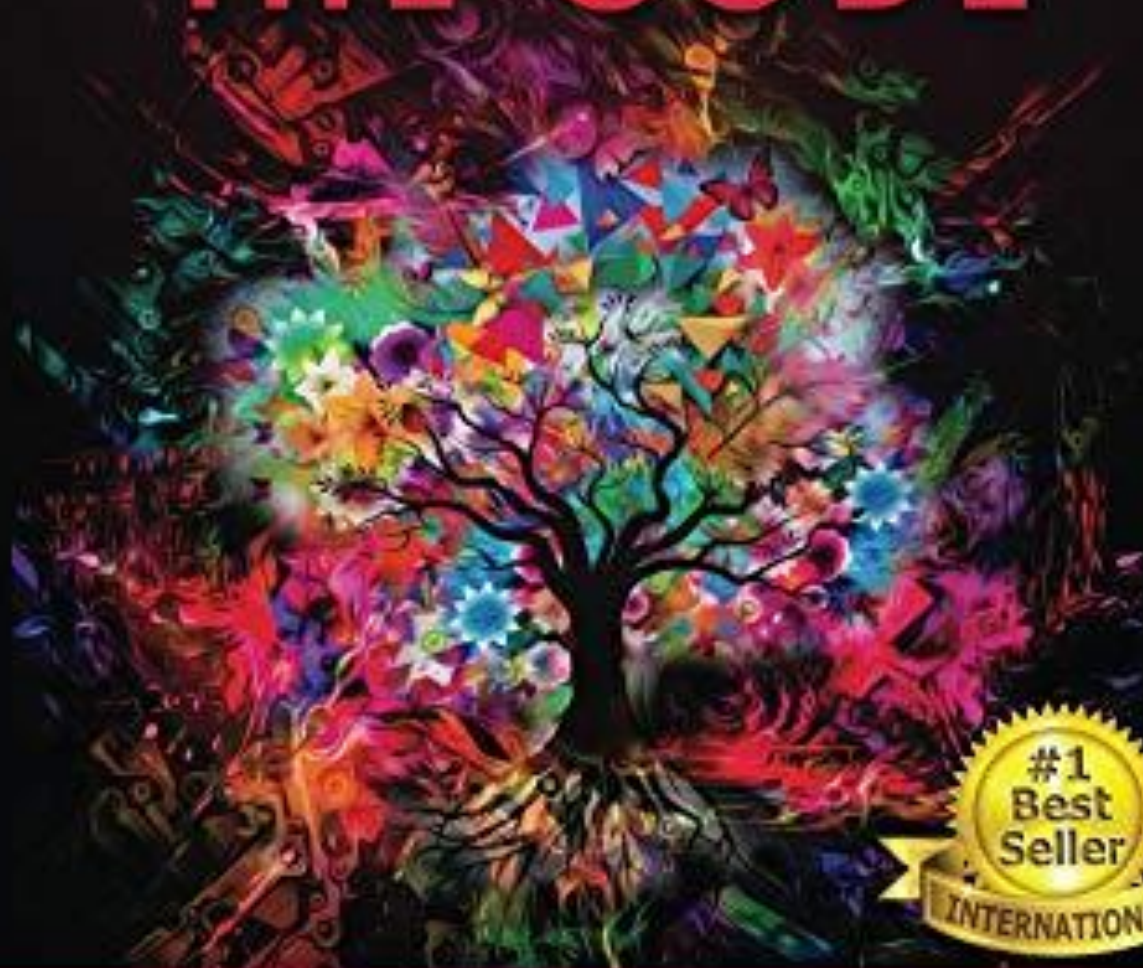


AUTISM DECODED

THE CRACKS

— in —

THE CODE



STELLA WATERHOUSE

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ENDORSEMENTS

This is a book for those who live with family members or friends on the Autism spectrum or for those who would just like to know and to understand more. It is not a medical textbook; it is full of personal observations and anecdotes of people, not patients, based on Stella's extensive experience.

An eminently readable book and sometimes difficult to put down, it portrays those with ASD in an understanding and compassionate light. It will add a great deal to these complex and very often misunderstood syndromes.

Elizabeth Rowse, M.R.C.P (Retired), Salcombe, Devon

Note: this series owes a great debt to Elizabeth for it was her initial reaction to it that kept me going when the going got tough....

Stella's summary of the experiences of people with ASD was particularly captivating to me. I have been seeing the parallels among us since reading Donna Williams' first book in 1991, and the internet has made it ever so much easier to track all the similarities among us. My special interest has been to bring those in-common experiences together with the science that makes sense of them, and to translate this into ordinary English for people who would like to reduce or eliminate the challenging symptoms of autism.

"Recovery" is a poor word for the return of physical, mental and emotional health that is possible for us autistics, because although we may lose our diagnoses, we will never be neuro-typical. Different parts of our brains have taken on different tasks, and that is something which brings both challenge and benefit... but as autistics, we truly appreciate the benefits.

I will look forward to reading *The Ciphers*. The Markrams, Dr. Squibb, and Professor Paul Tallal are on the right tracks... and I had heard of none of them previously. It is wonderful to have that information.

Jackie McMillan, BES, Aspergers, ThriveWithAutism.ca

INTRODUCTION

Author's log

Place: Tenth Grade study room. **Date:** September 1967. Two weeks into term.

I'm bored out of my mind and facing two more endless years if I want to be a teacher. The less studious read comics, swop jokes and even smoke illicitly. Their latest ploy: launching sporadic "missile" attacks across our heads.

A paper plane grazes my ear.

Decision made, I bury my dream.

Place: The Camphill Community. **Date:** One week later.

My first real job: looking after staff children. Great fun. Look forward to traveling the world via other Camphill schools.

Date: Three months later.

Some of the pupils intrigue me.

Beautiful and serene, Cara is "otherworldly": an enigmatic Mona Lisa with a faraway look who is, seemingly, unaware of her surroundings.

In sharp contrast, Tommy is a real live wire who needs watching constantly as he eats anything and everything – food or not – gulping it down, regardless of how hot or cold it is.

Mandy too is a proverbial wild child. A haunting beauty, she lacks any sense of danger and often disappears, only to be found wandering aimlessly, miles away.

Three very different children.

One diagnosis: Autism.

Camphill Communities

enable people with learning disabilities and other special needs to live, learn and work together in an atmosphere of mutual care and respect.

The first community was founded by Karl König, an Austrian physician, in 1940, at Camphill House, in Aberdeen, Scotland.

It was based on the ideas and work of [Rudolf Steiner](#). He founded Anthroposophy and also the Waldorf schools which began in 1919.

Postscript

I was captivated.

And that enduring enchantment launched me on the journey of my life.

Initially, with my understanding limited by a lack of experience, I began by following the well-trod Camphill line that such children simply followed a different drummer. Unwilling to accept that it was simply happenstance or destiny I sought that drummer for much of my life. And yet, in time, I came to realize that it is an illusion: a device to help explain the seemingly inexplicable.

Even so, as you'll see during this series, such differences have a reason; namely that such children lived, as many still do, in a place where truth is far stranger than fiction.

My credentials? The mystique of Cara, Tommy and Mandy took me to St Christopher's School in Bristol, England, where I trained as a Steiner teacher.

It was there that I met Jenny. More communicative than the others, she tolerated people standing nearby and talking to her, but only ever responded by repeating the same phrase over and over. And yet she too shared the same diagnosis.

I went on to work with children with a variety of learning disabilities: children who became my teachers.

In the mid-seventies I took a sideways step, leaving teaching behind to cross the divide into "care"; working with severely emotionally disturbed adolescent boys at the Cotswold Community. Poles apart from Camphill, it was then based on psycho-therapeutic lines; introducing me to a totally different approach.

Ten years later I returned to my roots, working in a residential community specifically for people with autism spectrum disorders or ASD, where I eventually became Deputy Principal. As ever, the residents there taught me a great deal, although, even with their help, some aspects of ASD continued to mystify me for many years.

Fast forward to the late 1980s when I began to write a short book on the role of anxiety in autism: a topic generally omitted from the literature at that time. That project quickly took on a life of its own, evolving into something much larger for, unsurprisingly, the more I read the more avenues for exploration opened. Over the ensuing years that small project has expanded most latterly culminating in this series; although whether this will be the end of my search is a moot point.



If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away.

Henry Thoreau

Initially some of the clues I unearthed seemed contradictory or confusing which is why, ever a “doubting Thomas,” I investigated many of them myself. By discarding the red herrings and those that ended in blind alleys I found that a pattern gradually emerged, affording me an insight into some of the underlying problems of ASD.

Ever since the beginning of the 21st century ideas about, and knowledge of, ASD have expanded greatly. Today information abounds, multiplying almost daily: making it absolutely impossible to take everything into account. So, although this book does not aim – or claim – to be comprehensive, it is comprehensible and will certainly “crack” enough of the code to engender a deeper understanding of ASD.

Over the years there have been many conflicting ideas about ASD, its origins and the best way to help those with it. That’s why it is vital to listen to the people with ASD themselves who, as [Temple Grandin](#) famously said, feel like “anthropologists on Mars.” We must include both those people who, regardless of their abilities in their early years, now speak fluently, as well as those to whom speech does not come easily; many of whom have given written accounts – some writing independently, others with support.

Unfortunately, although such people offer a unique insight into the daily problems of life with ASD, over the years many professionals have ignored their testimony or questioned the veracity of their experiences; often dismissing them as “anecdotal.”

That seem unlikely given that, over the years, many articles and books have been written about or by people with ASD. They come from people of all ages and abilities, living in different parts of the world. Accounts so remarkably similar and consistent, that it seems foolish, nay impossible, to dismiss them as unreliable.

To add to that, some of the people now writing and speaking about their experiences of living with ASD are graduates with doctorates in a wide range of subjects, several of whom have careers in which they are well respected.

If their views do not reflect our ideas, perhaps we shall need to revise our ideas.

With a million ways to tell the story of autism what should you expect? Like my earlier books, the four books in this series, *Autism Decoded*, involve detective work, looking for patterns, connections or links. Much of it comes from new research, but along the way I have also reviewed, revised and/or expanded some of my original ideas, oft-times because I have finally begun to fully understand things that have stared me in the face for several years. That has enabled my research to culminate in an ambitious, original and ground-breaking series that will help unlock the many mysteries of ASD, like the often-overlooked link between the sensory differences, anxiety and obsessions and compulsions: all of which we’ll look at in more detail later.

The Cracks in the Code takes a light and somewhat controversial approach to this weighty and complex subject, being illustrated by personal accounts, film and literature. Along the way it will also take a look at the lives of some people who, while they may not have autism, bring new, and often surprising, insights to the search.

Of necessity it also includes a picture of autism as seen through the eyes of some of the great educators, physicians, psychologists and researchers. It will detail, discuss and assess some of their ideas and theories while also looking at some of the treatments and therapies that have been developed over the years.

Seeing ASD from this wide variety of perspectives will give you a real insight into the world of autism, both throughout history and as it is today. That will provide a solid foundation for what will follow in the rest of the series, as we clarify both the criteria and the causes. Ideas that will challenge you to reassess your thinking and join the debate.

The second book, *The Ciphers*, will aim to clarify just where the spectrum begins and ends. Along the way you will meet a wide range of people with related disorders and/or mild sensory differences as well as others who had the misfortune to be in the wrong place at the wrong time. At first sight, some of the latter, like American Explorer Admiral Byrd and former hostages Brian Keenan and Terry Waite, appear to have nothing at all to do with ASD and yet all have something to add to this quest.

The knowledge they offer will enable us to identify the ciphers, by which I mean those difficulties that underlie the diagnostic criteria, and, by determining which are unique to ASD, will also enable us to clearly differentiate between ASD and other similar conditions.

The third book seeks *The Source Code*, just what causes ASD in the first place: be that one thing or several. Along the way it will also address one of the most hotly debated topics in autism today: the role that vaccinations may or may not play in its onset, introducing new and relevant information that has, thus far, been overlooked by mainstream researchers.

I am well aware how sensitive and controversial that topic is but would ask that you do not make any premature judgements about my views. No doubt some people would prefer me to ignore the debate but that would be both cowardly and foolish. I intend to follow the evidence wherever it takes me: regardless of the outcome. Thus, in that, as in all other sensitive areas of autism, I intend to write without fear or favor.

The fourth and final book? Once all the pieces of the puzzle are in place, we'll be able to assess the validity and efficacy of some of the many treatments and therapies used, both mainstream and alternative: from the most controversial approaches (like electric shock "treatment") to some of the most unconventional...the use of animals as therapists. Hence the title *Decryption*.

What makes this series different to other books about autism? The answer lies in the word “series” for while some books offer more detail and others more depth, the series is able to be far broader in scope.

Its aim? To alter society’s perception of people with ASD, raise awareness of the problems that underlie it and cut through the maze of conflicting advice, treatments and therapies to offer unbiased information to parents.

Four points need noting.

One is that some names have been changed to protect people’s privacy. Second, that because many people feel their autism is integral to their being and dislike being referred to as “people with autism,” I shall generally refer to them as Auties and those with Asperger’s Syndrome (AS) as Aspies. Even so for the sake of brevity, the phrase “people with ASD or autism” will also be used to encompass both groups. Third, no disrespect is intended by the cartoons and anecdotes; they are merely intended to enhance the text: laughter being a saving grace for parents and care-givers the world over. Finally, I should also note that while this book often refers to “he,” autism clearly affects both sexes.

This book is aimed at anyone with an interest in ASD, particularly those who enjoy a good mystery, crossword or puzzle. You need no prior knowledge to join the search. Indeed, it will be an advantage to have none, for preconceived ideas can often be a hindrance.

It is a mystery with an abundance of clues, not all of which are genuine so in order to crack the code, we will need to examine each clue (even those that are unpalatable), sift the evidence and make a few deductions. That should enable us to draw the threads together to form a coherent picture that fits the evidence. Although the conclusions are mine and mine alone, that means that you too can follow the trail and join the debate.

Along the way I shall also attempt to correct some of the common misconceptions about ASD, from the increasingly common myth that autism is solely a product of the 20th century or that most such people are mentally handicapped to the misapprehension that they will all need lifelong care if not given treatment in their earliest years.

What’s in a name?

In 2013 the American Psychiatric Association published the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders called DSM-5.

It modified the criteria for ASD; incorporating Asperger’s Syndrome and several other disorders under the umbrella of the Autism spectrum.

However, many people who have already been diagnosed still refer to themselves as having Asperger’s – or being Aspies.

Nor can we ignore the unfortunate fallacy that gave rise to a recent article which suggested (perhaps tongue in cheek?) that all British men have AS. No need to worry though, for it is not only a British phenomenon, as can be seen on one dedicated internet site that cites a whole range of highly successful people as having either AS or autistic traits: a list that includes Bill Gates, Al Gore, Woody Allen, Bob Dylan and numerous others. Rooted in science and exaggerated by the spotlight of publicity is it fact, fallacy or fiction? We'll see.

The type of character associated with AS is typified in the British TV comedy [Doc Martin](#). Based on a socially inept doctor, played by Martin Clunes, who goes to work in a small Cornish village, much of the show's humor revolves around the Doc's interaction with the local villagers, for despite his surgical brilliance, he lacks personal skills, understanding of others and any semblance of a bedside manner; while also having great difficulty in either demonstrating or dealing with his emotions.

Thus, even when he finally falls in love with local schoolmistress Louisa, she has to make all the moves while he constantly squashes every opportunity for a romantic encounter; often by commenting on something embarrassing, such as her perceived halitosis. Even when the opportunity arises to say he loves her, Doc Martin just babbles on about the fact that they do not know each other well and that there are many illnesses that masquerade as love...

And yet, despite all that, Doc Martin does not have Asperger's. Or does he?

Perhaps we'll find out later?

Autism and AS are arguably two of the most complex disorders known; puzzling many people even today. Since the late 1980s the incidence of autism has increased, altering many lives irrevocably.

Currently the "A" word evokes strong emotions. All too often such emotions are driven by fear: both of disability and difference. Thus, some parents (and wannabes) are afraid; of needs they feel unable to meet, of demands they feel they lack the ability to fulfil, of children who may not relate to them, of the world's judgment of their child, and even its judgment of them as parents.

Surely the best way to dispel such fear is through knowledge.

Up for the challenge?

Follow me.

Changing times

Twenty years ago, women of a certain age would come to us, and say: "Doctor, my husband is a jerk, what should I do?"

Now they say: "Doctor, my husband has Asperger's, what should I do?"

A New York psychiatrist

PART ONE
PERSPECTIVES

It is a riddle, wrapped in a mystery, inside an enigma; but perhaps there is a key.

Winston Churchill

CHAPTER ONE

MIRRORS OF REALITY

Autism is a journey and not a destination . . .

Gillian Naysmith

So just what is autism?

Once thought to be a term misappropriated by middle-class parents who didn't want to believe that their child was "mentally handicapped," people on this spectrum come from all social strata, races, creeds and abilities. Even so, regardless of ability, age or place on the spectrum, all have a few things in common and, to borrow a phrase from the [Horse Whisperer Monty Roberts](#), are both as different and alike as snowflakes.

If your information comes solely from early popular films, you could be excused for thinking that everyone with autism is a savant.

That rare but extraordinary condition is found in some people with serious mental disabilities, including autism, who have exceptional skills or extraordinary abilities. Islands of genius that contrast sharply with their ability to cope with daily life.

That was certainly the view of many people who watched [Rain Man](#), the highly acclaimed film which won Dustin Hoffman an Oscar in 1989 for his sensitive portrayal of Raymond. Ray is a "high-functioning" savant who, being unable to fend for himself, lives in an institution.

Raymond's brother Charlie Babbitt (Tom Cruise) is a selfish, arrogant wheeler-dealer. When his father dies all Charlie inherits is an old Buick, while the large family fortune is left in trust for a brother Charlie didn't even know existed.

Savant skills fall broadly into five groups: the arts, music, calendar calculating, lightning arithmetic and mechanical spatial skills.

Some "savant" musicians combine great skill at improvisation with a fantastic memory and can play complex pieces of music by ear after hearing them only once.

Others focus on practical matters; some being gifted sculptors or artists, others extremely good with mechanical things.



In great financial difficulties Charlie attempts to gain a share of the inheritance by kidnapping Ray from the institution and then takes him on a cross-country trip back to Los Angeles to meet with Charlie's attorneys.

It proves to be a life-changing journey for both brothers as Raymond's odd mannerisms and behaviors constantly thwart or curtail Charlie's plans.

Ray refuses to fly (except on Qantas), insists on breaking the trip to watch his favorite program every day at a certain time, and at one point gets out of the car and starts walking. He has other obsessions which hinder their trip so that he insists on eating the same food on the same day every week, won't go out in the rain and will only wear clothes from Walmart to name but a few.

Dr Bruner (Jerry Molen), head of the institution in which Raymond lives, attempts to get Charlie to return Ray. And yet as the plot unfolds Charlie gradually realizes that there is far more to Ray than he thought; and at one point he even contradicts Dr Bruner's idea that "Raymond's unable to make decisions," saying "He's capable of a lot more than you know!"

While much of the plot is ostensibly concerned with how Charlie intends to use Ray, the brothers gradually become friends; as is clearly shown towards the end of the film when Ray nuzzles his head against Charlie's and at the end, when with Charlie reluctant to return Ray to the institution, Raymond looks directly at him for the very first time.

Less well known in the northern hemisphere is the quirky and award-winning Australian comedy *Malcolm* by Nadia Tass and David Parker. Gentle, funny and warm, the movie is dedicated to Tass's late brother Malcolm who inspired it. A film in which Colin Friels gave an award-winning performance as the shy and innocent Malcolm: a savant who, in sharp

The late **Kim Peek** lent inspiration to the character of Raymond Babbitt in *Rain Man*. Although he was not autistic Kim was a prodigious savant, many of his abilities and disabilities being attributed to a "split-brain."

Kim read voraciously (the left page with his left eye and the right page with his right eye) and could remember almost everything he read.

~

Dr Bruner tells the skeptical Charlie about Ray's problems:

Dr Bruner – *"He's an autistic savant. People like him used to be called idiot savants. There's certain deficiencies, certain abilities that impair him."*

Charlie – *"So he's retarded."*

Dr Bruner – *"Autistic. There are certain routines, rituals that he follows."*

Charlie – *"Rituals, I like that."*

Dr Bruner – *"The way he eats, sleeps, walks, talks, uses the bathroom. It's all he has to protect himself. Any break from this routine leaves him terrified."*

contrast to Raymond, lives independently, albeit under the watchful eye of the local shopkeeper.

Thus, Malcolm generally enjoys life, spending his spare time inventing gadgets to help him to do his daily chores; from buying milk to feeding his pet bird by remote control. After he is sacked from his job as a maintenance man for a streetcar company – for joy-riding through Melbourne – the shopkeeper persuades him that taking in lodgers would help him pay the rent and other expenses.

Along the way this movie offers several brief vignettes of Malcolm's social ineptitude. Thus, when the potential lodgers knock on his door, he shuts the door on them, while he fetches the list of questions he has been told to ask. On another occasion he is set up with a date, only to “entertain” the young woman with an exposition on trolley-cars throughout the years. Unsurprisingly his naivety leaves him vulnerable to manipulation by his lodgers who are really criminals who need Malcolm's talents to help them pull off the ultimate heist... although I won't spoil the ending.

Another award-winning and quirky comedy-drama is *Adam*, in which the main character of Adam Raki is played by Hugh Dancy. First shown at the Sundance Festival in 2009, this film, intriguingly, focuses on romance. In an interview with Rebecca Murray, the writer and director Max Mayer says he came up with the idea for Adam after listening to a radio program in which a young Aspie talked about his life and the challenges he faced. As Mr. Mayer said:

He was talking about how life felt to him and the challenges in his life and how he looked at peoples' behavior and couldn't figure out how they knew when to talk and when not to talk and when to smile and how close to stand to one another and how to gesture, and all kinds of things.

And it was like life was a joke that he wasn't in on. It moved me a lot so I thought I should research this a little bit and figure out (a) why it moved me and (b) what it was.

So I did, and the more I researched it, the better metaphor it felt like to me for human relationships in general...

Brilliant at astronomy, Adam's behavior is both quirky and obsessive. A likeable innocent, who tries hard to be accepted, his limited social skills and inability to understand other people make life difficult; as does the fact that he takes every statement literally and has no understanding of jokes or metaphors.

Adam desires a relationship but can't imagine how to go about it until Beth (played by Rose Byrne) moves into the New York condo where he lives. After a relationship turned

sour, Beth is intrigued by the handsome but odd fellow in the downstairs apartment who avoids eye contact and stands by while she drags a heavy load up the steep stairs.

Gradually though, despite his obliviousness to social convention, she is drawn to him. As the movie unfolds, we begin to see Adam through Beth's eyes; watching entranced as he regales her with an elaborate outer-space light show, that provides a magical moment as their connection becomes palpable. A feel-good film which offers a happy ending; although not necessarily the one you might expect.

Bollywood too took up the "A" theme with the award-winning and contemporary story *My Name Is Khan* in 2010 in which well-known Bollywood actor Shah Rukh Khan portrays the simplicity and innocence of Muslim Aspie, Rizwan Khan.

In part a love story, much of it focuses on prejudice towards those who are in some way different. Made just a few years after the four terrorist attacks that devastated the US on 9.11.2001, it is set in a time when the western world seemed to view all Muslims, and, with the blindness of prejudice, Hindus, Sikhs and others, as suspect.

An unlikely hero, this film begins with Khan's childhood in India, giving us an insight into the complexities of family life, as his younger brother Zakir becomes jealous and resentful of the extra attention Rizwan receives from his mother.

And once again we see the sharp contrast between his talents – which enable his mother to persuade a reclusive scholar to tutor him – and his difficulties. Thus, a peek into his daily life highlights how distressed he gets by noise and how even his talent with mechanical things does not stop other people making fun of him.

Such incidents lead Khan's mother to teach him the lesson that is one of the keystones of the film: that the difference between people is not social ability, intelligence, race, color or creed but rather the simple fact that good men do good, bad men do bad.

After their mother dies Zakir puts their troubled past aside and sponsors Rizwan to emigrate to live with him in San Francisco. And it is there, after various trials and tribulations, that he woos and finally weds Mandira (played by the actress Kajol), a Hindu single mother; taking Dr Ruth's *Sex for Dummies* to bed with him on his wedding night.

The tragedy of 9.11 changes everything. As its aftershock disrupts his life and his marriage, he travels across America to meet the President so that he can "clear his name" and, more importantly, win back the love of his life. Without giving too much away, this incredible and, at times, extremely fraught journey sees him incarcerated and tortured as a terrorist, while also touching many other people's lives.

There are several other films that feature or have been inspired by that dichotomy between the savant skills and social difficulties, with characters like Donald in the comedy

Mozart and the Whale and Simon in the thriller *Mercury Rising*. However, the one that received most plaudits from people with ASD themselves was *If You Could Say it in Words*. This too is a story of the love that gradually develops between two disparate individuals: Nelson, a poor African-American artist, played by an extremely convincing Alvin Keith, and Sadie, (Marin Ireland) whose big-city dreams have come to naught.

Stuck in a job she dislikes and sleeping with her married boss, Sadie takes a liking to one of Nelson's paintings. That eventually leads to a one-night stand and the gradual blooming of an unlikely romance. But of course, as in all good stories, that romance is fraught with problems, jeopardized not only by Nelson's difficulties and Sadie's expectations but also by interference; especially from her boss.

This film cleverly uses both sound and vision to create an unsettling and disorientating atmosphere; a good insight into how most Auties and Aspies experience the world. It also highlights some of Nelson's other differences, like his hatred of being called a "guy"; because he associates it with times past when it meant "grotesque" or "weird-looking." It also aptly demonstrates how even some independent Aspies can have difficulties dealing with their emotions or act in ways that seem extremely strange to other people.

Of course, some movies veer away from special talents. One such is *Snowflake*, which stars Sigourney Weaver as Linda, a feisty, independent mother, who just happens to be autistic and likes to eat snow and play with sparkly toys and trampolines.

After her daughter Vivienne is killed in a car accident, Alex, the driver of the car (Alan Rickman), goes to meet Linda intending to explain what happened. He is flummoxed by her strange reaction, for she shows no grief and initially shuts the door in his face. She then changes her mind and invites him to stay because she needs someone to carry out the tasks that she can't deal with – like feeding Vivienne's dog and taking out the garbage – as well as helping to plan the funeral.

Fortunately, this potentially gloomy subject is leavened by humor, such as when he believes – and even acts on – some of her more extreme statements: one being that her neighbor is a whore.

Finally, in stark contrast to many films about ASD, I'll mention just two that stand out because they explored what was then new territory, depicting life at the extreme end of the spectrum; those children and adults who need constant care.

First, a bitter-sweet comedy-drama made in 1993 called *What's Eating Gilbert Grape?* In this poignant story we meet Gilbert (Johnny Depp) who has to care for both his "mentally challenged brother" Arnie (Leonardo DiCaprio) and his grossly obese mother; while also falling in love.

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Although the theme of the film is broad it is stuffed full of little vignettes about the difficulties that Arnie has – or causes – especially if left unsupervised.

Played with great glee, and accuracy, by Leo DiCaprio, Arnie, whose speech is severely limited, loves to climb the town's water tower; watching delightedly as the police and fire service are repeatedly called out to rescue him.

It also highlights some of the more intriguing challenges that families face, as when Gilbert leaves Arnie – who is about to turn eighteen – in the bathtub by himself, believing he is old enough to get out on his own. And yet after spending the night out with his girlfriend Gilbert returns the following morning to find Arnie shivering – and still seated in the tub.

Film Review rightly praised DiCaprio's Oscar nominated performance as “of astonishing innocence and spontaneity,” which brought “a touching credibility to a very difficult part”: a difficult feat to carry off so well. DiCaprio offers an insight into his performance when he says:

I had to really research and get into the mind of somebody with a disability like that. So I spent a few days at a home for mentally retarded teens. We just talked and I watched their mannerisms. People have these expectations that mentally retarded children are really crazy, but it's not so. It's refreshing to see them because everything's so new to them.

Then there is the multiple award-winning Australian film *The Black Balloon*, which came out in 2008. This features a non-verbal and extremely challenging Autie named Charlie, convincingly played by Luke Ford; whose unusual and unpredictable behavior leads to some embarrassing predicaments.

Having just moved into a new home, younger brother Thomas (Rhys Wakefield) is about to start a new school and, like all teenagers, wants to fit in, but with his pregnant mother confined to bed, he has to help look after Charlie.

Meanwhile Charlie is making his presence felt: announcing his arrival by banging a wooden spoon and wailing on the front lawn; running away from home semi-naked; having tantrums in the shopping center; and indulging in some more disgusting antics which evoke ambivalent feelings in his brother and possibly some viewers too.

While this film certainly gives an accurate portrayal of some of the challenges that families can face when living with a child with more severe problems, it may make uncomfortable viewing for some.

Unsurprisingly most actors and actresses find such roles intriguing but their attitudes

vary greatly, perhaps depending on the characters they portray. Thus, after playing Ray, Dustin Hoffman took a somber view, saying that “These children are denied the greatest gift of life – the joy of a relationship with another person.”

In contrast, Sigourney Weaver, who spent a short time living with an autistic woman and absorbing some of her behaviors as she prepared for her role in *Snowflake*, was far more upbeat, saying:

I think we have to begin to see it [autism] as a gift. We may not understand what it's there for, but if you're in the presence of someone with autism you learn so much. You learn how to play, you learn how to see things, you learn how to experience things and how jarring the world is.

Interestingly, Hugh Dancy's research for the character of Adam led him to challenge some of the common preconceptions about ASD, as he told interviewer Rebecca Murray:

I think that in fact in meeting all the people, all the various Aspies that I did, the main realization and the most important revelation was the differences between all of them and the range of personalities, the variety in expression and humor and different symptoms and so on.

There's a humorous appreciation of many things, including themselves. In fact, watching the film with people with Asperger's, there's a lot of laughter and recognition of some of it. That doesn't mean to say that they're going to tell a joke brilliantly. There's not necessarily the perfect timing or anything, but that's far from being humorless.

Today there is a new genre as an increasing number of films are based on real-life characters, one of the best-known being Temple Grandin who, in the biopic of the same name, is played by Clare Danes.

Originally diagnosed as autistic, Temple is now said to have AS: an interesting concept in itself.

Hers is a story to which we'll return later but I'll give you a taste of the film now for, despite her many earlier difficulties, she has succeeded in single-handedly revolutionizing the USA's cattle-handling industry.

Today she is probably the most well-known and successful designer of cattle handling equipment as well a consultant to Burger King and McDonald's and others while also lecturing and writing on animal welfare and autism.



Temple Grandin
Photo Rosalie Winard

Each of the biographical films offers an insight into some of the difficulties that families, parents, Auties and Aspies face. In *Miracle Run* we follow Corrine Morgan-Thomas's (Mary-Louise Parker) journey, from her initial concerns to eventual diagnosis and her shock and anger at discovering that her twins Steven and Phillip are autistic.

She has to deal with not only the boys' oft-times odd and sometimes embarrassing behaviors but also the stresses that their diagnosis has on her partner, who ups and goes, leaving her to support the boys on her own.

Determined that the twins should be treated like their peers, she initially refrains from telling their new school about their diagnosis. In doing so she inadvertently enters every parent's nightmare, for the staff mistake some of the boys' behaviors as indications of abuse. Left with no option but to tell the school about their autism, she is then promptly asked to move them elsewhere.

Eventually though her struggle to get appropriate help pays dividends and we see the boys beginning to make progress, although adolescence brings further complications to their lives. And yet, despite all the trials and turmoil, *Miracle Run* is an uplifting and positive film as, against all the odds, the boys determine to succeed. And do.

Then there is the Korean film *Marathon*, a touching biopic, which is based on the true story of Autie, Bae Hyong-Jin, a skilled marathon runner. Interestingly it tackles the subject from an unusual viewpoint, looking at his relationship with his mother and her feelings of insecurity; something that is resolved when his running coach inadvertently helps bring them together.

This film became a smash hit in 2005 and has had a far-reaching effect, greatly increasing autism awareness in some areas of Korea, where such people had long been highly stigmatized. It has even led to a popular soap opera, *Letters for my Parents*, about a family raising a boy with autism.

While no doubt other movies will have joined the list by the time this book is published, the mixture already mentioned features a diverse group of people bound by one commonality, for they all fit somewhere on the autism spectrum.

Finally we come to autumn 2011 which saw the debut of a crime drama, created and written by Hans Rosenfeldt which turned out to be one of the most memorable of that era.

Other television programs also feature autism. One is *The A Word* featured on UK television in 2016 with a sequel in 2017.

Billed as a "family drama with a boy with autism at its heart" we initially saw it gradually dawn on parents Alison and Paul Hughes that their 5-year-old son, Joe (played by Max Vento), has difficulty both with communication and in responding emotionally.

The Bridge, a Scandinavian crime series filmed in Malmö, on Sweden's south-western tip and the nearby Danish capital Copenhagen, and the bridge between the two. It featured a pair of detectives, Saga Norén (Sofia Helin) from the Swedish side along with her Danish counterpart Rohde (Kim Bodnia).

As the series unfolded we found that Saga was an emotionally detached, socially awkward character who was forthright in the extreme, while her sensitive counterpart Martin provided the perfect foil. Many viewers thought Saga was on the autistic spectrum – as was the writer's intention – although Saga herself was supposed to be unaware of it.

So, how did Sofia set about playing such a part? Initially, as she told Rebecca Nicholson in an interview for the Guardian newspaper, Saga's strange character and lack of social ability was so confusing that she did not know how to play her (or even whether she wanted to). As she said: "My brain moves in circles, but Saga thinks squarely – I could almost feel my brain changing as I played her."

While Saga learnt how to behave in different situations she lacked emotional intelligence; making Martin's friendship very special because, unlike other people who avoided her, he remained friends in spite of her "difference." That friendship led viewers to see Saga in a different light and to admire her honesty and lack of pretension; something that made both the characters and the series extremely popular.

Time now to move on to literature, excluding autobiographies which will be explored in more detail later. As ever art parallels real life, so early literature has several characters who appear to be fools or simpletons.

In *Twelfth Night* Shakespeare uses the slow-witted but excessively wealthy Sir Andrew Aguecheek to provide the comedy with his slow speech, strange mannerisms, garish dress sense and his lack of awareness. It also highlights how vulnerable some people are. Thus, to the amusement of his companions, Sir Andrew wrongly believes he is a great dancer and swordsman; while his gullibility enables Sir Toby Belch, a right rogue, to gradually pilfer much of his money.

The author [Charles Dickens](#) was also greatly interested in the vagaries of life and cast a rich pantheon of characters in his stories; some of whom might be considered simpletons. In *Dombey and Son*, we find two characters that fit the bill.

One is "Mr. P. Toots, a wealthy young gentleman, of good heart but inferior abilities." Mr. Toots provides much of the comedy, for he is incredibly "scatterbrained" and naïve; constantly confusing people's names. Despite everything, he is so good-hearted that, in stark contrast to Sir Andrew's companions, other people generally like and respect Mr. Toots and treat him kindly.

As the author G. K. Chesterton wrote:

Nowhere else did Dickens express with such astonishing insight and truth his main contention, which is that to be good and idiotic is not a poor fate, but, on the contrary, an experience of primeval innocence, which wonders at all things.

Next, Mr. Dombey's son Paul, who makes the briefest of appearances before succumbing to illness. Despite this, we learn a great deal about him from Dickens' eloquent description:

Yet, in spite of his early promise, all this vigilance and care could not make little Paul a thriving boy. Naturally delicate, perhaps, ... Every tooth was a break-neck fence, and every pimple in the measles a stone wall to him. He was down in every fit of the [w]hooping-cough, and rolled upon and crushed by a whole field of small diseases, that came trooping on each other's heels to prevent his getting up again. Some bird of prey got into his throat instead of the thrush; and the very chickens turning ferocious – if they have anything to do with that infant malady to which they lend their name – worried him like tiger-cats.

Thus, Paul grew to be nearly five years old... His temper gave abundant promise of being imperious in after-life; and he had as hopeful an apprehension of his own importance, and the rightful subservience of all other things and persons to it, as heart could desire. He was childish and sportive enough at times, and not

of a sullen disposition; but he had a strange, old-fashioned, thoughtful way, at other times, of sitting brooding in his miniature arm-chair, when he looked (and talked) like one of those terrible little Beings in the Fairy tales, who, at a hundred and fifty or two hundred years of age, fantastically represent the children for whom they have been substituted.

Charles Dickens had a particular interest in the treatment of “idiots and imbeciles,” and publicly commended the humanitarian efforts of English prisons that improved the self-reliance of inmates with “rickety intellects.”

In 1853, he visited the Essex Hall Asylum for Idiots near Colchester UK, where he saw several children who, having first been trained in proper hygiene, had learned to write a little, or even complete simple mathematical problems.

Interesting to note that Paul's “old-fashioned” manner seems linked to something that happened in his early life: an idea we'll return to later in the series.

Another book.

Another character.

In *Little Dorrit* we find Maggy who “acquired her differences” when she fell gravely ill with a fever at the age of ten; which led to brain damage. Thus, it seems that time effectively stopped for her at that point, so that, when we meet her at the age of twenty-eight, she still retains the mental age of a ten-year-old.

Dickens describes her in great detail telling us that she had a curiously fixed smile, poor vision, an unseeing expression, physical weakness and a predisposition towards spontaneous laughter. She wore tattered clothes and an enormous “great white cap, with a quantity of opaque frilling” and eked out a living by selling potatoes and running errands. Happily though, she gradually progresses until, by the end of the tale, she has learnt to read, and is even allowed out without an escort.

More recent times have seen an influx of fictional characters whose differences more overtly fit ASD; whether it be in savant skills, obsessions or compulsions or sensory differences.

The Curious Incident of the Dog that Barked in the Night by Mark Haddon, introduces fifteen-year-old Christopher who is skilled in mathematics and science but finds it hard to communicate with, or understand, other people. A child whose literalness, unsurprisingly, lands him in difficulties time and again.

Christopher also has many other familiar traits so he dislikes being touched; is unable to understand jokes; can hardly distinguish between a smiling face and a crying one; and, when overloaded by information, crouches on the floor and groans.

Then there is the award-winning comic novel *The Rosie Project* by Graeme Simsion which also offers a moving and original take on love and attraction. It is narrated by Associate Professor of Genetics Don Tillman, a single socially awkward genius who is thirty-nine years old; “in excellent health” and of “relatively high status and above-average income.”

Although he thinks that he should, logically, be attractive to a wide range of women he notes that women find him unappealing and that never having found it easy to make friends, his “deficiencies” in that area have “also affected [his] attempts at romantic relationships.”

Don leads a highly regimented life, with a regular seven-day menu and a very clean flat, but, nearing the age of forty, feels a need to solve “the wife problem,” so he creates a questionnaire to ascertain the perfect candidate, who cannot be a smoker, a drinker, perpetually late or work in a bar. Then in walks Rosie, a graduate student (who is all of the latter) and is looking for her biological father. Don agrees to help and gradually falls in love. And that leaves him with several dilemmas, such as whether he should change his daily food plan or make his shower two minutes shorter.

Do the outcome and ending fit? You decide.

The sensory differences are extremely fertile ground for they are easily woven into fantasy and science fiction. Thus, in *Young Wizards* (a series by Diane Duane) Darryl's unusual perspective gives him unique abilities as a wizard, while Manfred, who is apparently severely autistic, operates on a different time-scale to the rest of us. In fact, one well-known and best-selling fantasy fiction author, Carseal Mor, is an Autie who clearly uses some of his own experiences in his books.

The engrossing science-fiction tale *The Speed of Dark* by Elizabeth Moon poses an interesting dilemma that echoes much current debate as Lou Arrendale, a bioinformatics specialist, is pressured to undergo an experimental "treatment" that "might cure" his autism, even though he's happy with his life. Lou doesn't think he needs "curing" but risks losing his job unless he agrees to treatment. What does he decide? I'll leave you to find that out for yourself.

Next the intriguing series by bestselling author *Estelle Ryan*, whose heroine is the insurance investigator and world-renowned expert in nonverbal communication, Dr Genevieve Lenard. A codebreaker whose astounding analytical skills help solve numerous art frauds she also has to cope with the daily challenges of living with autism and the social challenges that arise when working as part of a team. A fascinating mix for those who enjoy crime fiction.

Meanwhile *The Autism War: A Novel* approaches the subject in a really unusual way: alluding to many real life "autism related" news events on the darker side of life. Written by Louis Conte, a New York law enforcement officer and leading advocate for people with autism, it features Tony Colletti, a suburban cop whose son has autism, who finds himself drawn into the vaccine controversy. And that latter point has led some families to see it as "their story" and others to find it extremely controversial.

Sadly, nowadays ASD has begun to appear as some crime novels incorporate characters who are supposedly Aspies, portraying them either as victims – of their families, other people or their own limitations – or as sociopaths.

This chapter has given you a very mixed picture of ASD, offering many and various permutations. A picture so diverse that if you saw *Rain Man*, *Malcolm* or the like and then chanced upon *The Black Balloon* you could easily miss the connection between the characters.

Where does the truth lie? Let's visit some families whose experiences of ASD are rooted in reality to hear their point of view.

CHAPTER TWO

SIX DEGREES OF SEPARATION

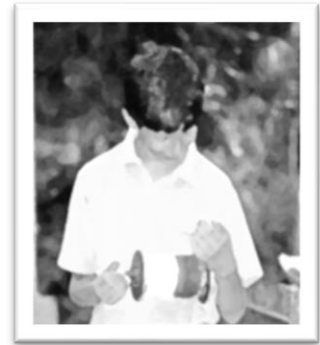
...everybody on this planet is separated by only six other people.

John Guare

While each child has his own timetable, and develops at his own pace, the order in which those developmental milestones occur always remains the same. Even so, there are many stumbling blocks along the way. They can, potentially, interrupt or disrupt that process; giving rise to a child of difference: some of whose behaviors are seemingly strange.

The reality of living with such differences? Perhaps at this point, readers who have not experienced it for themselves should try to walk in the parents' shoes for a while in order to experience life in this, often alternative, reality.

Initially it is the simplest things that distinguish the differences: from the baby who ignores you totally while spending endless hours happily watching the mobile dangling above his head or waving his fingers at the light which streams in through the window. You pick him up to feed him only to be met with resistance as he struggles to get free.



As he grows older he has little tolerance for you or the games you try to play with him, often withdrawing into himself. Rather than exploring or playing, he spends long hours doing repetitive things like lining toys up in rows, flicking a shoelace in front of his face or twiddling with something.

Even so, many first-time parents may not be aware that such things are unusual until their child begins nursery school, which is where his difference from other infants suddenly becomes only too apparent.

Alternatively, your child may initially develop in much the same way as his siblings, albeit a little slower to walk or talk perhaps. No need to worry though, for most families can quote tales of relatives or friends who were similarly slow. It's only when he begins to regress and loses the skills he had, becoming withdrawn or solitary, or crying inconsolably for lengthy periods, that you cannot help but begin the search for answers.

And while that search continues you have to find ways to live and cope with the consequences of that difference.

To begin with, regardless of just where the child is on the spectrum, most parents share common worries regarding the lack of real communication and social abilities. For many parents the most pressing of these concerns speech, which arises from the perfectly natural and almost overwhelming need for the child to call them mommy or daddy and say those all-important words, “I love you.”

Even parents whose child acquired speech at about the same time as his peers may gradually become aware that their child’s speech differs in quality from that of others. Such children may use words and language that seems too grown-up for their age or do not understand the nuances of speech. Some bring every conversation around to the topic they are interested in; or speak too loudly or too softly or lack expression.

Those speech problems have sometimes led people to accentuate the negative. They have even led a few professionals to extrapolate that the inability to communicate or socialize indicates that such children care nothing for other people: an idea that arouses great concern in parents. And yet that is both biased and incorrect, as Dawn Prince-Hughes tells us in her moving and thought-provoking memoir *Songs of the Gorilla Nation*.

In her experience the opposite is true for, as she tells us, a significant number of Auties and Aspies care deeply about all manner of things and get extremely emotional about some of them. She also tells us that such feelings are generally kept private and often only mentioned in their writings, diaries or poetry.

But when it’s your child who can’t express his or her feelings, it can feel oh, so very different. Easy to see why some parents labor under the misapprehension that having language skills will make their child “okay.”

Now, you might think that is clearly a misconception for both love and emotion, and even that elusive social interaction can, and does, take place without speech, as many members of the deaf community can attest. Similarly, many creative people communicate volumes through other mediums, including musicians, dancers, footballers, artists, sculptors, mathematicians – and even authors: some of whom can seem inarticulate when they revert to speech.

And yet, sadly, there is some truth in the idea, for all too often it seems as if the world conspires against those who are unable to speak, for in situations where they are dependent on others for their needs – whether in a school, hospital or residential home – it is not uncommon to find that they are overlooked or left till last.

Frequently the speech of children with ASD is described as “deviant” (an ugly word) or “impaired.” And yet that area is full of smoke and mirrors, for nothing is as it seems. The three main examples commonly consist of echolalia, which is the repetition of things

that have been said to the child by others; pronoun reversal, which means referring to oneself as “you” rather than “I”; or extreme literalness. And yet, each of those things happens naturally during a certain stage of child development, for it is only by imitation and repetition of both actions and words that children learn the various skills they will need in life. Let’s delve a little deeper, looking at each of those facets in turn.

Born in Australia in 1963, Donna Williams, who sadly died in 2017, was raised in an inner-city area, in a working-class family which had, as she said, “more challenges than my own.”

Thus, in her autobiography *Nobody Nowhere*, she told us that she was a distractible and impulsive child. A child who didn’t stay in one place for long and often appeared drugged (due to repeated doses of antibiotics). Initially echolalic, she was unable to answer a direct question and couldn’t even understand three sentences in a row until she was nine years old; so she has great insight into echolalia. As she tells us:

As an echolalic child, I did not understand the use of words because I was in too great a state of stress and fearful reaction to hear anything other than patterned sound . . . When I later repeated phrases, it was simply because I sensed that some sort of response with sounds was required. Mirroring . . . was my way of saying: “Look, I can relate. I can make that noise too.”

AUTISM DECODED

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