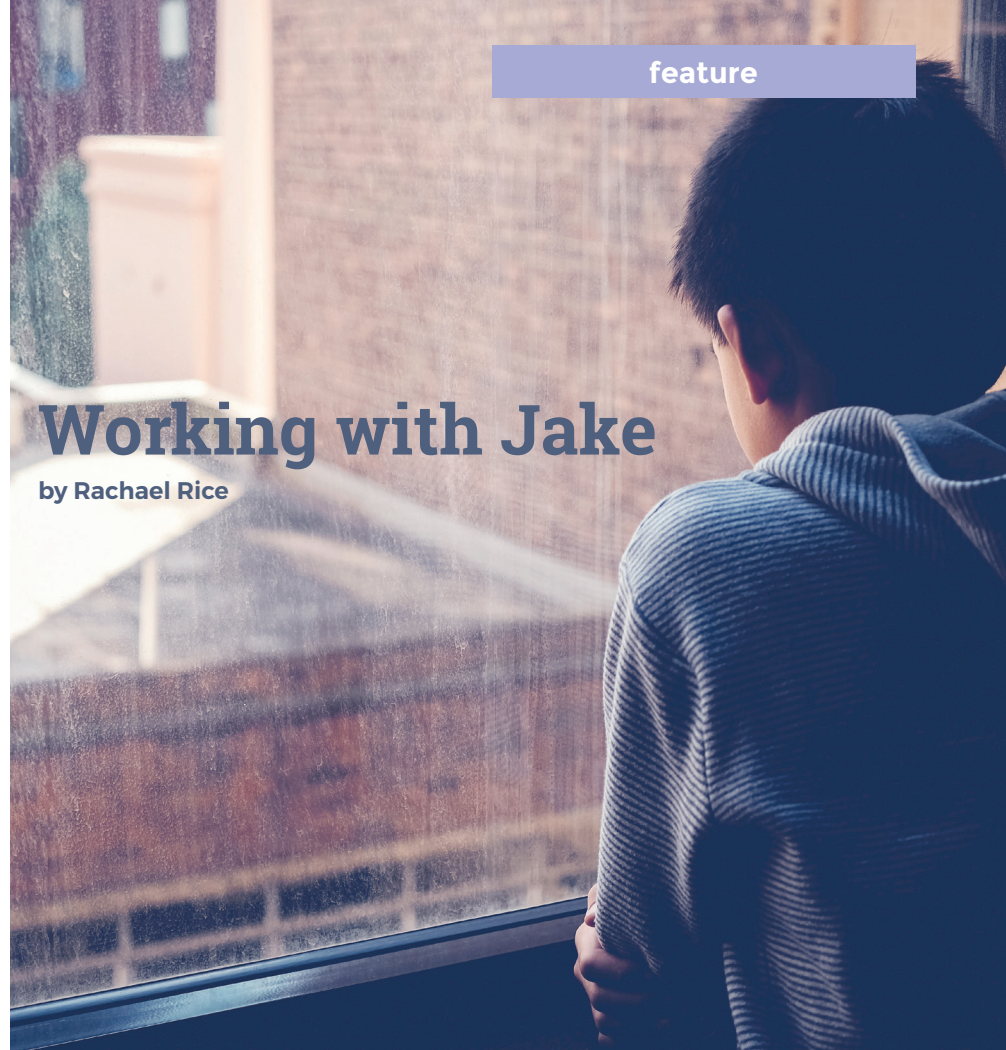


## A WINDOW TO JAKE'S WORLD

He sits on a windowsill. "No one likes me so I may as well die", he says. He is 15 years old, and he has gathered labels: ADHD, Dyslexia, Tourette's syndrome and finally Asperger syndrome, but more than that he has gathered labels from teachers and peers: naughty, disruptive, socially unacceptable. He is invited to no parties or sleepovers but although others think this doesn't matter to him, it does. He hurts as he watches his sister with her rich social life and many friends. Why doesn't this happen for him? Is he simply bad? Can he change anything - can he change himself? He decides that is not an option. The teacher said, "Be like the other boys and you will be fine". That teacher minimises the boy's issues. And anyway, how can you be like the other boys, and which other boys? There is a classful to choose from! Can you really be someone else and why would you do that? Can't you just be yourself?

## MASKING AND MISERY

And so begins a journey of masking in order to fit in. It is pain-filled and hard work, and rarely successful long-term. To those labels is added another one: mental ill health. And that stops the world. This young person will now remain in his bedroom and refuse school. What is there to encourage him out to face more of the same? Nothing. The future looks bleak for this teenager. In the meantime, his family face the fear of fines and condemnation on another level: they are deemed to have failed as parents. There will be a financial penalty and maybe sitting in a court room setting where the Chair wags a finger at parent and child for this failure. It is public. It brings no hope and no help and little understanding. They have no voice, and they would not be understood even if they did speak out: and where would they begin anyway? These parents love their child, but their experience is one of bereavement - the dreams



# Working with Jake

by Rachael Rice

they held for him, that is, a future of independence and thriving out in the world and using his gifts and talents and achieving fulfilment... and maybe finding a life partner, making a home of their own, creating new life.

*And it is at this stage that I have received a phone call - can I help?*

## CLAY, CORNFLOUR AND CROCODILES

My therapy room is full of options - a large whiteboard on the wall with an array of coloured pens. A den in the corner with cushions and blankets and pieces of soft fabric. A sand tray sitting on top of drawers filled with dinosaurs, My Little Pony toys, Lego people, trees, fences and little pottery houses. A bookcase with tomes on Pokémon and horses and Star Wars and Marvel characters, and games - chess and cards and the Yes/No game with its silver bell. There is

clay, paint and paper, and printers. In the cupboard, there are balloons with a blower, and dishes to make potions with cornflour, shaving foam and hair gel. There is a large doll's house, and shelves mounted on the wall with moving mouth puppets... a policeman, a granny, a fairy and a crocodile. In the drawers I keep the books that the young people have made, each so personal to them and something they will take with them at the end of therapy. This is the space I invite the young person into.

## BODY LANGUAGE, A BUTTON BOX AND A BLOB TREE

Jake's mum has rung me. In desperation she has taken Jake to the GP, and he has suggested I might help. The law states that Jake should remain in education until he is 18, but at 16, after a lot of school absences, Jake has refused to go anywhere. In fact, I am surprised when he comes to my

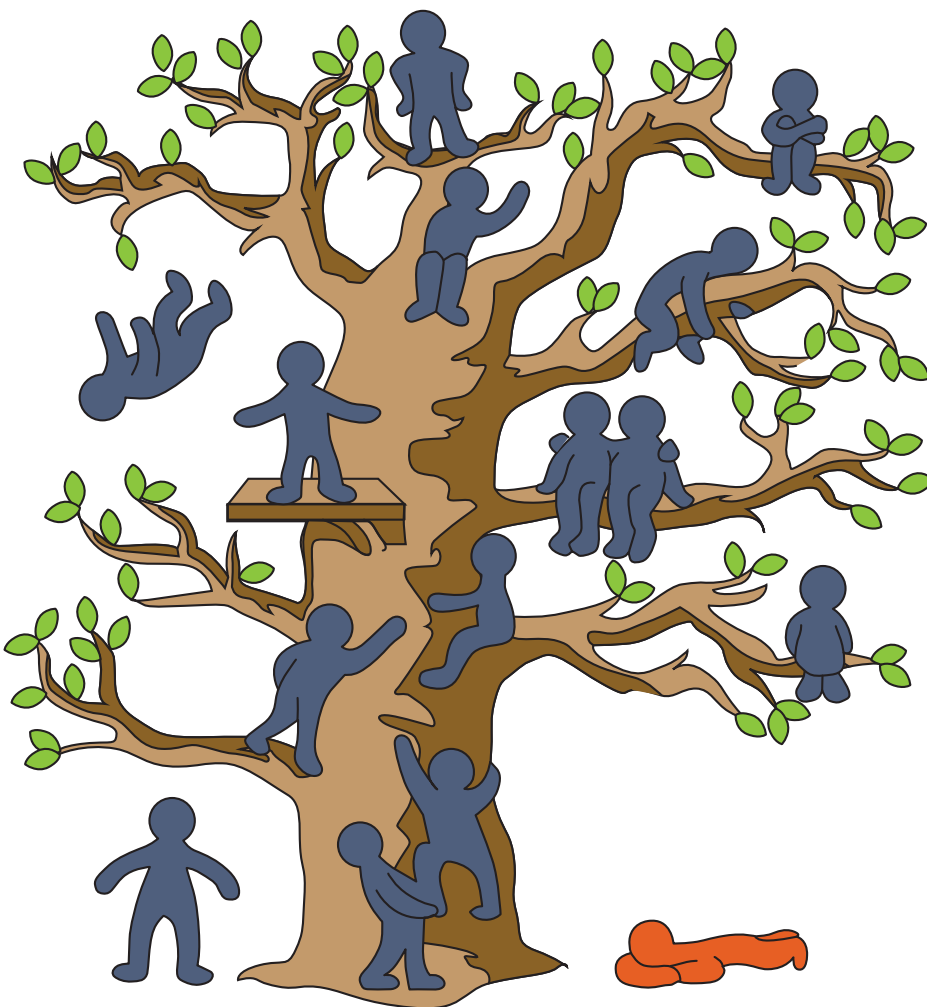
home as well. I watch him walking down the path to my front door and I know that he would rather be anywhere else than here, meeting a stranger, with expectations that he might have to speak about things he doesn't want to speak about. I sense he has come because his mum has pleaded with him to do so. He enters my room and chooses a space to sit. I sit alongside him. His eyes are averted, and I notice he is very thin and pale. He looks so anxious. Mum tells me that he composes music and puts it on YouTube, and he wants to learn to drive when he is old enough. Beyond that he has no ambitions. When they do things as a family, Jake is often too anxious to participate, even with people close to him.

I am aware that as humans, very little of our communication is verbal. Much is nonverbal - body language and tone of voice can be much more important. And here in the therapy room, I seek to provide a peaceful space in the way that actually means peaceful for Jake himself. I take out my folder of blob sheets and show them to Jake. We don't need eye-to-eye contact or words. I invite Jake to look at the Blob Tree and ask if he would like to show me how he feels today (bearing in mind, of course, that 'no' is always a perfectly acceptable answer). Jake takes the sheet and chooses a dark brown pencil. He colours in a blob hanging from a tree branch. He colours in another which is lying face down on the ground. He does not colour in the one looking triumphant at the

top of the tree or the one sitting alongside a blob friend. I ask if he would like to create a book where we could stick in the blob sheet and create something that is just about him. Jake nods and chooses a book from the ones I show him. We stick in the first sheet and date it. Periodically through the time I see Jake, we will revisit this Blob Tree as it will give us a measure of how he is feeling about his life.

Then I take out my button box. I tell him that I know nothing about his family and friends, and I wonder if he would like to show me. He sits with the tray balanced on his knees and picks out a button for his mum (he is very close to his mum) and his dad (who has a lot of problems and no longer shares the family home). He picks out another button for his sister and for the two friends he has - I learn that he meets them sometimes at KFC although he cannot get through the door himself because of his anxiety and they have to get his meal for him and bring it outside. (And they do; they seem to be friends who accept Jake just as he is.)

We are talking very gently but there is no pressure to talk. Jake decides to use the watercolour paints and I pass him a piece of paper. He seems very content and uses just blue for a geometrical design. We will stick this in the book too. While he is painting, he tells me about his first school and about how when he was born, he needed an operation on his legs which makes him very self-conscious and means he doesn't like to wear shorts or go swimming. He tells me that as a little boy he loved rolling balls up and down on the kitchen floor, and that he had a large box of toy cars; he loved spinning the wheels on them. He found it very soothing. He also has a bookshelf of books on cars especially about the working parts under the bonnet. He can name them all and what each part does. He has thought he might like to be a mechanic one day. And then he goes silent and looks up



at me for the first time and tells me: "I can't do school anymore. I just can't" and he looks down again and is silent. He just can't do school any longer. And that is what dominates his life and why he is here sitting in my room today. All of this I will record for him in his book, with a date. It will become his journal, about him, over the coming weeks, and I will add to it with photos from Google Images – a photo of his first school, balls on a kitchen floor and a box of toy cars and a picture of what lies under a car bonnet.

### TABLE TENNIS AND TABLE FOOTBALL

Our first hour is nearly up and I show him my football table. We have ten minutes of fun, and this will become a regular part of our session. Jake changes the rules and sometimes we play with three balls rather than one and sometimes we play with our non-dominant hand. Later we will have fun playing table tennis and changing the rules for that too. And then Jake's mum is there to collect him. "Would he like to come again?" I ask. It is an open question because although parents and carers may feel it is a 'good idea', I feel it is empowering and important for the young person to feel they can choose. Jake nods "yes".

Jake is autistic and the social and sensory side of school has been overwhelming for him. The noise and bustle in the corridors, and wondering if that person bumped into him and knocked his bag out of his hands on purpose. The dinner hall echoes with noise and the fluorescent lights buzz. He cannot even get in there for the sensory overload and even if he did, where would he sit and who would he sit with? Everyone seems to come in with friends, but he doesn't have this protection in school. And in the classroom, he holds his breath for almost the whole lesson. It is not that he cannot do the academic subjects – it is just that he cannot concentrate when all the energy



feature

of his concentration is fixed on watching the clock and willing the school day to end. And when he walks up the drive, will he face the bullies again – the people who make fun of his legs and jostle him and laugh at him as he goes red in the face. He is alone in an alien world, a world that is overwhelming and makes no sense, and where he is obliged to go every day until he is 18. The day comes when he says no and nothing his mum says will make him change his mind. This is the day when he retreats to his room and stays there. This is the day when school starts to put the pressure on, and threats start to come in the post.

### TWO THOUSAND PUPILS BUT ONLY ONE CHAIR

*We are sitting in a large room with a long table in the council offices. Mum has received many letters regarding Jake's non-attendance. She will be fined, yet this is a single mum on very limited resources. Jake is 16 and autistic. Crossing the threshold into school is now impossible for*



**Through my training, I learned some very big lessons that underpin my work today**

*him. He simply collapses to the floor in the school entrance. There is no way of getting him in, as he sobs and flays on the floor. It is public. And in the eyes of the education system both he and his mum have failed. And if they did manage to force him in, is there any way he can access learning when his emotional system is flooded with panic? Yet this boy is bright and loves to learn about the things that hold his interest – things that the psychologist at the children's hospital has called 'obsessions' (with disapproval in her voice). What doesn't he know about every aspect of a car engine? He loves to learn, just not in the environment of a school of 2,000 pupils where he is not included on any level and where the subjects hold little relevance for him.*

*The man chairing the meeting in looks over his glasses at the mother and her son, both of whom are overwhelmed by the formality of this setting. An officer outlines the failure of Jake to attend school and the failure of his mum to 'make him'. The Chair gives them both a lecture about the importance of attending school and the consequences if Jake doesn't. And he doesn't, so the consequences are implemented. There is no help and no understanding and no compassion, only a great deal more distress for Jake and his mum. I have not long been meeting with Jake and my heart sinks for what may be ahead for*



*this family, yet I know that Jake really cannot get into school and that his mum is a good mum and does her very best for Jake.*

Currently there are some very depressing statistics about autism. It is estimated that about one in 100 children will have a diagnosis of autism. I wonder if in fact there are a lot more, especially as girls mask well and are often not identified until they are at least in their teens when often their mental health is faltering and their anxiety has become overwhelming. In my experience, autistic boys are often labelled simply as 'naughty boys' especially in primary school where there is a reluctance to give a more appropriate label and never-ending waiting to get into any service like Child and Adolescent Mental Health Services (CAMHS). With the inability to 'fit in' or be accepted, comes increasingly poor mental health and self-esteem. For me the tragedy is that in all this, the gifting of autism often goes unnoticed. Only about one in five adults diagnosed with autism is in paid employment. Many have serious mental health issues on top of their autism, which impact their lives. These may include massive social anxiety, depression, suicidal ideation or attempts, agoraphobia and anorexia and a general dis-ease with living. Why would it be otherwise when so many in the school system which lasts from four to 18 give you negative feedback? This is

something that in my experience, autistic people are very well aware of, yet are unable to change. The biggest lesson that many of them learn through their school life is that they are simply unacceptable the way they are and that to be acceptable is to be or do your best to imitate being neurotypical.

### RESPONDING BY RETRAINING

For many years, I was part of groups where parents had major struggles with their children, children like Jake, involving school refusal, meltdowns and difficult social behaviours – and yet, search as they might, there seemed to be little professional help available and the queue and waiting time for CAMHS was as great as it remains today. I decided that I would retrain, knowing that I would only be able to help a few of this number, but on the basis that every child helped is a family supported.

Firstly, I embarked on an MA in Autism and chose as my dissertation to research meeting the emotional needs of autistic children. I followed this with a training in person-centred counselling and further training for working with children and young people. I knew that this was the group I wanted specifically to help.

Through my training, I learned some very big lessons that underpin my work today.

Firstly, different is not wrong – it is simply different. So being autistic is not wrong but it is being part of a minority group and being a part of any minority group can be very challenging, especially in the world of school. School is designed to fit the majority of children – but it cannot fit all of them.

I learned too that there is always a reason for a behaviour; behaviours have a function and a message of their own. Meltdowns and challenging behaviours are often an issue within autism but what is the message of the behaviour and where does it come from – and can I help with it if I look for the source, rather than simply condemning the behaviour? I learned that living out of the emotional centre in our brains is not just about fighting and fleeing but a lot more expressions, such as tummy troubles, extreme fear, selective mutism and using repetitive behaviours (such as stimming) to reduce stress. These are behaviours that show up in the classroom. Autistic people may respond in these ways because the school environment is quite simply overwhelming to their sensory systems and different ways of being. Can we find the reasons for the behaviours and start there? Can we reduce the stress for that young person that is driving these behaviours? Is this even a viable goal in most mainstream schools?

A third thing that has seriously impacted me is that our response is too often to want to make the child fit the environment and not accept that they may not be able to and that their behaviours are simply telling us this. My question would be: why is neurotypical deemed right and autistic deemed wrong? This is how it seems to be. Schools are designed to fit neurotypical children and this is fine for most. If, though, a school was designed with autistic children in mind, what would it look like? If this was how schools were, how would the neurotypical children cope in an environment that was designed with the autistic child

at the centre of planning? These are thoughts that have seriously challenged me.

A very big part of my training which links both counselling and my Christian faith, is the person-centred nature of it. As a Christian I know that God starts with me where I am. I believe he loves me right in that place. I don't have to do anything to find that acceptance from him. He works with me there, in that place of acceptance. For me, this is mirrored in my understanding of person-centred counselling. Non-judgemental acceptance is powerful, and I seek to make that psychological connection which will allow us to work together. I seek to sit in the world of the client and feel how it may feel for them, to learn about what makes sense to them. I offer no direction and no strategies but I do offer lots of options and choices and respect the young person in front of me: art therapy skills, offering an opportunity to use visual expressions of a client's world view, drama with the moving mouth puppets, sitting with the open doors of the doll's house while the client carefully places each item and the little figures into the rooms, clay where the client models something of their choosing or simply sitting alongside a hurting young person who chooses the den and wraps themselves in the blankets.



Acceptance and safety mean different things to each client. That is where we work from. For young people who have had few choices in school and have not been accepted for themselves but have often received so much negative feedback, this can be a powerful time of making some choices for themselves and being empowered, of learning for themselves what is important and where they might feel comfortable and able to be fully the person they were created to be. Therapy can offer a time of real growth for an autistic young person, a time of finding a place of peace and an opportunity to thrive.

### DELIVERING FOR JAKE

At this time of writing, Jake and I are having our last session. He has become a chatty young man with a lot of opinions and views on what he wants to do. He goes wild camping with his friends, which he loves, and he brings photos from his trips that we can add to his book. Jake is now 18 and he has obtained his driving licence. His driving instructor told him he had a natural aptitude, and he passed on his first attempt. Now he is working delivering parcels and there is a lot of demand for him in this post-pandemic world. It also suits his preference to work alone – plus he really loves driving. It has been a long time since we first met and together, we have created a book charting his history and feelings about life along with many pictures and his own paintings and a large selection of blobs which he has chosen himself to explore his feelings. It is a journal about him and about his journey at this period in his life and it is a concrete witness to that journey. Jake himself has made choices for his own life and he is beginning to thrive in a way that makes sense for him. He has found a place to be comfortable within himself, his autistic self. It is a joy to see. Would that this were so for every autistic person.

### References:

*Martian in the Playground: Understanding the Schoolchild with Asperger's syndrome.* Clare Sainsbury. SAGE Publications Ltd; Second edition, 2009.

*Not Even Wrong: A Father's Journey into the Lost History of Autism.* Paul Collins. Fusion Press, 2004.

### Clarification of terms:

**Neurotypical person:** A person who shows patterns of thought and behaviour that are typical of most people who are not on the autism spectrum.

**Autistic person:** A person whose brain development is different leading to challenges in the ability to communicate and form relationships. Some people feel this is about 'diffability' or being 'differently able' rather than being disabled.

**Stimming:** Stimming – or self-stimulatory behaviour – is repetitive or unusual body movement or noises.

### Rachael Rice

#### About the author

Rachael Rice is an accredited person-centred counsellor who works from home in Rochford, Essex and more accessible rooms nearby if stairs are difficult. She work specifically with children and young people and loves to use paint, sand, puppets and creative ways of exploring feelings. Rachael has an MA in Autism and has been an adoptive mum for nearly 30 years. This has brought her into contact with many young people with a diagnosis of ADHD, Autism, Tourette's syndrome and issues around attachment.

