

## Definitions of Autism in Fiction

If a writer sets out to portray autism in a character, they will – hopefully – value accuracy over artistic leeway. However, by labelling characters as autistic, this condition gets redefined. Thus, labelling characters could simply amount to muddying the water and might cause more harm than good in the long run. I have discussed this conflict at length in Chapter 2.

Intentional portrayals, on the other hand, can be criticised for their realistic representation or lack thereof. Here, it could be argued that autism is but a mimetic component of a character, for it cannot be generalised to fit all. However, all novels I examined, with the exception of *The Curious Incident of the Dog in the Night-time*, give a definition of autism, thus these characters are not simply mimetic, but their autism makes them thematic, i.e. representative of a certain class, albeit with an educational claim. The protagonist will often either explain their condition to other characters or address the reader directly in the form of a first-person narration. In the following, I wish to point out three aspects of these definitions: the circumstances under which it was given, the medical vocabulary which directly links to the definition given in the DSM-5, and the order in which characteristics are mentioned.

### *Marcelo in the Real World*

‘The primary characteristics of AS, which is what Asperger’s syndrome is called for short, occur in the areas of communication and social interaction, and there is usually some kind of pervasive interest. The AS person is different than most people in these areas.’ (*Marcelo* 56)

Here, Marcelo explains Asperger’s Syndrome to his co-worker, a diagnosis that was merged under the Autism Spectrum Disorder in 2013.<sup>3</sup>

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3 The novel was published in 2009, hence they now outdated use of Asperger’s Syndrome. However, definitions for Asperger’s Syndrome and Autism Spectrum Disorder vary only slightly, thus no further differentiation is needed at this point. For more details, see Chapter 6.3.

Interestingly, Marcelo does not give any specifics on the ‘characteristics’ other than that they occur in the areas of communication and social interaction. However, his co-worker has previously been told that Marcelo has a ‘cognitive disorder’ (*Marcelo* 54), thus probably assuming some form of deficits, because she does not ask for clarification. The definition clearly references ‘deficits in communication and social interaction’ Marcelo also mentions his special interest religion (*Marcelo* 57), which plays an important role in his philosophy of life and his ideas of morale (e.g. *Marcelo* 115f.), ultimately leading to tension and furthering the plot.

### *What to Say Next*

Yes, I can get myself into trouble in social situations; I like order and routine; when I’m interested in something, I can be hyperfocused to the exclusion of other activities; and, fine, I am clumsy. But when I have to, I can make eye contact. I don’t flinch if you touch me. I tend to recognize most idioms, though I keep a running list in my notebook just in case. I like to think I’m empathetic, but I don’t know if that’s true. (*What to Say Next* 3)

As a first-person narrator, David addresses the reader directly, delivering a monologue on his thoughts on diagnostic criteria. He explicitly refers to the *DSM-5* and reflects on his own strengths and weaknesses in terms of the criteria for Autism Spectrum Disorder. By doing so, David acknowledges that he at last partially fits the criteria ‘deficits in communication and social interaction’, as well as ‘restricted, repetitive patterns of behaviour, interests, or activities’. Additionally, clumsiness is an associated feature that supports diagnosis (APA, *DSM-5* 55). However, while David’s awkwardness in social situations certainly shapes his relationship with Kit, his clumsiness is not particularly characteristic. In fact, he uses Krav Maga to fight the school bullies (*What to Say Next* 189). At the same time, he refuses to be categorised in diagnostic terms to avoid certain assumptions or stigmata (autists do not like to be touched, they do not make eye contact, they are incapable of recognising idioms, they are not empathetic). David’s portrayal emphasises that autists want and

need meaningful friend- and relationships, even when they are struggling to establish and maintain them (“... of course I get lonely. Just like everyone else”, *What to Say Next* 40).

### *Mockingbird*

#### **Asperger's syndrome** ▸ noun

A rare and relatively mild autistic disorder characterized by awkwardness in social interaction, pedantry in speech, and preoccupation with very narrow interests.

(*Mockingbird* 5, original layout)

Again, this novel was published before 2013. In this case, the story is prefaced by the definition, both priming the reader and educating them. The definition itself focuses on deficits in social interaction and communication, as well as specialised interests, similar to *Marcelo in the Real World*. Pedantry in speech and a coinciding interest in language is a characteristic of Caitlin's portrayal (cf. *Mockingbird* 14, 15, 22, 51, 52...). Despite the definition given in the preface, Caitlin clearly also features 'restricted, repetitive patterns of behaviour and activities', such as Thursday being pizza night (30), or very explicit rules for clothing (101). Moreover, she has internalised many principles (cf. 35, 59, 60...), which she will not only apply to her own behaviour but to others too, at times admonishing them for not sticking to the rules.

### *The State of Grace*

'It's like living with all your senses turned up to full volume all the time,' I say. ... 'And it's like living life in a different language, so you can't ever quite relax because even when you think you're fluent it's still using a different part of your brain so by the end of the day you're exhausted.' And I think about getting home from school and the effort of making it through the noise and the lights and the people and the change and the cars and the smells and the sun and the rain and holding it together through all that, and then getting home. And how when I get

home and I can switch off, that's when I blow up because it's safe. (*State of Grace* 135)

Grace's experience of autism is dominated by her hyperreactivity to sensory input. She is the only character to foreground her hypersensitivity instead of deficits in social interaction. Although Grace has no fixed routines as such, she has difficulties dealing with changes in social dynamics, e.g. her father being away for work or her mother making new friends. She also has a special interest in horses, which, however, is only portrayed as a hobby. However, Grace does refer to difficulties in social situations and communications, too. She describes it as trying to speak 'a different language'. Although hyperreactivity to sensory input is listed under the criteria for 'restricted, repetitive patterns of behaviour, interests, or activities', foregrounding it leads to a new perspective on autism. By doing so, other difficulties are subordinated to this characteristic, including being easily distracted in social situations and thus losing the thread in conversation (*State of Grace* 1).

#### *The London Eye Mystery*

'It's like the brain is a computer,' I said. 'But mine works on a different operating system from other people's. And my wiring's different, too. ... It means I am very good at thinking about facts and how things work and the doctors say I am at the *high functioning end of the spectrum*. ... But I'm rubbish at things like football. ... My syndrome means I am good at remembering big things, like important facts about the weather. But I'm always forgetting small things, like my school gym bag. Mum says I have a brain like a sieve. ... They [the kids at school] don't like me because I only talk big. I'm trying to learn how to talk small. But it's hard. ... Sometimes it's like a big empty space where I'm all on my own. And there's nothing else, just me.' (*London Eye Mystery* 37ff.)

Ted uses a computer metaphor when explaining his condition to his cousin. Here, he mostly refers to 'restricted, repetitive patterns of behaviour, interests, or activities', such as being good at remembering facts, never forgetting his homework, or reading encyclopaedias (*London Eye Mystery* 37–8). His special interest is meteorology, and he is also clumsy. Although Ted's portrayal appears to be dominated by his restricted interests, he admits to having difficulties in social situations. Because he wishes for friends, he would prefer to be 'normal' (38–9). However, *The London Eye Mystery* portrays very few instances of harassment. Even though Ted struggles with communication from time to time, he is surrounded by family and friends who are accepting and understanding of his difficulties. Therefore, 'deficits in communication and social interaction' are mentioned but tend to be subordinated to his special interests and restricted, repetitive behaviours.

#### *Trueman Bradley*

'I sometimes have problems with idioms...' I said to myself. 'I can't always interpret other people's emotions. But I have a great ability to see details. I have a powerful visual memory and I'm an expert at recognizing patterns. ... In addition to my other difficulties, I am also sensitive to certain sounds, like traffic. They distract me and sometimes they're actually painful to my ears. I'm capable of great concentration, but I'm easily distracted by sudden noises or anything unexpected. Such things are very disturbing to me. I need everything to be neat, predictable and in perfect symmetrical order or I can become very tense. (Trueman Bradley 16)

Trueman's monologue is disguised as a pep-talk for himself but is obviously intended to educate the reader. He first mentions difficulties in social communication and interaction but downplays them ('sometimes', 'not always'). However, Trueman struggles consistently with understanding figurative language, slang, etc. (Trueman Bradley 7ff.) and he has difficulties recognising emotions in other people most of the time (14f., 25f.). On the other hand, he compulsively adheres to his

checklist, on which he notes everything he is going to do. Thus, whenever unexpected situations arise, Trueman will add items to his list before acting (22f.), or else he becomes too overwhelmed (20). He is portrayed as having an exceptional memory and attention to detail, which is beneficial to his crime-solving activities, but he is also easily overwhelmed by his hypersensitivity. Trueman Bradley thus portrays a character that struggles with ‘deficits in communication and social interaction’ as well as showing ‘restricted, repetitive patterns of behaviour, interests, or activities’. Despite him fulfilling all criteria of the diagnostics manual, including subdifferentiations, his portrayal might arguably not be more accurate but less so. After all, Loftis argued that autism is an experience, not a list of criteria (Loftis).

#### *Can You See Me*

Perhaps the most encompassing ‘definition’ is given in *Can You See Me*. This novel features the protagonist Tally’s diary entries, including fact-sheets on autism, which she intends to share so that the world “can see autism from another perspective” (11). The cover states that these diary entries were written by autistic Libby Scott, but I must assume that they were modified to fit the narrative. For example, since this novel was written with the intention of (self-)advocating ASD, I can expect a (at times overly) detailed list of symptoms that may not necessarily co-occur or may be exaggerated for educational purposes. Whereas other definitions were tailored to fit the character, such lists aim at broadly educating a reader on autism. They share thus more similarities with diagnostic manuals, although Tally’s ‘facts’ do not necessarily coincide with the diagnostic criteria given in the *DSM-5*. In a sense, the fact sheets still provide an ‘insider’ definition of autism, as they, too, were made to fit the character and of course, they are not completely Tally’s words, nor Libby’s, considering they employ terminology coined by the medical discourse, such as Pathological Demand Avoidance, thus causing discourses to blend into each other (see also *autism narratives*, 5.5).

Either way, the ‘fact sheets’ provide significantly more explicit information on autism than any of the definitions given in other novels. Tally’s ‘autism facts’ include hypersensitivity (*Can You See Me* 11f.), PDA (Pathological Demand Avoidance) (40–41), meltdowns (63f.), stimming (self-stimulatory behaviour) (109f.), sleep difficulties (153f.), anxiety (189f.), ‘getting stuck’ in bad moods (229ff.), mood swings (273ff.), and masking (303ff.). They also feature a few advantages Tally sees in being autistic, including better memory and higher awareness of sound, touch, smell etc. Some of her characteristics, Tally describes as involuntary, including meltdowns after sensory overload, ‘getting stuck’ in bad moods, anxiety, overthinking, and the fact that she has to appear normal and fit in: “Actually, the more I think about it, the more I reckon that a lot of the cons of autism are not really caused by autism but by how other people react to it” (110). This, of course, reflects ideas of normality and deviance of the activist movement. The struggle is further emphasised by Tally’s Pathological Demand Avoidance, which causes her to become defensive whenever demands are placed on her. Incidentally, none of the other protagonists are portrayed as struggling with PDA. However, whenever Tally is expected to conform to society’s standards of normality, her deviance increases. Other examples include sensory overload, which may occur when Tally is forced into social situations she is not comfortable with, yet still expected to attend. Similarly, her anxiety and overthinking are linked to being deviant and trying to appear normal (cf. 152f., 188f.).

Obviously, Tally’s self-account opposes the standardised medical definition in more than one way. Similar to the other definitions, it prioritises those symptoms that affect the character’s life in a significant way. Thus, for example, none of the bullet points fit the criteria of ‘deficits in social communication and interaction’ as stated by the DSM-5 (which is not to say they are not prevalent in conversation). Yet, all previously discussed definitions mentioned this aspect. Vice versa, meltdowns and PDA are neither included in the DSM, nor in the definitions given in other novels. However, anxiety, sleep difficulties, and depressive episodes are listed under comorbidities, and several characters report suffering from these (e.g. David, Grace, Ted...). Nevertheless,

one might conclude that Tally's 'autism facts' are in fact 'Tally's autism facts' as they provide the reader with a detailed symptomology of her autism, including comorbidities and subtypes. Still, Tally experiences her autism very differently to what the main diagnostic criteria as given in the *DSM-5* might suggest; and on a related note, certainly very different than what Kanner's 'autistic loneliness' and Baron-Cohen's 'mind-blindness' theory suggest.

I believe this demonstrates two important fallacies. First of all, the diagnostic criteria are not boxes to be ticked; even if one or more of the criteria are absent in an individual, they might still be diagnosed as autistic.<sup>4</sup> Secondly, the prevalence and intensity, i.e. the impact on everyday life, vary heavily between individuals, as well as over time (age, sex, comorbidities, etc.). Thus, comparing portrayals to lists of diagnostic criteria will establish neither 'good' nor 'accurate' portrayals. Put more lyrically, being autistic is a very unique experience. It also appears that autism portrayals in fiction perpetuate stereotypes and ideas that do not necessarily coincide with the diagnostic criteria. They specifically emphasise difficulties in social situations but are also often adapted to fit the character. Readers' stereotypes will further warp the individual's interpretation, to the point where they might consider portrayals unrealistic if they do not match their concept of autism. Fictional portrayals thus provide an opportunity to explore the uniqueness of 'being autistic' without having to supply an encompassing list of symptoms or a definition that fits all. On the other hand, these portrayals can easily perpetuate misconceptions because they still tend to feature definitions without explicitly stating their limitations and fictionality. Moreover, a set of stereotypes is commonly portrayed, thus again furthering the idea that these portrayals are representative – or vice versa, that stereotypes have to be catered to so as to make a portrayal 'realistic'.

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4 There is certainly a grey zone with less impacted individuals, where they may fall in or out of a diagnosis, or remain undiagnosed. This also works independently of labels, i.e. subjects may be labelled even though they do not fulfil diagnostic criteria, thus rendering the label somewhat unattached to the diagnosis, whereas the diagnosis will necessarily be accompanied by a label.

Taken together, all portrayals mention ‘difficulties in social interaction and communication’. However, *Mockingbird*, *The London Eye Mystery*, and *What to Say Next* foreground ‘restricted, repetitive patterns of behaviour, interests, or activities’ in their portrayals. This could potentially coincide with the fact that the stereotype ‘Robot’ was most prominent here. However, the other novels are more diverse. *The State of Grace* is the only novel to emphasise hypersensitivity as the main characteristic. This novel also toys with the alien trope rather than the other stereotypes. In *Marcelo in the Real World*, the definition foregrounds difficulties in social situations as well as special interests, whereas the portrayal of Trueman (*Trueman Bradley*) tries to incorporate all diagnostic criteria. Finally, in *Can You See Me*, much of Tally’s experience is dominated by her Pathological Demand Avoidance combined with her hypersensitivity. Arguably, the ‘diversity’ of these portrayals could be deemed realistic since autism symptomology is generally considered diverse. However, these characters are still one-sided in that they only portray the ‘high-functioning’ part of the spectrum, additionally often combined with special talents, extraordinary memory, etc. Thus, explanations given in a novel might be confusing for readers who are unaware of the multifaceted nature of autism. A definition, especially as ‘official’ in appearance as the one in *Mockingbird*, which imitates an encyclopaedia entry, might lead readers to assume representativeness that exceeds the novel itself. The definitions showed, however, that although they tend to reference the same two main criteria as mentioned in the *DSM-5*, they do so covertly, often only portraying single characteristics. Additionally, the definitions are bent to fit the character. Therefore, readers who are unaware of the ‘larger picture’ of autism might be misled whenever the limits of such definitions remain undeclared. Although it can be argued that readers have a working concept of autism rather than a set definition and are therefore able to meaningfully integrate additional information, there is a distinct possibility of misinformation.

Generally speaking, however, the more individual the experiences of an autistic character are portrayed, the less stereotypical they are. Since the autism community prides itself on the diversity of its members, this is also a reoccurring topic in most novels (e.g. the snowflake metaphor

in *What to Say Next, Can You See Me*; opposing stereotypes in *The State of Grace* or *Marcelo in the Real World*). For example, in order to explain his behaviour, David gives Kit a copy of the *DSM-IV*<sup>5</sup> where he has highlighted the section on Asperger's Disorder. He also attaches a note reading:

There's a famous expression that if you've met one person with autism, then you've met one person with autism.

So you met me.

Just me.

Not a diagnosis. (*What to Say Next* 274)

Curiously, Christopher (*Curious Incident*) ticks all the boxes for the *DSM-5* diagnosis of Autism Spectrum Disorder<sup>6</sup>, yet his portrayal was heavily criticised by the autism community for being majorly flawed. I therefore suggest that fictional representations of autism are not 'accurate' in terms of diagnostic criteria, nor do they have to be. However, fictional portrayals have additionally developed their own momentum. Novels explore the lives of individuals and their normalities, whereas the medical discourse seeks to sharpen categories and labels. Fictional portrayals individualise autism whereas the medical perspective tries to generalise it, but neither of them fully encompasses the 'experience' of being autistic.

## High- and Low-functioning?

The idea of a spectrum has certainly caught on within the last decade, and yet it remains contested. Some laud it as combining diagnoses that were impossible to clearly differentiate, but many have voiced criticism over

5 Up to the *DSM-5*, editions were identified by Roman numbers.

6 He struggles with communication and social interaction (cf. 2f., 7f., 10, 19f., etc.) and displays restricted, repetitive patterns of behaviour, interests, and activities (cf. 4, 8, 14, 16f., 31f., 52f., etc.), which were present from an early age on (cf. 145) and cause impairment in differing areas of functioning (cf. 59f., 149, etc.). However, not necessarily for AS in the *DSM-IV*, at least Christopher does not appear to be independent and 'age-appropriately' skilled.