

autistic individual, which their 'mind-blindness' conveniently explains away but retells the story with the parents (families, relatives, society...) as victims. Because the rhetoric suggests that these individuals are not fully human, they can be abstracted in terms of something alien or perhaps animalistic. The strain it puts on families to raise a child with special needs should not be glossed over in favour of an overly positive representation. However, the assumption that a person has nothing to communicate, and the act of telling their story for them, will blur the lines of cause and effect and may muzzle minorities.

## The Importance and Risks of Autism Narrative

In a black-and-white world, the conservative movement certainly paints a grim picture of autism. Its counterweight could be considered autists who publish their own stories as a form of self-advocacy and activism. This activist movement advocates for acceptance and against a cure, arguing that autism is merely a difference in thinking rather than a 'disorder'. I have previously stated that the neurodiversity movement should be apprehended as something abstract rather than measurable, whereas labels such as autism, Asperger's, or ADHD are of particular relevance to the self-understanding of the individual, not least because they are usually integrated into their identity. In *The State of Grace* by Rachael Lucas, 16-year-old Grace is officially diagnosed with Asperger's. When she goes on a date with Gabe, she finds out that he has ADHD and they have a conversation about the impact neurodiversity had on their lives.

'Sorry about that,' says Gabe, breaking into my rambling thought circles. 'I had to –' He pauses for a moment before all the words come out in a tumble. 'I've got these pills I have to take twice a day 'cause I've got ADHD. I forgot to take them with me.'

'What happens if you don't?'

'Best case – I end up a bit spaced out and I'm crap at paying attention. Worst – well, that's why I ended up moving schools.'

For some reason we both stop and sit down on one of the benches that look across at the big wooden climbing frame in the gardens by the lake. ... There's one [child] banging a huge stick down on the roof of the lookout shelter, and I realize that the parents below are yelling at him to get down.

'There you go. That's the sort of thing I used to do. Only sort of louder and bigger and messier. And pretty much every day. Like someone had forgotten to turn on my *dangerous stuff* filter.' (*State of Grace*, 132–133, original highlighting)

At the beginning of the dialogue, Gabe hesitates to tell Grace about his diagnosis, likely because he is used to hiding it as well as fearing a social status loss. He then describes his symptoms, placing them on a gamut ('best case' – 'worst'), from being 'spaced out' and 'crap at paying attention' to putting himself at risk by being reckless. Interestingly, Gabe does not so much describe his own feelings and emotions but how others would perceive him, i.e. being inattentive or loud and messy. Quite likely, he has adopted the words others have used to describe him, i.e. he has adopted the others' point of view and made it normative. The pills allow him to manage both his ADHD and his stigma.

'I spent a lot of school sitting outside the head's office.' Gabe shifts sideways so he's facing me more. He picks up the string of his hoody and pulls out the threads, untangling them, his mouth twisting sideways in thought.

'When they finally worked out I had ADHD and I wasn't actually as much trouble as they thought, Mum and Dad decided it would be better if I moved schools and started all over again.'

'Because you had a reputation for being tricky?'

Gabe laughs. 'Tricky. I like that.' (*State of Grace*, 133)

As the conversation continues, it becomes clear that Gabe had previously been stigmatised as a 'troublemaker' and changed his stigma to ADHD when he was diagnosed. Such a change of labels as well as the consequent change in stigma can have opposing effects. For example, pleading insanity is sometimes used to defend criminal behaviour, and if successful

will result in the stigma of 'insanity' trumping the stigma of 'criminal'. In this case, Gabe's stigma 'improved', if one were to grasp it in terms like that. He is no longer considered a 'troublemaker' but his difficulties are now – at least in parts – attributed to his ADHD. The change coincides with Gabe moving schools to start afresh, i.e. leaving his previous stigma behind, which he did successfully since he is now popular (cf. *State of Grace* 67, 71, 138f.). Arguably, a stigma in the form of a medical diagnosis may be easier to manage since it usually involves higher social acceptance, lower culpability, and possible treatment as opposed to 'mere' (and potentially wilful) deviance. Here, the first two are intertwined, since the diagnosis makes Gabe less liable for his actions, thus attributing his behaviour to his neurodiversity and not ill intent. He also describes his neurodiversity as 'someone had forgotten to turn on my dangerous stuff filter', his words suggesting something went wrong in his 'configuration', for which he is ultimately not to blame. Only upon receiving a diagnosis, Gabe internalised his stigma (previously he referred to it as external; 'they thought'), but he is still aware of social repercussions and opts for managing the stigma via medication. He again hesitates to tell his story, instead fumbling with his sweater. Here, his hesitation could also be an indication of how he manages his stigma, in this case deciding how to frame his narrative so that he will not suffer a potential loss in status. When Grace calls his stigma 'tricky', he is relieved, because it is a harmless way of paraphrasing it.

The two continue their conversation and it is now Grace's turn to reveal her diagnosis.

'Me too.'

I'm surprised I say it. It sort of falls out of my mouth. Gabe raises an eyebrow in question.

'Except autism, not ADHD. I was the weird kid in primary school.' I pull a face and I feel my face prickle with heat but I don't stop talking. 'I mean, weirder.'

'I like weird,' says Gabe ... .

'Lucky. Anyway, now I'm older I don't take rucksacks full of fossils on school trips to London, or lie on the floor in H&M hooting. Or have

meltdowns in the classroom.' I think about the moment when they handed me the time-out card so I could escape before the feelings began to boil over inside me. 'Well, not much, anyway.'

And for some reason this makes us both giggle and we start laughing at the idea of it and then Gabe does a sort of honking noise.

'Like that?'

I do a sort of whoop.

'More like that, I think.'

'Hooooot,' says Gabe.

'HOOOOT,' I say back, and an old man passes by and shakes his head at us. (*State of Grace* 133–134)

Grace is not used to openly admitting to her diagnosis ('I'm surprised I say it') and she is unsure what Gabe's reaction will be, fearing a potential face loss, as well as feeling embarrassed ('I feel my face prickle with heat'). However, in this section, both characters are united in the fact that they were outsiders in primary school, which, since nobody else is around, allows them to form a group and thus bond over their experiences. Although the old man shakes his head at them making hooting sounds, in this situation they are (for once) not in the minority and thus do not have to fear any repercussions. Instead, Grace's earlier missteps have become an inside joke.

Grace also admits to still being 'weird', i.e. still being deviant, although less so than in primary school. Upon looking back, she now classifies her previous behaviour as unusual and has since moved on, indicating progress she made when it comes to complying with social norms and aligning herself with them. However, even though her diagnosis may not be open knowledge (cf. *State of Grace* 34f.), she is not able to camouflage or mask her stigma as well as Gabe does, who only had to admit to it when he had to go home to take his medication. Thus, I may state that Grace is more limited by her autism than Gabe is by his ADHD diagnosis. Yet Grace, too, has opted to keep her diagnosis confidential, presumably because she expects a greater status loss than any possible gain from revealing it. Additionally, because she is working towards 'being normal', revealing her diagnosis would likely label her as

deviant, for at least the rest of school. Thus, even though camouflaging and hiding her autism is taking a toll on her mental health, as well as leaving her with the constant fear of not being 'normal enough', Grace keeps working towards fitting in. However, openly talking about her autism allows her to relay some of her thoughts and experiences, foster understanding, and ultimately defy stereotypes.

'So apart from the hooting situation,' Gabe says, swinging my hand, 'what's it actually like?'

And I think for a moment, because people don't actually ask that very often. They tell me what they think I feel because they've read it in books, or they say incredible things like 'autistic people have no sense of humour or imagination or empathy' when I'm standing right there beside them (and one day I'm going to point out that that is more than a little bit rude, not to mention Not Even True) or they – even worse – talk to me like I'm about five, and can't understand.

'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.'

*(State of Grace 134–135)*

Grace's experiences reflect how her own life is dominated by autism narratives that can very well be traced back to what Duffy and Dorner called the 'Pathos of Mindblindness'. Grace acknowledges the assumed lack of Theory of Mind and consequently her alleged absence of humour, imagination, or empathy. The fact that these topics are discussed in her presence, or alternatively her being addressed like a child, signifies that other people assume her to be either mentally impaired or void of any emotion that could be hurt by their slander. It certainly refers directly to the stereotypes 'Child' and 'Robot'.

Curiously, even though Grace is verbal and able to express herself, other people seem to rely more on books – written by non-autistic persons – instead of asking her. Granted, Grace too has likely acquired her understanding of autism from the multitude of narratives the discourses provide, however, her experience clearly differs from the assumptions

others make about her. She even mentions a place called 'Jigsaw Centre' she had to visit "before Mum realized that place was hellish, and that forcing me to go there was causing everyone more stress than anything else" (*State of Grace* 109). Here, 'jigsaw' is a nod toward the puzzle piece symbol that is used by the *Autism Speaks* organisation and thus the conservative movement. It is regarded as outdated by autism activists as it also stands for conversion or behaviour therapy (see Chapter 6.4). In a twist, then, Rachael Lucas incorporates two narratives ('mind-blindness' vs. neurodiversity), as well as the critique that too many assumptions are made, which result in stereotypes that are linked to a label. By giving Grace a voice, the novel allows for a self-advocating and -empowering perspective that is contrasted with the powerful 'mind-blindness'-theories as well as ideas of the conservative movement. However, as she herself reports, 'people don't actually ask that very often', implicating how her life is dominated by the narratives spun by medical discourses. Even though reframing her autism diagnosis allows Grace to renegotiate her stigma, she is ultimately trapped within the autism discourse and its narratives, walking a thin line between embracing and fighting the label.

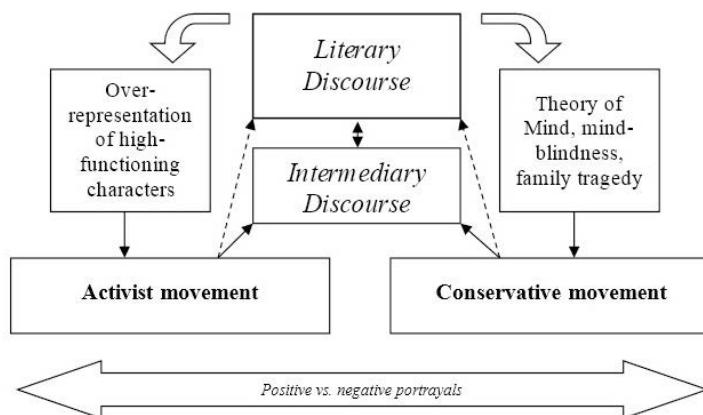
I have, I believe, identified two important influences on the intermediary discourse and literary portrayals. On one hand, there is the activist movement seeking to normalise autism in accordance with disability studies, as well as trying to increase acceptance, tolerance, and awareness for autists. This movement opposes the idea of a cure for autism. Because it is strongly supported by the fact that 'high-functioning'<sup>14</sup> characters are overrepresented in literature, thus portraying autism as a quirky but harmless character trait, I can state that the activist movement dominates current fictional portrayals of autism. On the other hand, the conservative movement has a less favourable view of autism. Here, autistic children are presented as 'non-human' and the cause of family tragedies, thus this movement advocates for finding a cure. It also perpetuates the

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14 I am acknowledging the use of 'high-functioning' in the context of mental health, where it indicates individuals are capable of completely hiding their diagnosis to others.

idea of a deficient Theory of Mind and mind-blindness in autists. Although ToM could be considered a neutral model medical experts use to conceptualise certain difficulties, it is often seen as disabling and limiting by activists. Unfortunately, one of the most widely known autism narratives is *The Curious Incident of the Dog in the Night-time*, which perpetuates negative stereotypes and presents the protagonist as the cause of the tragic family history.

Figure 1: Two autism narratives influence the intermediary and the literary discourse, own graph



Source: own work.

I am assuming that both movements seek to influence the public opinion on autism by feeding their narratives into the intermediary discourse. This discourse will process the information, potentially resulting in public opinions, as well as influencing the literary discourse. Interestingly, it was found that "lay audiences seem to prefer fiction by a non-autistic over the non-fiction by an autistic" (Draaisma 1480). This could be because laypeople rely on public stereotypes which are perpetuated within the intermediary and the literary discourse. Consequently, liter-

ary portrayals share a family resemblance. However, I suggest that both movements also feed directly into the literary discourse. These works would be considered written by experts, be it medical professionals, autistic self-advocates, or personal accounts of parents, etc.

Figure 1 is a visualisation of how the two movements affect the intermediary and literary discourse.

The arrows indicate how the *activist movement* seeks to normalise and humanise autism. It advocates for embracing autism as part of one's identity and opposes finding a cure. Meanwhile, the *conservative movement* lobbies for finding a cure. Their narrative can be traced back to Kanner's research and is thus historically linked to the medical discourse. Both narratives influence the *intermediary discourse*, where the public seeks to integrate different oncoming knowledge on autism, as well as the *literary discourse* through works published by 'experts'. Both movements are technically discourses in their own right, but they are also both part of the general autism discourse and they both feed into the intermediary and the literary discourse. Here, I am under the impression that two narratives co-exist. One is that of the high-functioning individual as it is often represented in the media, i.e. in novels, movies, or TV series. It is overly positive and thus unrealistic. On the other hand, there are the narratives that make autists into tragic beings. These are overly negative and paint a very dark picture. Such accounts might sometimes be conceptualised as 'realistic' in contrast to fictional portrayals because they are generated by parents or caregivers. Additionally, 'high-functioning' verbal individuals will campaign for their cause and against discrimination and harassment. There is also a growing number that reject therapies or treatments for autism. However, most severely autistic individuals will never become activists in their own rights, nor will they voice their experiences and thoughts. These autists are spoken for by others, like Alison Singer, who advocate for a cure. Individuals at the 'high-functioning' end are offended by such claims, but might at times gloss over the fact that some autists are severely affected. Vice versa, those advocating for a cure are unwilling to accept that autists might not actually perceive themselves as disabled or deficient. I believe these are two fundamentally different conceptions of

autism which cannot be easily reconciled. At their extreme ends, both sides are unwilling to acknowledge the larger picture. However, the fact that autism was reconceptualised as a spectrum has fuelled this discussion – or perhaps even enabled it in the first place – because now both sides are fighting over the same label, while arguably not referencing the same individuals.

Again, I am making generalisations about the discourse(s) to demonstrate two contrasting movements. The curse-or-blessing dichotomy might not be as strong as I make it out to be. However, I do believe that there are two parallel running narratives that at some point will have to be meaningfully reintegrated within the intermediary discourse. Here, literature, and young adult fiction in particular, has the potential to foster awareness, educate on autism, and create means of identification, while also imagining (new) ways in which autistic individuals can be integrated into society, thus reducing the stigma. At the moment, autism portrayals in young adult fiction are overly positive but they lack diversity to serve as adequate application templates. These narratives lean towards making autists into heroes capable of saving the world. Ideally, autism portrayals would represent low- and high-functioning individuals in different settings to create awareness on both sides. However, whenever autists do not appear capable of speaking for themselves, others will narrate their story for them, which often results in a rhetoric of sadness. Such figures are either considered too boring to be featured in novels, or they are steeped deeply in tragedy, thus no positive life can be imagined for them or their families unless they are cured.<sup>15</sup> Consequently, both sides fight over what compels an ‘accurate’ portrayal. This was further intensified by the medical discourse merging different diagnoses under the label *Autism Spectrum Disorder*, thus essentially contrasting different understandings of autism.

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15 Or killed, see also stereotype ‘Disabled’ in Chapter 3.3.