The Medical Discourse of Autism

Even though some autism activists, the neurodiversity movement, and the field of disability studies seek to deconstruct the medical scaffolding of autism, it is first and foremostly considered a medical condition. Autism Spectrum Disorder (ASD) is characterised as a mental disorder with underlying physical, cognitive, and environmental causes. Although some self-advocates might disagree, research is still in large part focused on understanding the causes of autism and has not abandoned the idea of finding a cure. Here, one might argue that it is but the modus operandi of the medical discourse, which tends to frame conditions in terms of normal or deviant. Treatment or cure thus represents the urge to make these individuals as 'normal' as possible, e.g. through behavioural therapy. I am not concerned with the underlying causes because they are not relevant to the analysis of literary portrayals. As of now, however, there are no "definitive physiological or neurological markers" (Duffy and Dorner 210), although research favours congenital over environmental factors.

Diagnostic Criteria and Symptoms

What could be considered the official definition of autism is given by the ICD or the DSM. The ICD is the internationally acknowledged classification system for diseases and partly serves as an encoding tool in medical systems, e.g. communication between doctors. It may also be used for diagnostics (DGKJP 18) and is complemented by diagnostic

tools such as ADI-R, ADOS or ADOS-2[1]. Additionally, the APA (American Psychiatric Association) publishes the DSM (Diagnostic and Statistical Manual of Mental Disorders) which focuses on mental disorders only. All studies used in this paper referenced the APA and DSM, thus I conclude that within the medical specialised discourse, the DSM is of particular relevance. It was also the first classification system to merge different (autism) diagnoses into ASD (Autism Spectrum Disorder). This diagnosis was already adopted in the *DSM-5* (2013), preceding the *ICD-11* (2022) by nearly a decade. However, when the *DSM-5* was first published, it received considerable criticism for various reasons, such as the medicalisation of human conditions, a flawed revision process, as well as financial conflicts of interest for panel members (Wakefield; Cooper; Cosgrove and Krimsky). Although not the topic of this study, it demonstrates how diagnostic criteria are part of discourses and therefore caught up in power structures, too.

There are only subtle differences when it comes to the definitions of Autism Spectrum Disorder in the *ICD-11* and the *DSM-5*. For example, the latter differentiates contexts only in connection with social interaction and communication, while the *ICD-11* refers more broadly to deficits in functioning (see Appendix A). However, such differences are negligible for my study. ASD is currently considered the most up-to-date diagnosis, as opposed to earlier differentiations. The German directive on autism diagnosis states:

> New studies that have dealt with the question of dimensionality or categoricality have recently shown that although it is possible to differentiate between autism spectrum disorders and non-autistic disorders in the sense of a categorical differentiation, it is not possible to differentiate between different subgroups within the autistic spectrum. (DGKJP 18, own translation)[2]

1 ADI-R=Autism Diagnostic Interview Revised, ADOS=Autism Diagnostic Observation Schedule

2 Neue Arbeiten, die sich mit der Frage nach Dimensionalität oder Kategorialität beschäftigt haben, konnten zuletzt zeigen, dass zwar eine Differenzierung zwischen Autismus-Spektrum-Störungen und nicht-autistischen Störungen im

I will pointedly state that the medical discourse with its desire to categorise and define probably benefitted the most from merging autism onto a spectrum. Diagnostic criteria as featured in the *DSM-5* now include the whole spectrum of characteristics that may present; hence they are organised as a modular system according to three main aspects, i.e. social interaction, social communication, and restricted, repetitive behaviour, interests, and activities (RRBIAs). Onset is stated as 'early childhood', and the diagnostic criteria include everyday life impairment that may vary according to context. Here the spectrum goes from 'no disorder of intellectual development and no impairment of language' (*ICD-11* 6A02.0) to 'disorder of intellectual development and absence of functional language' (*ICD-11* 6A02.5), more commonly known as high-functioning and low-functioning respectively. Criteria may be specified according to severity (Level 3 'Requiring very substantial support', Level 2 'Requiring substantial support', and Level 1 'Requiring support'). It should be noted that symptomatology might fall below level 1, "with the recognition that severity may vary by context and fluctuate over time" (American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders* 51–52, see also Chapter 6.4).

Diagnostic criteria of Autism Spectrum Disorder as defined in the *DSM-5*:

> A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history …:
> 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
> 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body

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Sinne einer kategorialen Differenzierung möglich ist, dass aber innerhalb des autistischen Spektrums die Unterscheidung verschiedener Subgruppen nicht möglich ist. (DGKJP 18)

language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. …
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history … :
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g.,strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). …
C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked be learned strategies in later life).
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism

> spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder. (APA, DSM-5 50–51, see Appendix B for examples, original enumeration)

It can thus be said that the diagnosis ASD is at the overlap of 'deficits in social communication and interaction' and 'restricted, repetitive patterns of behaviour, interests, and activities'. Difficulties in diagnosing ASD may arise from the fact that both criteria could indicate a plethora of other conditions in children, including ADHD, Fetal Alcohol Syndrome, epilepsy, obsessive-compulsive behaviour, global developmental delay, or intellectual disabilities ((Kamp-Becker et al. 463). Because symptoms tend to present differently over time, differential diagnoses for ASD in adulthood include – amongst others – depression, PTSD, schizophrenia, and personality disorders (463). Indeed, "70% of individuals with autism spectrum disorder may have one comorbid mental disorder" (APA, *DSM-5* 58). All this taken together, it becomes clear how many different manifestations of autism are subsumed under the same label, further underlining how stereotypes cannot possibly do this diversity justice. Even socio-economic factors will play into the diagnosis (57).

I will nevertheless briefly comment on the stereotypes I identified and some obvious parallels to the diagnostic criteria. In Chapter 3.4, I stated that all characters examined portrayed similar characteristics: a need/love for routine, hyper-attentiveness and/or -sensitivity, and special interests. These clearly relate to 'restricted, repetitive patterns of behaviour, interests, and activities'. Secondly, characters were portrayed as having a barrier when it comes to communicating feelings. They were also very honest and tended to communicate very literally. Here, the parallels become less obvious, although "[m]any individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language" (APA, *DSM-5* 53).

The novels in my analysis only featured instances of (overly) literal language, and a few instances of stilted language and echoed speech (e.g. *London Eye Mystery* 8, 121f). Of all associated language deficits, autism portrayals appear to emphasise literal language and difficulties in understanding figurative language, a narratological feature of autism portrayals to which I will return in Chapter 7. It can thus be argued that the portrayal of honest characters that communicate very literally is a stereotypical representation, which simultaneously excludes non-verbal individuals (or those with other language deficits) and individuals who do not have language deficits at all. However, I neither can nor wish to comment on the representativeness of stereotypes and/or diagnostic criteria for autism. Perhaps, one might cautiously state that the stereotypes identified partially coincide with the diagnostic criteria for ASD, but only for a very specific combination. In other words, although the stereotypes can be understood as part of the spectrum, they do not actually refer to its totality.

In those few studies that analyse autism fiction (e.g. Kelley et. al, van Hart), it seems a common approach to use the DSM diagnostic criteria for estimating 'good' portrayals. As I have stated before, I believe these studies are based on the misconception that symptoms equal accuracy (cf. Chapter 5.2). Yet, autism is not the totality of its symptoms but the plethora of its combinations. The diagnostic criteria might aim at comprehensiveness, but autism portrayals should not, if they claim to be representative. Indeed, the major flaw of autism stereotypes is not that they are 'unrealistic', but that they present only a section of the picture without communicating it as such. Unfortunately, the multifaceted nature of autism thus also creates a loophole for writers to justify artistic liberties and to purport these stereotypes. Indeed, it appears as if autism portrayals are actually representative of the author's concept of autism, to the point where definitions given within the novel are made to fit the characters (or vice versa).

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.[3]

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.