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Exploring neurodivergent young peoples' perspectives

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Literacy

Representation of neurodivergence in fiction books: exploring neurodivergent young peoples' perspectives

Charlotte Webber , Elena Santi, Katie Cebula, Catherine J. Crompton and Sarah McGeown 6

Abstract

In recent years, there has been growing awareness of the importance of representation in fiction books, to ensure all children and young people can see themselves reflected in what they read. Much of this work has focused, importantly, on increasing ethnic representation, yet there has been much less exploration of the representation of other minority experiences, such as those of neurodivergent young people, and how these are perceived by neurodivergent young people themselves. This article provides new insights into neurodivergent young people's perceptions of representation of neurodivergence in fiction books (and other text types) based on semi-structured interviews with 16 neurodivergent young people (aged 14 to 17 year olds) from 2 high schools in Scotland. Using an inductive data-driven thematic analysis process, three themes were identified: (1) representation of neurodivergence should be complex, realistic, and positive; (2) representation of neurodivergence should be normalised; (3) representation of neurodivergence beyond books is important. Each of these themes is explored in detail, followed by implications for future research, practice and the publishing of Young Adult fiction.

Key words: representation, neurodiversity, neurodivergence, fiction, reading, books

Introduction

Fiction books often represent the social world we live in (Eekhof et al., 2022) and can support readers' understanding of themselves (Slater et al., 2014) and others (Mar and Oatley, 2008; Vezzali et al., 2015). Indeed, books provide opportunities for readers to engage with personally meaningful content, develop and consolidate their identities, and to achieve greater self-awareness and understanding (Fialho, 2019; Lawton and Cain, 2022; Schachter and Galili-Schachter, 2012). Furthermore, fiction books can

introduce readers to more diverse social experiences and people than they would encounter in their daily lives, offering opportunities to learn about those whose experiences are different from their own. Indeed, previous research has indicated that reading narrative fiction can reduce prejudice towards those perceived as different (Vezzali et al., 2015), and support the development of social abilities (e.g., Eekhof et al., 2022; Mar et al., 2006).

However, for these benefits to be realised, it is essential that young people have access to books which reflect the rich and diverse society we live in, and important work over the last two decades has focused on raising awareness of this (e.g., CLPE, 2020; Ramdarshan Bold, 2018, 2021; Ramdarshan Bold and Phillips, 2019), yet there is still further progress to be made. Indeed, a recent large-scale survey with 58,346 UK children and young people (aged 9–18) found that 39.8% of children and young people would like more books with characters who are like them, and 47.3% would like more opportunities to read about those who are different to them (Best et al., 2020). This indicates the importance of commissioning new books, which reflect the diverse lives and experiences of children and young people; however, understanding how they want to be represented is also essential to inform this work.

To date, the majority of research and related advocacy work focused on increasing diversity within children and young people's books has focused on the representation of people of colour (Ramdarshan Bold, 2021). While essential, greater awareness of the representation of other minority or marginalised identities (e.g., gender, sexuality, disability, and class) is also important to ensure all readers "see themselves" in the books they read. The focus of this article is on the representation of neurodivergence in YA fiction books and neurodivergent young people's perceptions of this representation. Neurodiversity is a term used to explain the fact that "humans vary in their neurological make-up and that this variability dictates the ways

in which we process information—and therefore our experiences of and responses to the world" (Fletcher-Watson, 2022; p. 418). This variability acts as a driver of clusters or "neurotypes". Individuals thought to be part of the most common neurotype are often described as "neurotypical"; individuals whose neurotype overlaps with diagnostic categories such as autism, ADHD, dyslexia, dyspraxia, among others (and including those with co-occurrences), may be referred to as neurominorities, or neurodivergent (Fletcher-Watson, 2022). Importantly, the neurodiversity paradigm emphasises the importance and value of all forms of neurological variability.

In the United Kingdom, it is estimated that approximately 15% of the school-aged population are neurodivergent (Department for Education, 2023; Scottish Government, 2022), yet neurodivergent young people's perspectives on the extent and quality of representation of neurodivergence in YA fiction remains underexplored. Notably, a recent systematic review by Jones et al. (2023) aimed to examine "the accuracy and authenticity of fictional media portrayals of autism ... [and] the impact of viewing such portrayals on knowledge about autism and attitudes towards autistic people" (p. 2205). The review identified "several unhelpful and stereotypical portrayals of autism" (ibid.) (e.g., presentations of autism as non-human and othering, as heroic, as one-dimensional, or lacking a personal narrative), as well as portrayals which highlighted strengths and reflected nuance. For adolescents identifying as neurodivergent, opportunities to see their experiences reflected in the books they read could have powerful effects on their sense of belonging and self-worth (see Barrio et al., 2021). For neurotypical readers, learning about the experiences of their neurodivergent peers through accurate representation in fiction could help to promote understanding and attitudes of acceptance (see Hayden and Prince, 2023). For example, previous research has indicated that neurotypical children may have little to no exposure to autism/autistic characters but that viewing an animated television show featuring an autistic child superhero could increase understanding of autism and perception of autism as a positive characteristic (Chow and Hayakawa, 2022).

This article therefore aims to provide detailed insight into neurodivergent (e.g., ADHD, dyslexic, and autistic¹) young people's perspectives and experiences

Throughout the article we use identity-first language (e.g., autistic person and autistic young person), rather than person-first language (e.g., person with autism), as the former is often preferred by autistic self-advocates (Haller, 2016). Person-first language may accentuate stigma by implying that the individual could exist without autism, instead of autism being fundamental to them. Interviewees own words have not been edited however, and their own language with regard to self-description has been retained.

of the representation of neurodivergence in fiction books (and other text types). The project was carried out by team of researchers and other professionals working across University and third-sector organisations (see below) and adopted a qualitative approach, with initial input from neurodivergent young people, to ensure their voices were central to this work.

Method

Research-practice partnership

This project was a research-practice partnership between a group of university-based researchers (n = 6) and practice partners (n = 8) with a shared interest and commitment to improving young people's literacy experiences, and understanding and amplifying the voices and perspectives of neurodivergent young people. The researchers were based in Schools of Education (CW, ES, KC, and SM) and Clinical Brain Sciences (CC), with degrees in Education, Psychology, and Children's Literature. The practice partners were based in literacy advocacy organisations (BookTrust, National Literacy Trust, and Scottish Book Trust), or within the publishing sector (with a specific focus on supporting neurodivergent readers and/or including neurodivergent characters within fiction books), or were teachers currently teaching in UK schools. All 14 members of the project team contributed to, and were named on, the original grant application, and through online meetings and offline communication, agreed on the research questions, methodological approach, and the first draft of the interview schedule. The interview schedule was then shared with three neurodivergent young people for consultation. During this process, the neurodivergent young people each received an accessible summary of the project aims and a copy of the interview schedule prior to meeting with a member of the research team. During the meeting, they were encouraged to reflect on the questions and suggest revisions to improve relevance and accessibility, and/or suggest new questions, which they felt were important. Several revisions were made as a result and these were agreed with the entire project team. Aligned with open research practices, the project was then preregistered on the Open Science Framework, and can be found here: https://osf.io/b4cfh.

Participants

In total, 16 neurodivergent young people (aged 14 to 17 years old) from two urban high schools in Scotland participated in one-to-one interviews with the second

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author. Participants were asked to self-report their gender: six participants identified as male, nine identified as female, and one identified as trans. The majority of participants were White Scottish. Participants had a range of diagnoses including autism (N = 6), ADHD (N = 1), autism/ADHD (N = 1), dyslexia (N = 7), and dyspraxia (N = 1). Participating schools were selected based on existing relationships with the research team and students were invited to take part through their teacher/school librarian, with a request to ensure diversity within sample (in terms of diagnoses, gender, age, ethnicity, and socio-economic status) as much as possible. Within the sample, participants' experience with reading about neurodivergent characters was diverse (i.e., some reported having read many books featuring neurodivergent characters, whereas others reporting having read very few and/or only encountered them in school).

Interview schedule

The interview questions first introduce young people to the topic of representation in general, before asking them about their own reading habits and preferences. The majority of questions then focus on neurodivergent representation in fiction books. A copy of the interview schedule can be accessed within the preregistration: https://osf.io/b4cfh. Participants were not asked their opinions about specific texts (although some participants did reference particular titles to contextualise their responses), but were encouraged to reflect on how they would like to see neurodivergence represented in fiction books in general.

Procedure

Ethical approval was sought and granted by University of Edinburgh Ethics Committee. Following consent from headteachers, parents, and participants, semi-structured one-to-one interviews were conducted in a guiet room within participants' schools. All participants received a copy of the interview schedule in advance so they could prepare for the interview, if they wished. To improve accessibility, participants were also offered the opportunity to give written responses to the interview questions, rather than being interviewed in-person. All took part in in-person interviews which were audio recorded using a dictaphone. All interviews were then transcribed in full by the first author and shared with the second and final authors. Anonymised data collected as part of this project will be made publically available on the UK Data Service in September 2024.

Analysis

The analysis was conducted from within a constructivist paradigm, using a data driven inductive approach and following Braun and Clarke's (2006) six stages of thematic analysis (see Table 1). Three researchers (CW, ES and SM) initially read the first four interview transcripts independently, reading them twice in full (Phase 1), generating initial codes to identify interesting features of the data in a comprehensive way (Phase 2), and sorting the codes into themes (Phase 3). The researchers then met to discuss codes and preliminary themes. This process (Phase 1–3) was then repeated for the entire dataset by the first author. Once completed, the themes were reviewed and refined

Table 1: Illustrative example of Phase 1–3 of thematic analysis.

Example quote	Code (Phase 2)	Theme (Phase 3)
"I think especially if you don't know that you're Autistic or, like, you have, like, an abnormal, atypical portrayal of autism, it's important to feel like you're understood" "Because not everybody's the same, like, my dyslexia is in my writing, but some people could have it in their reading"	Representation should feature diversity/complexity of neurodivergent experiences	Representation of neurodivergence should be complex, realistic, and positive
"People that take you-, think that you're a bit silly or are a bit dumb because of this, like, if a book is like, really biased about a person because of that, then I would feel like that's quite unrepresentable of the people". "If it was, kind of, like, sort of, harmful I'd probably prefer not [to be represented]".	Representation should not problematize/present neurodivergence negatively	

in-depth by the same three researchers to ensure that they accurately represented the data (Phases 4–5). This stage resulted in some amendments to theme names to ensure absolute clarity, before being written up for publication (Phase 6). Notably, the codes did not cluster according to diagnostic label or gender.

Results and discussion

Three themes were identified during the thematic analysis which aim to capture neurodivergent young peoples' perspectives on the representation of neurodivergence in fiction books: (1) Representation of neurodivergence should be complex, realistic, and positive; (2) Representation of neurodivergence should be normalised; (3) Representation of neurodivergence beyond books. These are discussed below, including relevant subthemes related to each. Please note that quotes have been attributed with participants' self-reported gender and diagnosis. This is to exemplify that responses from participants with different diagnoses and gender identities are represented across all themes and did not cluster according to gender or diagnostic dimensions. However, it is important to emphasise that the reflections made by participants reflect only their own experiences; readers should not assume that individuals who share the same diagnostic labels will necessarily have the same set of experiences (see Astle et al., 2022; Fletcher-Watson, 2022).

Representation of neurodivergence should be complex, realistic, and positive

For neurodivergent young people participating, "good" representation was about more than simply having a neurodivergent character visible within a narrative; they emphasised that representation should be accurate and realistic, featuring aspects of their dayto-day lives as well as explorations of experiences unique to them as neurodivergent young people. They highlighted that representation should also be broadly positive and, ideally, challenge stereotypical assumptions and the problematising of neurodivergence. They suggested that "good" representation also requires an intersectional approach, whereby overlapping marginalisations (e.g., marginalised genders) are represented and celebrated. Notably, the literature surrounding intersectionality emphasises that representing and celebrating overlapping marginalisation should still be understood as inextricably intertwined with societal and institutional structures interlocking systems of privilege and oppression (Buchanan and Wiklund, 2021).

Representation should feature the diversity and complexity of neurodivergent experiences. Neurodivergent young people participating emphasised that representations of neurodivergence should capture the full complexity of the neurodivergent experience. This relates to the diversity which exists both between diagnoses (e.g., that ADHD experiences are not the same as autistic ones) and within diagnoses (e.g., that no two autistic individuals have the same set of experiences) (see also Astle et al., 2022). Participants noted that representing neurodivergent experiences in ways which do not reach beyond stereotypes could reinforce a perception that every neurodivergent person encounters the same set of experiences. They pointed out that even individuals with the same diagnosis will have vastly different experiences, and that representing this was important in building up an accurate and realistic picture of neurodivergence.

Because not everybody's the same, like, my dyslexia is in my writing, but some people could have it in their reading ... So, I would like to see it represented in more different ways. (Dyslexic, male)

I think especially if you don't know that you're Autistic or, like, you have, like, an abnormal-, atypical portrayal of autism, it's important to feel like you're understood, like, even within a fictional setting like, 'I relate to this character, I experience this'. (Autistic, Trans)

For example, with ADHD, if they were trying to represent something like that, they probably always make the characters space out and do the most, like, obvious things ever and just make it ... Like, that's the only interesting thing about them. And it would just be kind of-, it's not cliche, but it's a stereotype in a way. (Autistic, female)

Indeed, only engaging with subset neurodivergent experiences amounts one-dimensional (Jones et al., 2023) or "partial representation" (McCoy et al., 2020), which can lead to skewed outcomes where certain interests are over- or under-represented in comparison with others. This, in turn, may lead to the development of suboptimal or harmful policies, practices, or other means of engagement with neurodivergent individuals (McCoy et al., 2020). Therefore, ensuring the inclusion of diverse neurodivergent experiences is essential. For example, representing the experiences of nonspeaking²

²The term nonspeaking is preferred (as opposed to non-verbal) within the autistic community, according to the Autistic Self-Advocacy Network. The term "non-verbal" implies the inaccurate assumption that individuals without speech are unable to use words entirely. However, many nonspeaking individuals communicate using words even if they do not *speak* those words.

individuals, or those who use AAC (augmentative and alternative communication).

As well as representing the diversity and complexity which exists within and between diagnoses, participants also emphasised the importance of seeing their day-to-day experiences represented in fiction books. For example, one participant noted that most of their friends were neurodivergent, but that the books they had encountered which feature a neurodivergent character often did not situate them within a group of other neurodivergent characters.

"[In] books where they're trying to do, like, representation it's maybe just one character with that as opposed to multiple, but ... most of my friends are neurodivergent ... and that's not always portrayed in, like, books, if that makes sense. It's always just, like, the sort of the token represented character." (Dyslexic, female)

Jones et al. (2023) highlight a negative portrayal of autism in fictional media which positions autistic characters as "socially dysfunctional" (p. 2211) and unable to form interpersonal relationships. While more recent research has challenged this deficit-based stereotype (see "double empathy problem" e.g., Chapple et al., 2021; Crompton et al., 2021), research has also found that neurodivergent (e.g., autistic) people feel more socially comfortable, and have a better understanding of social interactions with other autistic individuals than they do with non-autistic individuals (Crompton et al., 2020; Heasman and Gillespie, 2019). For this participant, seeing representation of neurodivergent friendship groups was not only important for validating their everyday experience, but also for challenging assumptions about neurodivergent individuals being socially isolated.

Another participant commented that the more nuanced, everyday aspects of neurodivergent people's lives often did not receive as much attention as more stereotypical experiences did.

Kind of like how-, how Autistic people go around, like, how they see day-to-day life. How sometimes they get confused and sometimes, like, they pay attention to certain things and less attention to some things. (Autistic, male)

Where disabled experiences are represented in mainstream media, they are often presented in such a way as to become "extraordinary, noteworthy, and, sometimes, inspirational when they involve disability" (Raw, 2019; p. 188). Jones et al. (2023) point to the presentation of autistic characters in fictional media as "heroic", for example, being portrayed as savant-like or an as "eccentric genius" (p. 2210). However, incorporating the day-to-day experiences of neurodivergent

people into fictional representations builds up a more nuanced and realistic picture of their everyday lives, depicting their routine and authentic experiences, rather than sensationalising them for the purpose of driving a story.

Representation should not problematize or present neurodivergence negatively. Participants emphasised the importance of not problematising neurodivergence or presenting it as negative. This links with literature which emphasises the importance of breaking away from stereotypical portrayals of neurodivergence, which often conceptualise neurodivergent realities in deficit terms (Bailey, 2023). In fact, participants in the current sample emphasised that not being represented at all was better than representation which reinforced negative stereotypes.

[Avoid] putting it like, 'oh this person's dyslexic so they're really stupid', or 'that person's Autistic, they're really funny how they walk' or something ... if they put it across in a bad way, that's a thing they should avoid. (Dyslexic, male)

Don't make [the neurodivergent character], like, the useless person of the story. Make them actually worthwhile. (Dyslexic, male)

If it was, kind of, like, sort of, harmful I'd probably prefer not [to be represented]. (Dyslexic, female)

negative As exposure to stereotypes neurodivergence may impact younger consumers' perceptions of neurodivergent individuals (and these perceptions may become foundational to negative attitudes which persist into adulthood; Favazza et al., 2017) ensuring exposure to positive and accurate representations of neurodivergence is essential for improving attitudes and knowledge towards neurodivergent individuals. To ensure representation is positive, participants in the study noted the importance of books foregrounding neurodivergent people's strengths (although not in a way which saw them "overcoming" their disability), of neurodivergent characters being written by neurodivergent authors or those with good knowledge of neurodivergent experiences, and for authors to discuss representation with neurodivergent young people themselves prior to writing, to ensure they are not inadvertently reinforcing harmful stereotypes.

[Authors should be] talking to neurodivergent people and seeing what it's like for them rather than just going off the stereotypes ... Because I guess with, like, ADHD and dyslexia, dyspraxia and autism, like, they'll have their stereotypes and it's very easy to just go straight off of that, but actually learning what it's like and kind

of going straight to the source of who actually has like, you know, that would be a lot better. (Dyslexic, female)

I need them to be a good character, you know, because I feel like not all neurodivergent people, barely any are, like, bad people, they're all amazing and I feel like if you could incorporate, like, cool things that-, for example, Autism, like, cool things that autistic people go through, but like, after they go through it they learn from it, [that] would be awesome. (Autistic/ADHD, female)

Representation doesn't need to be identical neurodivergent young people's own experiences, but some similarities are important. Neurodivergent young people in the study noted that in order to relate to neurodivergent characters in fiction books, the characters did not need to be identical to them (e.g., same gender, ethnicity); simply having some elements they could relate to could help them feel "seen". They also suggested that reading about a neurodivergent character who was in some ways different from themselves could help them gain a greater understanding of the experiences of other neurodivergent people.

It doesn't have to be exactly like me, it just has to have some elements that I can relate to. (Autistic, male)

I don't mind like, what they look like, I don't mind what they are. I don't mind any of that ... I don't mind if it's the main character, a side character, or any of it, I just like that there's something that has a certain ... relatability (Autistic/ADHD, female)

You need to make a character feel quite close to you, quite similar to you and having similarities is very important ... but in the same sense that they're like you, but they're going through other things so you can get a better understanding. (Dyslexic, male)

Participants also noted that representations of neurodivergent characters could only provide some insights into neurodivergent experiences. As each representation could provide only a snapshot or one perspective on neurodivergence, representing its full diversity and complexity within one book would be challenging.

Of course, you can't take everything at face value, because everyone's different. (Dyslexic, female)

It's probably quite difficult to, like, show how, like, these types of things affect people because it will affect lots of people differently so I think even if it has been represented in a story, then it might not be the same as the way that affects me. (Dyslexic, female)

Indeed, being neurodivergent is only one aspect of an individual's identity; intersecting and overlapping identities also affect their experiences, perceptions and interpretations of the world, and others' interactions with them. In this sense, having many and varied representations of neurodivergence means that neurodivergent readers are more likely to be able to find a character which they can relate to. As participants noted, having a character whose experiences are identical to their own would be difficult to achieve (especially as characters may feel more or less relatable at different points in a reader's life, depending on the experiences which are most important to them at the time), and reading about neurodivergent characters whose experiences are different from their own could support them to learn about others.

Representation should be intersectional. Neurodivergent young people in the study also noted how representations should be intersectional, foregrounding the ways in which neurodivergence overlaps and connects with other social categorisations (e.g., gender identity), and exploring how this creates different systems of discrimination or disadvantage. Intersectionality is a conceptual framework which is central within Black feminist activism and scholarship Buchanan, 2020). It has a central focus on social justice, exploring how societal and institutional structures and interlocking systems of privilege and oppression can be applied to understanding experiences of compound advantage and disadvantage (Buchanan and Wiklund, 2021). In the current study, neurodivergent young people noted that representations of overlapping marginalised identity are generally lacking in the books they read, with many featuring only white, cisgender male characters.

Oftentimes, when we see [Autistic] representation, it's only ever men. And so there are certain aspects, of course, of life that are different between people who are men, people who are women. And I don't think that it's properly represented. (Dyslexic, male)

I think it it's definitely important for, like, especially women to be able to see themselves because ... a lot of time [representation] is quite sort of orientated on the way it impacts men, and I think that you see that more with things like Autism or, like, ADHD as opposed to dyslexia, but there's still, like, difference. (Dyslexic, female)

Especially as a trans person, like, usually if you see Autistic representation it's, you know, a cisgender white child and it just doesn't feel very true to life, and my experiences as an Autistic trans person aren't going to be reflected by that. (Autistic, Trans)

Notably, young people mainly mentioned gender in relation to this issue (i.e., that representations of female, nonbinary, and transgender neurodivergent characters were lacking in comparison with male representations), however there are other social categorisations, such as race and class, which overlap with neurodivergence and situate individuals within different, yet overlapping, systems of marginalisation. Rather than illustrating that the representation of these intersections is not important in writing neurodivergent characters, it is likely that the lack of diversity in our sample with regard to these characteristics led to gender being the focus of this discussion. Nevertheless, the young people in this study make a call for greater diversity in the representation of neurodivergence in fiction, which foregrounds the experiences of those who are not usually represented.

Representation of neurodivergence should be normalised

As well as discussing the ways in which unique neurodivergent experiences should be represented, neurodivergent young people in the sample also emphasised the importance of these representations being normalised (i.e., seen as standard and accepted) and recognised that they had seen increasing awareness of neurodivergence in recent years (e.g., in school, in the wider media). However, they also emphasised the importance of not drawing attention to neurodivergence, and including implied/coded neurodivergent characters as well as explicit representations and situating them within engaging stories which normalise their appearance within fiction books.

I like how it did say [the character] was different but didn't like, like, just focus on that fact because it could be a completely different story ... I just like when it's like, it's something in it but it doesn't like, burst in your face. (Autistic/ADHD, female)

If it's, like, the book doesn't, like-, isn't around the person's neurodivergence, it's, like, a plot and how that interacts with such neurodiversity, I think that would maybe get more parents with, like, neurotypical children to, like, sort of, read books with representation. (Dyslexic, female)

The Dyslexic participant here suggests that stories which do not centre entirely around neurodivergence may be more appealing for neurotypical readers. Indeed, for neurotypical individuals to learn about neurodivergent experiences through fictional texts, these books need to be engaging in their own right.

In addition, for neurotypical readers, seeing neurodivergent characters embedded in a multi-dimensional narrative may help to normalise the presence of neurodivergent individuals in every-day life (rather than seeing them as a separate group with whom they never come into contact).

Representation should normalise rather than draw attention to neurodivergence. Neurodivergent young people in the study noted the importance of a character's neurodivergence not being the central focus of a narrative, emphasising that embedding neurodivergent characters into fiction without drawing attention to their diagnosis could make seeing neurodivergent characters in books less of a "big deal". This links to the argument above that incorporating the day-to-day experiences of neurodivergent people into fictional representations helps to normalise their presence within a diverse society. Notably, "normalisation" here is not referring to a process of "restoring" neurodivergent people themselves "to 'normalcy' [or] indistinguishability from peers" (Kapp, 2020; pp. 188-189), but making standard their presence in society.

Just don't make a big deal out of it. Making a big deal out of it sort of gets rid of the actual point that we want this to be casually embedded, we don't want a big deal made. We just want to be there. It shouldn't be like, 'oh my God, they're Autistic!' it should just be 'oh, they're Autistic, cool'. (Autistic, female)

One way I think the representation would be quite beneficial is if the book didn't surround against around the neurodivergence ... it's, like, a plot and how that interacts with such neurodiversity. (Dyslexic, female)

Whilst narratives which make obvious reference to neurodivergent experiences might help neurodivergent young people feel seen and represented in fiction, making these the most prominent features of a story risks reducing neurodivergent characters to their diagnosis alone. Therefore, representing neurodivergent characters as part of rich narratives which acknowledge their unique experiences, but which normalise their participation in stories which are not solely governed by their diagnosis could help neurodivergent young people feel represented without positioning their diagnosis the sole definition of who they are.

Representation does not have to be explicit. Relatedly, neurodivergent young people noted that part of normalising neurodivergent representation was to have representations which were coded (i.e., where it is implied, but not specifically stated, that a character is neurodivergent), as well—or sometimes instead of—explicit representations.

The series I read, especially the sort of-, with manga and the graphic novels, oftentimes, its characters I quite relate to [which] aren't like, inherently, you know, said to be on the spectrum, but are very implied ... having that character as sort of, like, a relation point is something that I really like about the series. (Autistic, female)

They noted that especially for neurodivergent voung people who were undiagnosed, coded representation could help them feel like they could relate to others. However, they also noted that finding coded representations could be more challenging than identifying books with characters who have particular diagnosis. Explicit mentions of autism, ADHD, dyslexia, and other diagnoses can be identified in book blurbs and summaries and can be used as search terms when looking for books online; when neurodivergence is coded, young people noted that they might have to read the whole book to establish whether or not it features a coded neurodivergent character. In relation to these findings it is important to emphasise that it is not possible to accurately "diagnose" a fictional character and measuring the "accuracy" of fictional portrayals has limitations in terms of both what is being assessed and how it is being measured (Jones et al., 2023). Therefore, signposting to less explicit representations of neurodivergence (i.e., via booklists, recommendations) could help young people find a greater variety of characters that they can relate to.

Representation of neurodivergence is generally becoming more prominent. Neurodivergent young people noted that they had perceived a recent increase in the representation of neurodivergence within the media and society more generally, and that this could partly explain an increasing normalisation of neurodivergent representation in books, TV, and film.

I think, at the moment, there's certainly a change that's happening ... I think, sort of, in lockdown when everyone had a bit of reflection sort of, realised that 'hey, we need to sort of start representing everyone', not just the vast majority, we need to start representing those ... whose voices aren't as loud. (Autistic, female)

"I don't think there's many ways neurodivergent people have been represented up until maybe 2020. I think that's when it really spiked or peaked more, like, with representation and such." (Autistic, female)

Although there is currently no comprehensive data available regarding recent trends in neurodivergent representation in the media, the participants' sense of increasing representation of diverse voices is reflected in research which has found growth in inclusive reading materials (e.g., CLPE, 2020). A recent review has

indicated that representations of autistic adults in popular media have increased since 2011 (Akhtar et al., 2022), and in the United Kingdom, children's books featuring "neurodiverse main characters" has been described as the "latest publishing trend" (Hill, 2023). However there remains disagreement about whether these portrayals will increase acceptance or further stigmatise neurodivergent people (see Jones et al., 2023). More recent popular representations of neurodivergent characters in books (e.g., A Kind of Spark by Elle McNichol and the Antigone Kingsley series by Marina Magdalena, both neurodivergent authors writing neurodivergent characters) and TV shows (e.g., Everything's Gonna Be Okay, which features an autistic actor playing the autistic main character), as well as discourse in the media criticising stereotyped representations of neurodivergent characters contributes towards a climate where accuracy of representation is increasingly scrutinsed.

Representation of neurodiversity beyond books

While this project focused specifically on the representation of neurodivergence in fiction books, neurodivergent young people in the sample also talked about the ways in which representation extends—and should extend—beyond books. For example, they noted that books represent one means of education about neurodivergence, but alone are insufficient. They emphasised that greater representation both within and outwith fiction books was necessary in order to access a wider audience, especially those who may not read books regularly, or may struggle with reading.

Books are one form of education, but alone are insufficient. While young people in the sample noted that representation in books could be a beneficial means of teaching others about neurodivergence, they also noted that this alone would be insufficient in tackling the stigma and misunderstandings associated with neurodivergence. They spoke specifically about education and training for others in understanding neurodivergence; representations in books could form part of this education, but this should be combined with more explicit education.

Representation is more than just, sort of, like, a character on a TV show, or sort of, a brief glimpse ... [it's about] teaching people about the condition and, sort of, trying to erase any stigma that surrounds it. (Autistic, female)

I think lots of teachers ... you can tell that they haven't got, like, proper training with [dyslexic] people ... I do think they need to just know a little bit more about all the kinds of things that people need. (Dyslexic, female) I think sometimes people need to get a little bit more of an education on some of this [neurodiversity] stuff as well. (Dyslexic, male)

This emphasises the need for accurate representations of neurodivergence across society. As deficit understandings of disability persist in educational settings and neurodivergent people continue to face disadvantage and discrimination in organisations "constructed on normative understandings of the world" (Bailey, 2023; p. 120), it is paramount that accurate representation be combined with education about authentic neurodivergent experiences alongside. Tokenistic representation (i.e., where efforts to be inclusive are simply symbolic) is not the same as meaningfully embedding and authentically including neurodivergent voices. Representations of neurodivergent characters in fiction books should be combined with representations in film, TV, social media, popular culture, workplaces, and schools. In the current study, young people also called for better education and training for those who work with neurodivergent people in improving understanding and ensuring they are clear on how to provide support.

Neurodivergence needs greater representation (in books and more generally). Relatedly, participants noted that while they perceived the representation of other marginalised identities (e.g., non-white characters, queer characters, characters with physical disabilities) to have received greater and/or growing representation in the media, they felt that neurodivergence was relatively underrepresented.

I've seen lots of other like, different types of things be represented in books, but neurodivergence is, I think, one of the least common examples of being represented. (Autistic, male)

Other, like, groups of people get their representations, so just because it's not a physical difference doesn't mean it shouldn't get the same representation. (Dyslexic, female)

I don't really think there's a great deal of representation at the minute, especially within fiction books, because a lot of the time they try, like, within, like, the media and TV shows and stuff, they try and portray this like idealised society and Autism doesn't really fit into that.(Autistic, Trans)

As explored above, characters with multiple marginalised identities were also perceived as not well represented, suggesting that greater and more diverse representation is necessary for neurodivergent young people to be able to find fictional characters to relate

to. It is notable too that even within neurodivergent representation, some experiences have currently received more attention than others. For example, Chapman and Botha (2023) note that within cultural representations, policy, research, and clinical practice, most discussions of neurodiversity focus on autism. Greater breadth and variation of neurodivergent representation is clearly still needed for different neurodivergent "ways of being" (Sinclair, 1992) to be visible in fiction, media, and society more generally.

Books with disabled characters are often marketed for disabled people, rather than for a general audience. Young people in the sample also noted that books featuring disabled characters are often marketed specifically at disabled people, or those who have disabled people in their lives, rather than being marketed towards a general audience.

A lot of the books that have neurodivergent characters are specifically marketed around those characters to sort of, bring in people with disabilities, instead of, you know, the series having a general audience of people who maybe don't have the disabilities that they write about. (Autistic, female)

This means that while neurodivergent readers may be able to experience the benefits of reading about neurodivergent characters, non-neurodivergent people are less likely to encounter them. For information about neurodivergence to reach a general audience, books with neurodivergent representation need to be visible outside of the neurodivergent community, as well as within it. This raises important implications for how books featuring neurodivergent characters are advertised and marketed. As learning about the experiences of neurodivergent peers through accurate representation in fiction could help to promote understanding and acceptance, it is important to ensure that these books also reach audiences beyond the neurodivergent community. Additionally, as the effects of fictional media featuring neurodivergent characters are likely to be cumulative, interact with other exposures, and rely on opportunities for individuals to "implement" knowledge through interactions with neurodivergent people (Jones et al., 2023), books featuring neurodivergent characters being visible and accessible to all readers is essential.

Fiction books aren't necessarily the best way to reach young people. Young people in the sample also noted that fiction books might not necessarily be the best way to reach young people. They noted that some neurodivergent young people may have reading difficulties, making books less accessible as a medium for encountering neurodivergent representation. They also noted that young people might not read books

regularly, and/or that they have different preferences regarding the books they read (i.e., preferring non-fiction).

I'm not sure how many of [my classmates] read books. My friend-, my friend, she also struggles with reading, so neither of us can do that part. But then, I don't know if anyone else reads books ... everyone is all techy these days. (Autistic/ADHD, female)

If I have to in English, I will [read], but most of it is more non-fiction, like more-, most of it is more fantasy and picture books because I have a hard time reading. (Dyspraxic, male)

Occasionally read fiction, but I think I read a lot more nonfiction because my reading, kind of, habit is not always constant, so it's just easier to, I guess, pick up a nonfiction. (Dyslexic, female)

It is necessary to bear in mind that although books can be an important access point for representations of neurodivergence, for both neurodivergent readers and a general audience, barriers such as reading difficulties, preferences for other text types, and the disinclination towards reading generally may act as barriers towards accessing these representations. In this sense, it is important for all audiences to be able to access many and varied representations of neurodivergence, both in fiction (i.e., through written texts but also in audiobook and picture book format) and in the media more generally (i.e., film, TV, social media).

General discussion

This study is, to the best of our knowledge, the first to seek neurodivergent young people's perspectives on the representation of neurodivergence in fiction books. Discussions with 16 neurodivergent young people demonstrate their awareness and understanding about issues surrounding the representation of neurodivergence in books, and in the media more generally, and provide novel insights into the issues that are most important to them. For example, that accurate and realistic representations of neurodivergence are important, and that these should feature the nuance and complexity of neurodivergent experiences, rather than reemphasising the most widely known/assumed characteristics of the neurodivergent experience. Participants also stressed the importance of challenging negative and stereotypical depictions of neurodivergent realities, and gave examples of the types of representation they felt to be problematising (e.g., positioning neurodivergence/disability as a "struggle" to be "overcome"). They also emphasised the importance of

foregrounding the experiences of those with multiply marginalised identities (e.g., non-white, non-male characters) in books to feel that they can really "see themselves" in neurodivergent characters. They also noted that they felt the representation of neurodivergence is increasing in the media more generally and that accurate representation in books is necessary, but not sufficient, for them to feel supported, understood, and accepted; representation in other forms of media and society is needed, in addition to education for peers and teachers.

Implications

This study has important implications for teachers, librarians, authors, and publishers. Schools and libraries are an essential point of access for young people to find books representing neurodivergent characters and therefore it is important that book provision reflects this dimension of young people's lives and experiences. In addition to provision however, it is important that teachers and librarians are confident talking about neurodiversity with young people, and feel confident being able to recommend books, respond to queries, and engage in discussion. Notably however, some young people in the sample noted that they wouldn't want books about neurodivergent characters to draw attention to their own diagnosis. Therefore, within school contexts, teachers should be mindful of these potential tensions if considering using books with neurodivergent characters as a teaching tool.

For authors and publishers, this article provides important insights into the considerations which should be borne in mind when writing or commissioning YA fiction featuring neurodivergent characters. In this study, neurodivergent young people stressed the importance of representation being complex, realistic, positive and normalised. Representation needs to reflect the intersectional make-up of society and does not always need to be explicit, but can be coded too. In addition, books need to be easy for young people with reading difficulties and/or are disengaged readers to access. We hope these insights from young people support with the commissioning and writing of books which amplify awareness and increase understanding of neurodivergent experiences, and celebrate the full diversity of neurodivergent realities.

Limitations and future research

Whilst this study is, to our knowledge, the first of its kind to seek qualitative insights from neurodivergent young people themselves on the issue of

representation, it is important to acknowledge the limitations associated with the project. First, we recognise a lack of diversity in our sample, for example, the lack of non-speaking participants, and those in Alternative Provision (AP; education outside school). Furthermore, the majority of our sample were White Scottish, as this reflected the school community. It is also important to recognise that demographic factors play a key role in unequal access to diagnosis (e.g., Macdonald and Deacon, 2019; Mandell et al., 2009) and in individual experiences of neurodivergence. We note that we did not have information about other demographic factors (e.g., economic background) which interact with neurodivergence, gender, and other aspects of identity to inform experience (see Lovelace et al., 2021; Udonsi, 2022). It is important that in future research, the experiences of marginalised groups are explored, as centring the experiences of white, English-speaking, and otherwise majority identities can risk reinforcing issues only which are relevant to the majority. Indeed, participants in this study made a call for greater diversity in representation (including intersectionality), demonstrating that this is an important issue for young people as they are appraising representations in books and in the media more generally.

Conclusion

Over the last decade there have been important and necessary shifts in children and young people's fiction books, to better reflect the diverse society we live in; however, more work still needs to be done, and young people's voices need to be central to this. Based on in-depth interviews with 16 neurodivergent young people, three core themes were identified as important for neurodivergent representation in fiction books. Representation should be (1) complex, realistic, and positive (2) normalised and (3) reflected beyond books. This article provides important insights for teachers, librarians, authors and publishers interested in supporting and celebrating the diversity and complexity of neurodivergent realities.

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Positionality statement

Within the project team, two members identify as neurodivergent, six members have a personal interest in neurodivergence (e.g., close family member/s) and six members disclosed no information relevant to this. All members of the project team were White, and the majority were female.

Conflict of Interest Statement

The authors report no conflict of interest. The research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Rights Retention Statement

For the purpose of open access, the authors have applied a Creative Commons Attribution (CC-BY) licence to any Author Accepted Manuscript version arising from this submission.

Open Research Statement

This study was preregistered and details (including interview schedule) can be found here: https://osf.io/b4cfh. The research team intend to make the anonymised qualitative dataset available on the UK Data Service in September 2024.

Additional Information and Resources

Further information and resources connected to this project can be found here: https://blogs.ed.ac.uk/literacylab/current-projects/neurodiversity-and-narrative-fiction/.

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