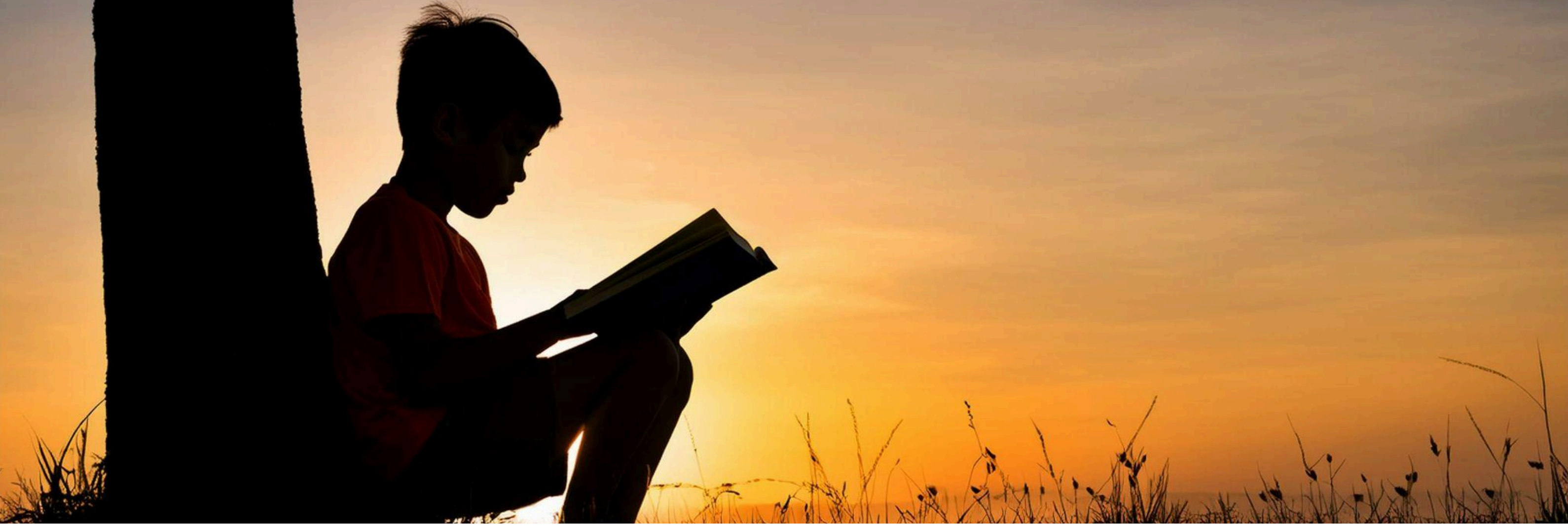

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Navigating Disability in Children’s Publishing: Insights from Disabled Authors

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Abstract
Despite making up an estimated 16% of the global population, only around 5% of children’s books feature disabled protagonists, and the majority of these are written by nondisabled authors. This article presents the findings of a study exploring the experiences of six disabled children’s authors navigating the publishing industry. It examines challenges they face in writing authentic disabled characters, barriers in accessibility, editorial biases, and the complexities of representing disability from lived experience. The study also looks at the impact of the #OwnVoices movement in promoting authentic disability representation, while addressing the potential limitations of the term as it has evolved since being coined by Corinne Duyvis in 2015. The findings highlight the need for systemic changes in publishing, such as improved accommodations, individualised support for authors, and better representation of disabled people in all facets of the publishing industry.

Keywords: *creative writing for young people, lived experience, disability, publishing, own voices*

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Introduction

Disability representation in children's literature remains disproportionately low, with only five per cent of children's books featuring disabled protagonists despite an estimated sixteen per cent of the population being disabled (Cooperative Children's Book Center 2024; World Health Organisation 2022). Data on the number of disabled people working in publishing is limited, however the Excluded Voices Report (Inclusive Books for Children 2024, p. 2) found that 'non-Own Voice creators' continue to dominate over marginalised voices in traditionally published children's literature. Additionally, little research exists on the lived experiences of disabled authors navigating the publishing industry. While research indicates a movement for greater inclusivity, this study seeks to examine the lived realities of disabled writers today.

This study was conducted by two disabled academics and children's writers, whose personal and professional experiences have informed our approach to the research. In this article, we explore the experiences and perspectives of six disabled children's authors, focusing on issues of accessibility, editorial bias, and the nuances of writing authentic disabled characters.

Research Design

The project was conducted following ethical approval from the Faculty of Arts Research Ethics Committee at the University of Bristol. Our research involved conducting semi-structured interviews with six traditionally published disabled children's authors in the United Kingdom and United States. Participants were given the option for anonymity or to 'receive recognition' (Saunders, Kitzinger and Kitzinger 2015, p. 618); some participants chose to remain anonymous, while others preferred to be identified by name. Participants were also given the choice between an email interview and a video-call interview over Zoom; five of the interviews were conducted via Zoom with the sixth conducted over email.

The design of the email interview was informed by Fritz and Vandermause's (2018) lessons on conducting in-depth email interviews. The participant was provided with the interview questions and given fifteen days to respond, after which a follow-up exchange allowed for a more flexible and conversational format, which facilitated a less structured interview approach, generating rich qualitative data (Dahlin 2021). The Zoom interviews were recorded with participants' informed consent and subsequently transcribed for analysis. The same set of questions served as a guide for the interviews; however, the conversations remained flexible, allowing participants to steer the discussion based on their experiences and perspectives. An inductive thematic analysis was conducted as we sought to generate insights and identify any similarities, differences and emerging themes from the data (Braun and Clarke 2006).

Findings and Discussion

Our participants provided detailed and insightful answers to the questions, offering a deep exploration of their experiences in publishing, from the initial stages through drafting up to post-publication. Their responses covered a range of topics, including the value of sensitivity readers, the impact of internalised ableism on their writing, the importance of good community support, and the intersectional barriers faced by multiply marginalised disabled writers. While all these areas warrant further discussion, this article will focus on three of the key themes that emerged from the data:

1. Ableism in the publishing industry
2. The abled gaze in editorial feedback
3. #OwnVoices and writing authentically

Ableism in the Publishing Industry

Participants shared both positive and negative experiences of navigating the publishing industry as disabled authors. Some authors reported supportive editorial teams and publishing professionals, such as children's author Meg Eden Kuyatt, who described her editor and agent as 'great allies and advocates'. She said they encouraged her to write about her neurodivergent experiences and gave her the space to 'more explicitly address that in [her] work'. Another author, Sophie Cleverly, said that the way her publisher had dealt with her illness and disability was 'surprisingly good', and a third, Karol Ruth Silverstein, referenced being reimbursed for a scooter rental at an event. Many of our participants' positive anecdotes related to specific individuals in the industry who demonstrated patience, kindness and support. While these experiences are certainly encouraging, as Sophie told us, 'There's been some negative sides to it as well.'

Authors recounted significant difficulties in accessing industry events, with some struggling to secure accessibility accommodations. Karol, whose publisher reimbursed her for renting a scooter at a convention, had to cover out-of-pocket expenses for a companion to travel with her and provide assistance. This highlights the extra barriers that disabled people face when trying to participate in the same events as their non-disabled peers.

Karol's experience was not unique. Other participants also expressed concerns about event accessibility, particularly noting that the shift from online to in-person events after the COVID-19 lockdown made participation more difficult for them. Sophie, for example, shared her experience at the UK's Young Adult Literature Convention (YALC), highlighting the challenges she faced due to the event's crowded nature and lack of adequate accommodations: '[It] was a really cool event. But it was just so bad for me, specifically, because it was extremely busy. There were no chairs anywhere [and] I think all the toilets were closed.' Sophie's account captures a broader sentiment among authors, as she reflected: ‘Maybe I don’t feel very welcome, or don’t feel very thought about as a disabled person.’ Similarly, an anonymous participant had a comparable experience at an awards event, stating, ‘It just completely wore me out, but you sort of felt like you had to do it.’

This sentiment of feeling as though they ‘had to’ conform or behave a certain way was also identified by other participants. Specifically, they mentioned feeling uncertain about how much they could push back or request in terms of assistance without coming across as difficult or risking the loss of opportunities. Sophie, for example, shared that earlier in her writing career she would avoid asking for things for fear of being ‘blacklisted as being too difficult to work with’. However, she went on to emphasise that disabled authors should feel empowered to ask for help and accommodations, asserting that any agent or publisher who perceives them as too difficult is not one they should want to collaborate with. Nonetheless, this experience stresses a very real concern among new, emerging, and inexperienced disabled writers who are unsure how to advocate for themselves: specifically, the fear of being perceived as challenging or difficult.

Other authors highlighted the inaccessible nature of the publishing industry itself. Lack of transparency about the publishing process, inaccessible and confusing information and instructions, and inflexible deadlines were some issues that were discussed. One anonymous participant stated: ‘It would be nice if sometimes there was clearer information about how things work, like the structure of stuff or the time length of stuff. But publishing doesn’t really work like that. So you don’t really get it.’ This lack of clarity and flexibility can make it very difficult for disabled writers, particularly neurodivergent writers who may require clearer information and further support to navigate the processes of publishing. Furthermore, the expectation to conform to traditional, often ableist, practices indirectly excludes and punishes neurodivergent authors for not adhering to normative, neurotypical ways of thinking (Mitchell 2024).

Overall, while there were instances of excellent support and accommodations by individuals within the publishing industry, there was a general consensus that the industry at large could do a better job of including and accommodating disabled writers. When asked what advice they would offer to new disabled writers navigating the industry, most participants suggested reaching out for help early on, seeking support from other disabled writers who have experience in the industry, and ultimately being brave. While systemic change within the industry will not occur overnight, there are many disabled people and advocates actively pushing for progress. As one author told us, ‘I’d like people to feel like they can be brave in a way that I don’t think people ever really told me that you could or should be.’ This quote underscores the power that disabled voices can have as a force for change, pushing the industry towards greater inclusivity. Ultimately, the responsibility lies with the industry to dismantle the barriers that disabled writers are forced to navigate. However, it is equally vital for disabled writers to feel empowered enough to assert their voices, and rights within the industry.

The Abled Gaze in Editorial Feedback

Building on the discussion of ableism in the publishing industry, many participants also highlighted instances of ableist feedback, specifically about their writing, from agents and editors. Nearly every participant shared that representations of their own disabilities in their work had at some point been criticised as 'inauthentic', 'unrealistic', 'unlikeable', 'unrelatable', or 'uncommercial.'

Meg shared that she had received ableist feedback suggesting that certain events in her books simply 'don't happen anymore', even though they were based on real, current experiences. Another author said that publishing seems to be holding on to the idea that 'there can only be one facet to somebody's identity in stories, because otherwise it is too much and nobody will get it.' Similarly, Sophie told us: 'I did get the feeling that if I'd written something that was a lot more straightforward […] it might have been more understood. There's kind of what narratives they expect.' These concerns are ones that we have heard anecdotally from many disabled authors, and it is significant that so many of our participants mentioned it in some capacity. In fact, another anonymous participant went as far as to state, 'I don't think I know a single disabled writer who hasn't come across it in some form, at some point. Which is sad.'

This consistent pattern of ableist feedback reflects the dominance of the abled gaze within the publishing industry, where the perspectives and lived experiences of disabled writers are often dismissed or misunderstood in favour of narratives that reinforce dominant ableist stereotypes and assumptions. The term 'non-disabled gaze' (Hughes 1999) describes how disability is represented and constructed by dominant non-disabled society. The term 'abled gaze' emerged organically within disability studies and media discourse and is more commonly used in disabled communities and media discussions. The 'abled gaze' refers to the objectification of disabled people, describing a gaze that constructs narratives and images of disability that privilege the expectations of implied non-disabled audiences, at the expense of disabled audiences and wider disabled society.

Much like how through the male gaze, as coined by Laura Mulvey (1975), women are objects of male pleasure, the abled gaze situates disabled people as objects for the entertainment and gratification of assumed non-disabled audiences. While the male gaze is often centred on the hyper-sexualisation of women's bodies (Mulvey 1975), the abled gaze objectifies disabled people, and constructs narratives and images of disability for the pleasure, comfort, or benefit of the implied non-disabled viewer or reader. In children's fiction, this dynamic can significantly influence how non-disabled children perceive their disabled peers and how disabled children feel about themselves. Sophie recalled her own childhood, saying that growing up she read books with disabled characters written by non-disabled writers and often felt that there was something 'not quite right' or uncomfortable about the portrayals. She said that this is one of the reasons authentic representation matters to her as both a reader and writer.

Ultimately, the abled gaze both reflects and creates society's understanding of disability. From what our participants have shared, it seems the abled gaze permeates the editing process, with editors' preconceived ideas and expectations about disabled people influencing how they interpret disabled stories written by disabled people themselves. Karol referenced the abled gaze directly, and stated, 'When you're able bodied, you really can't help but see things through this lens. We tend to be put into three categories: objectified, infantilised, or erased.'

When criticism from editors and agents is rooted in ableist assumptions about disability, it effectively limits the scope of representation available to readers by stifling disabled writers' ability to tell authentic stories that do not conform to ableist expectations. The Excluded Voices Report voiced similar concerns and called for: 'children's book publishing to look beyond tokenistic, trend-driven commissioning, and pigeonholing of Own Voice creators into issue-only books, and instead address inclusivity more deeply, genuinely and rigorously' (Inclusive Books for Children 2024, p. 3). Until the industry challenges the abled gaze and prioritises disabled authors' perspectives on disability, disabled writers will continue to encounter obstacles that restrict their creative expression.

One participant, Anna Bowles, spoke from her perspective as both author and editor. She observed that, with the way that publishing currently works, in order for books to be more commercially successful, 'you need to be more exploitative about your condition' in some ways, leaning into the abled gaze. However, she also emphasised that authors have a responsibility not to 'present disabled characters in a way which [suggests that] some people are born to suffer and just have inherently limited lives, [or] that some people are born to be an inspiration to others while suffering themselves'. To Anna, 'exploiting your condition' did not mean reinforcing harmful stereotypes, but referred to 'sensationalising' one's experiences to pique interest. She did not endorse this as positive, nor did she criticise it as inherently negative, but rather made an observation about how the industry currently works and what she believes is more likely to result in success.

Another anonymous author also believed this to be the case, however he added that the more that disabled writers 'flood editors' inboxes with stories that are different than they are currently expecting […] the more chance we have of getting some through, and the more we get through, the more they'll be written'. This sentiment emphasises the idea that consistent, diverse submissions from disabled writers could gradually shift industry expectations and open doors for more inclusive stories. As Abad (2021) writes on the topic of autistic-authored Young Adult Fiction, 'the publication of autistic authors becomes a way for the autistic community to reclaim ownership of our disabled identities, pushing back against a history of marginalization and stigmatization.' Essentially, by challenging industry norms, disabled writers expand the landscape of authentic storytelling, reclaiming agency over narratives that have historically been shaped by non-disabled voices, and gatekept by mainstream publishing.

#OwnVoices and Writing Authentically

Originally coined by disabled author Corinne Duyvis (2015), #OwnVoices was intended as a social media hashtag to help readers identify books about marginalised or diverse characters written by similarly marginalised or diverse authors. The term has gone on to serve a useful purpose in helping recognise 'authentically' written stories and amplify marginalised voices in an industry where, historically, their stories have been told by authors writing from the outside looking in.

The Excluded Voices report (Inclusive Books for Children 2024, p. 6) uses the term 'Own Voice representation' to refer to the 'symmetry between marginalised creator and main character,' and found that, not only was the total number of books with disability representation low, but that most of the stories that were published were not written by Own Voice authors. The report (p. 29) argues that, when 'most of these stories are told by non-disabled creators, it allows the disabled narrative to remain in their control. This, in turn, contributes to ableist tropes persisting in the popular imagination'. In the report, the term Own Voices was a vital piece of language that helps to categorise books and identify 'authentic' representation. While the report does recognise that there are some limitations to the term, stating that 'categorisation according to socially constructed aspects of identity risks being reductivist and presumptuous', it ultimately decides that it is currently the best term to use for the purposes of their research.

Our findings, however, indicate that authors may be moving away from using #OwnVoices to describe themselves and their own work. Most of our participants expressed reservations about the current usage of the term. Some referred to it as outdated, while others noted that it has often been co-opted in ways that place additional pressures on disabled and other marginalised writers by expecting them to 'out' themselves, or disclose private details about their lives. As Abad (2021) argues, 'this kind of disclosure can also constitute a kind of self-injury, forcing disclosure from those who would not otherwise do so.' Some of our participants preferred the term 'writing from lived experience' as a more accessible and less loaded alternative.

One author explained that the original intent behind the #OwnVoices hashtag was to help readers find nuanced representation from those with lived experience, because so much harmful representation was being written by outsiders. He noted that the term had evolved and said, 'it's not always used in the best ways,' and has sometimes been 'taken slightly too far by some people'. Anna felt similarly, describing Own Voices as a 'crude tool for pointing out something important'. She emphasised the need for its careful use, adding, 'Own Voices needs to be used sensibly. But humans do not behave sensibly.'

Karol shared a similar concern, stating, 'I thought it was really, really empowering until it was just sort of dirtied by capitalism as things tend to get, and now we talk a lot about lived experience and it's a good term.' She also noted that people outside of the publishing industry might not be familiar with 'Own Voices', whereas 'if you say lived experience, those are common words.' Karol raises an important point here about accessibility and gatekeeping. The use of industry-specific, 'buzzword' terms can sometimes alienate people, whereas a phrase like 'writing from lived experience' is more widely understood.

These concerns highlight the need for a more nuanced and flexible approach to recognising authentic representation – one that does not weaponise marginalisation against the marginalised authors it aims to uplift. While the term 'Own Voices' is not inherently problematic, and as the 2024 Excluded Voices report states, remains valuable, there does appear to be a trend of authors and other industry professionals moving away from the term and re-focusing on using 'the language that authors want to celebrate about themselves and their characters' (We Need Diverse Books 2021).

When asked what writing authentically meant to them, some of our authors highlighted the importance of pushing back against ableist narratives. While this has been discussed earlier in this article as a way to challenge ableism within the industry, in this context it was framed as an integral part of what authentic writing involves. Karol shared that part of writing authentically for her meant 'pushing back against my editor about taking out a scene because it's more convenient, it's more palatable'. This highlights the battle many disabled authors face between prioritising authenticity over marketability.

The participants also shared their thoughts on people writing outside of their own experiences, including disabled authors writing about disabilities they do not share. Karol said that while authors *can* write about disabilities they don't share, they should ask themselves why they want to, and consider taking a step back. Most of our participants clarified that there is a difference between including characters in our stories who have disabilities we do not share, and actually writing a story *about* a disabled experience we don't share. One author told us, 'I think there are stories that aren't mine to tell, more than characters that aren't mine to explore and share.'

Several reasons were given for this. Karol explained that it was an issue of opportunity. Inequality within the industry creates a situation where there is a finite number of 'slices of the pie'. As a result, stories about disability written by non-disabled authors will take up space and reduce opportunities for disabled writers to have their stories told. The Excluded Voices Report found similarly, noting that, 'in an ideal world, all creators should be free to create whatever they wish, but plugging gaps with a majority of non-Own Voice creators, while well meaning, does have drawbacks' (Inclusive Books for Children 2024, pp. 2-3). The report ultimately calls for publishing to make more space for marginalised creators 'who wish to tell their own stories'.

Another reason offered for why authors should avoid writing disabled stories outside of our experiences is the layer of authenticity that is often missing in these stories. Meg said that she felt really uncomfortable with non-disabled people writing about disability. As an autistic person, she said that 'an autism mom's experience is going to vary so differently to the kid's.' Karol felt similarly, stating, 'I know from my own lived experience that there are so many little nuances and things, that no amount of research could give me the insight that actually having a lived experience would give me.' Essentially, because she knows her own disability so intimately, she recognises that people with different disabilities also have unique lived experiences that cannot be fully understood through research alone, and she would therefore approach those with more care. Another author concurred, saying 'there are stories I wouldn't have the authority or know what it's like enough' to write about.

Finally, our authors also told us that finding community has been invaluable and made them feel less alone. One author shared, 'If you find people like you, things are easier to bear when they're horrible and better when they're great, and you celebrate with each other. And people understand you and you understand them. And everybody should have that.' This sense of belonging not only provides emotional support but also empowers authors to continue pushing boundaries in their writing, and tell the stories they want, in the ways they want.

Recommendations and Conclusions

This study has highlighted both the progress and continuing challenges that disabled writers face within the publishing industry. While much work has been done towards greater inclusion, significant barriers remain, particularly around accessibility and society's tendency to value non-disabled perspectives on disability over disabled voices. While our study focuses on disabled authors, many of the findings apply to many other marginalised authors more broadly within the industry. The need for equity and inclusivity in the industry applies to more than just disabled authors and extends to all marginalised voices in the literary world.

For the publishing industry, the following actions can help create a more inclusive and equitable environment:

- Expand accessibility at events and ensure appropriate accommodations are available
- Take a nuanced, personal approach to support each disabled writer individually
- Actively work to increase the number of disabled authors and professionals employed across the industry
- Address editorial biases by educating agents and editors on the abled gaze and offering opportunities for reflection and improvement
- Improve transparency around publishing processes and provide clearer tools to help marginalised authors navigate the industry.

Encouragingly, Penguin Random House (2022), reported that in 2022, twenty per cent of their colleagues and new hires were disabled or had a long-term health condition—an eleven per cent improvement on the previous year. While this indicates a positive trend, it is important to note that this study was conducted prior to the recent political resistance to Equity, Diversity and Inclusion (EDI) initiatives in the United States (Kassam 2025; Moore 2025). The long-term impact of these developments remains uncertain but is already being felt by disabled and other marginalised communities in the United States and beyond.

For disabled writers, the following recommendations can help on a personal level, while also contributing to broader change within the industry:

- Build networks and communities that foster connection and solidarity
- Seek support when needed, and learn about your rights and any accommodations you may be entitled to
- Where possible, resist editorial pressure to conform to non-disabled expectations.

Non-disabled allies should also use their voices and platforms to uplift disabled writers, challenge normative perspectives and stand alongside disabled advocates who are striving for change.

The findings presented in this article, informed by the lived experiences of our participants, call for continued advocacy and systemic change to ensure that disabled authors are not only empowered to tell their stories on their own terms, but that those stories also make it into the hands of readers. The publishing industry has an opportunity to learn from the diverse perspectives of authors like our participants, and work towards a more inclusive literary landscape for all marginalised voices.

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