



Who's In The Mirror?

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This Edition Published by Thee Sim Ling, 2021

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Dedication

To all disabled writers, artists, activists and readers: no matter who you are,
thank you for making a difference.

Who's In The Mirror?

Introduction

I have always been an avid reader. In kindergarten, I fostered a love for reading books as well as newspapers. As I grew older, I started to write stories, poems and articles not just for school, but outside the realm of academics. Even till now, my family visits the library every two weeks to find gems hidden on the shelves. I regularly read books in a diverse range of genres and topics. Some of them are books from centuries ago, while others are more modern creations. I always deeply enjoy reading, especially children's literature, which holds endless possibilities and ideas. I only have one gripe with the genre.

Where's disability in children's literature?

Disabled people are considered the largest minority group in the world. According to the World Health Organisation, over 1 billion people, or 15% of the world population, live with some form of disability. With such a large number of disabled people in society, it's shocking that disability is invisible in children's literature, a genre which is supposed to allow children to see themselves in stories and learn valuable life lessons. Furthermore, disability is often portrayed terribly, as a flaw, a lightning rod for bullying, as a device to move the plot forward.

Is this the message we want to send to future leaders and changemakers?

Ableism and systemic discrimination against disabled people are problems the disability community have tried to face for the longest time. While it is hard to change the engraved mindsets of grown-ups, we can look to the youth of today, who are already so passionate about making a difference. If we create the accurate and authentic representation of disability in kidlit, we can raise awareness of disability and foster an inclusive and welcoming society for both disabled and non-disabled people.

Now, onto this creative writing portfolio. *Who's In The Mirror?* is not like any usual book you may take up from the bookshelf. In fact, it may not resemble any book you have ever read before.

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Perhaps because the central theme of the book is unlike any other.

If you haven't guessed already, this book is focusing on disability representation in children's books. It covers many areas of literature, from creating disabled characters in the first place, to improving representation by highlighting problems in the genre such as stereotypes and language use.

This book is a series of written essays discussing issues present in disability representation found in children's literature, interspersed with short stories and poems. This book does not need to be read in the order you find it in. You can read any essay that interests you. If you're in any doubt, you can always return to the content page and refer to the headings.

This book was written by me with reference to published research and sources available online. It is also done with primary research conducted by myself. In order to better gain insight into the view of both disabled and non-disabled people regarding disability in children's fiction, I created an accessible survey and collected 75 responses. The full statistics can be found at the back of the book in the section "For Data Whizzes: Survey Findings".

This edition was published by me, Thee Sim Ling, and I-CREATE YOUTH, an international youth-led non-profit organisation dedicated to spreading creative writing education, opportunities and resources to visually impaired youth. If you love this book and want to share it with family and friends, I would be grateful if you do not distribute this copy to anyone else and instead refer them to I-CREATE YOUTH's website (<https://icreateyouth.wixsite.com/site>) or my website (<https://lucindathee.com/>) where they can get their own copy! Also, please leave a review.

I hope you enjoy reading my book!

Poem: where are we?

i looked for us,
but we were invisible
not among the library's shelves of pearls
not among its make-believe worlds

i checked the big screens of the theater
i scrutinised the guest list at the premieres
i looked for us,
but we were invisible

year after year
from the western to eastern hemisphere
i looked for us,
but we were always invisible

Representation: The Fight To Be Featured

When was the last time you read a book that had a disabled character? It probably took some time for you to actually remember if you have ever read one at all.

Disability representation in children's literature is a rarity in the otherwise booming publishing industry hyper-focused on diversity. According to a 2019 study done by the Cooperative Children's Book Council, only 3.4% of children's literature had a main character who is disabled. 3.4%. That's smaller than the percentage of people who die when struck by lightning.

It really says something about kidlit, a growing sector of the publishing industry that raked in US\$ 2.84 billion. There have been many moves to increase diversity in books aimed for children and youth. These may have resulted in some progress, but children's literature still has a long way to go in order for disabled children to see themselves in the books they write.

The biggest hurdle we have to overcome to ensure great representation in children's literature is making sure they are actually present. It's not uncommon for books to feature no major characters that are disabled, or exist in storyworlds with no disabled characters featured at all! When you write a book about a magical school, or thrilling police chase, or historical saga, it's easy to forget the role disabled people play in stories, especially when we live in a world with entertainment media dominated non-disabled people.

Writers need to recognise that there are a diverse range of people living different lives from themselves. Disability and diversity shouldn't be left as an afterthought, like a box to be checked or an aspect of society that is forgotten; disability affects millions of people around the world every day. Those ramps at the foot of your apartment block serve disabled people. Your family, friends, neighbours, colleagues, classmates, and even your local postal worker may be related to disability one way or another.

If you're a scribbler of words like me, or if you just love telling stories, try this simple exercise to create a disabled character for a story, or your

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current work-in-progress. Imagine your character in your head, or give them a name. They shouldn't be some foreign, abstract creation, but rather a make-believe friend who confides in you their deepest fears. Ponder about their age, background, and personality— these characters are firstly human, just like you and me. Then, think about their disability or disabilities and how it affects their lives. It doesn't have to be a disability you know a lot about; you can always do research. How does it affect the way they eat, sleep, move around, interact socially, build relationships, learn, work and more?

It's okay if not every story has a disabled main character— sometimes, making a character disabled just isn't realistic for the plot, or writers may feel they can't invest enough time and energy to research on disabilities for accuracy. Rule of thumb: If you believe you can't ensure an authentic and well-developed portrayal of disability in your work, then don't write that disabled main character. No representation is better than harmful and offensive representation.

Instead, writers can experiment with the idea of casual diversity. Casual diversity is creating marginalised characters that do not need to be part of the main cast but are present in scenes as supporting characters such as friends, mentors, staff and more. Writers do not need to proclaim their disabled identity and all the injustices that their character may have faced throughout their lives, but rather casually mention their identity, such as using their wheelchair to move around or signing to communicate. This simple act will open young readers' eyes to the different ways of living for disabled people.

Some people may argue that because disabled people are essentially a minority group, few readers of commercial children's literature are disabled, and thus non-disabled people will always be the target audience. However, there is a sizable number of readers who are disabled, and an even larger number of non-disabled people who interact with disabled people in daily life. In researching this book, I conducted a survey on disability representation in children's literature. The majority (74.67%) of respondents were disabled, while the rest were non-disabled. There clearly is no lack of disabled readers who want to see themselves in the books they read.

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While disability in children's books may be rare, there are books out there that feature disability one way or another. Although some respondents may not be satisfied with disability-related children's fiction, many of them had read such fiction and found a few favourites, such as *Percy Jackson*, *Wonder*, *Six of Crows* and *Mockingbird*.

Here is a list of recommended books with disabled characters by respondents:

- *Six of Crows* by Leigh Bardugo
- *Lair of Dreams* by Libba Bray
- *Beauty Queens* by Libba Bray
- *The Vanishing Stair* by Maureen Johnson
- *Percy Jackson* series by Rick Riordan
- *Wonder* by RJ Palacio (Note: [criticised by disabled readers](#))
- *The Call* by Peadar ó Guilín
- *Rogue* by Lyn Miller-Lachman (disabled author!)
- *A Wrinkle In Time* by Madeleine L'Engle
- *The Fault in Our Stars* by John Green (Note: [criticised by disabled readers](#))
- *Heidi* by Johanna Spyri
- *Warcross* by Marie Lu
- *The Dark Artifices* trilogy by Cassandra Clare
- *How To Disappear* by Gillian McAllister
- *Are We All Lemmings and Snowflakes?* by Holly Bourne
- *Out of My Mind* by Sharon M. Draper
- *Rules* by Cynthia Lord (Note: [criticised by disabled readers](#))
- *Crooked Kingdom* by Leigh Bardugo
- *Captain Underpants* series by Dav Pilkey
- *On The Edge of Gone* by Corinne Duyvis (disabled author!)
- *Mockingbird* by Kathryn Erskine (Note: criticised by disabled readers)

It is possible for writers, both disabled and non-disabled, to include disability representation in their work. It's just a matter of taking initiative to do so.

Icing on the Cake: The Benefits of Disability Representation in Children's Literature

"You've been rambling a lot on how we can have disability representation", you may be thinking, "but why exactly should we promote it? What concrete advantages are there to writing disabled characters? Or are we just riding on another 'woke' trend?"

Reading books with disabled characters has been shown to allow disabled and non-disabled children to develop empathy and understand themselves better. For non-disabled children, it allows them to better learn about disabled people's lives, and better accept disabled classmates. For disabled children, it allows them to celebrate their identities and know that their dreams and ambitions can be fulfilled.

Here are some other benefits to accurate disability representation.

- Exposing children to other perspectives and other ways of living: Disabled people need accommodations and accessibility practices to go about their daily lives. For example, wheelchair users need to use ramps and lifts. They may also need others to assist them in bathing or making food. It can allow children to develop sensitivity and be better educated about rights issues concerning the disability community.
- Show disabled children can develop meaningful friendships and make their dreams come true: Disabled readers may feel outcast or ostracized because their peers may not be accepting of them, and even bully them. They may also have ambitions and desires, but find others around them laugh at the prospect of achieving them because it is "unrealistic". Finding fictional role models can inspire them to reach greater heights (literally or figuratively).
- Celebrating diversity: All of us have different needs, bodies and ways of thinking, and instead of pressuring disabled people to conform to the "normal" or hide themselves away, these should be accepted and appreciated.
- Allow readers to learn accurate and realistic information about disabilities: Much information non-disabled people have about disabilities is based on their biased observations, prevalent stereotypes or charity drives many do not pay attention to. Portraying the lives of

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people with different disabilities allows disabled people to better understand the symptoms, challenges and impact of these disabilities on people in real life.

- Correct misconceptions and stereotypes: Do all blind people wear sunglasses? Do all d/Deaf or Hard-of-Hearing people use sign language? Do all wheelchair users like to be pushed by strangers without them asking? There are many myths in society that need to be busted, and kidlit can help by informing our future leaders accurate facts about disability.
- Promote empathy and acceptance: Instead of ostracising or pushing away disabled children because of their differences, non-disabled readers can understand that these children are just like them, with similar interests and aspirations. Readers can empathise with the challenges disabled people face from unwelcoming environments and promote awareness on how to build a more inclusive world.

The majority (56.60%) of respondents in my survey felt that these books allowed them to better understand disability, while the remaining respondents (43.40%) did not.

Disabled people were equally split on the impact of children's books they read on their understanding of disability. Some respondents felt they were not only able to learn more about their own disabilities, but also gain insight into people with other disabilities. One participant stated she could finally see herself in a book after 50 years of life. It's clear that these benefits apply not just to the young, but to the young-at-heart as well.

Non-disabled respondents (80%) overwhelmingly agreed with the statement. They thought the books allowed them to learn about disability and empathize with disabled people, because it exposed them to different types of disabilities and looked at the world from a disabled person's perspective, giving them new insight on disability. This shows the positive impact of proper disability representation in children's literature and should encourage more authors to include disabled characters in their work.

This benefit can also extend to the people who make publication of these stories possible: writers, editors, agents, publishers and reviewers. More books on disability increases awareness among people who may not typically

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interact with disabled people or read work with disabled characters. It can change entrenched and tired industry norms. These books can encourage and inspire aspiring writers to include disability in their work as well.

However, not all books are created equal. Inaccurate portrayals of disability can reverse the positive effects of representation and cause more harm than good. Let's see how.

Not All Books Are Good Books: Combating Problematic Portrayals of Disabled Characters in Fiction

Can there be too much of a good thing? Unfortunately, yes. Drinking too much water leaves us overhydrated and bloated. Even breathing in too much oxygen can lead to fatal consequences.

This is the same with disability representation in children's literature. Not all representation is helpful, positive and promotes disability rights and inclusion in society. Although these stories may be created without a conscious aim to cultivate ableism, and may even be written with good intentions, they undoubtedly do nothing to advance equity for the disability community.

A lot of books with problematic representation of disability may surprise non-disabled readers because to them, they may see no inherent problems with such portrayals. Inauthentic disability representation can be found everywhere. It's prevalent in classics from centuries ago, such as *The Secret Garden* by Frances Hodgson Burnett. It's present in commercial successes such as *The Westing Game* and *Me Before You* by . It's even glaringly obvious in children's books marketed as true and "never-before-seen" narratives of disabled characters, such as *The Curious Incident of the Dog in the Nighttime* by Mark Haddon and *Wonder* by R.J. Palacio, a favourite of various non-disabled respondents in my survey.

When you read reviews of these books, you can see concerned disabled readers and allies pointing out aspects of representation they disagree with. However, non-disabled commentators often praise these same aspects as "authentic" representation, and are the first to defend the author and story for portraying disability in these outdated ways. It's alarming that many of these readers, often adults, have never been educated on disability in another light. Do we want the current generation of children to turn out this way as well?

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There are several common defences that advocates of these books often fall back on. The first is that the books are “just fiction”, so readers should not take offence at these portrayals and “stop being ‘woke’ or quick to cancel” them. Yes, these books are part of entertainment media, but nobody can deny that the media we interact with influence our beliefs, opinions and attitudes. Young, impressionable readers can easily take these fictional stories as examples of how real disabled people lead their lives.

Another defence is that many of these authors are parents or caregivers of disabled people and thus have the “ability” to tell these stories accurately based on their experiences of caring for disabled people. Famous books of disabled characters are more likely to be written by non-disabled caregivers instead of disabled authors themselves. Just because someone is a caregiver for a disabled person, does not mean they can automatically tell an authentic story or can be let off the hook for stereotypes of disability.

Of course, all disabled people have different experiences of living with disability. We can’t hold up one book and proclaim it depicts the “universal experience” for everyone with that disability. That’s why there needs to be more authors writing more of such books depicting a wider spectrum of experiences.

It can be hard to tell which books that feature disabled characters are accurate representations and which books are just ableist, stereotypical and harmful to the disability community. Here are a few guiding questions to consider (from [disabled artist-activist Liz Crow](#) and [educator Monica Kleekamp](#)):

1. Is the character dynamic and multidimensional?
 - a. Does the book overly focus on the disability label, or on the person’s disability?
 - b. Does the book focus on “overcoming disability”?
 - c. Is there a character arc, and does the character change and grow throughout the story?
 - d. Does the character seem flat, or like a stereotype?
 - e. Is the character a stereotypical straight, white, middle-class or well-off male?
2. Does the character have a life?

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- a. Do the characters have lives outside of the plot? Are their accessibility challenges portrayed? Or are they just totally dependent on other people, isolated with empty lives, ignorant, uncultured, and submissive?
3. Whose story is this?
 - a. Is the story told from the disabled character's point of view? If it's told by a friend or sibling, readers do not see the world from the disabled character's perspective and instead see it from the eyes of someone else. The best books focus only on the disabled character's voice in first- or third-person, and not jump around or hand the camera to someone else.
4. How is the reader supposed to view the character?
 - a. Does the author portray the disabled character as an object of pity?
 - b. Does the author portray the disabled character as a burden to others around them (especially siblings and family members)?
 - c. Does the author portray the disabled character as a victim?
 - d. Does the author portray the disabled character as someone inspirational and superhuman?
 - e. Does the author portray the disabled character as the "Other" in any way?
5. Does the disabled character have deep, authentic relationships?
 - a. Often, disabled characters only have relationships with family, and one-way, "flat" friendships with others. They may even be considered only acquaintances. They seldom have Best Friends Forever or romantic interests, unlike most non-disabled protagonists. Does the author invest in meaningful relationships with peers?
6. What is the disability's role in the plot?
 - a. Is it just a plot device or tokenistic diversity? Is it just a metaphor for evil or misfortune? Is it a hook?
7. Does the book view disability from a medical perspective or social perspective?
 - a. Does the author portray it as something that needs to be fixed? Does the author focus on the symptoms rather than the character's life?

- b. Does the author portray it as a human rights issue, weaving the plot with realistic descriptions of ableism and other forms of discrimination?
- 8. Does the book use appropriate language?
 - a. Does the book use outdated terms such as “handicapped”, “special needs” or “challenged”?
 - b. Does the book use ableist terms such as “crazy”, “psycho”, “cripple” or “retard”?
- 9. Does the author have experiences with disability?
 - a. The most authentic books are written by disabled authors
 - b. Does the non-disabled author personally know, is related to or works with disabled people?

You may be dismayed that, in applying these questions to books with disabled characters, you may realise they aren't as inclusive or diverse as you had thought. Fret not!

In the publishing industry, the number of books that cast disability in a negative light overwhelmingly outnumber the ones that portray disability as something to not be ashamed of.

However, moving forward, we can use these books with negative tropes to stimulate discussion with the children and adults around us to understand why these attitudes are harmful and correct misconceptions still existing in our society. This can act as a springboard to better books with accurate disability representation.

Reading books with inaccurate and problematic portrayals of disabled characters and teaching them in class can provoke much-needed discussions about the representation of disabled people in the media as well as existing attitudes towards disability in the world today. We do not take hurtful portrayals of disability as true depictions of disabled people's lives, but with a grain of salt, allowing parents, teachers and readers to highlight the concept of stereotypes and discrimination surrounding disability.

Here are some questions to ask readers of books that have been criticised by the disability community for inaccuracy and inauthenticity:

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Elementary Readers

1. What does the disabled character make you feel? Do you feel pity or any other bad feelings for them? What makes you feel that way?
2. Do you think disabled people in real life will think and act like these characters? (Give examples of disabled people in your neighbourhood or famous disabled figures.) Why or why not?
3. Imagine you are this character and write a short paragraph with this character's voice. How would they think or feel? (Compare it with an essay or story written by a real-life disabled person.) What is different between your thoughts and this person's experiences? Does reading this make you understand the lives of a disabled person better?

Intermediate Readers

1. Create a character profile for this disabled character. What is their age, race, gender, sexuality, background, and personality? Is the "disability" part larger than the other parts of the profile?
2. Who does the character usually interact with? Family? Friends? Best friends? Romantic interests? Neighbours? Medical professionals or social workers? Are these characters disabled or non-disabled? How do they treat the disabled character— in a positive or negative way?
3. Write an outline or story mountain to track the events of the story. What main challenges does the disabled character face? What is the "moral" that the reader is supposed to learn? Does the character change and grow throughout the story?
4. Is the disabled character's story similar to any other stories of disabled people you have come across? (Show them similar stories of disabled characters.) Why do you think these stories are so common? (Show them the list of stereotypes found in this book and explain what they are.) Have you come across any of these ideas?

Advanced Readers

1. When authors write about disabled characters, many times, they write about the disabilities wrongly or write the characters in the same way over and over again. We call them "stereotypes". (Show them the list of stereotypes found in this book and explain what they are.) Have you come across any of these stereotypes? Do you think any of these stereotypes are found in this book?

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2. What is the author's experience with disability? Are they disabled or non-disabled? How may that have coloured their perceptions of disability?
3. Write out a character analysis for the disabled character. Do you think that the portrayal of that character was fair, or did it come from a place of pity and negativity? How might the author have improved the representation of this character? If unsatisfied, try rewriting a scene or the ending of the book.
4. Research on current-day issues surrounding ableism, equity and disability rights. What challenges are the disability community facing? How are they reflected in the story, or how the story was written? How can you help find a solution to these problems?

More of these exercises can be found under "In The Classroom: The Role of Teachers in Educating Children About Disability and Diversity".

Are all these questions making your head spin? To avoid dumping your brains with heaps of information, let me devise a simple test with three questions to gauge whether a book has great disability representation, or may need a little work. This is a spin-off from the Bechdel test which sets a benchmark for the portrayal of women on screen. Here it is.

A work which means the Thee disability portrayal test (yes, I made that up) must:

1. Have at least two disabled people in it who
2. Talk to each other about
3. Something other than disability

Do your favourite books with disabled characters fit these criteria? Admittedly, this won't be suitable for every book, but I hope this gives you some food for thought on the state of disability representation in the publishing industry today.

Unseen and Unheard: Disabilities Not Commonly Written About In KidLit

Recollect all of the books about disability you have ever read and list down all the disabilities that are portrayed in them. You don't even need to have the disabilities stated explicitly in the book; if a character has certain traits that point to a disability, note it down.

Ready?

Let's compare the representation of disability in books with real-life demographics and statistics. As I said before, I carried out a survey with both disabled and non-disabled respondents on this topic. I also asked about respondents' disabilities and background.

In your list, it's likely that each character has only one disability and multiple characters across different books often share the same disability. However, in my survey among those who were disabled, the respondents often had more than one disability. (Surprise!) There's also a far wider variety of disabilities than I would have ever imagined. The disabilities stated include:

- autism
- Attention Deficit Hyperactivity Disorder
- depression
- anxiety
- seizure disorders
- chronic pain/fatigue
- congenital glaucoma
- visual impairment
- Post Traumatic Stress Disorder
- limited mobility
- Systemic Lupus Erythematosus
- narcolepsy
- Polymyositis
- hearing loss
- Obsessive Compulsive Disorder
- Dissociative Identity Disorder

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- psoriatic arthritis
- anaemia
- bipolar disorder
- borderline personality disorder
- psychosis
- Crohn's disease
- dyslexia
- scoliosis
- dysgraphia
- Turner Syndrome
- spina bifida
- sacral agenesis
- fibromyalgia
- rheumatoid arthritis
- sleep apnea
- Tourette's syndrome
- alexithymia
- aphantasia
- cerebral palsy
- hyperacusis
- hypersomnia
- Auditory Processing Disorder
- dyscalculia
- dyspraxia
- autoimmune disorder
- adjustment disorder
- schizophrenia
- Trigeminal neuralgia
- Acquired Brain Injury
- congenital talipes
- erbs palsy

Now, compare this list of disabilities with the ones you have listed down. How many of these disabilities are represented in books you have read? Chances are, you may have not read (or even know about) at least five to ten of the close to 50 disabilities stated right here. Of course, some of these disabilities overlap (such as hearing loss with Auditory Processing Disorder) and others may be common in books you read (such as autism and

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depression). But, what is worrying is that many of these disabilities are rarely or never portrayed in books, much less children's books.

People with rare or uncommon disabilities often face unique challenges because of a lack of awareness about their disabilities. If I go up to a stranger and say "I am autistic" or "I have scoliosis", the stranger would at least have an idea of what I was talking about. But, if a disabled person goes up to a stranger and says "I have lupus" or "I have sacral agenesis", they are more likely to be greeted with bizarre looks or confused questions.

People with disabilities hardly discussed in literature and entertainment media are often faced with questioning, doubt or ignorance. Even medical professionals may be inexperienced to treat these people because they simply don't know what these disabilities are. These disabled people can't get the accommodations or treatment they need.

One way to combat this is raising awareness. And, as I mentioned before, starting young with children's literature is a great way to educate people about these disabilities and advocate for acceptance of them.

Kidlit still has a long way to go, though. Back to my survey. When asked what disabilities they have read in children's books, the most common answer was neurodiversity/learning disabilities such as autism, dyslexia and Down syndrome, followed by mental illness and physical disabilities. Blindness/visual impairment, chronic illness and deafness/hard-of-hearing were less frequent in the fiction respondents read.

You may ask, "Why are authors always writing about the same disabilities in their work? This can't be a coincidence!" A lot of these "unknown" disabilities affect less people, meaning there's less awareness around them. Many of the authors are also non-disabled, and their perception of disability is shaped by the media they consume and people they interact with. They're more likely to learn about dyslexia than fibromyalgia, and thus write books based on their knowledge and research about dyslexia.

Raising awareness of these disabilities is key to educating more readers and writers. For example, in the UK, the campaign ["I Am Number 17"](#) was launched to amplify the voices of people with a rare disease, based on the

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statistic that 1 in 17 people in Britain is affected by a rare disease in their lifetime. Stories of people living with rare diseases and their caregivers were featured along with artwork created by collaborating artists.

What can you do? Take some time to research a disability you are unfamiliar with on the list I had put above, and read the anecdotes found on the "I Am Number 17" website. Find writers and bloggers with these disabilities and find out more about their lives. If there are books written about characters with these disabilities, get a copy and read.

Poem: I'm Sorry For Using The Word [Redacted]

I'm sorry for using the word

autistic

because you don't like it. I'm sorry for using it just now because you think it's a disgusting swear word and from now on I will mark out all those

[redacted]

words with your permanent marker. I'm sorry for being a little

[redacted]

thief who stole the digits on your clock. I'm sorry for dressing up as a grown-up when I don't even have an IC, those tiny digits divided by black lines. I'm sorry for saying that because I *do* have an IC from my home country Malaysia and I hid those digits I stole from your clock among the jungle of lines. I'm sorry for standing up for myself because my dirty

[redacted]

feet ruined your prim carpet of diversity you advertise on your cover page. I'm sorry for that email, those tiny words transformed into the tiny digits I stole from your clock as they left my inbox, because "diversity" apparently only belongs to everything except disability. I'm sorry for using my pencil to write the words

[redacted]

and "disabled" because the millions in the

[redacted]

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community don't deserve to choose our own name. I'm sorry for arguing because we can't choose our own names, only society can. I'm sorry for my silly

[redacted]

tantrum because "inclusivity" is erasing every last ugly graphite mark and using your permanent marker to write "has/with autism" and "special needs" over it. I'm sorry for explaining

[redacted]

to you because you have a Master's degree in special education and since I'm

[redacted]

with no PhD, I don't deserve a say. I'm sorry for drowning you in my silly words because you didn't use the word "leper" 25 years ago so you should be given a diversity badge. I'm sorry for putting up a fight because the marker ink has dried, the damage has already been done. I'm sorry for being

[redacted]

in the first place because it's not allowed in a perfect world. I'm sorry for using the word

[redacted]

because you don't like it.

The Power of Language: How Labels and Slurs

Create A Lasting Impact

Language is a powerful tool in human civilization, and when in the wrong hands, can be a destructive weapon. In the context of disability, there have been many words invented to describe the experience of living with disabilities. Some of them are outdated and offensive, but have evolved into popular slang, with many people who use them unaware or ignorant of their ableist origins.

When we grow up, we often do not come into contact with offensive or derogatory language in our natural environment. We get discriminatory ideas or learn about vulgar words through people who have a big influence on us, such as family, friends and even teachers. In turn, they have absorbed these ideas from other people around them, as well as the media they consume. The stories we come across and the language used in these stories shape societal norms and our personal values and beliefs. If we read a children's book using the word "crazy" or "wheelchair-bound", we'll be more inclined to think these terms are acceptable and thus use them. As we grow older, our beliefs become more ingrained in us and we are less likely to change our opinions or be able to consciously alter our language use.

The language authors choose to use to describe disabled characters makes a big impact on impressionable readers. Many non-disabled authors unconsciously reflect ableist attitudes on their characters by allowing the characters to use negative language to describe themselves. For example, characters may use [slurs](#) such as "cripple", "dumb", "stupid", or "crazy". While some of these slurs are being reclaimed by the disability community, such as "cripple" or "mad", they're often used in a self-deprecating and toxic way for characters to describe themselves, or other people and things they don't agree with. These words mostly began life as derogatory labels for disabled people in medical journals and these words should not be taught and made acceptable in kidlit.

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Authors may also choose to use terms that are [outdated ways to refer to the disability community](#). They may say their characters are “handicapped” or use euphemisms such as “special needs” and “differently abled”. While some may find these terms acceptable, they are rarely used by the majority of the disability community. They also hide from the fact that disabled people are actually disabled by their environment and social constructs which do not allow them to lead the best lives possible. Authors should be encouraged to say the word “disability”, or use a range of terms to better reflect the diversity of the disability community.

Authors should always stay away from [language that diminish the value of disabled people and treat them as objects of pity](#). These include terms such as “wheelchair-bound”, “confined to a wheelchair”, “victim”, “suffers from”, “challenged”, “poor”, “pitiful”, and other negative terms. These words all paint a one-sided and bleak picture of disability that isn’t the case for many disabled people. Sure, we all face problems every day that may or may not be related to our disability, but don’t we all have good times as well? Instead of portraying disabled people as helpless or worthless, we should treat them as empowered individuals who do not suffer as objects of pity and sympathy.

Finally, authors should [trim out ableist idioms and figurative language](#) that convey negative or unfactual assumptions about disability. For example, “blind leading the blind” compares being blind or visually impaired with ignorance and foolishness, unfair towards the blind/visually impaired community. Idioms such as “fall on deaf ears” or “deaf as a post” make derogatory assumptions about being d/Deaf or hard-of-hearing. “Dumbstruck” or “dumbfounded” also is ableist towards non-speaking people or people with intellectual disabilities, because “dumb” is usually used to describe a lack of speech or intelligence. Use synonyms or just go straight to the point with a simple definition.

Poem: In Our Box

Society put me in a box Wouldn't let me show who I was Stripped me of my identity I'm
 n c e y o u n g t h e y i k n e w t h e i r v i e w
 They said autistic culture doesn't exist Shouldn't celebrate diversity N
 e e d e d t o s t o p i t
 We aren't allowed to speak for ourselves Th
 e y s p e a k w e c a n n o t
 If only they would L
 i s t e n
 f o n l y t h e y w o u l d l i s t e n
 e a r e i n v i s i b l e i n t h e m e d i a t h e w r i t i n g i n d u s t r y s h u t u s o u t
 I'm not autistic. I'm not different. Since young I knew their view. "Why would I want to be like the low-functioning people?" "You don't look autistic what."
 They said autistic culture shouldn't exist. Shouldn't celebrate diversity. Needed to cure it. To stop it. They said "use Person-First language" like we don't have our own opinions. Of course we don't.
 We weren't allowed to speak for ourselves. They speak we cannot. We are invisible in the media. The writing industry shut us out.

Image shows four rectangles of poetry arranged in size order, from largest to smallest, with the larger rectangles surrounding the smaller rectangles.

Transcript:

Society put me in a box. Wouldn't let me show who I was. Stripped me of my identity. "I'm not autistic." "I'm not different." Since young I knew their view. "Why would I want to be like the low-functioning people?" "You don't look autistic what."

They said autistic culture shouldn't exist. Shouldn't celebrate diversity. Needed to cure it. To stop it. They said "use Person-First language" like we don't have our own opinions. Of course we don't.

We weren't allowed to speak for ourselves. They speak we cannot. We are invisible in the media. The writing industry shut us out.

Who's In The Mirror?

If only they would listen. If only they would listen.

Stereotypes: The Lasting, Invisible Harm

Think about the books you have read about disability. If you haven't read many, search online for books with disabled characters and read their blurbs. Do you see any recurring words, ideas or plotlines expressed in them?

When authors write about disabled characters, many times, they write about the disabilities wrongly or write the characters in the same way over and over again. We call them "stereotypes". Stereotypes often signal at best lazy writing, and at worst, no genuine effort to include diversity in written work.

Stereotypes dealing with disability include being "cured" of their disability, side characters with no individual personalities, tough people who need to learn to accept help, "burdens", siblings or superhumans. Have you come across any such ideas?

Among respondents, the most commonly seen stereotype was that the disabled character is the only character in the book! This is troubling as disabled people are considered the largest minority group in society, and many authors fail to reflect this diversity in their work, treating their disabled characters as "tokenistic" moves.

This is closely followed by the fact that disabled characters are written by non-disabled authors, instead of disabled authors. While it's encouraging that non-disabled authors choose to write such characters, oftentimes the work of non-disabled authors is chosen over disabled authors who have authentic experiences of what living with disabilities is like. More disabled authors need to be supported and published in the industry if it really wants to stand for diversity, as many non-disabled writers and publishers claim.

Other common stereotypes include (in descending order):

- The disabled character is not the main character
- The disabled character is "saved", or pitied by the main character
- The disabled character is from a certain background (white, male, straight, middle-class/well-off)

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- The main theme of the book is about perseverance
- The disabled character is disliked or considered a "burden" by their family only because of their disability
- The book uses ableist language like "crazy", "psycho" and "retard"
- The disabled character is "cured" of their disability
- The symptoms of the disability are inaccurate
- The disabled character is disabled because of an accident
- The disabled character dies in the book
- The disabled character never faces discrimination because of their disability

In The Classroom: The Role of Teachers in Educating Children About Disability and Diversity

[Teachers have a part to play](#) in exposing children to disability-related books and teaching about diversity in the classroom. There is a lack of resources to help them, especially when the books that win awards usually do not portray disability accurately. There are several resources already available, such as [Disability in KidLit](#), [Indigo Project](#) and [Disability Visibility Project](#). More resources should be created to allow teachers to talk about disability in school.

Interviewees reported that they discovered the books by themselves at the library or online on promotions/book review sites. This shows that libraries play an important role in allowing children to read books about disability. Almost all respondents were not introduced to any books about disabled characters by parents or teachers. As one respondent pointed out, these books were often not on the top of teachers' minds.

Teachers should keep diversity top of mind and actively seek out books with disability representation. They can refer to existing resources or seek out new books by following the disabled writing community on social media or keeping tabs with librarians' and educators' reading trends.

Here are some topics that teachers can explore with books on disabled characters:

Elementary Readers

- What is disability? Why do people look, act, think and feel differently from us?
- Why should we treat disabled people kindly? How can we help them or assist them?
- What are some rude words to describe disabled people? What words can we use instead?

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- Who are the disabled people in my community? Do I interact with them often?
- What questions do I have on disability? Who can I ask to get the answers to these questions?

Intermediate Readers

- What is the “social model of disability”? How are disabled people treated differently?
- What are certain disabilities and how do they impact the people who live with them? Who are famous disabled people?
- What challenges or obstacles do disabled people face in their daily lives? How can we accommodate them?
- What is ableism? What examples of ableism do we see in our daily lives? Why is it wrong? How can we combat it?
- How are disabled people shown in the stories I read? In a positive or negative way?

Advanced Readers

- How do the books we read and media we consume affect people’s perceptions of disability?
- What issues surround ableism, inclusion or disability rights? How are these reflected in the books I read? Does it link to other issues, such as systemic discrimination, inspiration porn or civil rights?
- What are some stereotypes or inaccurate beliefs about disability I have? Are they true? Are they found in the books I read?
- Why is it important for disabled authors to be given a platform for them to write stories? Why are more non-disabled authors than disabled authors published for writing stories about disability?

Disabled Authors And Disabled Stories: Why #OwnVoices is So Important in Children's Fiction

Throughout this portfolio, I have been emphasising again and again on the importance of stories with disabled characters. I have covered many aspects of this issue. If you're a non-disabled person, you may already have learnt a lot from these pages. We need more characters! We need more research! We need more awareness! We need more *books*! Yes, we need all of these. But, we don't just need any books. We don't just need more books from non-disabled authors, we also need more books from disabled authors themselves.

Multiple studies have confirmed that the highest-quality portrayals of disability come from authors and illustrators whose life experiences allow them to make authentic disabled characters come to life. That makes sense.

But, the publishing industry isn't listening to the disability community. Of the many books about disabled characters that have won awards or met with commercial success, few are written by disabled writers themselves.

More agents, publishers and publications should support disabled writers, and those who write the best books should be given recognition for doing so. But how can we uplift disabled voices, when the industry is dominated by non-disabled people?

Actively seeking out and supporting books written by disabled writers can send a great signal to publishers that disabled voices should be uplifted and supported. Whether following disabled writers on social media, picking up books written by disabled people in libraries and bookstores, or spreading awareness about hurtful and inaccurate disability representation by non-disabled authors, these all make a huge difference.

In fact, you're already reading an #ownvoices work now. Now that you have taken the first step, start on your journey for better disability representation in kidlit.

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Acknowledgements

The idea that writing a book is a solo pursuit is a cliché far from the truth. To publish a book requires the effort and assistance of so many people, and below are the many individuals who have contributed to this project.

First and foremost, I would like to thank my Fellowship mentor Dhwanee Goyal and the I-CREATE YOUTH team for seeing this project from start to finish. Even though I was just a 13-year-old with humongous dreams, they offered me a place as a Writing Fellow with the I-CREATE YOUTH programme and I haven't looked back since. Thank you Dhwanee for your patient guidance even though I went Missing-In-Action way too often. A much more talented writer than me, you can read some of her work at this link (<https://dhwanee.carrd.co/>). Also, thank you to fellow Writing fellow Andrea Salvador for encouragement and advice.

Now, I am the Chief Content Officer for I-CREATE YOUTH helping other disabled young creatives turn their dreams into reality as well. Visit us at this link (<https://icreateyouth.wixsite.com/site>).

Growing up in Singapore, I never thought there would be any autistic advocates out there. I'm extremely lucky to have met two trailblazers in their own right. Dr Dawn-joy Leong was an extremely supportive and sagacious "mentor". Eric Chen was a thoughtful guide who gave in-deep advice and feedback. Together, their staunch promotion efforts led to more than half of my responses.

Next, I would like to thank each and every respondent for my survey. Added appreciation to those who graciously were available to be interviewed! I read every single one of your answers and was heartened at your efforts.

And lastly, from the bottom of my heart, thank you to all the readers of this book. This would not have been possible without all of you.

For Data Whizzes: Survey Findings

In order to better gain insight into the view of both disabled and non-disabled people regarding disability in children's fiction, I created an accessible survey with JotForm and collected 75 responses.

The majority (42.67%) of the responses were from people who were 17-25 years old, 40.00% were from people 25 years old and above, and 17.33% were from teenagers who were 13-16 years old. The majority (74.67%) of respondents were also disabled, while the rest were non-disabled. Among those who were disabled, the respondents often had more than one disability. The disabilities stated include:

- autism,
- Attention Deficit Hyperactivity Disorder,
- depression,
- anxiety,
- seizure disorders,
- chronic pain/fatigue,
- congenital glaucoma,
- visual impairment,
- Post Traumatic Stress Disorder,
- limited mobility,
- Systemic Lupus Erythematosus,
- narcolepsy,
- Polymyositis,
- hearing loss,
- Obsessive Compulsive Disorder,
- Dissociative Identity Disorder,
- psoriatic arthritis,
- anaemia,
- bipolar disorder,
- borderline personality disorder,
- psychosis,
- Crohn's disease,
- dyslexia,
- scoliosis,
- dysgraphia,

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- Turner Syndrome,
- spina bifida,
- sacral agenesis,
- fibromyalgia,
- rheumatoid arthritis,
- sleep apnea,
- Tourette's syndrome,
- alexithymia,
- aphantasia,
- cerebral palsy,
- hyperacusis,
- hypersomnia,
- Auditory Processing Disorder,
- dyscalculia,
- dyspraxia,
- autoimmune disorder,
- adjustment disorder
- schizophrenia
- Trigeminal neuralgia
- Acquired Brain Injury
- congenital talipes
- erbs palsy

When asked what disabilities they have read in children's books, the most common answer was neurodiversity/learning disabilities such as autism, dyslexia and Down syndrome, followed by mental illness and physical disabilities. Blindness/visual impairment, chronic illness and deafness/hard-of-hearing were less frequent in the fiction respondents read.

The majority (56.60%) of respondents felt that these books allowed them to better understand disability, while the remaining respondents (43.40%) did not.

Disabled people were equally split on the impact of children's books they read on their understanding of disability. Some respondents felt they were not only able to learn more about their own disabilities, but also gain insight into people with other disabilities. One participant stated she could finally see herself in a book after 50 years of life.

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However, those who disagreed pointed out that disability was portrayed in a stereotypical or inaccurate way. They felt that all of the books they knew of only portrayed disabled characters from a one-sided, non-disabled person's perspective.

Non-disabled respondents (80%) overwhelmingly agreed with the statement. They thought the books allowed them to learn about disability and empathize with disabled people, because it exposed them to different types of disabilities and allowed them to look at the world from a disabled person's perspective, giving them new insight on disability.

This shows the positive impact of proper disability representation in children's literature and should encourage more authors to include disabled characters in their work. Authors must also keep in mind that characters should be dimensional and not just a non-disabled person's idea of how someone with a particular disability looks.

Although some respondents may not be satisfied with disability-related children's fiction, many of them had read such fiction and found a few favourites, such as Percy Jackson, Wonder, Six of Crows and Mockingbird. However, when they were presented with a list of books actually loved and recommended by disabled writers (found at <http://disabilityinkidlit.com/honor-roll/>), many could only name one or two, with some knowing none at all.

Here is a list of recommended books with disabled characters by respondents:

- Six of Crows by Leigh Bardugo
- Lair of Dreams
- Beauty Queens
- The Vanishing Stair
- Percy Jackson series
- Wonder by RJ Palacio (Note: [criticised by disabled readers](#))
- The Call by Peadar O'Guillin
- Rogue by Lyn Miller-Lachman (disabled author!)
- A Wrinkle In Time

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- The Fault in Our Stars by John Green (Note: [criticised by disabled readers](#))
- Heidi
- Warcross
- The Dark Artifices trilogy
- How To Disappear
- Are We All Lemmings and Snowflakes
- Out of My Mind
- Rules by Cynthia Lord (Note: [criticised by disabled readers](#))
- Crooked Kingdom
- Captain Underpants series
- On The Edge of Gone by Corinne Duyvis (disabled author!)

Among disabled respondents, some did face challenges when reading books. The most commonly cited challenges were difficulties with font. Disabled participants wanted dyslexia-friendly fonts that were big and easily readable. Another problem they faced was simply the lack of motivation and concentration when reading. Some could not sit down and focus on texts for a long period of time. They wanted intriguing and immersive stories that hooked them. For some, reading visually was a challenge and they preferred audiobooks or books with pictures.

When authors write about disabled characters, many times, they write about the disabilities wrongly or write the characters in the same way over and over again. We call them "stereotypes".

Among respondents, the most commonly seen stereotype was that the disabled character is the only character in the book! This is troubling as disabled people are considered the largest minority group in society, and many authors fail to reflect this diversity in their work, treating their disabled characters as "tokenistic" moves.

This is closely followed by the fact that disabled characters are written by non-disabled authors, instead of disabled authors. While it's encouraging that non-disabled authors choose to write such characters, oftentimes the work of non-disabled authors is chosen over disabled authors who have authentic experiences of what living with disabilities is like. More disabled

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authors need to be supported and published in the industry if it really wants to stand for diversity, as many non-disabled writers and publishers claim.

Other common stereotypes include (in descending order):

- The disabled character is not the main character
- The disabled character is "saved", or pitied by the main character
- The disabled character is from a certain background (white, male, straight, middle-class/well-off)
- The main theme of the book is about perseverance
- The disabled character is disliked or considered a "burden" by their family only because of their disability
- The book uses ableist language like "crazy", "psycho" and "retard"
- The disabled character is "cured" of their disability
- The symptoms of the disability are inaccurate
- The disabled character is disabled because of an accident
- The disabled character dies in the book
- The disabled character never faces discrimination because of their disability

I asked respondents these questions in email interviews:

1. How did you find out about the books with disabled characters you read?
2. Has your parent or teacher ever introduced or discussed such books with you?
3. What are some disability stereotypes you are really annoyed about in children's fiction?
4. How can authors better write disabled characters? For example, should they interview disabled people or find disabled editors? If they do research, how much would be considered a good amount of research? Or are only books by disabled authors considered good representation?
5. On a scale of 1 to 7, how satisfied are you with disability representation in fiction? Why?

Interviewees reported that they discovered the books by themselves at the library or online on promotions/book review sites. This shows that libraries play an important role in allowing children to read books about disability.

Who's In The Mirror?

Almost all respondents were not introduced to any books about disabled characters by parents or teachers. As one respondent pointed out, these books were often not on the top of teachers' minds.

Stereotypes included being "cured" of their disability, side characters with no individual personalities, tough people who need to learn to accept help, "burdens", siblings or superhumans.

Majority advocated for the need to consult disabled editors, sensitivity readers and the community in general. Non-disabled authors can write disabled characters, but disabled authors' work should also be promoted.

The average rating was 5.58, or about 6 out of 7.

About the Author

Thee Sim Ling (she/her) is a young Southeast Asian writer. She has placed in numerous writing competitions, including being the only international winner for the 2021 Inklings Book Contest, and her work has been published or is forthcoming in Stone Soup, Shameless Magazine and Skipping Stones. She is also the Chief Content Officer for I-CREATE YOUTH, as well as a staff member for multiple writing organisations. Outside of writing, she's a cybersecurity enthusiast and a proud INTJ.

She has published a mystery novella titled *Enigma Hawker Centre* which was a finalist in the Young Author Awards 2019/2020. In the vein of classic whodunnit duos such as Sherlock Holmes and Dr Watson, Enigma is a unique Singaporean and disabled take on detective mysteries.

Visit her website at <https://lucindathee.com>.

Disclaimers

This book is entirely a work of fiction. Names, characters, places and incidents portrayed in it are either the product of the author's imagination or are used fictitiously. Any resemblance to actual persons, living or dead, events or localities is entirely coincidental.

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First ebook edition 2021

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*Published by Thee Sim Ling
www.lucindathee.com*