

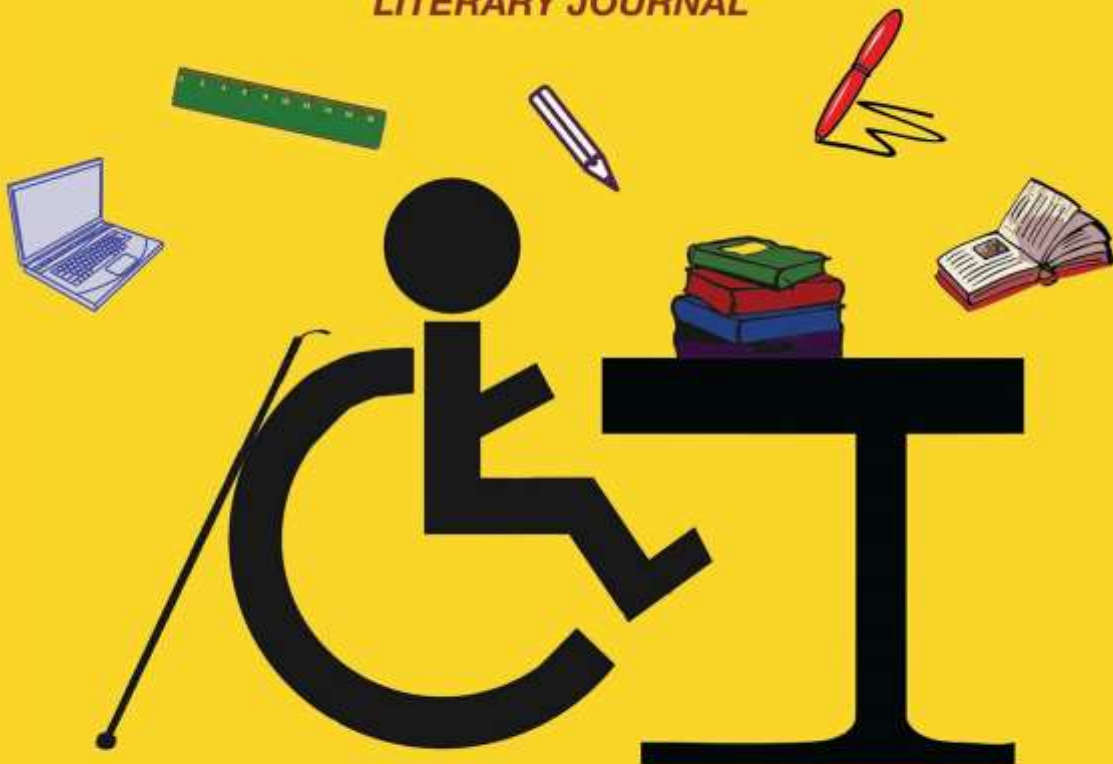
**LEEDS DISABLED PEOPLE'S ORGANISATION**



**LDPO**

**DISABLED VOICES**

**LITERARY JOURNAL**



Cover design by Laura Deakin (@ld\_printandpattern)

An illustration of a wheelchair user at a desk, on the desk is a stack of books, leaning against the back of the wheelchair is a cane. A laptop, ruler, pencil, pen and notebook are around the person. The LDPO logo is displayed above. The background is bright yellow. Text reads: Leeds Disabled People's Organisation, Disabled Voices, Literary Journal.

Leeds Disabled People's Organisation presents:

## **Disabled Voices**

A new literary journal

LDPO would like to dedicate this journal to the memory of Mike Oliver, a foundational figure in the Disabled People's Movement, and a personal inspiration to so many of us.

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## Introduction

P.B. O’Dea

“Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write.” – Douglas C. Baynton.

The history of disabled people in the UK goes as far back as the history of humanity on these islands, but our modern understanding of ‘disabled people’ can largely be traced back to the passing of the Old Poor Law in the 17th century. This act marked the beginning of the forced institutionalisation of disabled people in “alms-houses” or “poorhouses”, where they would live off charity, beginning toxic narratives about us that are still present in popular discourse over four hundred years later.

Despite this attempt to simply lock disabled people up and out of existence, our voices have never really gone away. In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) published *Fundamental Principles of Disability*, which argued that disabled people were an oppressed group in society. This led to the coining of the term “the social model of disability” by activist-academic Mike Oliver in 1983.

Oliver gave a name and thus new life to UPIAS’ pre-existing argument that, on top of the limitations caused by one’s impairment (e.g. deafness, blindness, etc.), disabling social barriers excluded certain people from full, equal participation in society.

The work of the early Disabled People’s Movement, inspired by the social model, managed to vastly improve the lives of disabled people, culminating in the passing of the Disability Discrimination Act in 1995. Unfortunately, progress is seldom static, and in the New Labour era disability rights began to be eroded once again. This slide into oppression has only intensified since the Tories have returned to office, resulting in the UN’s Committee on the Convention on the Rights of Persons with Disabilities (CRPD) issuing a damning report in 2016, which condemned the government for “systematic human rights abuses against disabled people”, and a further UN report in 2018 about dangerous levels of poverty in the UK, owing to the Tories’ austerity programme.

Where does a literary journal by a fledgling organisation such as LDPO fit into this rather grim picture?

Disabled people have always been in the stories we tell as part of our human culture. According to oral tradition, the legendary Homer, attributed with creating the two epic poems the *Iliad* and the *Odyssey*, was blind. However, while we have always been there, usually in the periphery, but sometimes centre stage in films, novels, plays, poems, television series etc., often these depictions are given life by the non-disabled. Of course, non-disabled writers inventing disabled characters is not an inherently bad thing, but it is a problem that they dominate our narratives about disability, and that the lived experiences of actual disabled people are often ignored.

Therefore this journal aims, just like previous works such as *Disabled People Destroy Science Fiction* (2017) and Anne Finger’s short story collection of revisionist literary and historical works *Call Me Ahab* (2008), to give disabled people the opportunity to tell our own stories. If indeed the pen (or

keyboard) is mightier than the sword, then we are in need of some mighty pens today in the UK to give voice to issues facing disabled people the length and breadth of the country.

Within the pages of this journal you will find an essay on breaking down the disabling social barriers that visually impaired people face in museums, expertly dealt with by Gill Crawshaw; a poem about the frustration and dread of having to contend with the UK's toxic benefits system by Jonathan Eyre; a whimsical, thought-provoking and uplifting retelling of Humpty-Dumpty by Leo Gunn; a poem relating to depression by Mark Wilson; a piece about getting over a bad relationship by F. R. Kesby; and perhaps one of my favourite pieces, by Emma Roberts, which I will take the liberty of quoting two lines of within the introduction:

“They call it Disability, I call it ability.

An ability to keep going within a broken world.”

These are only a few examples of the works you'll find. Please note that, while we are a Leeds-based organisation, not all the writers whose work has been published in the journal are from Leeds. This decision was made to allow for as wide a range of works as possible, and to amplify the voices of as many disabled people as possible.

There are twelve entries in total, some relating to themes surrounding disablement, and others about broader issues, but all of them are bound together by the fact that they offer the reader a chance to step into the shadows and see that they do not harm, and that we disabled people merely request that you lend us an ear and you will hear our voice.

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## 1. All the King's Men

Leonora Gunn

“Disability is an art. It’s an ingenious way to live.” – Neil Marcus (Storm Reading, 1988)

His silly name, always followed by his absent father’s whisper: “Made wrong.” He heard their sing-song chatter about him, he registered it as it flitted over what passed for his ears, but he sent it twittering away with his hand.

Their breath is wasted on him. It evaporates from his surfaces. He swings what passes for his legs absently, enjoying the loose jingles of their nuts and bolts.

The tin soldiers march over the hill, the horrifying unified clattering of their feet in perfect synchronicity. No need to announce, “Left! Right!” They march regardless. He adjusts his eyes, tweaking their screws so that he can make out the nose on each exactly identical, expressionless face as they perform with their goosey legs so perfectly in tune; they are like tiny marionettes. They are him perfected. He would scowl, if he could.

*Why do they bother? It’s not as if they have anything to prove.*

The townsfolk watch the procession with the same absent-minded fear as always. This is nice because it means the back of his head goes unobserved for a short while, and so he scratches it. He doesn’t understand why, it is not as if it itches, until he finds a curious gooey blob at the nape of what might have passed for his neck, if you were squinting. Who knows when someone stuck it there, or how long it’s been there, making them laugh. He can’t really begrudge them it, though. He’d chuckle himself, if he had real lungs, and not just an expanse of interwoven cogs that propel his not-real chest up and down in a sad imitation of life, of freedom.

He watches the soldiers until every last boot stomps heavily off the end of the earth, back to the castle beyond the horizon, and that’s all for today, folks. Their eyes return to him. He moves to swing himself back down to their side of the wall, to give his adoring public a nice, hideous target for whatever overripe insult they might be desirous of hurling. He doesn’t. Instead, for some reason, he looks past his feet at the ground far, far below on the other side, and it calls to him.

*You are made wrong, it says. There is no place for you but here, beneath me.*

And, for the first time, he listens.

He is plummeting now into its hard embrace, landing with a not-real-ear-splitting clatter that would rend his heart if only he had one. The world turns black, but remains loud. He wishes he couldn’t hear the gasping and the giggles.

*Oh well. At least I gave them one last show.*

That’s the last thing he thinks for quite some time.

Someone sends for him, eventually. His creator's hands pick at the scraps of him, and he can feel the stare of all his indifferent brothers and all the king's rotten hoi polloi glaring down at him in regal masculine impotence. He isn't even worth the sum of his parts, his father says contemptuously, and they leave him there to rust. He'd rot if only he could.

As the day slopes toward its western bower and the crowd at the top of the wall finally dissipates in boredom – his bits will not leap up and put themselves back together again, ding dong, the monster's dead; as he has given in to the ground and is waiting for her to swallow him – he would knock at her gate to beg for this mercy if only he had his not-quite-fingers still to scrunch into a fist, if only he still believed that she could love him still, that the wind was her caress and the grass her gentle hands, that silly little lie he made up for himself when he was only a sort-of-boy, oh-so-very long ago, although he has not aged a whit, never will, shall never grow grey and feel a loving touch fold him into sleep and let him finally be truly *still*; as he wishes, not for the first time but surely, *surely*, the hardest, that he could really shed a tear, could prove the lightening and the joy and the echoes of flesh that thundered within him, for his not-ears only; as every little molecule of him sank into the inevitable; she came.

Tender hands gather him up, all his imperfect ticking pieces, folding him into her voluminous pockets, stopping to rest a hand on her stooping back now and then, letting out little *oomphs* and *aahs* of humanity. Grumbling to herself all the while, muttering in a funny little language that he has never learned. There's something enchanting about the way it tumbles off her tongue, and he thinks she must be a faerie.

“Ooof,” she says, as her old bones creak.

A crotchety faerie.

When he is all neatly tucked away they disappear into the evening sky, her footsteps inkily padding into nothingness. He sleeps and sighs.

He awakens to a tingling. In his not-hands, his not-feet, his not-ears, his not-eyes, his not-nose... The whole world is vibrating gloriously. He opens his eyes – bafflingly, they are somehow there to open – and the whole world is laughter: tinkling, jingling, beautiful little trilling metallic giggles burst out all over everything. Unimaginable contraptions of incomprehensible purpose and proportion drift sweetly all above him, clinking in a way that sounds just as he has always understood the stars to twinkle.

Hands.

There are hands moving over him, on him, around him, inside him. There is a screwdriver. He has never felt safer. Hands, soft and shaking, flecked with flaws.

She is not as old as he had thought. Or is she? Time itself seems to bounce off her, confused and shaking itself off as if to say, *Well, that was weird*. She is radiant. Luminescent. Her face is beautiful – or is it ugly? He never has been able to remember which is which – but the kindness in it is so palpable he knows it has to be beautiful. He feels her kindness in his soul, penetrating so purposefully that he hesitates to remind himself he has no soul.

“You're awake,” she says, and he understands the words, although somehow he knows they have mutated on their path from her tongue to his ear. He only has one, so far. He can see his other ear in the distance on a revolving worktop whose brass feet appear to be tap-dancing.

*Why do they move?* He wonders, marvelling at machinery that echoes life more masterfully than he could ever dream to.

She shrugs. "Because they feel like it. Now, hold still."

Her hands on his face are an absolution. No one has ever held him before. His eyelids droop under the soporific effect of her tapping, greasy, delightful fingers. Something clicks, and suddenly he can taste again.

*Oil. Oil and... lavender?*

"It's my hand cream," she says.

And then something occurs to him that should definitely have occurred to him sooner.

*You can hear me?*

She grunts. "I s'pose you could call it hearing, if you wanted to."

He has the sense not to press her on that, and watches as she dodders away from him and expectantly extends her hand. A wooden stick flies into her grasp with magnetic force. She leans on it and limps across the floor to something that is definitely a kettle. It looks nothing whatsoever like a kettle, but somehow he knows a kettle is what it is. She makes tea, sips it, and comes back to him. She moves relentlessly, unapologetically, like no one he has ever seen before. Like a vine thwarted yet determined, adjusting its route and finding a new way to creep on to its destination undeterred, but possibly rather irritated.

"I can't put you back the way you were," she tells him, her expression scrubbed clean of even an ounce of pity.

*I was made wrong,* he apologises. *Not even worth the sum of my parts.*

"No." And she looks angrier than he would ever have believed possible, just not at him. Slightly over his shoulder, at something he can't see.

*I'm not hard enough. Not strong enough.*

"Not stupid enough," she huffs. "You," she says, and her eyes bore into his in a way that has no business feeling so comfortable, "are fearfully and wonderfully made. Best thing that eejit ever did."

*My shell is too thin. I'm not like them. I shatter.*

"Not like them, indeed. Vastly superior, in fact. Your softness is nothing to be ashamed of. Better to be infinitely shatterable than to sully your hands shattering others. Far, far better."

And, oddly enough, he believes her. She seems to understand this, and her hands turn to his knee, rotating it and coiling its wires with her calloused thumb. It is only then that he realises he can't move, not without her hands. Funnily enough, it doesn't bother him at all.

## 2. Benefits

Jonathan Eyre

I will pull myself up onto the butcher's table  
for You to pick your weekly cuts,  
the Nation's Rich deem  
we no longer deserve our souls,  
Every day we can be called forward to be inspected  
whilst the rich do the 'accepted' thing,  
cheat on paying their full taxes, a 'cultural' norm  
to claim THEIR expected cash benefits,  
and so YOU, the jealously ill,  
are let loose,  
to hound US  
the poor, unemployed and disabled,  
rallying to hunt us down,  
the Media branded unworthy,  
the head-boys calling their minions  
to chase down the quarry,  
to harry us, split us off,  
in these 'Benefit Games'  
until we fall exhausted and broken  
then rationally and fairly,  
crushing our bones to make a pleasing sound,  
encouraging the tearing of flesh from the fallen,  
to learn the joy of spinning us again and again  
on pins of intimidation, on pins of interrogation, on pins of unheeded intrusion, on long steel sticking  
pins of tick-box denial,  
normalise these jaws of deviance



organising the Transport of our lives through  
'unexpected' non-payments, water-boarding sanctions, poverty taxes  
so I will pull myself back up onto the butcher's table  
for YOU to view my weaknesses,  
to ask again for all my intimate details,  
to pick through austerity's collateral  
for your pound of flesh.

### 3. Changing museums – and society – through touch

Gill Crawshaw

Historian Mary Beard sees no reason why visitors to the British Museum shouldn't be able to pat the Rosetta Stone. But what if someone goes beyond a gentle pat? One man was recently convicted of criminal damage because he pulled an object from the wall of the V&A museum, and then smashed it into pieces.

Beard was advocating for more touching in museums as part of a television debate last May (Beard, 2018). The criminal conviction and a warrant for arrest were issued a few days before and reported in *The Telegraph* (Lowe, 2018). Both of these events caught my attention as I've been reading a lot about touch and museums recently, as part of my research into blind and partially sighted people's experience of museums and galleries. (I have just finished an MA in Curation Practices at Leeds Arts University.)

These media stories highlight a particular tension around touch in galleries and museums: the tension between accessibility and conservation. Conservation for museums and galleries means looking after collections so that they will be available for future generations. But museums and galleries should also be thinking about the needs of today's generations of visitors, and developing long-term relationships with a range of audiences. So how can museums best address the needs of those visitors, including blind and partially sighted people, whose connection with objects and works of art is greatly enhanced by being able to touch them? How do curators' decisions about conservation affect their relationships with communities?

Touch tours, touch exhibits and handling sessions aimed at blind and partially sighted people are established practice in museums. V&A Director Tristram Hunt's response to Beard, in the TV debate, was that:

Lots of museums have, quite rightly, touching areas, so that you do have this sense of physicality and a sort of haptic power. But also people who are visually impaired can also sense what it's about (Hunt, 2018).

In fact, the banister damaged in the V&A was in their 'touching area' for blind and partially sighted people (although the convicted man is sighted). This fact was used to underscore the scale of the damage, perhaps trying to illicit sympathy, with a spokeswoman for the V&A saying:

It was a particularly important part of the visitor experience for our blind guests... The information sign which accompanied the baluster was also written in braille so that blind visitors could learn more about the piece (Lowe, 2018).

However, the standard of some of these touch tours has been called into question: do they give blind and partially sighted people an equitable experience? Zoe Partington, a partially sighted artist and consultant who works extensively with museums, has said:

If you are a blind or partially sighted person you don't want to arrive somewhere and there are ten items you can touch when there are 44,000 pieces in the collection and every year there are the same ten pieces to touch (2017).

Candlin (2010) is also critical, feeling that these types of tours and handling activities often fail to take into account that touch offers a different way of understanding objects and sculpture than sight. She also writes that when museums set up their touch tours,

... disability was understood as being an impairment or lack that as far as possible needed to be made good through the other senses, and so touching functioned as a substitute, albeit an inadequate one, for sight (Candlin, 2010).

Hetherington (2003) states that adjustments made for blind and partially sighted people in museums actually benefit the museum rather than visually impaired people. They can be used to justify museums' ownership of contested objects and signal, rather than deliver, accessibility.

A more strategic approach would be for galleries and museums to adopt the social model of disability (Barnes, 2012). Developed by disabled people, the social model identifies disability as being caused by barriers in society, largely organised without taking the needs of people with impairments into account (Shape Arts, 2017).

In galleries and museums, barriers that people with visual impairments face can include: assumptions about how people engage with art; lack of information and interpretation in accessible formats; inadequate staff training; poor signage; low lighting levels; and not being allowed to touch artworks or replicas. Because the social model locates disability in society's structures and organisation, rather than in individuals, it essentially provides a framework for change. Rather than focusing on a perceived lack or deficit, as Candlin describes above, museums should be thinking about their own organisation, practices and policies, to identify and tackle disabling barriers. This gives opportunities for doing things differently.

Some of these opportunities, in terms of touch in galleries and museums, are offered by technology. Museums are trialling a range of approaches, such as 3D printing, printing on 'swell paper', providing scale models, multi-sensory activities and virtual reality. Because this is a rapidly developing area, none of these approaches have become widespread across galleries and museums. Replica objects, tactile models and samples of materials are perhaps most common, but they may be of limited value to blind and partially sighted people, being either too intricate to interpret or because they fail to give a proper sense of an object, such as the weight, texture or overall impression.

Are replicas, models or samples a satisfactory substitute for being able to touch the real thing? Beard doesn't think so in terms of the Rosetta Stone, where a replica is available - she proposes that this lump of granite could withstand a great deal of touching. Visitors are being denied the opportunity to 'touch the past' (Beard, 2018), to connect with past civilisations and artists.

On the other hand, if developed as interpretation tools, and in partnership with blind and partially sighted people themselves, replicas, models and sample materials can open up collections to blind and partially sighted people - as well as to a wider audience. Visually impaired curators are leading the way in this area. Kojiro Hirose, a blind curator at Japan's National Museum of Ethnography invites all visitors to become 'astonished by touch', encouraging a gentle and unhurried handling of objects that unlocks imagination (2013).

Georgina Kleege, an American blind academic who has written about blind and partially sighted people's engagement with art and museums (2018) has developed 'haptic encounters' where handling objects and materials are accompanied by audio recordings.

Many people are now calling for galleries and museums to re-evaluate touch in museums; re-thinking who is allowed to touch what, and how. While conservation is important, it should not be used as an excuse to restrict access. Touch must be recognised, not as an alternative or substitute for visual perception, but as an equivalent way of understanding, learning about and connecting with works of art and museum objects. While blind and partially sighted people are one group who stand to gain

from this, it would in fact benefit all visitors and has the potential to attract more people into galleries and museums. Not only that; as Hirose (2013) states: 'Tactile learning will change the museum, and the museum will change society!'

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#### 4. Depression Takes Hold

Mark Wilson

Depression is a monster that attacks our brain  
It puts thoughts in our minds over and over again  
It's hard to control no matter how much we try  
It just won't let things lie  
It puts dark thoughts in our head  
We would love to think good things instead  
But it won't let us, it just chips away  
We just don't know what to do or say  
We try to hide, it's something we don't like to show  
We just pray that this monster would just go  
But it's a tough enemy who won't give any reprieve  
Even though we want it to leave  
It's something we just can't hide  
Some of us even suggest suicide  
We feel very much on our own  
And want to be left alone  
It's hard to deal with, we get into such states  
But we know it's not our turn at the Pearly Gates  
Other people that suffer the same understand  
Just reach out – you will find a helping hand

## 5. **gaia**

Jessica Wing

That which has nurtured me thus  
is a lie.

It is either: be at war with you,  
or else myself. I fall silent  
under your weight and am coaxed  
back to sound.

I anticipated a lot but never this.

A sure silence –

Moving images bare and hostile:  
a white paint wall  
against which I throw the hope-pottery  
fired well before this diagnosis.

Everything I am is all I can write.

Never has it been clearer that it is  
not enough to be me.

## 6. Getting Clean

F.R. Kesby

When I woke this morning, the heavy gap that was your side of the bed, that had somehow tripled in weight since you stopped being there, was empty. The dense after-knowledge of you had lifted and when I pressed snooze I rolled over, eyes closed, and spread myself out into the space. I stayed there, enjoying the freedom for the ten minutes before the snooze clicked off and I really did have to get up. And for the ten minutes before the next alarm shrilled, when I really, really had to get up. And until the one after that insisted that I really, really, really had to get up right now or there would be trouble.

I don't know what it was that took you away. Maybe it was that girl who smiled at me on the bus and who I smiled back at without even a trace of guilt. Maybe it was the trip to the big Asda I had finally endured alone and found surprisingly easy, found that I did know what the aisles held and I did know who to ask for help getting stuff off the shelves and I could get the wheelchair through the checkout without crashing. Maybe it was the not quite masturbating but definitely enjoying myself a little that had gone on the night before without any thoughts of you. Maybe it was just that the requisite length of time the universe decides you need after a break up had finally passed. Maybe I am not giving myself enough credit, maybe I decided before going to sleep that it would be the last time I did so while avoiding touching the pillow which was no longer really yours. Maybe I had just wallowed so long the mud I was in had simply run out. Whatever the reason, I woke up that morning and you had finally left my bed.

I dragged myself to the shower, sat on the slimy plastic chair and paused with my hand hovering over the two buttons. High or low. You'd told me once, when the shower was new, how strong the high setting was and I'd avoided it always, sticking with a low steady pulse instead that I knew was safe, that I knew couldn't hurt me. I chose high, holding my breath for that second while the water surged through the pipes with a far-off whoosh sound in the walls before it shot out, hitting my chest and shoulders with enough force that I yelped. There was a slight flush of pain as my skin reddened in the hot, sharp spray, then I grew used to it and it calmed and I watched as the skin on my legs grew first red, then pale, then back to their normal pallor without more than a shimmer of discomfort.

I felt the last of you leave as I stuck my face in the water, felt you sloughing from my skin under the harsh spray. The water drummed firework lights into my closed eyelids. I could feel my skin drinking in the water, the way it soaks in the sun on the first bright day after our long, grey, northern winters. I turned my head down to shampoo, rubbing the minty suds deep into my scalp and watched the water swirl around the drain, watched the dregs of our relationship slip into the dark hole and down, out of sight and out of mind. I was finally clean.

## 7. Misconceptions

P.B. O’Dea

Karlisle came alive at sunset, with its busy streets, flooded in a sea of colour, all the visible colours of the rainbow and more, but Stefan wasn’t there to drink in the vibrant scene. Stefan was there for blood. As he strolled past the fortune telling district of the city, where the downtrodden, the cripples, the undesirables made their homes, he was reminded of how he himself would have ended up there if it hadn’t been for Elisabeth Lochforne, or “The Empress Elisabeth” as she styled herself on her own minted currency. He removed from his red-coloured tunic a coin which bore the face of the current claimant to the throne of the Dulmanian Empire, and kissed it reverently. He had been nothing but a mere child of the streets, fighting and stealing to make a living, but the Empress had raised him up and made him her chief assassin.

When Elisabeth, then still a relatively minor princess of the nobility of Dulmania, had announced her intention to dethrone Emperor Leopold II and had thus sparked a civil war, Stefan had known that his blade would be called upon, and called upon it was.

“Stefan,” the Empress had said. “You have served me faithfully this last decade.”

“I try my best, majesty,” he had replied in earnest.

“If possible, I would like to take the throne of Dulmania without too much bloodshed,” she had said. “A quick end to this war is desirable, do you understand me?”

“Yes,” he had retorted. *What quicker way to end the war than cut off the head of Dulmania itself?* And that is what he would do. He had secured, with the aid of a contact within the Imperial Palace, some forged papers that would enable him to get into the palace, and from there? Well he’d worry about that then.

He came to the gold-decorated fountain that was right in the centre of the Dulmanian capital city. Here he spied a man dressed in a gold tunic, who was leaning a little too casually, his back to the fountain.

“Rodrigo?” Stefan hissed. The man gave a start.

“In the name of the moon goddess!” he swore. “Stefan?”

“Who else?”

“She sent you then?”

“Well I’m here, aren’t I?” Rodrigo merely made a coughing noise in response to this, or it might have been a laugh, Stefan would never find out.

“Of course, the Emperor has a son, they say, a bastard, who lives overseas; he will have to be dealt with in due course. For like his father he too is a cripple,” Rodrigo warned, waving a stern finger at his contact.

“Does he have the same affliction?”



“The very same,” Rodrigo confirmed with a nod. “The medical men, whose vocabulary seems to be ever growing, call it cerebral palsy.”

“A cripple cannot sit on the throne of Dulmania,” Stefan said dogmatically. “The Empress must prevail.”

“Aye, good fortune to you,” Rodrigo said, clapping him on the shoulder. “The letter of introduction I gave you will see you safely inside the palace gates. With a bit of luck you’ll get back out again afterward.”

Stefan nodded, he didn’t want to think about the aftermath; if all else failed he had a vial of poison upon him which would spare him the prospect of torture followed by a brutal execution. As he mulled these thoughts over in his mind, he came upon a beggar, who was in a wooden chair with wheels on it. *A cripple*, he thought to himself with disgust.

“Good evening, young man,” the cripple said affably enough. Stefan grunted and moved to go past him, but the man wouldn’t move out of his way. “Of course it is a crime to carry daggers within the capital city of Dulmania.”

“Really?” Stefan said in his best attempt at a nonchalant voice; he didn’t need this mindless distraction, he had a crippled Emperor to kill.

“Rodrigo Carpengo was never the best at court intrigue,” the beggar continued in an almost conversational tone.

“What?” Stefan could feel himself beginning to sweat; something was wrong here, something was very wrong indeed.

“I imagine the royal guard will have apprehended him by now,” the beggar said in the same blithe voice. “They’re good at that sort of thing, you know.”

Stefan had a vague inclination that he should run, but something was rooting him to the spot, a nameless dread. At that moment the coin with the face of the Empress fell from his tunic. Before he could stoop to retrieve it, the crippled beggar had lurched from his chair; Stefan noted that he wobbled while he walked and he also had a speech impediment. *Some possible symptoms of cerebral palsy*, he reflected.

“My cousin always looked good in portraits,” the beggar said as he sat back in his chair, the coin clutched in his right hand. “Nice to see it’s the same with coinage.” It was then that Stefan gasped with dismay.

“Emperor Leopold?!” Not waiting for an answer, he drew his dagger, but it was then that he saw the blue cloaks of the Imperial Guards closing in; sure enough, as the beggar – Emperor – had predicted, he could see that a separate group of guards held a struggling Rodrigo captive.

“The idea of a monarch dressed as a beggar,” the Emperor mused as if he had forgotten that Stefan was there, “a fairly old literary device that everyone should read up on, for you disregard beggars at your peril; at least that tends to be my experience.”

“Long live the Empress Elisabeth!” Stefan cried, for he did not know what else to say, as the Imperial Guards closed in upon him.

“She may live a long life yet,” Emperor Leopold said. “That all depends on her next move. If she stops this foolish pursuit of my throne, I will pardon her for her misconceived ambitions and I will name her regent, till my son comes of age.” Stefan blinked at this, he wasn’t expecting to hear the musings from the mind of the powerful – he was nothing but a hired hand, a doomed hired hand at that – but to his surprise the guards, who had him in their clutches by now, made no effort to harm him, they merely held him where he stood, away from the royal beggar. Rodrigo on the other hand was still struggling. He had, Stefan saw with some hope, managed to put one of his hands on the hilt of his dagger, and was in the process of drawing it, when there was a sharp swooshing noise through the air, and then a flash of silver, accompanied by an agonising scream. One of the guards holding Rodrigo had severed the hand that had clutched at the dagger clean off.

“An inconvenience,” Leopold observed, glancing at the scene that was happening to his side. “Now, sir,” he said, turning his chair to face Stefan. “Will you deliver my terms to my cousin? For I too am eager to avoid civil unrest.” Stefan swallowed and then nodded his head. Leopold was wasting his time, for Empress Elisabeth would never consent to those terms, why settle for temporary regency when she could take the crown? But he would offer those terms to her, for at least it meant he got to keep his head, at least for a little while. The Emperor of Dulmania smiled, and gestured to the guards who were holding Stefan. “Remove him from the city,” he said blandly, and then his eyes fell on Rodrigo. “As for this palace traitor: I don’t want it said I was too lenient, take him to the cells.”

“Majesty,” Rodrigo spluttered, still bleeding from the loss of his left hand. “I never intended to betray you.”

“Be quiet, sir, you insult both yourself and me,” the Emperor said. “You misconstrued me as a fool, and now you will pay for that error.”

Stefan did nothing to intervene, what could he do? Instead he allowed himself to be marched towards the gates that acted as an exit to the city of Karlisle. As he left the city, he looked up to the sky, which had been a blood red upon his arrival; now it was merely black, with a few stars watching him from above, passing their seemingly eternal, silent celestial judgement on the follies of mankind.

## 8. My lived experience of ‘disabling barriers across borders’

Mostafa Attia

In this article I will use my story as an example of different challenges that could be faced by a disabled person, regardless of which country they live in. While the literature records a variety of barriers, each country’s specific context influences disabled people’s level of access to services, and the degree to which they are mainstreamed within their communities. In addition, the wider culture contributes to the stigma that deprives disabled people of equality of opportunity.

I am a disabled activist and researcher, born in Egypt, who has interacted with a multitude of academic, professional and activist experiences in different countries. This has exposed me to the wider context of many barriers and deprivations that disabled people face in accessing services. My childhood journey started at a segregated governmental boarding school for blind students in Egypt. While this boarding school built my capacity for independence, along with my ability to devise many creative solutions to overcome both the educational and social challenges that I faced, I was deprived of interaction with daily community activities. Visiting my family only one day a week cost me the familiarisation of that warm environment, which was replaced with the feeling of being a guest or temporary visitor. It is worth noting that the blind education system in Egypt at that time faced multiple challenges related to the lack of either tactile mapping or audio descriptions of the physical world. As a result, students were deprived of an equivalent education because they could not study subjects such as geometry.

Despite this, I managed to move from pre-university education to the university stage. This was the first opportunity to be mainstreamed with my non-disabled colleagues, many of whom regarded me as an unable body and/or somewhat different. They could assist me but would not consider me a friend. Their awareness about the degree to which disabled people are able to deal with the world was poor, owing to the prior segregation. This segregation also built a barrier between the community and their understanding of the capabilities and equal qualifications that disabled people may have. As a result, we disabled people were struggling to be mainstreamed in university life at a social level. I have observed that this issue also exists within British universities, where there are also issues with inclusion. Although policies tend to mainstream disabled students in pre-university education in principle, the reality is variable as inclusive education is not always open to everyone defined as ‘impaired’. Consequently, a level of isolation still exists within university life. In addition, funding cuts in recent years have obliged universities to decrease their level of assistance to mainstreaming individuals.

In Egypt, although higher education has begun to be more aware of disabled students’ inclusive rights, they still face barriers at the admissions process, during their course study, and most importantly with exam arrangements. These arrangements depended mostly on staff initiatives and goodwill, instead of following a concrete system. My experience as an MA and current PhD student at the University of Leeds suggests that although each UK university may differ while supporting disabled students, my disabled colleagues experience tends to indicate that there is a slight delay in receiving the required assistance. They spend extra time arguing for support on a regular basis, and they are forced to go the extra mile to organize all sorts of academic arrangements, including asking for Personal Assistants (PAs), or for their academic materials to be prepared in appropriate formats. It is worth noting that Egyptian universities do not have PA schemes or notetaking support as part of their system. As a

result, some Non-Governmental Organizations (NGOs) established initiatives to support disabled students, but the level of efficiency and the cost required differs from one to the other. Due to the uneven geographical coverage, not all disabled students can access these, which is not the case with UK disabled students. As documented by the USAID 2017 report, disabled students do not have the right to access the majority of higher education disciplines and in some cases decisions are left to the discretion of Faculty Deans (USAID, 2017). This results in huge inequalities. Nonetheless, it is positive that the 2014 Egyptian Constitution and the 2018 new disability law give wider access to disabled students entering university faculties. In addition the universities' recognition of their accommodation needs has improved (Egyptian Constitution, 2014).

Following my graduation, I was denied access to join both the Media and Communications department and the Arabic Music Institute owing to the Faculty Dean's argument that my impairment disqualified me from accessing these faculties, despite being qualified for both. Disabled students' exclusion, and the stigma they face, result from policy makers lacking the necessary knowledge about capabilities and qualifications. My situation was especially frustrating as I had music history and experience, having played keyboard in bands in Egypt from the age of 18, and also having been part of my university's band.

My journey to working in the field of disability started in 2004 with joining the National Council for Childhood and Motherhood, and the National Council for Disability Affairs - both policy-making organisations. This involved me with disability rights policies and practices, including the gap that exists between both. My knowledge at the national level was expanded by my obtaining an MA in Disability Studies from Leeds. It was the first time I travelled outside of Egypt - an interesting and challenging experience as a blind person. A new country with a new language, customs and cultural differences took some time to adjust to. This showed me that people in other countries also faced a multitude of barriers which required their advocacy and calling for their rights. During my PhD, which started in 2015, I became more involved within the UK disability context by chairing Leeds Disabled People's Organisation, as well as being a member of some think tanks and consultancy groups. My journey also included joining academic conferences, fellowships, and disability activism all over the globe. One interesting example is the 'Economic Empowerment Fellowship' hosted by Access Living. Among other responsibilities, this organization advocates for disabled people's rights to education, employment and housing, and addresses any challenges that disabled people may have faced in these areas. It uses the USA's legal framework as a means to achieve this, and hence working with this organization further expanded my knowledge regarding the disability context within the USA. Finally, this practical experience was joined by optioning various diplomas in relation to public policy, governance and disability studies.

In Egypt, in 2011, I lived through the events and consequences of the Egyptian revolution, where we disabled people fought for inclusion by participating in marches and demonstrations. Although there were a multitude of physical barriers, disabled people were very keen to participate in the events of the revolution. We saw these as a moment to elevate and loudly express our demands, and the revolution slogan – freedom, dignity and social justice – has supported our disability rights. Immediately after the revolution, I was engaged in the creation of some national policies, e.g. the Egyptian Constitution of 2014 and the new Egyptian Disability Law (Egyptian Constitution, 2014; Shalabi, 2018). In addition to these, I became a member of various global alliances of the disability movement e.g. the Arabic Regional Office for Disabled People's Organisations (DPOs).

This wider engagement with the field introduced me to the disparity between the barriers faced by disabled people in Eastern and Western communities. Inclusive education is one example, as Egypt

and other countries in the Global South started only very recently to issue ministerial decrees examining the feasibility of this concept. However, the case is different in the UK where the concept of inclusion among the fields of education and employment has been longer established. This is not to say that the Western barriers are lighter or of less importance than those faced in the Global South, but the debates and discussions, as well as the co-operation between government and disabled activists, are more developed, as, at least in my personal experience, more channels of communication are available. According to the 2030 agenda, the solidity and unity of the disability movement at both the global and national levels is key for disabled people's voices to be heard and for them to attain their inclusive rights (UN, 2015).

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## 9. The Alchemist

Rosamund McCullian

It's in every cell,  
The opposite of photosynthesis,  
Exothermic, searing heat like  
Lava oozing in the veins,  
No chemotherapy could counteract,  
A self-negating poison, elements  
Collide, co-mingle, corrupt  
In impossible permutations, valencies  
Adrift in a sea of primal blue and  
Screaming, blue whales beach themselves  
Along the rocky shore to flee the  
Twisted tides.

## 10. They call it Disability

Emma Roberts

They call it Disability, I call it ability.

An ability to keep going within a broken world.

In a world where people gain from causing pain, ignoring the suffering  
focused only on personal gain, their hearts closed to forgiving.

An ability that no matter what, I make a choice to see the good in others.

An ability to get up every day and do life again.

An ability to find the courage to trust, to meet someone new,

To talk it all through, to share with them that you feel blue.

An ability to be vulnerable when less and less do,

To trust knowing they can use your words to hurt you.

An ability to persevere, to figure it out, sort out the mess inside,

To go out into the world when all you really want to do is hide.

An ability to generate a stunning smile, for even a stranger,

when a moment ago you were dying inside, tears falling down your face,  
the panic triggered by each interaction a sign of danger.

An ability to choose life, self-care, to take the medicine,

go to the peer support groups and not feel out of place.

An ability to continue to put one foot in front of the other,

even when you feel so anxious you just threw up in the bushes,

and to walk through the door with only a smile on your face,

to speak up and out when you're used to being belittled by shushes.

An ability to listen to someone tell you every day of your formative years,

how worthless they think you are, yet having the courage to keep uncovering how you are lovable,  
despite the lies you were fed, that screwed up your head, left you in tears, almost half-dead.

## 11. Waiting Room

Emma Hewitt

Bright colours on crumbling walls  
Bedecked with children's feet-finger scribbles  
Tacked on  
Clashing colours joyfully enfold allergy notices  
And pictures of shingles, sun cancer and sores  
Waiting, waiting, we are waiting here again

Cheerful germ monsters dance on posters  
Singing: "Wash your hands  
Or else  
*We will get you!*"  
Beneath the sanitation stations  
Waiting, waiting, we are waiting here again

Heat stuffs the air  
Nurse says: "We cannot afford such luxuries  
On the NHS  
As air conditioning and smiles."  
These are saved up and used sparingly  
In treatment rooms and surgery  
Waiting, waiting, we are waiting here again

Chatter children; wall of sound,  
Smother the beeping of machines  
Glue, paper, sticks and craft nestle on a jigsaw table



The children huddle round often encircled  
By machine trollies and salient tubes  
Into which they are  
Plugged in  
Waiting, waiting, we are waiting here again

The blinded windows dissect the light  
Protecting us from nosey passers by  
Cloistering us in safe stuffy lines  
Fake parental cheer fades as time passes  
Hypnotised into trance like boredom  
Waiting, waiting we are waiting here

Until  
We aren't  
When what is worse than waiting  
Is what comes next.

## 12. Where's Your Carer?

Emma Steer

Despite it being late afternoon I found myself sweating in the relentless heat of the midsummer sun as I waited for the bus home. There was only myself and one other person in line. I was dressed in stuffy formal clothes having just come from a job interview, and the stranger was wearing grubby clothes that indicated he had been working on the nearby building site. We were at opposite ends of the bus shelter ignoring each other's presence by looking at our phones, as is British custom. The bus arrived on time and I was delighted to see that the wheelchair space was completely empty, as the next bus wasn't due for another half an hour.

The doors of the bus hissed open and the driver, having already spotted the wheelchair, immediately climbed out of his cabin to pull the ramp out. He then asked the other person at the bus stop for two adult tickets. Despite us being spaced apart and dressed completely differently, obviously the stranger was my carer as I couldn't possibly be alone. In all fairness to the bus driver once I had cleared up the confusion he was suitably embarrassed, and very apologetic. However, this is far from the only occasion on which I have encountered this presumption.

It is not uncommon for me to visit the doctor's on my own, as after seven and a half years of chronic illness I am more than used to dealing with medical matters. The surgery is split over two floors, with the entrance on a mezzanine between the two. No staff are on this floor, just a touchscreen where you sign in and are told where to go. The lift is a temperamental platform lift with manually operated doors, the only problem being that once inside the lift there is no way of shutting the door behind you. Of course, when the door invariably fails to shut properly behind me the lift won't budge, leaving me stuck between floors. I regularly have to wait for a kind passer-by to push the door shut behind me.

Naturally I raised this with the members of staff as an issue, but no one seemed to see why this was a problem as they all thought I should have someone with me. I explained that I don't receive financial support for care, that my partner was at work, and that my family lived in Bradford. They shrugged and said I should leave extra time for someone to pass by so that I wouldn't be late to my appointment. When I explained that I was also in employment so didn't have time to spare, and that I wasn't paid for any time off I had to take, they were utterly flabbergasted but could offer no solution. Instead they reminded me how much it would cost to have the magnetic clamp on the lift door that was causing the issue fixed, and how tight NHS budgets were. They were equally perturbed when I then asked if one of the receptionists could close the lift door behind me so that I could go home, but they begrudgingly complied when they noticed the entire waiting room staring at them expectantly.

When visiting bars and cafes I have had staff ask the person behind me in the queue what we wanted, and on one occasion this also happened at the bank. Given that I tend to visit the same locations this has become less of a problem with time, as staff are now used to seeing me on my own, but I encounter similar reactions from members of the public. Often I will be referred to in the third person which is incredibly awkward and comfortable, both for me and the person unlucky enough to be in my vicinity who was assumed to be my carer.

The expectation for disabled people to always be with a carer doesn't just affect me when I'm out on my own. As couples are wont to do, my partner and I will often go out together. Unfortunately, because he is bipedal and I am distinctly not, he is automatically assumed to be my carer. Any kind of

display of affection such as holding hands, or even a familiarity in the way we talk to each other, leaves him exposed to some horrified stares. It saddens me that people assume disability means someone cannot form meaningful relationships with others, or that we are unlovable. It also infuriates me that people presume my partner to be taking advantage of some kind of vulnerability on my part.

Similar things happen when out with friends, colleagues, and family members. While it is true that they often assist me with doors, reaching things, and clearing a path for the wheelchair, they are not my carers. In exactly the same way women have had to fight for their independence and recognition of their individuality from husbands and fathers, disabled people face a similar battle.

Some disabled people need a carer and that is absolutely fine. Some disabled people don't need a carer, and that is also absolutely fine. Independence is something that should be encouraged in disabled people but not forced upon them. There is a possibility that some people will take this argument too far and refuse to help someone who is disabled, even if they specifically ask for help. No one should ever have to face something alone that will put them at risk, where a little assistance would prevent disaster. There is a balance between complete dependence and independence that will vary from person to person, and case to case. That said, I would be happy never to be on the receiving end of the question "Where's your carer?" ever again.

## About our Authors

Leonora Gunn, *All the King's Men*

Leonora (Leo) Gunn is doing an MA in Philosophy at the University of Leeds, with an interest in the philosophy of disability. She is one of two Deputy Chairs of Leeds Disabled People's Organisation, and is currently working with the Chronic Illness Inclusion Project.

Jonathan Eyre, *Benefits*

Jonathan Eyre – 'an absent poet' – has appeared at the Glastonbury Festival, published ten poems about the chronic illness M.E., and performs irregularly at open mics and poetry nights, engaging audiences with his poetry of participation, word jumbling and insight. "He speaks the truth!"

Gill Crawshaw, *Changing museums – and society – through touch*

Gill Crawshaw has been involved in the disabled people's movement for many years and now brings her experience of activism to curating. Gill recently curated two exhibitions of textile-based work by disabled artists in Leeds, where she is based: *The Reality of Small Differences* (2014), and *Shoddy* (2016). You can read about *Shoddy* here: <https://shoddyexhibition.wordpress.com/>

Mark Wilson, *Depression takes hold*

Mark lives with Parkinson's and has recently released a book of poetry called 'Hostage To The Mind', which is available on Amazon. You can read more of Mark's work here:

<https://www.facebook.com/parkinsonsat40/>

Jessica Wing, *gaia*

Jessica received her late diagnosis of autism while studying for her undergraduate degree in English Literature at Cambridge University. There, she became her student union's Disabled Students' Officer and upon graduation started working in the disability sector. She is now studying for her MA in Disability Studies at Leeds University. She can be found on Twitter @andiached.

F.R. Kesby, *Getting Clean*

F.R. Kesby is a political and feminist poet and writer from Leeds. She writes for [womensrepublic.net](http://womensrepublic.net), [fatfashionfaes.wordpress.com](http://fatfashionfaes.wordpress.com), her own blog [fayKesby.wordpress.com](http://fayKesby.wordpress.com) and is the current chair of The Leeds Savage Club. When not writing she likes to obsess over 70s glam rock and Doctor Who plot holes.

P.B. O’Dea, *Misconceptions*

I moved to Leeds from the Republic of Ireland originally to study the MA in Disability Studies at the University of Leeds. Since then I have helped found Leeds Disabled People’s Organisation (LDPO), and I am currently serving as one of two Deputy Chairs of LDPO. You can see more of my work here: <https://www.facebook.com/writerodeaauthorofmadness/>

Mostafa Attia, *My lived experience of ‘disabling barriers across borders’*

Mostafa Attia is a disabled activist from Egypt, currently completing his PhD at the School of Sociology and Social Policy at the University of Leeds. His research focuses on the Egyptian revolution, global development, and disability politics in Egypt. Mostafa has been involved in policy-making at the international level and in Egypt with the goal of promoting disabled people’s inclusive rights.

Rosamund McCullain, *The Alchemist*

Originally from Bradford, Rosamund has lived in Mid-Wales since 1983. Her poetry is predominantly about the inner landscape; she writes to preserve her sanity.

Emma Roberts, *They call it Disability*

Emma Roberts is a creative mother who likes to write and perform. Both she and her son, who she cares for full-time, are neurodiverse. She lives with PTSD, Panic Disorder and Anxiety, and is keen to reduce ableism. You can find her on Instagram @plantpoweredprincess18 and at her new blog, “The Neurodiverse Mum”: <https://medium.com/@NDmum>

Emma Hewitt, *Waiting Room*

I live in Leeds and I am a full time carer for my disabled son. I am disabled myself so my son and I spend a lot of time in what Dr Seuss calls “the worst place, the waiting place”. If we’re lucky there’s a good book or music to hide in and often writing helps.

Emma Steer, *Where’s Your Carer?*

Emma has her own blog, Diary of a Disabled Person, where she writes about anything and everything relating to disability, both good and bad. You can find it here: [www.diaryofadisabledperson.blog](http://www.diaryofadisabledperson.blog). Find her on Facebook @DiaryofaDisabledPerson, Instagram @diaryofadisabledperson, and Twitter @WheelsofSteer.