

THE PROTAGONIST
STUDENT ACADEMIC JOURNAL

ISSUE 2:

DIS ABILITY

WITH A SPECIAL INTRODUCTION BY JO BEAR

**Edited by Nathalie Lamprecht, Kateryna Trompak, Klára Witzany
Hutková and Marie Gemrichová**



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Graphic Design: Kateřina Kubišová



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Note from Editor

The second issue is always harder than the first. This is what we were told once we had published *Issue 1: Transnationalism*. In many ways, this proved to be true. In others, everything was much easier this time around. A big part of the reason why was the supportive atmosphere we worked in—everyone on the editorial team, our social media manager, our advisory board and, most importantly, our contributors were willing to give up their already limited free time to work on this project, which has grown so close to all our hearts. *Issue 2: Dis/ability* is particularly special, not only because it showed us that we could produce a second issue, but because it is full of important contributions to the field of disability studies. Following an insightful introduction by disability scholar Jo Bear are articles on fiction, form, and life writing, as well as deeply personal contributions from poets who graciously allowed us to collaborate with them to contextualise their work as best we could. A very special addition to our journal comes from Czech photographer Milan Roubal, who allowed us the use of his photography for both the cover and the inside of the journal, for which we are particularly grateful. Finally, in our review section, we have insights into representations of dis/ability on stage and screen, highlighting once again the range of areas a dis/ability studies lens can benefit. Overall, we are proud of the diverse and—thanks to our graphic designer Kateřina Kubišová—beautiful issue that we have created, and we hope that you enjoy reading it as much as we enjoyed making it.

Nathalie Lamprecht
February 2024

A note on our Photographer

Milan Roubal turned 45 on January 5th, meaning that he has been a Capricorn with a Scorpio Ascendant for almost half a century. In his own words, this is crucial as he is fascinated by his horoscope and the “game of stars” that has thrown him into many dramatic challenges throughout his life with stories that could fill a book.

The last of his major challenges forced him to settle down quite literally after a rather exuberant life. Eight years ago, while in the Italian Alps, Milan somersaulted from a trail bike and broke his neck. He ended up in an electric wheelchair with total paralysis, thankfully with partially mobile arms. All his life he has had creative inclinations, mainly making a living from crafts, and, thanks to current digital technologies, he continues to do so—through photography. It has become a hobby and a love through which he has investigated his own soul and, in the end, found his livelihood. Milan prefers to photograph situated scenes—pictures that convey a story and a deeper thought to the viewers.

Because of his passion he often turns to the nude, finding the human body beautiful in its full nudity. These particular pictures were not selected for our issue; however, they can be found on his website (<https://www.milanroubal.cz/>) or Instagram (<https://www.instagram.com/fotojetoto>). Milan also often takes the path of photographic documentary—one being his successful project called *Symbiosis*, which captures the coexistence of a person in a wheelchair with their assistant. Milan himself is always looking for assistants in his everyday life and readers, ideally those interested in studio photography adventure, are welcome to contact him.

transl.
Marie Gernrichová

Introduction

As I write this introduction, we are anticipating snow in so-called Pennsylvania here on Turtle Island, the land that many know as the United States. Snow removal is, of course, a disability justice issue as many disabled people are kept isolated while our roads and sidewalks remain hazardous for mobility aids and unsteady gaits. I am thinking of snow in the context of our shared climate emergency and how it is being brought to bear on the Global South by the white supremacy and colonialism of the Global North. I am thinking too of the most recent Israeli siege on occupied Palestine and the genocide the people of Gaza are experiencing as they move into the ongoing winter of the COVID-19 pandemic with no access to vaccines or adequate medical care.¹ This is the weather into which this issue emerges.

As Sins Invalid, a disability justice performance project “centralizing artists of color and LGBTQ/gender-variant artists”² reminds us in their “10 Principles of Disability Justice,” “Before the massive colonial project of Western European expansion,

¹ Buttu, “COVID-19 vaccinations.”

² Sins Invalid, “Mission & Vision.”

we understood the nature of interdependence within our communities. We see the liberation of all living systems and the land as integral to the liberation of our own communities, as we all share one planet.”³ It is this specificity of individual experience across shared imagining that makes the “yet to be”⁴ of disability justice possible. There is no disability justice without international coalition-building and without recognizing the vital contraction between what we know of each other’s histories and what we have yet to learn. This project is a necessary part of that process. After all, ours is never the only weather.

It is a great honor to be in conversation with the scholars and writers assembled in this journal and with the ways their pieces frame anew many of the pressing questions and tensions of this evergreen moment. The representations of disability they explore are thorny, multifaceted, and, of course, provide no easy answers. These are matters of the bodymind-texts that traverse geography, crip time and propose the possibility of breaking open convention and normativity to embrace

³ Sins Invalid, “10 Principles.”

⁴ Sins Invalid, “10 Principles.”

disabled hybridity. What does disability mean? What are the stakes of identifying with or feeling kinship alongside that label? How do experimental forms offer the potential of mobilizing against cure and normativity? How are disabled people disappeared from imaginings of nationhood and what does that mean in light of the eugenic history of the nation state? How do disabled and crip poetics involve and conceptualize the bodymind on the page? What are a parent’s responsibilities in terms of mobilizing change within an educational institution to better anticipate their disabled child? I feel deeply grateful to have been approached to be a part of this ongoing dialogue and to work alongside my fellow scholars in tending this bounty. Writing about and into disability is always an act of recognizing both abundance and absence. I encourage readers to interrogate those elisions and to ask their own questions in service of continuing to build our collective knowledge and solidarity.

My abiding gratitude goes to the entire *Protagonist*

team for their receptiveness and their generosity in making this issue a reality. The rigorous care with which they have met each piece is exemplary and has been a joy to witness. It is my hope that this is the first of many such entries into this ongoing dialogue. We begin here with the oncoming snow and the shared work ahead.

Onwards.

Jo Bear
January 2024

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SECTION 1

LITERARY REPRESENTATIONS OF

DISABILITY



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Making the Invisible Visible: The Interdependence of Invisibility and Disability in *The Secret Garden*

Carina Goißer, University of Vienna

Introduction

Although the concepts of disability and invisibility have received general attention in academic research, the main focus so far has been on invisible disabilities, meaning bodily or mental impairments that are not discernible to the outside world. That is to say, the degree of perception of a particular disability is linked to (in-)visibility.¹ The notion of invisibility has, however, also been taken up by researchers advocating for a more authentic depiction of disability in different literary genres and media. In particular, they criticise the lack of media representation of disability, as well as its common and unquestioned treatment as an exclusively medical issue.² In this respect, invisibility remains connected to a visual absence of disabled people altogether. However, there seems to be a scarcity of research on the relation of disability and invisibility in terms of socially created constructs. Increasing research suggests interpreting disability as a social construction rather than an inevitable consequence of physical or mental impairments.³ Yet, invisibility as a social construct has been insufficiently explored to this day. For these reasons, the aim of this article is to delve into the recurring concept of invisibility in Frances Hodgson Burnett's 1911 novel *The Secret Garden*, and to reveal its effect on representations of disability. The analysis, consisting of a close reading of a few selected scenes, seeks to specifically deal with the following research question: How does the recurrent concept of invisibility in *The Secret Garden* shape and affect representations of disability with regard to the novel's protagonist Mary and her cousin Colin?

For the purpose of this analysis, a social-constructionist approach is adopted and both characters

will be assumed to be disabled. Indeed, due to being surrounded by people who treat him as if he has a crooked back just like his father, Colin internalizes this belief and is convinced of being severely restricted in mobility. Mary, although not physically or mentally disabled as such, shows signs of emotional neglect, which have caused her to behave oddly in social situations and makes her appear contrary. People around her perceive Mary as other and make her feel like she does not comply with the norm that would be expected of a typical child in terms of behaviour, appearance, and attitude. This in turn renders her an outsider, like Colin. The main aim of this article is to show that invisibility is a construct that is closely connected to how a character is presented with regard to disability. The analysis will be guided by the hypothesis that the less disabled Mary and Colin are depicted, the more visible they seem to be to the household servants, as well as to Colin's father.

The first section of the article will provide the theoretical framework, while the ensuing sections are devoted to the interpretative analysis of Mary and Colin, respectively. It needs to be noted that the article is based on a specific and narrow focus and is limited in scope, which is why the role of British Colonialism in the novel is deliberately excluded. Lastly, the article concludes with a discussion of the research question.

Approaching Invisibility and Disability

While there is a comparatively clear answer to what invisibility is, disability seems to engender a lively debate as to what exactly is meant by it. The former can most basically be defined as the state of not being seen, recognised, or perceived. In this

visual sense, invisibility is absolute indiscernibility of objects and points in another person's perceptual field.⁴ Invisibility can, of course, also be applied to living beings, as they can literally be prevented from being seen by deliberately hiding them from the eyes of others.⁵ However, for the purpose of this article, invisibility may also be interpreted on a social basis, meaning that the term is strongly associated with any individuals that deviate, in whatever form, from the norms of society. According to Herzog, invisibility then becomes a "socially created capacity 'to look through' the other even when physically present."⁶ He elaborates that this form of invisibilisation, of being rendered invisible by deliberate will and corresponding behaviour, tends to overlook the complexity of human beings and primarily occurs with marginalised, stigmatised, and socially vulnerable groups.⁷ This is the line of argument that is of most interest when analysing the novel. Taking a constructionist approach into account, invisibility will be treated as a social construct in this article.

Closely connected to the constructionist perspective on invisibility is the notion of disability as a socially created and accepted construct.⁸ This article explicitly refrains from providing a comprehensive overview of the myriad of definitions that circulate around the concept of disability. Instead, the focus is placed on Critical Disability Theory and its view of disability as a social construct. As claimed by Hosking, there is a balance of factors equally contributing to disability, namely impairment (physical level), personal reactions to the impairment (individual level) and environmentally caused barriers (social level).⁹ Hence, disability is differentiated from the actual impairment of a person, which lends itself very well to this analysis.

The approach further mirrors the bio-psycho-social model the International Classification of Functioning, Disability and Health (ICF) suggested as a response to the incompleteness of previous models. In models such as the medical and the rehabilitation model, disability is treated as a disease and defective condition that has to be healed or repaired.¹⁰ In contrast, the bio-psycho-social model does take the medical aspect into consideration but attempts to concentrate more on disability as a social, as well as a cultural construction.¹¹ Disability is primarily perceived as a form of experienced restriction caused by society.¹² Yet, the social environment is not the only factor involved in constructing disability, but so is the culture that determines what is "normal" and accepted. Both disability and invisibility are therefore regarded as socially and culturally created constructs. As Honneth puts it: "The 'making visible' of a person," then requires that "the person is noticed affirmatively in the manner appropriate to the relationship in question."¹³ It is not just about visually perceiving a person but actively setting actions and displaying behaviours that affirm the presence of a fellow human being. Those actions and behaviours, in turn, are shaped by different underlying attitudes towards disability, and can either help visibilise or invisibilise disabled people.

For the purpose of this analysis, Mary and Colin are both treated as displaying some kind of disability, even though neither of them does in fact have an actual impairment. It is this circumstance that foregrounds the power and influence of the social environment on the construction of disability and invisibility in the novel.

Introducing Mary

Burnett introduces Mary as the "most disagreeable-looking child ever seen" with a "little

¹ Ann Davis, "Invisible Disability," *Ethics* 116, no. 1 (2005): 154.

² Leslie Fiedler, "Pity and Fear: Images of the Disabled in Literature and the Popular Arts," *Salmagundi* no. 57 (1982): 59–60.

³ Gareth Williams, "Theorizing Disability," in *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 125.

⁴ Axel Honneth, "Recognition Invisibility: On The Epistemology Of 'Recognition'," *Aristotelian Society Supplementary* 75, no. 1 (2001): 112.

⁵ Benno Herzog, "Invisibilization and Silencing as an Ethical and Sociological Challenge," *Social Epistemology* 32, no. 1 (2018): 18.

⁶ Herzog, "Invisibilization," 17.

⁷ Herzog, "Invisibilization," 17.

⁸ David Hosking, "Critical Disability Theory," A paper presented at the *4th Biennial Disability Studies Conference* at Lancaster University, UK (Lancaster University, 2008), 7, https://www.lancaster.ac.uk/fass/events/disability-conference_archive/2008/papers/hosking2008.pdf.

⁹ Hosking, "Critical Disability Theory," 7.

¹⁰ Edward Brandt, Andrew MacPherson Pope, and Institute of Medicine (U.S.), *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* (Washington, D.C.: National Academy Press, 1997), 64.

¹¹ Maria Berghs, Karl Atkin, Hilary Graham, Chris Hatton, and Carol Thomas, "Implications for Public Health Research of Models and Theories of Disability: A Scoping Study and Evidence Synthesis," *Public Health Research* 4, no. 8 (2016): 38; Hosking, "Critical Disability Theory," 8.

¹² Berghs et al., "Implications," 25; Lennard Davis, "Crips strike back. The Rise of Disability Studies," *American Literary History* 11, no. 3 (1999): 507.

¹³ Honneth, "Recognition," 115.

thin face and a little thin body, thin light hair and a sour expression.”¹⁴ From the very beginning, she is portrayed in an extremely unfavourable manner. The readers learn that she has been unwanted since birth, because her mother wanted to remain childless. Mary was always “kept out of the way,”¹⁵ and solely accompanied by her servants. It already becomes clear from these introductory lines that the little girl has never been truly looked at but only looked through her whole life.¹⁶ Although she always got her will and everyone around had to please her, she was never affirmatively recognised as a human being in her own right. Intriguingly, Herzog argues that “this ‘looking through’ is more likely to occur with people of lower social status”.¹⁷ Mary actually comes from a rich family and therefore has a high social status. However, the statement makes sense if read it in the context of Mary being marginalised within her own family structure. While she does not have an impairment as such, Mary obviously experiences emotional neglect, which causes her not to be properly socialised and leaves her unable to connect with other people. It makes her a “tyrannical and selfish [...] little pig,”¹⁸ who is even forgotten when the cholera takes almost all the lives in her estate.¹⁹ It can be argued that this lack of proper socialisation is what makes the girl appear disabled and adds to the reason why people throughout her life have deliberately overlooked her and effectively made her invisible. Due to constant parental neglect, Mary started to develop certain patterns of behaviour, which eventually earned her the nickname Mistress Mary Quite Contrary. This contrariness, however, can be seen as being grounded in an impairment, provided that the lack of affection and its impact on Mary’s socio-emotional development are interpreted as a form of disability. By applying the concept of disability to Mary, it gradually becomes apparent that it is the

environment that excludes her and actively constructs her invisibility. Here, the emotional neglect causes Mary’s invisibility, which can in turn be equated to a form of disability.

When Mary arrives in England, she seems even more disconnected from her surroundings, as evident in the narrator’s observation that “Mistress Mary arrived at Misselthwaite Manor and she had perhaps never felt quite so contrary in all her life.”²⁰ This feeling is reinforced by the conduct of the servants who want Mary to behave as unobtrusively as possible and therefore, again, keep her out of sight. She is right away told that she should not “expect that there will be people to talk to.”²¹ This is reminiscent of her childhood days in India. The social environment contributes to this process of invisibilisation, which constructs Mary as an outsider.

Moreover, Critical Disability Theory explicitly points to the fact that disability is largely determined not only by social factors but also by cultural environment.²² This becomes most apparent when, after Mary asks who will dress her and Martha, the housemaid exclaims “Canna’ tha’ dress thysen!”²³ Back in India, the fact that she cannot dress herself would not have made her appear queer in any way, because it was simply acceptable behaviour. Mary even addresses this directly with the words “[i]t is different in India.”²⁴ The English culture, on the other hand, expects a certain degree of independence from children at age ten. In this respect, Mary can be interpreted as disabled, and this perceived disability is constructed through the difference of cultural norms. The label “disabled” is imposed on her, which highlights its social and cultural constructedness.

The key scene where Mary is, for the first time, actively needed and therefore looked at, is when her cousin is experiencing a tantrum and cannot be calmed.

The servants turn to her in the hope that she will have an impact on him. From this moment on, Mary’s invisibility successively lessens. This is especially reflected in bodily changes. She puts on weight, her skin colour becomes brighter and rosy, and she also learns to appreciate her meals.²⁵ Mary adopts a more positive view on life in general and takes notice of it. Presumably unintentionally, she uses a metaphor to describe this change: “The grass is greener and things are sticking up everywhere and things are uncurling and green buds of leaves are showing.”²⁶ This seems to be not only about the garden but also about her transformation.

Mary is actively recognised by others, whereby Colin, as well as Martha and Dickon, Martha’s twelve-year-old animal-loving brother, play a vital role in deconstructing her invisibility and thus her perceived disability. In the course of the novel, Mary begins to explore her surroundings and successively opens up and enjoys herself. She is, in a way, able to overcome what previously disabled her. People cease to construct her as being disabled and instead refer to her as “a sort of blessing,”²⁷ thereby focusing on her improving conduct and character. Especially due to Colin’s insisting on seeing Mary on a regular basis, he is a key factor in her increased visibility. The way the environment responds to Mary simultaneously allows for the interpretation that the reason for her outsider status is not grounded in an impairment, but rather, to a large extent, in invisibility as a social construct. Assuming that, in Mary’s case, the impairment is a lack of socio-emotional skills, it is the social and cultural environment which construct her as disabled and, therefore, invisible.

Meeting Colin

The readers only learn about Colin because of Mary’s persistence to discover the reason for the cries she hears time and again. Quite some efforts were

made to hide him from the rest of the world. This is shockingly evident in the fact that the only way to his room leads through a tapestry door. Deliberately neglected by his father, who cannot bear to look at him because of the fear that his son will develop a hunchback like him, Colin has been confined to his room since early childhood. He has no contact with the outside world, except with his servants, who have received the strict instruction to refrain from talking about him.²⁸ Although everybody seemingly knows of his existence, he is concealed and overlooked. Colin, a slim, sharp-faced, and ill-looking boy, is strongly convinced that he “shall have a hunch on [his] back and then [he] shall die.”²⁹ The physical impairment he describes excludes and separates him from society. At this point, a parallel can be drawn to Mary’s experiences. Colin, too, is rendered invisible by the behaviour and responses of his social environment. The reason for doing so seems to be the wrong conviction regarding his physical impairment. Since all Colin ever hears is that he will soon die, he eventually starts to internalise this firm belief and becomes “accustomed to the idea.”³⁰ Cameron argues that “[t]he meaning attributed to impairment profoundly determines the sense that can be made of the experience of living with impairment.”³¹ As for Colin, he attaches too much weight to what others say about his alleged illness, which results in his moodiness. He is described as being fretful, passive, weak, miserable, and dependent—all negative stereotypes associated with the portrayal of disability in the early 20th up until the 21st century.³² These perceptions serve to construct Colin’s disability and even his impairment, which is, in fact, non-existent.

Speaking on a meta level, the novel contributes to a discourse on disability, whereby the only character that displays an actual impairment is Colin’s father. This reinforces the perspective of this article to interpret disability as a socially fuelled construction

¹⁴ Frances Hodgson Burnett, *The Secret Garden* (South Caroline, USA: CreateSpace Independent Publishing Platform, 2013), 5.

¹⁵ Burnett, *The Secret Garden*, 5.

¹⁶ Herzog, “Invisibilization,” 17.

¹⁷ Herzog, “Invisibilization,” 17.

¹⁸ Burnett, *The Secret Garden*, 6.

¹⁹ Burnett, *The Secret Garden*, 6.

²⁰ Burnett, *The Secret Garden*, 15.

²¹ Burnett, *The Secret Garden*, 12.

²² Berghs et al., “Implications,” 38.

²³ Burnett, *The Secret Garden*, 16.

²⁴ Burnett, *The Secret Garden*, 17.

²⁵ Burnett, *The Secret Garden*, 42.

²⁶ Burnett, *The Secret Garden*, 78.

²⁷ Burnett, *The Secret Garden*, 76.

²⁸ Burnett, *The Secret Garden*, 64.

²⁹ Burnett, *The Secret Garden*, 89.

³⁰ Burnett, *The Secret Garden*, 65.

³¹ Colin Cameron, “Impairment,” in *Disability Studies: A Student’s Guide*, ed. Colin Cameron (London: Sage Publications, 2014), 77.

³² Alexandra Valint, “‘Wheel Me Over There!’: Disability and Colin’s Wheelchair in *The Secret Garden*,” *Children’s Literature Association Quarterly* 41 (2016): 263.

that can be imposed even on individuals who do not have impairments. Especially in Colin's case, disability is something that others repeatedly ascribe to him, which in turn results in a child that ceases to question his condition and instead wallows in self-pity and depression. Because of his hysterical behaviour and tantrums, he is quickly stigmatised. Goffman introduced the phrase "spoiled identity" in relation to stigma, which is seen as an attribute responsible for reducing a person "in others' minds from a whole and usual person to a tainted and discounted one."³³ Both Mary and Colin are repeatedly described as spoiled, which suggests a link between disability and their identities or character traits. Both are made invisible due to their otherness and supposed impairments. Here again, disability and invisibility are strongly inter-related as one is mutually dependent on the other.

Another aspect worth analysing is the novel's premise that disability can and needs to be overcome or cured. This holds especially true for Colin, who has been receiving medical treatment since birth. Brisenden challenges this model and points out that "medical treatment is in itself one of the most disabling factors about being disabled."³⁴ Colin is largely seen as disabled because of the medical interventions he has received since early childhood. The doctors considered it necessary to keep him in bed and move him around as little as possible in order not to aggravate his condition. As a result, his back muscles and limbs have become weak and his whole musculature is presumably shortened. His weak body is not a consequence of biological or inherited dispositions but, in this particular case, rather the result of unnecessary medical treatment. Colin's social environment, which is limited to the manor's service staff and his more or less absent father, is greatly involved in constructing him as disabled on the basis of an alleged impairment. Due to the fact that his father

has a crooked back, it is assumed that the boy must also develop back problems. Curiously enough, even his own father, who does have a physical disability, perpetuates this misbelief. From infancy onwards, he is put in a sick role, which, according to Green and Barnartt, equals the (still) widespread medical model of disability.³⁵ This perspective on disability is, in turn, associated with primarily passive, infantile, helpless, and even whiney behaviour. It can be argued that Colin is trapped in a vicious circle of external medical misconceptions and internal incapacitating beliefs, which he cannot escape on his own.

This is the point where Mary is given a vital role in de-constructing his state of invisibility. After having discovered Colin, Mary excitedly exclaims "I looked at him all the time and he looked at me. We stared!"³⁶ She is the first person that not only dares to look at him directly and without any fear, she also is the first one to doubt his disability. When he and Mary are having their first quarrel, Colin throws in that he is going to die soon anyway. Mary immediately counters this argument with the words "I don't believe it!"³⁷ A little later, she finally convinces him that most of his illness is created by his misbelief taken over from others, and instils courage and hope in him, most evidently in his tentative question: "Do you think—I could—live to grow up?"³⁸ Mary lays the ground for Colin to become visible again by explicitly telling him that she does not believe in his alleged crooked back and short life span.

In line with the rehabilitation model, Colin wants to overcome his disability. Intriguingly, he decides to hide his healing process. It can be argued that he imposes invisibility on himself because no one should see his progress until he decides otherwise. Valint observes that Colin "performs a 'helpless' and pained invalid body."³⁹ Colin almost stages his healing, and his progress is first only visible to Mary and Dickon. Eventually, when Colin is able to stand up and walk,

he is no longer portrayed as a childish, needy, and weak boy but as "strongly and steadily as any boy in Yorkshire," as "Master Colin."⁴⁰ Both his invisibility and disability are overcome, and he is positively and actively affirmed in his presence.⁴¹

Conclusion

In conclusion, the analysis demonstrates that invisibility is a recurrent concept in *The Secret Garden*, which is strongly associated with disability. Mary and Colin experience a state of invisibility, which is imposed on them by others. Invisibility is regarded as a social construct and, in the context of the novel, as a concomitant of disability. With reference to the research question, it can be concluded that invisibility affects representations of disability insofar as it reinforces negative depictions of Mary and Colin. This is discernible in the fact that both children are represented in a negative and unfavourable way. While Mary is introduced as socio-emotionally disabled, selfish, and contrary, which is probably to do with parental neglect, Colin is described as a weak, dependent, and choleric little boy, whose existence is concealed with all available means. A parallel can be drawn because, based on an alleged impairment, both are rendered invisible through the actions of the people around them. Especially in the case of Colin, the social environment actively constructs his disability and prevents him from participating in society. Disability has an effect on how visible Colin is to his environment. For these reasons, disability and visibility can be considered interdependent. The analysis suggests that the less disabled a character is perceived and portrayed, the more visible he or she is to the social environment.

⁴⁰ Burnett, *The Secret Garden*, 147.

⁴¹ Honneth, "Recognition," 115.

³³ Erwin Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Harmondsworth: Penguin Books, [1963] 1990), 12, quoted in Colin Cameron, "Stigma," in *Disability Studies: A Student's Guide*, ed. Colin Cameron (London: Sage Publications, 2014), 147.

³⁴ Simon Brisenden, "Independent Living and the Medical Model of Disability," in *The Disability Reader: Social Science Perspectives*, ed. Tom Shakespeare (Continuum: London, 2000), 25.

³⁵ Sara Green and Sharon Barnartt, "Introduction: A Historical Overview of Sociology Looking at Disability: What Did We Know and When Did We Know It?," in *Sociology Looking at Disability: What Did we Know and When Did we Know it?* ed. Sara Green and Sharon Barnartt (Bingley: Emerald Group PL, 2017), xviii.

³⁶ Burnett, *The Secret Garden*, 70.

³⁷ Burnett, *The Secret Garden*, 85.

³⁸ Burnett, *The Secret Garden*, 90.

³⁹ Valint, "Wheel Me Over There!" 273.

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Disability and the Potential of Experimental Forms

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Introduction: Anti-normative Bodyminds, Anti-normative Storytelling

When I began researching disability and illness memoirs, I realised there were plenty to pick from. I have never, in my recollection, been assigned such a memoir—or even an essay—during any of my degrees in creative writing. Many of the memoirs that I had read followed traditional structures—chronological order, chapters on self-contained topics, clear and precise narration. But my interest soon turned to more experimental and hybrid possibilities. When I discovered Sonya Huber’s *Pain Woman Takes Your Keys, and Other Essays from a Nervous System*, it offered a text full of unconventional craft choices, as the essays convey the confusing, draining, and painful experience of chronic illness and disability.

Alice Hall writes in *Literature and Disability* that since many recent works of disability life writing are closely aligned with activist aims, they challenge both the status quo and the conventions of the genre of life writing itself; these accounts often shift the focus from a view of auto/biography as an individualistic endeavour to create narratives that chart the recognition of a collective identity.⁴² And Sonya Huber writes in *Voice First: A Writer’s Manifesto* that “[i]n our rush to persuade, to figure out what we’re arguing for and against, to conform to audience expectations, to fall in line with the way others express themselves in well-established genres, we lose touch with the wild inventiveness of writing. And as we lose that wildness, we may also lose our writing’s power, because inventive text often works better than cookie-cutter text.”⁴³ Hall specifically identifies “activist objectives” as the motivation for challenging the established

norms of life writing, emphasising the importance of individual self-expression in literary works.⁴⁴ This craft consideration is both textual and extratextual; it reasons by wielding an interior logic of how the text operates with a sense of a real author’s goals for how the text will be received. Huber draws attention to a rationale for innovation: “wildness” (which can certainly align with structural and narrative variations on traditional memoirs) is connected to “power.”⁴⁵ And power is a tricky thing for marginalised writers to navigate, even when telling a narrative about their own lived experiences.

The “established genres” of memoir that Huber alludes to overall prioritise linear narratives of time, grammatically traditional expressions, and the prosaic over poetic. Experimental and hybrid styles, however, allow for more freedom to explore the particularities of disabled/ill experience outside of able-bodied, able-minded, and neurotypical norms, often through techniques such as nonlinear storytelling and poetic engagement with language. Formal innovation follows personal experiences that don’t necessarily cohere in culturally expected ways.

Many disability and illness memoirs follow the paths of traditional craft, which can help with legibility for a broader audience of both abled and disabled readers. *Blind Man’s Bluff* by James Tate Hill and *Deaf Utopia* by Nyle DiMarco, for example, are organized primarily chronologically and use grammatically traditional prosaic expressions. *Sick*, a memoir by Porochista Khakpour, does not have quite the same linear fidelity; Khakpour instead organises chapters/essays by place. However, the more traditional grammar, prose, and scene building are still intact. This

contrast between “traditional” and “experimental” can also be observed in two comparable memoirs that take different approaches. In *The Collected Schizophrenias*, for instance, Esmé Weijun Wang gives deep insight into the experiences of psychosis and hallucinations through a very clear voice, building more traditional literary scenes. However, Stephanie Heit, who also writes about mental illness, describes her work *Psych Murders* instead as “a book of hybrid memoir poems about my experiences of shock treatment, memory loss, psych hospitalizations, and bipolar extreme mind states.”⁴⁶

Anti-normative, here, is an expansive, multi-faceted term. Experimental form choices, for example, can be anti-normative. However, what is anti-normative can also apply in terms of who is centralised in narrative. In a cultural landscape where centralising an abled writer is normative, centralising a disabled writer can become anti-normative; this also holds true in whether writing adheres to the normative practice of focusing on a primarily abled audience, versus writing that is anti-normative in terms of its focus on a primarily disabled audience. Sarah Fawn Montgomery writes about how “[w]riting about ourselves is difficult enough as nonfiction writers, but disabled writers face the burden of contextualizing their lived experience for an audience that does not inhabit the same world—an audience that sometimes fears, hates, and polices disability.”⁴⁷ And in *Literature and Disability*, Hall discusses Anne Finger’s assessment that “[d]isability life writing is also often informed by conventional narrative scripts such as the triumphant recovery story or narrative of overcoming.”⁴⁸ If an abled audience is centred, a disabled writer comes up against the need to be “relatable,” to follow legible and familiar cultural narratives such as the seeking of cure (which has nuanced differences from seeking diagnosis/seeking answers), inspiration porn, and/or the inherent tragedy

of disability/disabled life. Experimental narratives can be an act of unnarrating cultural narratives.

Cultural Narratives & Documentation

In working toward empathy, experimental forms can convey disabled experiences on a deeper level. In this way, form can be used to enhance thematic explorations of these specific experiences. Huber writes that she “[f]ound support from other disabled writers, and the work they’d done to reframe disability as an insight-giving window into reality, rather than a deficit.”⁴⁹ Society frames people’s narratives. Disabled/ill people are often on the margins of that frame. When disabled/ill writers have the power to frame their own narratives, the stories change. The way disability and illness are discussed changes; the humanity assigned to disabled/ill people changes. This shift allows readers to alter their own mindsets, to see the specific opportunities where disabled/ill people have to provide insight into different realities.

Gwendolyn Paradise writes, for example, about how “[m]y hearing loss allows me to experience a reality that others do not.”⁵⁰ Rather than becoming narratives of deficit, these can become narratives of possibility. I explore such possibilities in my own writing. What happens when medical forms and communications are rewritten by the disabled/ill person they speak about?⁵¹ What happens when the literal script of a doctor’s visit where the patient is disregarded is penned instead by the patient?⁵² What happens when dictionaries—lexicons that codify us—are rewritten from disabled/ill perspectives?⁵³ What opportunities can playing around with these different authoritative forms have in eliciting the empathy of the reader when they come to know what we know?

Huber plays with this technique explicitly in *Pain Woman Takes Your Keys and Other Essays from a Nervous System*. For example, in “Alternative Pain Scale,” Huber rewrites the medical pain scale that

⁴⁶ Stephanie Heit, “Disability as a Creative Practice,” *Mad in America*, published March 17, 2023, <https://www.madinamerica.com/2023/03/disability-as-a-creative-practice/>.

⁴⁷ Sarah Fawn Montgomery, “(Dis)Ableing the Creative Writing Workshop,” *Essay Daily*, published September 9, 2019, <http://www.essaydaily.org/2019/09/sarah-fawn-montgomery-disableing.html>.

⁴⁸ Hall, “Disability Life Writing,” 132.

⁴⁹ Huber, *Voice First*, 4.

⁵⁰ Gwendolyn Paradise, “Sudden and Marvelous Invention: Hearing Impairment & Fabulist (non)Fiction,” *Uncanny Magazine*, published 2019, <https://www.uncannymagazine.com/article/sudden-and-marvelous-invention-hearing-impairment-fabulist-nonfiction/>.

⁵¹ Audrey T. Carroll, “The Pain Scale,” *Glassworks Magazine*, published October 1, 2023, <https://issuu.com/glassworksmagazine/docs/issue27>.

⁵² Audrey T. Carroll, “Script Doctor,” *F(r)iction*, 2024. Forthcoming publication.

⁵³ Audrey T. Carroll, *Parts of Speech: A Disabled Dictionary* (Alien Buddha Press), 2023, <https://alienbuddhapress.wordpress.com/2023/04/09/spotlight-parts-of-speech-a-disabled-dictionary-by-audrey-t-carroll/>.

⁴² Alice Hall, “Disability Life Writing,” in *Literature and Disability* (Milton Park, England: Routledge, 2016), 133.

⁴³ Sonya Huber, *Voice First: A Writer’s Manifesto* (Lincoln, Nebraska: University of Nebraska Press, 2022), 50.

⁴⁴ Hall, “Disability Life Writing,” 133.

⁴⁵ Huber, *Voice First*, 50.

oversimplifies pain into a number from one to ten, as though the specificities of each number are clear to every patient and/or medical professional in the same way, and as if pain is a universally-agreed-upon experience for every person in every body. Huber uses this to convey different sorts of pain—from being “[i]n a sort of grinding, background-noise, world-clenching box of pain just beneath the edge of my consciousness,”⁵⁴ to “[e]verything is so beautiful and precious because I might die soon. I love that lampshade so very much,”⁵⁵ to “[...] Words are hard. My name is... something? Whatever. ‘Name.’”⁵⁶ This scale, rather than going from one to ten, reaches twenty-one. Each level is extremely particular; Huber uses the memoiristic elements to narrate her pain at each very specific level, which highlights the absurdity of the “1–10” scale with no further explanation required.

In “Note,” a section of *My Body is a Book of Rules*, Elissa Washuta similarly co-opts something from the medical field. Here, the document is a letter from a psychiatrist, which is noted as being edited by Washuta. She also incorporates other forms throughout *My Body is a Book of Rules*; for example, after some more traditional prosaic preamble in “Please Him,” the essay turns into a side-by-side of religious commandments and questions from *Cosmo*. Similarly, Huber is not confined to simply one form—or even one experimental form—in her deviation from otherwise traditional narratives in *Pain Woman Takes Your Keys*. As a craft approach that will later be explored in Leah Lakshmi Piepzna-Samarasinha’s *Dirty River*, Huber’s essays, such as “From Inside the Egg,” turn into sections of poetry, lines broken and playing with marginal alignments.

In the essay “Even If You Can’t See It: Invisible Disability and Neurodiversity,” Sejal A. Shah takes documentation and hybridity in a slightly different direction. Instead of co-opting an established formal document and rewriting the script from a crippled⁵⁷ perspective, Shah makes use of end notes. In this way,

the essay blends scholarly elements with creative ones. Some of these end notes clarify intertextuality, such as with the incorporation of a lyric essay/flash fiction Shah herself wrote. Others are more critical, sourcing the disability community’s use of the term “Spoon Theory”⁵⁸ and texts like Margaret Price’s *Mad at School: Rhetorics of Mental Disability and Academic Life*. This kind of tracing to other genres, as well as critical thinking about disability, is perhaps especially helpful to an abled audience. Simultaneously the style of hybridity that relies on end notes allows the narrative to continue without necessarily disrupting one’s reading. It is therefore possible for a disabled reader who is, for instance, already familiar with Spoon Theory, to continue reading without pausing to examine the end note in its entirety. Or, alternatively, it could work as a way to welcome newer disabled/ill community members into the discourse without forcing them to do the research entirely on their own. This takes on a kind of community-building/mentorship aspect that may otherwise feel unavailable to newly disabled/ill people.

Disabled and chronically ill people are often assumed to be unable to tell their own stories, or not skilled enough to be up to the task. This assumption, while often not discussed in direct terms, is implicitly understood at the cultural level. It is obvious when people talk to caretakers as if disabled people are not present; it is obvious when medical professionals refuse to take patients seriously, or in legal and governmental contexts where loopholes enable institutions not to provide access to disabled people. Memoir, as a genre, is “[i]n direct dialogue with, and part of, social movements agitating for cultural and legal change,”⁵⁹ and can reflect this in dialogue of choices of form. Hybridity and awareness of techniques outside of the essay can inflect how memoir might take shape. This could lead to a combination of processes that includes the rewriting of medical documentation. Erasure, for instance, is a form most common in poetry, but can

easily be used in memoir as well. The process likely looks like trying to find truth—personal truth, or communal truth—in the document used as the basis for erasure. This can operate as an act of reclamation for a disabled/chronically ill writer if they take the opportunity to recontextualise medical, legal, and/or governmental documents. Such a formal choice causes many questions to arise without posing them directly in the text: What are the true effects of these documents? How do these documents affect the emotional lives of disabled and ill people? What do these documents really mean if you read between the lines? What is a disabled/ill person’s perspective on the coded language these documents use and how they impact disabled/ill people’s lives? Erasure of these particular documents is only one of many possibilities for the hybrid and experimental approach, but it does allow for one method of reclamation that disabled/ill writers can potentially leverage in.

Poetic Narration & Crip Time

The lyric essay, as a form, offers a strong opportunity to centre voice in all its rhythmic specificity. It is possibly the most common way to blend memoiristic elements with poetic elements. Zoë Bossiere and Erica Trabold write about the lyric essay in “Writing from the Margins: On the Origins and Development of the Lyric Essay,” that this form

[i]s fluid, able to occupy both marginal and centre spaces [...] uniquely suited to telling stories on the writer’s terms, without losing sight of where the writer comes from, and the audiences they are writing toward. When we tell the stories of our lives—especially when those stories challenge assumptions about who we are—it is an act of resistance.”⁶⁰

This fluidity allows the lyric essay to take the shape of the container of the writer’s experiences, “telling stories on the writer’s terms.” It grounds the voice in these lived experiences, asserting the writer’s right—

the disabled/ill person’s right—to tell their own story their own way. This is, as Bossiere and Trabold phrase it, an “act of resistance.” It is resistance against the notion that we are voiceless, resistance against the ableist assumptions of who we are and what we can do, and resistance against the dictation that disabled/ill stories need to be narrated in expected ways in order to be respected and listened to.

The last of these is something which disabled/ill people—as storytellers on and off the page—face every day. How we convey symptoms orally and bodily, for instance, dictates the care we receive and the respect we’re granted. Our stories are received in particular ways depending on our embodiments, especially in the sociocultural context of intersectional vectors of marginalization and oppression. In some ways, all disabled/ill people are storytellers in their own right, navigating audience expectations and genre constraints as we attempt to have our basic needs met. The lyric essay rejects this imposition of how we’re “allowed” to tell stories—clear narratives, simple language, straightforward chronologies—and leans into our poetic abilities at the same time.

At first glance, Leah Lakshmi Piepzna-Samarasinha’s “The Last Time I Went Home for Christmas” might be a narrative like any other.⁶¹ However, it is possible to see a lack of fidelity to linearity pretty early on, an expression of “crip time.” (Alison Kafer muses in *Feminist, Queer, Crip*, about how “[e]xploring disability in time also includes speculation on temporalities of disability: how might disability affect one’s orientation to time?”⁶²) The first sentence that Piepzna-Samarasinha writes in “The Last Time I Went Home for Christmas” is a result, a conclusion. The second paragraph is a rationale with a backstory. Then we get a line that sets the scene, a context, before Piepzna-Samarasinha’s age is given in the same paragraph as a retrospective voice (“now that I am no longer twenty-one”⁶³). After this opening establishes a kind of when and why (at the age twenty-

⁵⁴ Sonya Huber, *Pain Woman Takes Your Keys, and Other Essays from a Nervous System* (Lincoln, Nebraska: University of Nebraska, 2017), 155.

⁵⁵ Huber, *Pain Woman Takes Your Keys*, 156.

⁵⁶ Huber, *Pain Woman Takes Your Keys*, 157.

⁵⁷ See <https://cdsc.umn.edu/cds/terms> on the usage of the term “crip” and related vocabulary.

⁵⁸ For further information on “spoon theory,” see: <https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/>.

⁵⁹ Hall, “Disability Life Writing,” 133.

⁶⁰ Zoë Bossiere and Erica Trabold, “Writing From the Margins: On the Origins and Development of the Lyric Essay,” *Literary Hub*, published April 10, 2023, <https://lithub.com/writing-from-the-margins-on-the-origins-and-development-of-the-lyric-essay/>.

⁶¹ Leah Lakshmi Piepzna-Samarasinha, “The Last Time I Went Home for Christmas,” *Dirty River: A Queer Femme of Color Dreaming Her Way Home*, (Vancouver: Arsenal Pulp Press, 2016), chapter 11, Kindle.

⁶² Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: University of Indiana Press, 2013), 26.

⁶³ Piepzna-Samarasinha, *Dirty River*, chapter 11, Kindle.

one, at Christmas, because of lice and dreadlocks), Piepzna-Samarasinha moves into what she labels as *Story Version One*, which gives the two-years-prior context of the dreadlocks, a choice that includes having taken drugs first and immediate regret after. *Story Version One* provides broader cultural context, too, about appropriation. *Story Version Two* picks up at the end of the opening section, then reminisces on how it reminds Piepzna-Samarasinha of her childhood, of how the way her white mother treats her hair feels wrong to her, including a broader cultural context of anti-Blackness and speculative elements as to her mother's disappointment in her. This section ends in abrupt verse—line broken and with little capitalisation. The final section, labelled *Backstory*, returns to when Piepzna-Samarasinha is eleven or twelve, the first time she notices her hair is curly—each sentence is given its own line break, until eventually the chapter/essay ends on an italicised stanza that is even more heavily broken in lines.

Huber writes that “[v]oices broaden and strengthen and proliferate when they are heard, responded to, and encouraged, and they wither in self-protection and hunger when they aren't listened to. Or if they're ignored and dismissed, they learn to explode and boom to make some space.”⁶⁴ Again, leaning on a cross-genre knowledge with poetry, playing with space on the page can be a way to “take up space.” For the marginalized, this can be a very literal way to centre our identities, to break free of the sides of the pages that we have been relegated to, instead breathing where it feels sensical to us, or condensing in other places.

Mimesis & Audience

As Huber points out, “writing about something traumatic in a way that invites the reader into the experiences and adds reflection and meaning is extremely challenging.”⁶⁵ Some readers may feel, however fairly or unfairly, that reading about illness/disability is too sad or depressing. This may turn them off from reading these narratives altogether, which

⁶⁴ Huber, *Voice First*, 73.

⁶⁵ Huber, *Voice First*, 86.

⁶⁶ Huber, *Voice First*, 86.

⁶⁷ Hall, “Disability Life Writing,” 132.

undermines writers whose aim is to use their literature as a bridge between their own life experiences and abled people's life experiences. When our experiences are dismissed or ignored because they include unpleasantness, then writing risks its potential to engender empathy.

There is nuance here, certainly: as already mentioned, disabled/ill writers should not be beholden to the frameworks imposed on them by abled people. While this may not work for every reader (no technique does), there is a mimetic approach to consider here. Some brains, for a host of different reasons, process and/or produce narratives in fragments. This may turn into a text that is something like Piepzna-Samarasinha's “The Last Time I Went Home for Christmas,” to highlight a previous example. A fragmentary style of brain processing can be imitated on the page, though it is, to use Huber's language, “extremely challenging”⁶⁶ to have this be engaging to a reader, especially a reader who lacks first-hand experience with such a way of thinking. The choices for fragments can vary with sentence-to-sentence shifts, dipping back and forth in a timeline that seems out of order; changes from paragraph to paragraph in topics, following thoughts in seemingly random directions that make some kind of an associative sense as experienced by the writer. This can also ease the writing process for some disabled/ill writers, while removing the pressure of “conventional narrative scripts.”⁶⁷ Such relief may come through in the narrative fluidity of the text.

Conclusion

Experimental forms are by no means the only method that disabled writers have at their disposal. Strong narratives have been constructed about these topics in more traditional forms. It would do no good to say that we shouldn't pigeon-hole disabled/ill writers into what is considered a more traditional style of writing, because they should instead be pigeon-holed into this other style of writing. In part, some of the discussion of possibilities here is born of my

personal affinity for queering narrative, for seeing the ways that we might be able to disrupt and generate in innovative processes. But it is worth exploring why disabled/ill writers may opt for an approach that may seem unexpected. The expected has rarely, if ever, served the disabled and the ill; sometimes, working outside of the expected seems like the most productive way to take up space, to make our voices heard, and to reclaim the stories that we've been dissuaded from sharing for so long.



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“But we are here”: Life Writing, Disability, and the Importance of Representation

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Introduction

While questions of identity and the genre of life writing have been important to the Irish literary scene for decades,⁶⁸ in recent years there has been a notable boom in life writing, often in essay form. Like most other literary genres, during the twentieth century, autobiographical writing was male dominated. In contrast, today it is women who are at the forefront of publishing memoirs, autofiction, collections of personal essays and other forms of life writing in Ireland. Examples of this trend include Emilie Pine’s *Notes to Self* (2018), Sinéad Gleeson’s *Constellations* (2019), Úna-Minh Kavanagh’s *Anseo* (2019), *Nanny, Ma and me* (2021) by Jade Jordan, co-authored with her mother and grandmother and, last but not least, the subject of this article, *Unsettled* (2021) by Rosaleen McDonagh. If, as Nicholas Allen claims, “to tell the story of the self is to write the narrative of Ireland,”⁶⁹ then female authors especially have every reason to write their own stories. Indeed, earlier autobiographies contributed to the normalisation of a certain image of Ireland, one that was mainly able-bodied, white, and patriarchal, leaving little space for other identities and lived realities within the cultural landscape of the island. Thus, it is noteworthy that several of the autobiographers mentioned above are not only marginalised due to their gender identities, but in fact face double marginalisation, be it because they are women of colour, members of the Traveller community, or disabled. Any analysis of their writing must accordingly be based on an intersectional approach, considering the various ways in which these women fit uneasily into preconceived notions of Ireland and its inhabitants. By

writing their own life stories, they help to portray Ireland as the multi-faceted place that it is, rather than the white Catholic monolith that some may still want to believe it to be.

This article will first provide a brief overview of the meaning of life writing in an Irish context. It will then address one exemplary text, namely, as mentioned above, Rosaleen McDonagh’s *Unsettled*, paying particular attention to the intersections of gender, ethnicity, and disability in the work. Through this focus, the article will attempt to draw conclusions on what can be learned from this autobiographical work about the importance of representation and the construction of identity in Irish life writing.

Writing the Self into the Narrative of the Nation

Life writing in its many forms has a long tradition within Ireland’s cultural landscape. Before the Republic gained independence, autobiography specifically was perceived as a vital tool in the nationalist struggle, one that could enable the creation of an Irish national identity that was separate from Great Britain. Later, autobiography began to be an important tool for the portrayal of “hidden Irelands,”⁷⁰ meaning voices that did not fit into the newly established state’s vision of itself. Indeed, “[a]utobiography’s potential not only to represent but to be representative,”⁷¹ as Claire Lynch calls it, makes it an ideal instrument for challenging accepted notions of Irish national identity. In both classical autobiography and other forms of autobiographical writing, such as personal essays, authors can explore their own sense of self and negotiate it with their surroundings. Indeed, Lynch argues that while

“identity is by its very nature ephemeral,”⁷² it tends to “manifest in physical form such as [...] personal writing.”⁷³ Therefore, it is through the telling of life stories that the overall image of Ireland may be augmented. Indeed, today national identity is no longer the focus of most autobiographical works; yet, for many authors, life writing is still a powerful tool when it comes to negotiating their own relationship to the country and their circumstances. Accordingly, by facilitating the production of autobiographical texts by a wide variety of writers, a more open, fluid, and therefore truthful image of Ireland may be created.

George O’Brien notes that oftentimes “[t]he autobiographical impetus derives from an interrupted experience of belonging.”⁷⁴ This inter- or disrupted sense of belonging can affect any and all marginalised groups and in turn makes the tool of autobiographical writing all the more powerful for these groups. Not only is it important for members of minority groups to see themselves reflected on the screen, in writing, and ultimately in the widely projected image of the nation, but representation is also vital when it comes to allowing for variety in the traditionally very narrow definition of Irish national identity. Liam Harte emphasises “[t]he working-class socialist, the Gaelic-speaking islander, the Traveller, the economic migrant, the non-white Irish citizen, the Northern Irish Protestant, the person with a disability, the survivor of childhood abuse, the LGBTQ person,”⁷⁵ when he speaks of the groups of people whose stories, if they are allowed to be told, can “contest hegemonic representation and contribute to a more complex, ambivalent narrative of ‘nationness.’”⁷⁶ In this sense, life writing can be seen as a form of activism by which the self as the other is written into the narrative of the nation. Indeed, as Bríona Nic Dhiarmada mentions, “[life writing] has brought forth the voices of many individuals whose

gender and class usually leave them outside literary discourse, voices which assert their cultural difference and their subjectivity while insisting upon their common humanity.”⁷⁷

Alongside class, gender, and ethnicity, disability is another category that needs to be considered when discussing the issue of identity creation and representation in life writing. Indeed, the dehumanisation many people with disabilities have faced, and to an extent still face in Ireland, makes life writing, with its focus on identity and the human experience, a poignant choice for disabled writers. Ireland’s history of institutional abuse has led to a strong tradition of what Moira J. Maguire has called “abuse survival memoirs.”⁷⁸ These works often overlap with autobiographical texts written by disabled authors, as disability was one of the leading factors of institutionalisation. Indeed, as Elizabeth Grubgeld summarises, “[p]ost-independence Ireland has come to be understood as an era in which the forces of church and state colluded to control the body and sequester those bodies that could not or did not conform.”⁷⁹ Instead of providing support and care at home, the state placed disabled children in hospitals or care homes, which many of those institutionalised would not leave until adulthood.⁸⁰ This practice was still common in the 1980s, with conditions in these institutions described by Grubgeld as “barbaric even by the standard of the times.”⁸¹ Those forced to live in hospitals or care homes regularly faced “severe corporal punishments for physical differences such as being unable to lift one’s arms, tie shoes, control the bowels or urinary function, curtail involuntary tremors, or speak in a socially normative voice.”⁸² Neither were they given sufficient schooling, and, if they ever left institutional life, they did so traumatised and unprepared for life outside the institution.

The practice of removing children with disabili-

⁶⁸ Lynch, *Irish Autobiography*, 2.

⁶⁹ Lynch, *Irish Autobiography*, 2.

⁷⁰ George O’Brien, “Memoirs of Irish Rural Life,” in *A History of Irish Autobiography*, ed. Liam Harte (Cambridge: Cambridge University Press, 2018), 200.

⁷¹ Liam Harte, “Introduction: Autobiography Theory and Criticism in Ireland,” in *A History of Irish Autobiography*, ed. Liam Harte (Cambridge: Cambridge University Press, 2018), 12.

⁷² Harte, “Introduction,” 12.

⁷³ Bríona Nic Dhiarmada, “Irish-Language Autobiography,” in *A History of Irish Autobiography*, ed. Liam Harte (Cambridge: Cambridge University Press, 2018), 228.

⁷⁴ Moira J. Maguire, “The Irish Abuse Survival Memoir,” in *A History of Irish Autobiography*, ed. Liam Harte (Cambridge: Cambridge University Press, 2018), 348.

⁷⁵ Elizabeth Grubgeld, *Disability and Life Writing in Post-Independence Ireland* (Cham: Springer International Publishing, 2020), 17.

⁷⁶ Grubgeld, *Disability and Life Writing*, 48–49.

⁷⁷ Grubgeld, *Disability and Life Writing*, 47.

⁷⁸ Grubgeld, *Disability and Life Writing*, 49.

⁶⁸ Throughout this article, the term “life writing” will be used as an umbrella term for various forms of autobiographical writing. “Autobiographical” is used as an adjective describing all forms of life writing. Whenever quotes used include the term “autobiography,” it may be assumed that they were chosen because the points made, in these specific cases, can also apply to a wider selection of life writing.

⁶⁹ Nicholas Allen, “Autobiography and the Irish Literary Revival,” in *A History of Irish Autobiography*, ed. Liam Harte (Cambridge: Cambridge University Press, 2018), 152.

⁷⁰ John Brannigan, *Brendan Behan: Cultural Nationalism and the Revisionist Writer* (Paperback reprint, Dublin: Four Courts Press, 2014), 15.

⁷¹ Claire Lynch, *Irish Autobiography: Stories of Self in the Narrative of a Nation* (Oxford and Vienna: Lang, 2009), 9–10.

ties from their homes disproportionately affected the poor, leading Maguire to argue that “[w]hat happened to them and to countless others happened in large part because a hyper-moralistic and intolerant society had difficulty coping with parents and children from working-class backgrounds who did not fit the middle-class ideal of ‘appropriate’ or ‘normal’ family life.”⁸³ If a family’s lifestyle did not comply with these ideals for any other reason, be it that there were unmarried or single parents, suspected promiscuity or homosexuality or, and this will be discussed in more detail in the next section, the family were Travellers, the risk of a child being taken away was even greater. In a majority of abuse survival memoirs, the fear of renewed institutionalisation is shown to remain a constant part of the life of survivors, especially those who face financial insecurities.⁸⁴ Accordingly, being aware of the history of both abuse survival memoirs and disability life writing in Ireland is vital, since, as Grubgeld notes “trying to understand Ireland without trying to understand the experiences of disabled people in Ireland produces a limited comprehension of a complex and diverse culture.”⁸⁵ Indeed, listening to or reading the life stories of those living with disabilities may help an understanding of the social issues still at stake within the country. Thus, the rest of this article will be devoted to the analysis of Rosaleen McDonagh’s collection of autobiographical essays *Unsettled*.

Unsettled

Unsettled is a collection of autobiographical essays by Rosaleen McDonagh, an Irish Traveller feminist, playwright and academic with cerebral palsy. Although in the introduction to her volume, McDonagh claims that “these pieces embody a diverse experience of what it is to be Irish,”⁸⁶ she rarely references Ireland or Irishness in the body of the text. Arguably, this is because to her, being Irish means being a Traveller. What she instead grapples with throughout the text

are the intersections of discrimination she faces as a Traveller woman with an impairment. It is these intersections which make her story a diverse experience of Irishness, one that functions as an important step towards a more inclusive narrative of Ireland. As McDonagh writes,

Reading [...] seemed to be reserved for settled people, for able-bodied people. [...] However, trying to find myself in these synthesised, curated versions of women’s lives was often futile. When you can’t see yourself on those pages, you write your own stories.⁸⁷

Thus, McDonagh provides vital representation for not only the Traveller community, but also for people with disabilities and institutional abuse survivors in Ireland, and she does so without ever presuming to speak for anyone but herself and without attempting to make her own story more palatable for outsiders.

A central part of McDonagh’s story is “what it is to be Irish and to have an impairment.”⁸⁸ Indeed, it quickly becomes clear that McDonagh’s autobiographical work may be classified as a recent instalment of an abuse survival memoir, as described above. Removed from her family at age four to live in what she refers to as a “residential special school,”⁸⁹ McDonagh came to experience the prejudice, inhumanity, and violence so innate to Ireland’s institutional systems. Maguire explains how “church and state in an independent Ireland that purported to cherish its children [...] allowed the most vulnerable of its citizens [...] to be subjected to a level of violence that by contemporary standards would be regarded as not only immoral but criminal.”⁹⁰ In the chapter “Clamped”—a wordplay that references inhibiting (involuntary) movement in a wheelchair, as well as being something that can be done to a caravan, hindering the Travellers’ traditional way of life—McDonagh mentions the two different kinds of abuse from authority figures she has experienced: “Disabled bodies didn’t have the exotic fetish association that

Traveller bodies did. The beatings were for my disabled body, and the sexual stuff was for my Traveller body.”⁹¹ As becomes apparent, even in a medical facility, there is no safety from discrimination. Not only are disabled women routinely put on birth control without their knowledge or consent, McDonagh is also scheduled for a hysterectomy she neither needs nor wants. In her essay, she connects this decision with her dating a Traveller man at that time: “The care workers in the residential centre believed pregnancy was imminent and that this man could be taking advantage of me. Racism is never subtle.”⁹² These connections between her disability and her ethnicity in her experience of institutional abuse are important to note, as they show the intersections of racism and ableism that led to the state’s failure to protect a young Rosaleen McDonagh from harm.

In addition to the horrific abuse suffered, to McDonagh, her isolation from family and community stands out as one of the most traumatising elements of living with an impairment and thus being institutionalised: “This life of mine exposed me to mainstream and settled culture. Being away from my family and my community, the force of that assimilation, broke me.”⁹³ Indeed, as Grubgeld notes, oftentimes “objections to a parent’s way of life [...] led to a disabled child’s removal.”⁹⁴ Of course, the Traveller way of life was and unfortunately still is perceived by mainstream Irish culture as such an objectionable lifestyle, which meant that McDonagh’s family was kept from visiting her:

The arrangement with the nursing home was that my family would stay away. [...] the guards would be called if my family were in the vicinity. Signing the form, crying, as I didn’t know when or if I’d ever see my family again. The word traitor kept running around in my head.⁹⁵

The state’s attitude towards Travellers and towards people with disabilities led not only to McDonagh’s temporary removal from her community, but also to repeated attempts at having her adopted into a settled family, instead of trying to help accommodate life with an impairment in her native setting.

As a result of her separation from the Traveller community, McDonagh frequently discusses “the cultural differences” between herself and her family that emerged through her experience with disability and institutional life.⁹⁶ “The convention of the time was that you would do what your mother or father had done – marry and raise a family. A person who didn’t live their lives in this pattern was considered odd, not a real Traveller.”⁹⁷ As her cerebral palsy progressed, it was deemed McDonagh could no longer live in a caravan, and she was removed from her family. In close contact with settled people, she was not only exposed to violence but also a completely different way of life, a settled one. Living in a house, albeit an institution, and with settled people, isolated McDonagh from her family and forcibly estranged her from her community. Furthermore, once she reached adulthood it became clear to McDonagh that her disability would make living up to the expectations towards Traveller women—birthing children and taking care of the home—near impossible. Thus, she expresses feelings of inadequacy:

The pain of knowing that fundamental aspects of life were closed off to me was often overwhelming. Knowing that if I was a man, it wouldn’t matter what impairment I had. There still would be a possibility. [...] It was excruciating, that strange sense of what it is to be considered a failed woman.⁹⁸

Elsewhere, McDonagh has discussed that institutional life, due to a lack of sex education, lingering trauma and, in many cases, physical intervention such as forced hysterectomies, hindered her and other institu-

⁸³ Maguire, “The Irish Abuse Survival Memoir,” 351.

⁸⁴ Grubgeld, *Disability and Life Writing*, 48.

⁸⁵ Grubgeld, *Disability and Life Writing*, 17.

⁸⁶ Rosaleen McDonagh, *Unsettled* (Dublin: Skein Press, 2021), xv.

⁸⁷ McDonagh, *Unsettled*, 71.

⁸⁸ McDonagh, *Unsettled*, xi.

⁸⁹ McDonagh, *Unsettled*, 1.

⁹⁰ Maguire, “The Irish Abuse Survival Memoir,” 349.

⁹¹ McDonagh, *Unsettled*, 23.

⁹² McDonagh, *Unsettled*, 17.

⁹³ McDonagh, *Unsettled*, xi.

⁹⁴ Grubgeld, *Disability and Life Writing*, 48.

⁹⁵ McDonagh, *Unsettled*, 38.

⁹⁶ McDonagh, *Unsettled*, 2–3.

⁹⁷ McDonagh, *Unsettled*, 36.

⁹⁸ McDonagh, *Unsettled*, 46.

tionalised women from making decisions about their reproductive plans.⁹⁹ At the same time, her family's acknowledgement of her need "to mix with settled people and make a life" means that McDonagh gets to take advantage of certain freedoms not available to her sisters.¹⁰⁰ One of them is her education, which she repeatedly emphasises as her own way to freedom and independence.

In her university days, McDonagh builds a friendship with Mary Elizabeth, another woman with cerebral palsy born into a Traveller family. However, unlike McDonagh, Mary Elizabeth was adopted and raised by a settled family. This apparently saved her from a lot of the abuse McDonagh herself went through in institutional care, but it also estranged her from an integral part of her own identity: "You're lucky your family accepted what came out of your mother's womb. They love and support who and what you are. When you look at photos, you know who you belong to. Not everybody has that,"¹⁰¹ Mary Elizabeth tells McDonagh. Her isolation from the community goes so far that when Traveller ethnicity is officially recognised, she cannot celebrate with McDonagh and her Traveller friends, but insists on a private celebration in which she finally tries to come to terms with her identity. In telling this story in her own narrative, McDonagh acknowledges that the same circumstances can lead to very different outcomes but that being separated from your community will usually have devastating effects on your own sense of self. Indeed, a forced separation may leave an individual feeling perpetually unsettled.

When speaking of autobiographical writing produced by authors with disabilities, Grubgeld notes that "Marketing material such as cover art, the back-cover biography, and advertisements also affects the presentation of identity in the text itself."¹⁰² Accordingly, a brief note on the paratext of *Unsettled* has to be made, starting with the title. "Unsettled" is a multi-faceted pun, referencing the status of the Traveller commu-

nity as opposed to the settled community, but also referring to McDonagh's in-between status as someone forcefully integrated into a settled environment, yet maintaining strong family ties. The word can, of course, also mean disturbed, as well as not resolved, both of which can again be connected to the Traveller community and McDonagh in specific, as she mentions in the introduction to her text that "[t]here was no triumphant moment of overcoming the violence inflicted on me."¹⁰³ Both the past trauma of abuse and the ongoing trauma of discrimination linger, leaving the person affected unsettled. The back cover quotes, supplied by influential Irish authors such as, amongst others, Anne Enright and Emilie Pine, emphasise the quality and honesty of the writing itself and express hopes that the book will lead into a more positive future. While the selection of quotes is, of course, meant to entice readers and the quality of the essays is deserving of praise, care must be taken not to make an example out of McDonagh. Indeed, the emphasis throughout the quotes on the book being about identity, and more specifically, McDonagh's unique story, lends itself to seeing her as an exception, as someone able to overcome all obstacles and become a writer—something the author herself explicitly wants to avoid. Furthermore, although *Unsettled* is an important piece of literary activism, it is only the beginning of what is needed in order to improve the lived realities of Travellers and people with disabilities in Ireland.

Throughout *Unsettled*, we can witness McDonagh working through past traumas and at the same time trying to negotiate her identity as a proud Traveller woman, a person with a disability, a highly educated woman, and a survivor of institutionalised abuse in the face of Ireland's prejudice against all of these identities. It is important to note that "autobiography can yet act as a vital form of self-creation,"¹⁰⁴ as Grubgeld claims. Indeed, especially for an author with a disability, taking control of your own narrative is of

crucial importance. While life writing in general is often about the establishment of an independent self, those living with disabilities frequently face difficult situations "involv[ing the granting of] intimate access to the body in need of assistance, and all such arrangements require ongoing negotiations regarding privacy and autonomy."¹⁰⁵ Grubgeld indicates that in this context,

history [...] urges the abandonment of yet another generic formulation, the tale of 'overcoming' one's own body. The conflict in [disability] life writings does not lie between one's ambitions and one's body; the conflict lies instead between one's ambitions for independence, however the term is imagined, and socially imposed restrictions.¹⁰⁶

Unsettled, in fact, is one example of an autobiographical text that challenges the tale of overcoming and negotiates the conflicting realities of needing assistance and wanting to live independently. An example of this can be found in the acknowledgments of the collection: due to her physical impairment, McDonagh can only put her life story down on paper with the help of someone else: "Enormous gratitude goes to Olivia Smith, who has sat with me and typed for the last two years. Her job is much more than a typist. Her patience, diligence and ambition to ensure she understands every word I say is empowering."¹⁰⁷ While life writing is always a vulnerable process, involving deep self-reflection and openness, for McDonagh the assistance needed in producing her autobiographical work heightens this aspect. Yet, by acknowledging her limits and being able to ask for the support needed, she is able to tell her story, perhaps more unfiltered than the generations of disabled autobiographers before her, successfully negotiating the line between dependence and finding your own, independent voice.

Conclusion

Readers may be tempted to see Rosaleen McDonagh as absolutely settled into her role as writer, teacher, and advocate and feeling absolved of any duty of their own. If McDonagh succeeded against all odds, then maybe the situation of Travellers, of disabled people, of Travellers with disabilities in Ireland is not so bad after all. This notion, however, belies the lived experience of these communities, and of the author herself. According to paveepoint.ie, the website of the Traveller and Roma Centre Pavee Point, 11% of deaths within the Traveller community are due to suicide.¹⁰⁸ The prejudice Travellers face in Ireland plays a significant role in this devastating number of suicides, as does the fact that it is near impossible to pursue a traditional Traveller way of life in Ireland today. There are few campsites available to Travellers, and many of the sites they are parked in do not have a stable supply of water, electricity or WIFI. Thus, especially Travellers with disabilities are forced to forego their traditional lifestyle in favour of forced assimilation into a settled culture—one in which it may still be difficult to find all the provisions necessary to live independently with a disability. Furthermore, to focus solely on the success of Dr Rosaleen, as McDonagh is affectionately known in her community, would be to minimise the various traumatic experiences she describes in her essays and the systemic issues underlying the abuse she has suffered. While it is important to read works like *Unsettled*, they should merely be reminders of the work still to be done until the lives behind these examples of life writing can unproblematically fit into the narrative of the nation. As Rosaleen McDonagh writes: "This book is not the Traveller story. It's just one of many to come. [...] Page after page, the details will hopefully motivate other Travellers to document aspects of their lives. We may not be formally recognised in Irish history, but we are here."¹⁰⁹

⁹⁹ Rosaleen McDonagh, "Rosaleen McDonagh: 'Traveller women who don't have children are pitied:' Cerebral palsy meant two mighty and brutal forces of patriarchy had a tight grip upon my body," *The Irish Times*, published 17 April 2021, <https://www.irishtimes.com/life-and-style/health-family/rosaleen-mcdonagh-traveller-women-who-don-t-have-children-are-pitied-1.4526284>.

¹⁰⁰ McDonagh, *Unsettled*, 35.

¹⁰¹ McDonagh, *Unsettled*, 94.

¹⁰² Grubgeld, *Disability and Life Writing*, 9.

¹⁰³ McDonagh, *Unsettled*, xv.

¹⁰⁴ Grubgeld, *Disability and Life Writing*, 7.

¹⁰⁵ Grubgeld, *Disability and Life Writing*, 10.

¹⁰⁶ Grubgeld, *Disability and Life Writing*, 62.

¹⁰⁷ McDonagh, *Unsettled*, v-vi.

¹⁰⁸ Pavee Point Traveller and Roma Centre, "Mental Health and Suicide in the Traveller Community," *Pavee Point*, published 2013, <https://www.paveepoint.ie/wp-content/uploads/2014/01/Travellers-Mental-Health-and-Suicide.pdf>.

¹⁰⁹ McDonagh, *Unsettled*, xiii-xiv.

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SECTION 2

DIS | ABILITY

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AND

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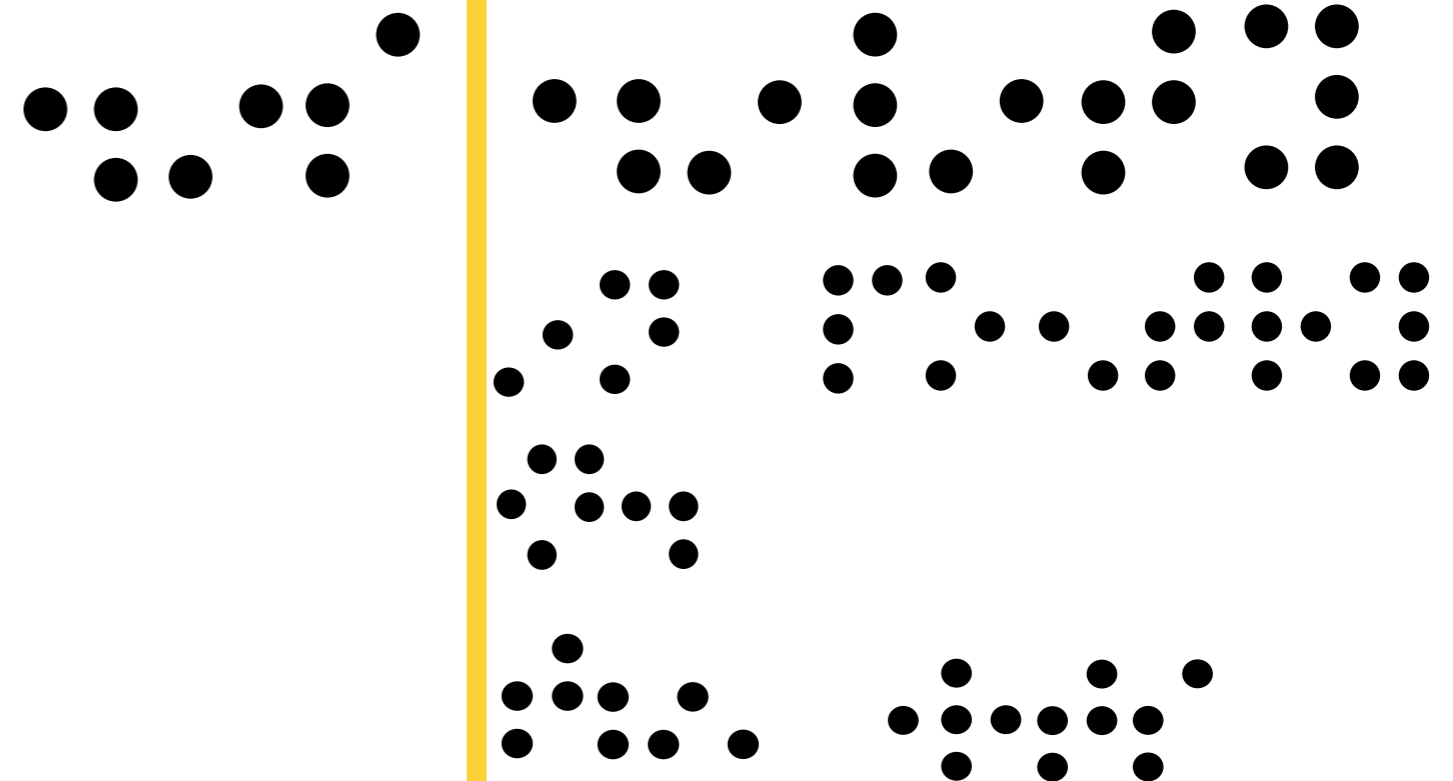
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Selection of Poetry

Shubhanku Kochar, Guru Gobind Singh Indraprastha University

GOOD BOY

Let's go for a walk,
Ok;
Let's go for a movie,
Oh!
Are you busy?
Let's go out for dinner,
What!
You are not feeling like eating.
Can we just sit and talk,
O no!
You can finish assignment tomorrow,
It is Sunday tomorrow,
Is it not?
Can we talk over a phone call?
O.M.G.

You are expecting guests;
Sorry,
I am sorry,
I will pray and go to bed
Without complaining
Like a good boy
That I am,
As mother repeats again and again,
Yes,
I am a Machine,
A Robot,
A Statue,
I do not feel anything,
I am a good boy,
GOOD NIGHT.

I LAUGH

I laugh
At your ignorance.
When you can not ,
See that I can not see.
When you try to make me sit
Without
Realizing that
I can stand without any problem.
When you say:
I do not look like Blind people,
I do not talk like Blind people,
I do not walk like Blind people,
I do not resemble Blind people,
As if,
Being a Blind is a formula,
There is no
Language,
Theory,
Template,
Process,
Of being a Blind.
Yes, I am Blind,
Like:
You are tall,
Short,
Fat,
Skinny,
White,
Black,
Brown,
Good,
Bad,
And
Anything.

JUST LIKE YOU

I am a Human being-
Just like you.
I have my own Dreams and Desires-
Just like you.
I have broken and fulfilled Promises-
Just like you.
I also Weep when hurt-
Just like you.
I also Laugh when happy-
Just like you.
I also crave Success-
Just like you.
I also fear Failure-
Just like you.
I am not
A Puppet,
A Soft-toy
A Pillow
An Artifact,
A Monument
A Door,
A Window,
A Table,
A Chair
Or
Devine,
I am a Human-Being
Just like you.
I wish you understand this,
Before it is too late.

Reflection on Shubhanku Kochar's Poems

Nathalie Lamprecht, Charles University, Faculty of Arts

Shubhanku Kochar's poems make use of simple, though effective language throughout, never failing to convey emotion. Written in free verse, the three poems speak to a variety of themes, including childhood trauma and life as a person with a disability.

Partly written in dialogue form, the poem "Good Boy" appears to portray a strained parent/child relationship. Throughout the first part, one person is repeatedly reaching out to the other, being rejected each time. Even a phone call takes too much time, as the other person is expecting guests. It appears that the adult persona present in the poem always prioritises other activities over spending time with their child. As a result, the child persona of the poem learns to "pray and go to bed/ Without complaining/ Like a good boy". To shield themselves from the pain of the parental rejection, the speaker of the poem tells themselves "I am a Machine,/ A Robot,/ A Statue,/ I do not feel anything." Although this poem does not outright reference disability, it shows the impact one's upbringing can have on one's mental state as an adult, touching upon themes of trauma and neglect.

Despite the ostensibly positive title, evoking laughter and joy, the poem "I Laugh" speaks of the deep frustration felt by the poem's speaker regarding their treatment by people unable to understand their blindness as a mere part of their entire being. A variety of responses to encountering blindness is touched upon, including being treated like a weak or sick person: "When you try to make me sit/ Without/ Realizing that/ I can stand without any problem.", and being questioned about not looking or acting blind:

When you say:

I do not look like Blind people,

I do not talk like Blind people,

I do not walk like Blind people,

I do not resemble Blind people,

The author plays with his words, making brilliant quips such as "I laugh/ At your ignorance./ When you can not,/ See that I can not see." Furthermore, he is able to express strong emotions through simple language, which is remarkable. Despite no clear negative phrasing, the poem resonates a certain (justified) anger, when it points out that there is no right or wrong way of being blind and that one cannot be reduced to blindness.

Finally, in the poem "Just Like You," Kochar highlights society's prejudices and superstitions when it comes to people with disabilities and speaks out against them. Particular focus is placed on the treatment of disabled people as passive, as akin to material objects that can be manhandled and are unable to move and act on their own accord, like "A Puppet,/ A Soft-toy." The poem cleverly points out, using just a few lines, that not only is the speaker of the poem a well-rounded human being, but also that this fact is not always apparent to the people surrounding them, which is criticised. The phrasing of the poem is reminiscent of Shylock's much-quoted speech in William Shakespeare's *The Merchant of Venice*: "If you prick us, do we not bleed? If you tickle us, do we not laugh? If you poison us, do we not die?"¹ Both aim to call to another's mind the fact that being different from a perceived norm doesn't make one less of a human—both are successful in doing so.

Overall, Kochar's poems speak to the ambiguous feelings experienced by a person with a disability in interaction with the non-disabled world in an accessible, straightforward, and honest fashion.

¹ William Shakespeare, *The Merchant of Venice*, Project Gutenberg online, Act 3, Scene 1, <https://www.gutenberg.org/cache/epub/1515/pg1515-images.html>.

Poems Connected to ADHD Problematics
Jana Moravcová, Charles University, Faculty of Arts

Diagnostics by Random Passersby

They tell you a lot
About what
You are not

Yet to learn what you are
They don't even try
Just let out a sigh

The Elephant in the Classroom

In the classroom there's an elephant
Over there, in the front row sitting
Unperturbed and silent
Sleeping
Let's not wake it
It's so quiet
Obedient

Or should we wake it?
What happens then?
What might or mightn't come
At those times, when
We step outside
Do not hide
Talk out loud
Could we make it?

What's voted for is option three
Let's admit that it is real
And act as if we understood
What is wrong and what is good
Let's talk about it as we do
And move the elephant to the zoo

Tolerance

Tolerance seems nice a thing,
but it implies suffering
something or someone you don't like.
And in fact
what's more preferred
is to kind of hide
the uncomfortable sight
of difference.

'Sure, of course, let them do what they need,
just clear them away where we don't have to see.
Because in our sight certain rules apply.
And shame on those who can't comply.'

And that's what tolerance is for you:
assimilate, segregate – up to you!
After all, perhaps tolerance is really not of use,
and it is rather respect that we should choose.

The Yelling in My Head

Yelling, they are always yelling,
no matter what I do.
Inside, they're always saying
things, and outside they do too.
Those things sound like some long-lost words,
though I don't think I comprehend
their meaning. It's like a greater force
is pulling me to the far end.
And all that's left is yelling.
I wish they'd see inside, start caring.

Guilt

I'm sorry, my darling,
It isn't your fault
I know we're both trying
It's hard to fight thoughts
Sometimes we're both wandering in the dark
And our worlds are simply set apart

Who's Mad?

Mad
– is it me or you?
Me – 'cause of the way I act?
You – at me for what I do?
I don't wanna – me or you – to fight
this exhausting,
and yet everlasting plight.

Communication Noise

Go do that
yeah
Did you hear me
what
What did I say
huh
Let's go already
uh

A Brief Reflection on ADHD in Children: Parents' Perspective

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When considering disability, one might ask what exactly the term encompasses, especially as regards psychological issues. In their case, the difficulty might be that they are not always easy to assess, and they are, therefore, often misinterpreted. Such is also the case of ADHD (attention deficit/hyperactivity disorder), one of the most common neurodevelopmental disorders, which often tends not to be regarded as a large issue by the majority population. However, ignoring or underestimating the condition is precisely what causes problems in understanding the children affected by it. For many people, children suffering from ADHD simply misbehave and can be “fixed” by a more disciplined upbringing. Sadly, these notions are not an exception even in the education system, where, theoretically, the authorities should be well informed about the nature of the disorder and the treatment of the impaired child. Thus, their parents are put in an uneasy position. With the prospect of witnessing the younger generations being inevitably processed through the institutions, parents are forced to view the education system critically, and to necessarily draw comparisons with what has changed since their time at school—and reflect on whether it is enough. This last question is what I have been confronted with myself rather recently through my eight-year-old, who has been diagnosed with ADHD. The diagnosis in the context of education has become an important theme in many of my poems; along with reflecting on the difficulties my son and I face in everyday mutual interactions. This paper attempts to describe an ADHD-child parent's perspective on the disorder's reception in institutions, as well as outside of them, in order to provide context for those of my poems dealing with this topic. Therefore, it is inevitably a personal

perspective and far from an expert attempt at mapping the issue in general.

Perhaps a short note to clarify the terminology first. My experience as a parent is limited to the diagnosis my son has been given, namely ADD, which is (as I understand it) a slightly outdated but, at least in the Czech environment, still widely used term,² which refers to ADHD with inattentive clusters of symptoms. As Dave Anderson points out in his article “What is the difference between ADD and ADHD?” the categorisation of the disorder has shifted profoundly in the past 30 years.

It was called ADD up until 1987, when the word ‘hyperactivity’ was added to the name. Before that [...] a child would be diagnosed with ADD, either with or without hyperactivity. From the early 1990s, the diagnosis included one of three types of ADHD. Children who only had the inattentive symptoms were called inattentive type. Kids who were only hyperactive and impulsive were hyperactive/impulsive type. Kids who had all three symptoms were called combined type. [...] The newest way of thinking about ADHD is actually to get rid of types altogether and just think about which symptoms present prominently.³

The approach to ADHD in the psychological counselling centres I encountered in the Czech Republic seems to be in accordance with this “newest way,” i.e., not labelling but describing. However, it seems to stick to established terms where terminology is concerned. In this paper, though, I will adhere to the term ADHD, as it seems to be generally more understandable.

There are a number of points which make one pause and reconsider the approach to disorders in Czech society in general; the first question being where the whole confrontation of the mainstream and the marginal begins. Indeed, it happens long before the child enters elementary school. Preschools are places where the child (and the parent) is confronted with a teacher for the first time, but I dare say that the clash comes even before that. Maybe on the bus where your child says something inappropriate? Or in the playground where elderly ladies give you contemptuous looks as your child is throwing a tantrum? Or is it at the doctor's, when the child, unable to cooperate, is hostilely glared at by the nurse? Honestly, I have come to think that an ADHD-child becomes stigmatised right after birth while still in the hospital. The fact is that they simply act differently from the majority and they, therefore, disrupt “the routine” (which is sacred in all kinds of institutions, particularly in the hospital).

The development from there is partly a matter of chance. As a parent, it soon dawns on you that your child is not mainstream. Your paediatrician possibly also realizes that the child possesses certain specifics and, if you are lucky, articulates the presumption in a sensitive way. Often, though, the doctor does not say anything, or, at times, says something insensitive. Preschool is what parents tend to see as something with the potential to be helpful, believing, or, at the very least, hoping that teachers will think of a useful strategy that would lead to the child's easier adaptation in an educational institution. Perhaps, a debate is what one would expect; a discussion between teachers and parents working together to find ways to respect the child's specifics *and* to integrate the child effectively into the class and its programme. However, the reality in most preschool facilities is different, and all that parents receive is complaints, often as if blaming the parent for having an “incompetent” child or for providing poor upbringing. I remember the comments that I used to be showered with the moment I arrived at preschool to pick up my son:

The kid did this or didn't do that and even

though *absolutely everyone* did that, the kid just wouldn't, and we don't know what to do, I've never seen anything like it in my twenty years of teaching, you should see a psychiatrist, there's something not right with the kid, really, go, we need a manual, or better yet, get us rid of the problem, the kid should go to a specialised school, yes, it shouldn't be our problem.

Those are statements that a parent of an ADHD-child may hear on a daily basis—a chain of complaints not aimed at a practical solution, but simply the venting of a teacher's unchecked frustration. A simple picking up from daycare becomes an overwhelming pressure.

Nonetheless, the criticism cannot be applied only to teachers; there are other factors, often intertwined, which complicate the situation for children with this disorder. In the education system, a word often debated in this context is “inclusion.”⁴ Unfortunately, there seems to be a gigantic gap between what is promised in official statements of the ministry and what happens in reality. “We'd need an assistant,” is one of the first responses to an ADHD-child's in-class behaviour. That in itself would not be a bad thing; on the contrary, a good assistant can be a blessing for an ADHD-child. The difficulty lies in three things. First, it is not easy to get a *good* assistant as, on the basic level, there are very few requirements for their qualifications.⁵ Having an assistant in class does not automatically guarantee their understanding of the child's condition or a supportive attitude towards the child, as their awareness of the disorder is mostly dependent on self-study. Second, there is often one “shared” assistant for several children in a class, which can only be fruitful up to a certain number of disordered children. The higher the number, the less of quality assistance can be expected per child. Third, to get *any* assistant at all, there are many administrative matters to be dealt with. The school needs a document from the educational and psychological counselling centre—and not just any document. The child would have to be diagnosed with a more severe form of the disorder which would

² Pavlína Hublová, “Problémy v chování – porucha pozornosti s hyperaktivitou (ADHD), opoziční vzdorovitě chování,” *NPI: Metodický portál RVP.CZ*, published February 5, 2020, <https://clanky.rvp.cz/clanek/c/p/22408/PROBLEMY-V-CHOVANI--->

³ Dave Anderson, “What Is the Difference between ADD and ADHD?,” *Child Mind Institute*, accessed October 3, 2023, <https://childmind.org/article/what-is-the-difference-between-add-and-adhd/>.

⁴ See, for example, Martina Vitáková, “Společné vzdělávání je přirozená věc,” *msmt.cz*, accessed May 15, 2023, <https://www.msmt.cz/ministerstvo/novinar/spolecne-vzdelavani-je-prirozena-vec-m-vitakova>.

⁵ Portál pro školní asistenty a asistenty pedagogů, “Kvalifikační předpoklady,” *asistentpedagoga.cz*, accessed May 15, 2023, <https://www.asistentpedagoga.cz/asistent-pedagoga/kvalifikacni-predpoklady>.

correspond to level 3, 4 or 5 of support measures.⁶ As for the children reaching level 1 or 2, no individual assistant can be assigned, which, however, does not mean that they would not benefit from one. Yet, the disorder cannot be conclusively diagnosed until the age of seven;⁷ as such, no professional psychologist can provide the diagnosis document at preschool age.

It is understandable that teachers in preschools are reluctant to take full responsibility for a “problematic” child. Among other things, as was explained to me, in case of an inspection there could be some inconvenient consequences for the teacher or, possibly, the institution (although what exactly could happen was never specified to me by the teachers). In elementary schools, teachers are better informed and possibly even trained for working with children with ADHD.⁸ Nevertheless, often the issue is the teachers’ capacity. There are approximately 19 children per teacher in a classroom.⁹ With such a number, it is extremely difficult to approach pupils individually, resulting in a learning environment where counsellor-recommended studying conditions for ADHD children are not guaranteed. Moreover, in connection to capacity, there are larger issues the school’s leadership has to address. Just recently, I discovered that for inclusion to have the intended impact—i.e., for the majority children to learn to respect otherness while setting an example for the “included” children—the maximum number of children with support measures in one class has been estimated to be around 5 (depending on the overall number of pupils in the class and the levels of support measures the “included” pupils have).¹⁰ With schools overcrowded, though, which is a phenomenon that has been making itself known acutely in the recent years, especially in cities, this is unsustainable. In my son’s class, a group of 26 pupils, 10 children are in need of a specific individual approach. Although the ministry’s directive says differently, the school simply does not have the resources—economical, personal,

or spatial—to ensure that. Yet, they cannot send the children away to another school, as they are lawfully bound to educate them. Needless to say, the situation may be very similar at other schools.

As a consequence, both teachers and parents are put under additional stress. Speaking from a plain human perspective, the working environment becomes extremely challenging for teachers, and not being able to sort the problem out systemically, they turn to parents, who, however, are even more powerless. Although I do believe that most teachers sincerely want to come up with a solution, the helplessness of the situation eventually drives them to similar frustrated venting that I witnessed at preschool. That results, for instance, in grading my son’s in-class work 5 for “rejecting to cooperate,” or in a note that I have received, which said “Please, explain to your son the importance of education.”

Teachers’ wellbeing has, rightfully, been a subject of more than one study.¹¹ The problem is that although, theoretically, there is a general interest in the wellbeing of both teachers and children, in practice less people ask about what would be beneficial for the child. And, let’s face it, the impaired children, although backed by their parents, always get the short end of the stick, in my experience, at least. Additionally, one thing that is being neglected but should be put in the spotlight is the wellbeing of parents. Partially, it seems logical to implement parents into their child’s education; however, this often consists of delegating the school’s responsibilities to them. When my son does not cooperate at school, all the work must be done at home, which often takes about two hours. Teachers—experts in education—are not able to motivate him, but we, parents, who are only qualified to work with children from the title of being parents, should know the way? What an absurd situation, even more so if we consider his disorder actually prevents him from staying focused for more than a short while, or even

from “turning” his attention “on” at all. But if I bring this point to discussions with teachers, I learn that this surely is not connected to ADHD, and that he is just lazy. A truly vicious circle. The system put in place by the state has poorly defined priorities, does not properly instruct teachers in preschool education, and it overworks those working in elementary schools. That all leads to an ineffective and discriminatory education system with potentially dangerous consequences for the psyche of teachers, parents, and, consequently, children.

Finally, it is quite safe to say that Czech society in general is not famous for its affability towards minorities.¹² It should not come as a surprise that the situation concerning attention-disordered children is not ideal either. ADHD is a very common diagnosis, reaching approximately 5% of the child population in official statistics, although the actual numbers are likely to be higher,¹³ as in many children, especially girls, ADHD is never diagnosed.¹⁴ Surveys focusing on the adult population have estimated the proportion of ADHD-adults to be around 8% of the population. Since the disorder persists into adulthood only in two-thirds of the cases, this necessarily means that the number for children must be even higher. Despite its high occurrence in the population, I dare say that the majority of people look at ADHD in a distorted way, not viewing it as a specific characteristic that should be respected and worked with. Rather, it tends to be seen either as a made-up term for difficult kids or as a nasty deviation whose label it is better to avoid, as it implies psychological problems and stigmatisation stemming from them. Therefore, even parents who suspect that their child could be impaired in this way often prefer not to seek expert advice: they are afraid of the reaction of the people around them, as well as of the threat of the child’s condemnation by teachers or other authority figures.

Indeed, the reactions to an ADHD diagnosis can be discouraging, starting with immediate family

members, but extending as far as experts in all sorts of fields. More than a few of my acquaintances have told me stories about their encounters with speech therapists who did not hesitate to label a child quite tactlessly with anything from ADHD to autism. Such “diagnostics” are completely misguided and based on impressions gained in half-an-hour sessions, such as the child’s unwillingness to cooperate during consultations or, for example, the fact that the child did not fancy drawing. (All sorts of children-focused professions work with the assumption that children like drawing; therefore, drawing is a fairly common activity even at the speech-therapist’s.) Additionally, the comments about a possible psychological issue were made in a very negative and accusing tone.

These are precisely the situations that contribute to ADHD having a derogatory connotation, informing its understanding by authorities and, as a result, by parents. Some of those children I mentioned in relation to speech therapists turned out to be quite fine psychologically; for the parents of others, however, the experience was so uncomfortable that they were afraid to address the possibility of ADHD in their child for many years after. Poor awareness of people in child-related professions about psychological disorders in general can, therefore, be quite harmful to children. And the issues become magnified when we consider ADHD-children who would benefit from medication. Leaving aside the fact that children’s psychiatric care (with the only sort of specialists who can prescribe the relevant medicine) is extremely hard to reach, the waiting time for a newly registered child to see a psychiatrist being approximately one year,¹⁵ the stigmatisation of child medication in Czech society is notorious. However, it seems to be improving.

Presently, the most important thing to be done is to raise awareness about the issue of attention disorders: show the public what a life with the disorder looks like, tear down the myths of “misbehaved boys,” and let people know that there are very individual

⁶ Portál pro školní asistenty a asistenty pedagogů, “Můžeme získat asistenta pedagoga na více dětí s PO2 ve třídě?” *asistentpedagoga.cz*, published June 5, 2020, <https://www.asistentpedagoga.cz/poradna/dotaz/3264>.

⁷ ÚZIS ČR, “ADHD U Děti: Příčiny a Diagnóza,” *nzip.cz*, accessed May 15, 2023, <https://www.nzip.cz/clanek/675-adhd-u-deti-priciny-a-diagnoza#:~:text=Sou%C4%8D%C3%A1st%C3%AD%20diagnostiky%20ADHD%20v%20d%C4%9Btsk%C3%A9m>.

⁸ Blanka Hrbková Hrudková, “ADHD - termíny, definice a integrační praxe,” *msmt.cz*, accessed May 15, 2023, <https://www.msmt.cz/vzdelavani/socialni-programy/adhd-terminy-definice-a-integracni-praxe>.

⁹ Jiří Svatoš, “Česko patří k zemím s nejvyšším počtem žáků na učitele v Evropské unii, vyplývá z údajů Eurostatu,” *iROZHLAS*, published September 14, 2019, https://www.irozhlas.cz/zpravy-domov/skola-ministerstvo-skolstvi-ceska-skolni-inspekce-ucitele-evropska-unie-eurostat_1909141847_gak.

¹⁰ MŠMT ČR, “Počet žáků ve třídě,” *msmt.cz*, accessed October 18, 2023, <https://www.msmt.cz/vzdelavani/pocet-zaku-ve-tride>.

¹¹ Irena Smetáčková and Veronika Pavlas Martanová, “Strategie zvládání stresu vyučujícími v základních školách,” *Orbis scholae* 14, no. 1 (2020): 101–19, <https://doi.org/10.14712/23363177.2020.16>.

¹² Amnesty International, “Inkluze je zrcadlem, které nám ukazuje, kde ještě máme v systému rezervy,” *amnesty.cz*, published June 30, 2020, <https://www.amnesty.cz/zprava/4905/inkluzje-zrcadlem-ktere-nam-ukazuje-kde-je-ste-mame-v-systemu-rezervy>.

¹³ Vítěk Svoboda, “Jako když člověku chybí tlačítko start. Stále více dospělých zjišťuje, že mají ADHD,” *Deník N*, published September 15, 2022, <https://denikn.cz/950400/roztomila-rozevlatost-ktera-muze-prerust-pres-hlavu-stale-vice-dospelych-zjistuje-ze-maji-adhd/>.

¹⁴ Svoboda, “Jako když člověku chybí tlačítko start.”

¹⁵ Iva Bezděková, “Překvapivá čísla: doktorů v Česku přibýlo, zdaleka ne však všude,” *Deník N*, published March 17, 2023, <https://denikn.cz/1103458/prekvapiva-cisla-doktoru-v-cesku-pribylo-zdaleka-ne-vsak-vsude/>.

manifestations of the disorder with very individual symptoms. People might say, “Well, of course we know about ADHD,” but being aware of its existence is not enough. Our society—from the children themselves to specialized children-oriented professions—needs to be better informed in order to provide the most suitable approach in education to talented kids who are congenitally handicapped in this way; and their parents need more information in order to be able to support their child. What I regret most about the journey my son and I have gone through is me not understanding him in everyday situations. I saw that attention was a problem, of course, but since there was no hyperactivity, I simply ruled ADHD out. I had no idea about the range of symptoms the disorder can include.

As these parenting mistakes cannot be taken back, and they are not easily avoided even if the parent is aware of them, misunderstandings, and troubles in communication are the theme of many of the poems that I write. These tend to be shorter and quite fragmentary, since the dialogue marked by ADHD, even an inner one, inevitably lacks focus. This is reflected in “Who’s Mad?” and, more explicitly, in “Communication Noise.” Another group of poems are the frustrated poems such as “The Elephant in the Classroom” or “Tolerance,” typically conceived as opposition to authorities, for whom it is naturally easier to focus on the majority children and neglect the needs of children from the inclusion group. These poems are also lined with the bitterness stemming from injustice, and disappointment with those who have the power to bring about change. They express disillusionment with those who are informed about the subject and the needs of ADHD-children, but who choose to ignore the supportive measures and try to remodel the children instead.

The poems do not offer reconciliation, hope, let alone a solution. They do not offer truth either, only a personal type of truth, ever changing. They are simply expressions of and reflections on everyday life’s struggle with a condition complicating interpersonal relations at home, school, or anywhere else. That

struggle is ever present and ever challenging, and it brings anxiety and frustration with the current status quo. Any prospect of change seems to be too far away and any legislation which might be approved by the system will come into effect rather late for my child. Nevertheless, as ADHD is a genetically conditioned disorder, future generations will still struggle with the same systemic issues as ADHD-people do today. To that end at least, it is worth attempting to amplify the discourse on the matter of ADHD through activism, education, media, or, at the very least, occasional poetry.

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SECTION 3

REVIEWS

**Portraying DHH Characters on Screen: Comparative Review
of *Sound of Metal* (2019) and *CODA* (2021)**

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Portraying DHH Characters on Screen: Comparative Review of *Sound of Metal* (2019) and *CODA* (2021)

Marie Gemrichová, Charles University, Faculty of Arts

With the current boom and public attention to the portrayal of minority characters and communities, as well as individuals with disabilities in media—be it fictional representation in books or on screen—and entertainment powerhouses such as the Marvel (Disney) Studios putting forward movies and TV series centring on DHH (deaf or hard of hearing) characters,¹ it is worth discussing how this particular disability has been recently represented in film, what kind of stories are put forward for the general audience, and the diverse responses those portrayals have received. As the American National Association of the Deaf comments on their website: “Too often media representations lack authenticity and present a distorted view of the deaf and hard of hearing community, and the misrepresentation deprives the public of an accurate understanding of a community that is rich in culture and language.”² This particular review, therefore, aims to discuss two recent American films—*Sound of Metal* (2019) and *CODA* (2021)—and both the praise and the criticism that have been aimed at them in relation to their representation and depiction of DHH individuals.

Sound of Metal, directed by Darius Marder, tells the story of heavy metal drummer Ruben (portrayed by Riz Ahmed), a recovering addict, who experiences a sudden hearing loss. Feeling that his life is over, as he cannot continue in his chosen career, and on the verge of returning to his addiction, he is accepted in a rehabilitation house for deaf individuals. Although he at first struggles and wishes for a simple and fast solution (during the film, Ruben even goes through a cochlear implant surgery), eventually he finds his place in this new community, learns ASL (American

Sign Language) and finds a different way to approach music, so important to his life before the hearing loss. Although written and directed by Marder and starring Ahmed, both of whom are hearing entertainers, the film did cast several actors from the DHH community. Importantly, Paul Raci, who portrays Joe, the proprietor of the rehab house, although not deaf, is a CODA (child of a deaf adult). While both Raci and Ahmed were nominated for their portrayals at the 2021 Academy Awards—for Actor in a Supporting Role and in a Leading Role, respectively—the film received two Oscars for Best Sound and Best Achievement in Film Editing, bringing it attention from the wider public.

The film has received, overall, very positive reviews, particularly Riz Ahmed’s portrayal of the main character has been applauded. Indeed, Ahmed, mostly known as a stand-up comic, shines in this serious role, illustrating well the frustration and fear of Ruben as his connection to music, presumably an aid in his addiction recovery, disappears in a single moment. Similarly, Paul Raci, portraying the quiet, level-headed Joe, is excellent and creates a formidable opposite to the quick and anxious Ahmed. What stands out, however, the most about the film is the sound design—the first loud, “metal” minutes are followed by white noise and silences intended for the audience as a means to follow Ruben’s own experience and the hardship of losing one’s hearing. As we observe Ruben both struggling to learn ASL and getting a cochlear implant—which he at the end of the film chooses to take off—the film also portrays the difficult and different ways of possible recovery and acceptance of a disability. However, it needs to be said that the film follows the usual cliché of a Hollywood recovery narrative; and disregarding the utilisation of the hearing loss and the DHH community, it is often indistinguishable from other films where a character

enters a certain type of rehab, learns about themselves and successfully leaves at the end of the film’s narrative with a “new” outlook on their life.

Turning now to *CODA*, a film by Sian Heder, which is comparable to *Sound of Metal*, particularly in terms of the public attention and the awards it has received. This recent movie focuses on the story of teenage Ruby Rossi, a CODA, whose main role in life is helping her parents and brother—all of whom are deaf—navigate issues at work, school, or at the doctor’s office. Although the family is heavily dependent on her, Ruby dreams of moving away for college and pursuing a career in music, which her family is at first incapable of understanding. Eventually, however, her parents and her older brother change their opinions and Ruby in the film’s final moments succeeds in her audition and eventually leaves her family for college. While, again, the main character of Ruby (and the actress) is a hearing individual, Ruby’s family is portrayed by Marlee Matlin (Jackie), Troy Kotsur (Frank), and Daniel Durant (Leo), all DHH actors.³ Importantly, *CODA* has received the Best Motion Picture of the Year award at the 2022 Academy Awards, as well as a nomination for Troy Kotsur for his portrayal of Ruby’s father.

CODA has gained again mostly good reviews before and following its awards. Particularly, being an adaptation of the French film *La Famille Bélier* (2014), Heder’s picture has been praised for the employment of DHH actors, whereas the original French one had mostly hearing ones, garnering understandable criticism. All four actors portraying the Rossi family have great chemistry together, wondrously depicting a difficult dynamic with particularly Emilia Jones (Ruby) and Troy Kotsur being the standouts. The film provides a great mix of funny and sad scenes, illustrating well the joys and frustrations of both Ruby and her family when navigating their surroundings. Similarly to *Sound of Metal*, however, *CODA*’s overall narrative is again somewhat of a stereotype

with a young character trying to distance themselves from their family and their values and the struggles that come with that; Ruby’s departure for college with her family looking at her car at the end of the film has been depicted many times before in other “coming of age” narratives.

While both films have been mostly applauded, some significant criticism has also appeared, particularly in connection with the portrayal of the DHH community and individuals. It is worth noting some of it, as it seems to correspond to a larger debate in Hollywood and in the film industry, namely whether films should be looked upon mostly as entertainment or whether they have a role in furthering minority groups and informing the larger public about them, and where the balance between that simple entertainment angle and the public service announcement should be. *Sound of Metal* has, for example, been criticised for not casting a DHH actor in Ruben’s role, although the character begins the movie as abled.⁴ Similarly, the film’s portrayal and simplification of Ruben’s cochlear implant surgery has been questioned, as in reality the process of evaluation, scheduling, and importantly paying for the procedure is much more difficult. Whereas this particular point appears valid, the film necessarily oscillates between a realistic representation and “movie magic,” where certain events need to happen faster and facts are obscured so a movie narrative can flow better.⁵ Both films have also been criticised for portraying deafness as a burden—although it can be argued that *Sound of Metal* smartly subverts the cliché with the main character accepting his disability in the end. *CODA* has specifically been castigated for Ruby’s own role in her family’s life as essentially a helper and a translator, although there is currently an abundance of devices that the DHH community can use, such as phone apps (or even a simple pencil and paper).⁶ Overall, both films have also been said to be aimed for the “hearing gaze,” particularly due to their interest in main—hearing—

¹ Besides portraying a minor DHH character in Marvel’s *Eternals* (2021), the upcoming mini-series *Echo* (2023) will focus on a deaf main character Echo, portrayed by a deaf actress Alaqua Cox, “Echo,” *IMDb*, accessed November 27, 2023, https://www.imdb.com/title/tt13966962/?ref_=nv_sr_srsq_0_tt_6_nm_2_q_echo.

² “Guidelines for Media Portrayal of the Deaf Community,” *National Association of the Deaf*, accessed November 27, 2023, <https://www.nad.org/about-us/position-statements/guidelines-for-media-portrayal-of-the-deaf-community/>.

³ Marlee Matlin has previously received the Academy Award for Best Actress for her role of Sarah in *Children of a Lesser God* (1988), a film portraying a school for the deaf; a film which is now often quoted as an obsolete example and a standard of *how not* to portray the DHH community.

⁴ Peter Bradshaw, “Sound of Metal review—Riz Ahmed keeps swirling disability drama on the beat,” *The Guardian*, published April 8, 2021, <https://www.theguardian.com/film/2021/apr/08/sound-of-metal-review-riz-ahmed-keeps-swirling-disability-drama-on-the-beat>.

⁵ Bradshaw, “Sound of Metal review.”

⁶ Laura Hood, “Despite its Oscar win, *CODA* is still a film that depicts deafness as a burden,” *The Conversation*, published March 30, 2022, <https://theconversation.com/despite-its-oscar-win-coda-is-still-a-film-that-depicts-deafness-as-a-burden-180222>.

characters pursuing traditional music careers.⁷

With many of the reviews of the films in printed media and online—both in magazines and journals, on personal blogs, or YouTube channels—it is important to note that there are valid, objective points of criticism (such as censuring *La Famille Béllier* for its employment of hearing actors for DHH roles, asking whether the reality of deafness is a mere plot device for these motion pictures or simply whether they portray ASL accurately). At the same time, there appears much criticism that speaks to an individual experience of the particular film goer and is quite subjective; a single movie character cannot encompass the experience of an entire and diverse community. It is similarly important to acknowledge that films continue to largely cast DHH actors and invent DHH characters for minor roles where they often lack names and backstories; however, it seems crucial to recognise that a great stride has been made in this respect. Additionally, particular criticisms such as “I would have liked the film to recommend things that young people could do to prevent their health,” in response to Marder’s picture—where the hearing loss happens due to loud metal music—undoubtedly interrogate films’ educational role,⁸ but could diminish the industry to an instructional enterprise.

Indeed, media portraying disability will always stand on the precarious point of being simply entertainment and a vessel for the furtherment of the portrayal of minoritised characters and communities, and such films must be both applauded and criticised. A recent article on *ASHA⁹ Wire* comments that “while there’s room for improvement in more authentic portrayals of DHH characters and technology, the media industry is on the right track with its inclusion of more characters and stories for the DHH population.”¹⁰ Both *Sound of Metal* and *CODA* appear to second this evaluation. While in no way perfect, often simplifying the experience of the DHH community, they importantly challenge the still lacking representation and can hopefully only aid in more films or TV shows coming to existence in the future.

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⁹ American Speech-Language-Hearing Association

¹⁰ Elizabeth Walker, Marcia Walsh-Aziz, and Andrea Warner-Czyz, “Media Representation and Hard of Hearing People,” *ASHA Wire*, published September 13, 2022, <https://leader.pubs.asha.org/doi/10.1044/leader.AEA.27092022.aud-dhh-media.16/full/>.

Lukáš Brutovský's *Hecuba* (Marina Carr) Klára Witzany Hutková, Charles University, Faculty of Arts

For one day only, the Czech audience had the opportunity to see a formidable production of the Irish playwright Marina Carr's *Hecuba*, directed by Lukáš Brutovský from neighbouring Slovakia. Staging the aftermath of the Trojan War, the tragedy focuses on Hecuba (Lucia Jašková), the fallen Trojan queen. An adaptation of Euripides' play of the same name, the tragedy had been previously produced in England by the Royal Shakespeare Company (2015) and in Ireland by the Rough Magic Theatre Company (2019). Brutovský directed his own translation from English into Slovak, titled *Hekuba*. This version premiered on February 17, 2023, in the Slovak Chamber Theatre in Martin, Slovakia, produced in collaboration with the Slovak Institute in Prague. The accurate translation, combined with Brutovský's fresh artistic vision, resulted in an impressive new stage adaptation, departing significantly from the previous productions.

On October 8, 2023, the Slovak cast performed Brutovský's *Hekuba* as part of a day of Slovak theatre at Divadlo Komédie in Prague. Preceded by *Iokasté*, Brutovský's own take on the myth of Jocasta, *Hekuba* was staged second and followed by *Bačova žena*, a Slovak play by Ivan Stodola. All three performances were directed by Brutovský and used the same basic set design. The overarching theme of the day was the representation of female characters. *Bačova žena* (*The Shepherd's Wife*), as well as *Hekuba*, present strong heroines navigating desperate situations. In contrast, the meta-theatrical *Iokasté* thematised the virtual absence of Jocasta as a character in canonical versions of the Oedipus myth. All three plays were followed by a public discussion.

During a conversation with the director, Brutovský explained that Carr's *Hecuba* had attracted him by the style in which it was written. Merging

various perspectives, the tragedy is told entirely in short monologues, with dialogue scenes retold by characters in the reported speech form. The effect of this experimental soliloquy technique has been debated by many critics, both in positive and negative terms. The style is often lauded for allowing for a much deeper elaboration of human psychology. The characters are continuously describing their feelings and sharing their inner thoughts, and these are spoken by the actors out loud with the same frequency as the words that have been uttered in the reported dialogues. At the same time, the style poses a great challenge for the cast and the creative team, as the repetition of speech tags, such as "I say" or "He says", is very frequent. The virtual absence of ordinary dialogue also has the potential to turn the play into an overly monolithic stream of overlapping consciousnesses.

This production's line of attack was two-fold, in addition to the overall very impressive acting. Pavel Baborák's set design, composed predominantly of a long, even slope on which the actors would walk, sit, as well as climb up and slide down, used lighting to foreground characters' speech. This is perhaps most impressive in the opening scene, where Hecuba, surrounded by all the other characters in the play, delivers her first lines with a bright rectangle of light cast over her. Throughout the performance, the light follows the speakers in this way, usually flickering on the character whose speech is almost over, as well as on the one who is about to speak next. Additionally, breaks between scenes are filled with dance-like motion, directed by Stanislava Vlčeková and performed by the actors currently on stage as isolated performances, thus strengthening the idea of their seclusion from one another in their individual subjectivities. The unnerving music and the movement

it inspires in the characters also add to the spectators' feeling of uneasiness, as they watch a civilisation fall and humanity disintegrate on stage.

Subverting the Homeric narrative of the Trojan war as a successful and just venture, Carr's adaptation foregrounds civilian suffering to imply that no war of conquest can ever be justified. As Hecuba is claiming that the mythical Helen has never existed, invented instead by the Greeks to be used as pretext for an invasion, the audience may be reminded of the second Gulf War, justified by unfounded assertions regarding Iraq's weapon programmes. The play is also a painful reminder of the war raging in Ukraine, and in other parts of the world. As in Carr's later play *Girl on an Altar* (first produced in 2022 at the Kiln Theatre in London), the patriarchal myth is reframed to convey an experience of helplessness and vulnerability in war, as regards both the conquered and the conquering. Hecuba sees her kingdom being overthrown, the bodies of her butchered children and husband following her wherever she goes. Her daughter Polyxena (Barbora Palčíková) is sacrificed by the Greeks during the play, and Hecuba's last living son, the child Polydorus (Matej Babej), is executed following a tactical decision made by the leader of the Greek armies, Agamemnon (Marek Gejšberg).

However, as opposed to Euripides' version, in Carr's adaptation, Hecuba does not let the soldiers take Polyxena away from her but follows them, looking her daughter in the eyes until they eventually close. In this way, Carr inserts a new form of heroism into the Classical tradition, portraying maternal enduring and self-sacrifice as not simply worthy of pity, but also of awe. Broken down by the experience, though, Hecuba very unexpectedly engages in sexual intercourse with Agamemnon. This narrative addition is another of Carr's artistic choices that has received mixed reactions in reviews, but it is staged slightly differently in this production. Usually, a certain connection, based on a mutual understanding, is implied to exist between the two members of royalty. Although they find themselves on opposing sides of the conflict, both

Hecuba and Agamemnon are forced into certain actions by external circumstances. Carr reframes the sacrificial killing of Polyxena as a public performance meant to strengthen Agamemnon's position as a leader, and to quell a possible rebellion. The script makes clear his unwillingness to perform what evokes the sacrifice of his own daughter, Iphigenia, that he had to make prior to the Trojan War. In the original 2015 production, two cones of light are cast on Agamemnon and Hecuba at the end of the sacrificial scene, at a moment where the Greek tribes threaten to trample them both. For this brief moment, the two enemies seem united in their precarious positions. The shared experience of royals trying to, at different times, cling to their power, is thus a likely explanation of the ensuing connection between the two.

However, this theme of mutual understanding is missing in Brutovský's production, despite some potential for it in the original script. Brutovský decided to cross out the last section of the monologue that Hecuba delivers just before kissing Agamemnon, so that the queen's speech ends with her thoughts on Polydorus: "Polydorus. Spare him. It's in your power, I want to say, but some instinct silences me."¹¹ Unaware that he has already been murdered, Hecuba is still hopeful that Agamemnon will spare her son. However, the original script continues:

You do not bargain with love, you take it when it's offered. However fleetingly and from the strangest quarters, the last solace. Don't sully it. And something tells me Polydorus is gone.¹²

Consequently, the sexual scene is reframed in this production as primarily a maternal strategy to appease the invader and save what can be saved.

This is an excellent production with a very strong cast. Polyxena's emphasised sensuousness is interestingly contrasted with the majestic dignity of the prophetess Cassandra (Zuzana Rohoňová), the less likable of these two sisters in Carr's play. The Thracian king Polymestor (Tomáš Mischura) lacks a backbone, as opposed to his version in the English production.

¹¹ Marina Carr, *Marina Carr: Plays 3* (London: Faber & Faber, 2015), 254.

¹² Carr, *Plays 3*, 254.

An adult actor has been cast as the child Polydorus, which has been somewhat ambiguously mitigated by Markéta Sládečková's decision to dress him in diapers. Overall, this is a significant contribution to the list of productions of *Hecuba*, one that will be hard to top in the years to come.

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