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# »Represent Yourself!« Disability, Interpretation and the Commodification of Experience

In one of the founding works of literary disability studies – *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000) – David Mitchell and Sharon Snyder consider the narrative function of disability, arguing that »disability inaugurates the act of interpretation«.[1] Disability, they suggest, is »*hypersymbolic*«:[2] it is over-invested with meanings and deployed to do meaning-related work. Like many works of literary theory written during the long 1990s, when the influence of poststructuralism was hegemonic in the Anglo-American academy, *Narrative Prosthesis* displays a preoccupation with the play of meaning. It is fascinated by disability's unstable literary significance and the proliferation of ways it is used as narrative's »crutch«.[3] In this chapter, I suggest that from the vantage point of the 2020s, the interest in proliferative meaning and interpretive practice in *Narrative Prosthesis* signals the book's participation in a previous era of literary criticism. How can we understand the relationship between literary disability then and now? What are the stakes of writing about disability in the contemporary moment? I argue that literary disability has come to be much more about *sharing the ›written self‹* and much less about the multiple ways of thinking about *being* that disability can engender. I try to ground this argument in the changing material context surrounding writing, and selfhood, in the 21st century.

## Selves sell, disability sells

I am interested in what happens when disability becomes ›calcified‹ as the referent of a lived experience that, in being named, sells copies of a book. I aim here to begin to sketch out a shift in the functioning of literary disability that tracks the rise of memoir culture and autofiction, as well as the success of liberal discourses of inclusion. Specifically, I am intrigued by what has hap-

1 David Mitchell/Sharon Snyder: Narrative Prosthesis. Disability and the Dependencies of Discourse, Ann Arbor 2000, p. 6.
2 Ibid., p. 10 [italics in original].
3 Ibid., p. 49.

pened to Mitchell and Snyder's (2000) idea that »disability inaugurates the act of interpretation«[4] in the era in which we have become »entrepreneur[s] of our own sel[ves]«.[5] What does literary disability inaugurate now, and how does it introduce itself? I begin with this quotation about interpretation from the work of Mitchell and Snyder here, because this work is canonical within literary disability studies, and because this quotation refers to a mode of thinking and working within that discipline that is shifting, I argue. Yet I am conscious that my own case study in this chapter is drawn from a different genre (parental memoir), and produced in a different time, from the historical works of fiction that Mitchell and Snyder centre. My argument here is provisional; it is something I am trying out.

Questions of genre – as they pertain to both literary production and literary criticism – are important in this chapter, even if they might require a separate chapter for fuller working-through. The cultural move away from fiction and towards memoir might itself be understood as significant:[6] we can ask what happens to literary disability as a site of meaning-making in an era when, as Anna Kornbluh has argued, »fictional writing has no value«[7] and »*made-up people in a made-up, though realistic, world*« make the author »*nauseous*«, as Karl Ove Knausgård has written.[8] In what ways has disability been pinned down in the contemporary moment? Where does the naming of disability lead?

The issue of naming disability to sell books and sell selves brings literary disability studies into contact with cultural materialism. This is the idea that analysis of cultural forms and representational practices needs to be situated in relation to the historical conjuncture in which they emerge and take root, and the dominant socioeconomic conditions of that conjuncture.[9] How is the widening of access to publishing in an era that is both digital, and dominated by socio-legal discourses of inclusion, altering disability discourses? How is life-narrative being deployed within this new social arrangement, and how can we make sense of the commodification of stigmatised identities? Opportunities to create value are becoming increasingly scarce under post-2008

4 Ibid., p. 6.
5 Byung-Chul Han: Psycho-politics. Neoliberalism and New Technologies of Power, London 2017, p. 2.
6 This is discussed by Anna Kornbluh in Immediacy, or, The Style of Too Late Capitalism, London 2023.
7 Ibid., p. 65.
8 This is quoted in ibid. [italics in original].
9 Cf. Raymond Williams: Marxism and Literature, Oxford 1977.

neoliberalism,[10] even as we have become networked in ways that facilitate our status as neoliberal self-optimisers. Examining the effects of this shift on how we use our bodies, Hakim explains that while it has historically been women who have been »incited to sexualise their bodies« for financial gain,[11] in this contemporary moment, employment opportunities for workers of *all* genders have become increasingly scarce, even as platforms which induce forms of entrepreneurial subjectivity have proliferated. Perhaps this suggestion that memoir writers are to be thought of as workers appears beyond the purview of literary studies, yet this invitation to begin literary analysis by thinking about its objects as products of *labour* is of a piece with the cultural materialist lens I adopt in this chapter. By situating the memoir boom within its material context of both scarcity on the one hand, and the promise of validation and even celebrity on the other, we reframe works of art as the product of *work*, rather than confining art to a sphere separate from work and production.[12] We should understand life-narrative as working with and making use of a wider cultural turn to the self. This turn comprises both a twentieth-century emphasis on self-government underpinned by the progressive dominance of the *psy* disciplines as a key source of knowledge about the human,[13] and a more recent shift towards the valorization of entrepreneurial modes of subjectivity. For Byung-Chul Han, »the neoliberal subject has no capacity for relationships with others that might be free of purpose«.[14] While this may be a bleak assessment of the state of social relations and their total penetration by the imperative to monetise the self, it can move us beyond modes of analysis that would censure people for writing life-narratives seemingly for personal gain.

In this chapter I can only address a small portion of a wider project exploring the ›cultural turn to the self‹. I focus on the fate of practices of interpreting disability (Mitchell and Snyder, 2000), in relation to the twenty-first century memoir boom and self-curatorial digital practices. Whereas in 2000, the radical potential of *interpreting* disability's literary meaning was a focal point, I argue that today our focus has shifted onto the *sharing*, or *telling*, of disability stories. Sharing has been a locus of attention in digital media

10 Cf. Jamie Hakim: Work That Body. Male Bodies in Digital Culture, Lanham, MD 2019.
11 Ibid., p. 3.
12 Cf. Michèle Barrett: ›Materialist Aesthetics‹, in: New Left Review 1/126 (March-April 1981), pp. 86–93.
13 Cf. Nikolas Rose: Governing the Soul. The Shaping of the Private Self, London [2]1999.
14 Han: Psycho-politics, p. 2.

studies, but it has not been extensively explored in relation to the literary anchor concept of *interpretation*. I focus on memoir rather than autobiography because of the way that it is the former genre that has generally been adopted by writers who have a ›disability story‹ to tell, since memoir is deployed to tell a story with a particular thematic or emotional focus[15] – in this case, disability experience. Couser posits two types of memoir, the »somebody memoir« and the »nobody memoir«:[16] the latter is written by someone who is unknown and not already in the public eye, and who makes use of the form to reach an audience. The autobiography form, which typically narrates a life in its entirety,[17] is much more likely to be useful to figures who are already celebrities and already have a readership (and thus a market) on the basis of that celebrity. Thus, the »nobody memoir«, and the ways in which it promises recognition, success and celebrity, is a locus of interest due to the way in which it is a key genre of contemporary self-curatorial culture.

I begin by briefly dwelling with *self-representation* as a historical and contemporary practice with particular significance in disability studies, before turning to a section from a contemporary memoir written by a parent of a disabled child which puts forward the idea that the arrival of disability in the life of a parent »demands a story«.[18] I suggest the affordances of memoir as a form, and the entanglement of memoir culture within a naturalised entrepreneurialism of the self, lead the genre to reproduce a dominant idea of disability-as-exception.[19] I contend that even when individual memoirists seek to operate on the terrain of the political, calling for structural change, the constraints of the memoir form ultimately generate what Lauren Berlant calls a »scene of the generally human«,[20] and reinforce an idea that »everyone

15 Popular perceptions of the genre distinction are interestingly confirmed by blogs addressed to aspiring writers, published by companies that have a vested interest in the writer purchasing their software or content creation: see Doug Landsborough: Memoir vs Autobiography. What's the difference? www.dabblewriter.com/articles/memoir-vs-autobiography (12.2.2024) and The Urban Writers: A Path of Self-Discovery: Autobiography vs. Memoir. theurbanwriters.com/blogs/publishing/a-path-of-self-discovery-autobiography-versus-memoir (10.4.2025).

16 G. Thomas Couser: Signifying Bodies: Disability in Contemporary Life Writing, Ann Arbor 2009, p. 1.

17 See the blogs cited earlier in this paragraph.

18 Mitchell/Snyder: Narrative Prosthesis, p. 54.

19 Cf. Jasbir K. Puar: The Right to Maim. Debility, Capacity, Disability, Durham, NC 2017; see also Amanda Apgar: The Disabled Child. Memoirs of a Normal Future, Ann Arbor 2023.

20 Lauren Berlant: The Female Complaint: The Unfinished Business of Sentimentality in American Culture, Durham, NC 2008, p. 41.

has a story to tell«.[21] Whilst appearing to bring everyone inside the tent, the idea that »everyone has a story to tell« serves to mask differential access to the means of telling one's story. As such, I argue that it valorises the *telling of the story* itself in favour of any interpretive work, and leaves disability exceptionalism intact, re-invisibilising certain sorts of stories.

This chapter, while not a new departure for my work, is nonetheless work-in-progress, and I am still working through these ideas on ›interpretation‹ in 2020s literary disability studies. To further underpin and substantiate these ideas, a longer piece of work – comprising more comparative textual analysis – would be needed. In the meantime, I present here some initial reflections on how ›sharing disability‹ and the commodification of experience may be understood to be working in a memoir from 2013, Rachel Adams' *Raising Henry: A Memoir of Motherhood, Disability and Discovery*, alongside some theoretical reflections on the memoir form and its close relatives or progeny (autofiction; autotheory; self-curatorial culture more generally). I compare these with the framing of disability's narrative arrival in *Narrative Prosthesis*.

## Represent yourself! Emancipation or self-extraction?

The title of my chapter parrots the silent imperative of the platform-capitalist era of the 2020s: ›represent yourself!‹, which contains within it an invitation to ›build your stock‹.[22] I am intentionally invoking representation as a multivalent concept that has some specific histories pertaining to disability. Firstly, my title alludes – of course – to the preoccupation, within literary disability studies, with the *representation* of disabled people. Secondly, the field is engaged with questions of who gets to, or should be allowed to, represent disabled people. The idea of self-representation is historically linked with emancipatory discourses in disability studies, exemplified in the activist maxim: ›nothing about us without us‹. Thirdly, the verb form of ›to represent‹ is associated with legal and advocacy contexts as well as Public Relations (PR)

21 Anna Poletti: Coaxing an Intimate Life. Life Narrative in Digital Storytelling, in: Continuum 25:1 (2011), pp. 73–83, p. 76. N.B. In using this phrase, Poletti is quoting from Daniel Meadows: Digital Storytelling: Research-based practice in new media, Visual Communication 2:2 (2003) pp. 189–193, p. 190.

22 To my knowledge, this latter phrase is not used exactly in this form by the writers with whom I am in dialogue here. Yet the phrase is consonant with a contemporary cultural imperative placed upon the individual to try to create capital out of the self, which is discussed by figures including Byung-Chul Han, Jodi Dean, Jamie Hakim and Anna Kornbluh.

contexts. In literary studies, when academics talk about representation, we are not usually thinking about PR, or literary agents, yet today, in the era of the social media industry, everyone is their own PR arm. This PR version of ›self-representation‹ participates in a shadow economy of meaning that underpins so-called ›empowered‹ modes of self-representation. How should we understand this ›empowerment‹ and its relation to self-exploitation? How has the line between the two become so blurred and faint?[23]

The memoir form – and the more recent formations of ›autofiction‹ and ›autotheory‹ – can be interestingly understood in relation to a slippage between emancipatory self-representation and a self-extractive, yet desired, demand to ›perform‹ the self in the public sphere. My title seeks to unpick the effects of this uneasy co-existence of *emancipation* and *self-extraction* – which ought to pull in opposite directions – on the representation of disability in 2020s writing. On the one hand, access to the means of self-expression is seemingly democratised in the 21st century with the rise of communication technologies, yet it is the affordances of these technologies – how they shape our articulations, and enable certain modes and genres of articulation to dominate – that give primacy to an idea that emancipation *is* the sharing of experience. As Poletti intriguingly argued during the early part of the transformation of the social sphere by social media, discourses of community and inclusion within the context of digital storytelling workshops naturalise a notion that ›everyone has a story to tell‹.[24] Poletti draws on Smith and Watson's[25] work on autobiographical writing to argue that life narratives in the digital storytelling context need to be understood as ›coaxed‹ – that is, they are brought about in a relational context, in response to environments, to norms, and to expectations. For Poletti, the digital storytelling movement places emphasis on »the power of story to foster community bonds through exchange of narratives of life experience«.[26] While written in 2011 and focussed on the uses of a specific practice of digital storytelling, this article seems prescient in its identification of a now-pervasive reification of ›story‹ as a social or therapeutic tool.

23 This is the argument that Han makes in Psychopolitics.
24 Cf. Poletti: Coaxing an Intimate Life.
25 Cf. Sidonie Smith/Julia Watson: Reading Autobiography. A Guide for Interpreting Life Narratives, Minneapolis and London 2001.
26 Poletti: Coaxing an Intimate Life, p. 76.

In relation to mental health, we have seen the concept of the »Recovery Narrative« analysed as a »technology of recovery«.[27] We might think of this, too, as a form of ›coaxed‹ narrative. The embedding of the ›arts in health‹ movement in 21st century Britain has seen the proliferation of opportunities for service users to access creative wellbeing activities that rely on, or make use of, the individual's story or lived experience (e.g. bullet journaling), yet these activities often happen within an entrepreneurial but disjointed project economy which exploits those employed in the so-called ›creative industries‹ willing to put time into ›passionate work‹.[28] In the UK of the 21st century, activists have struggled without reward for more progressive taxation to allow disabled people to lead dignified lives, but disabled people are everywhere able to encounter stories, endless stories of what their lives are like, and the obstacles they have overcome.[29]

In the UK, emancipation and self-extraction come together in the irony of health and social care policies that theoretically empower disabled people to live independently but that simultaneously require them to do work for free in order to enable this.[30] For example, personal assistance (PA) is a »model of support where disabled people take control of recruiting, training and managing the people that support them«,[31] and in many respects this has been an enabling and »empowering« model.[32] It moves away from a model of disabled people as the subjects of *care*,[33] instead placing them in the structural position of the employer, with the sorts of power linked to this role. Yet this structural position carries responsibilities, and entails work: the budget holder will usually have to put in the hours to interview people for the PA role, and to

27 Angela Woods/Akiko Hart/Helen Spandler: The Recovery Narrative. Politics and Possibilities of a Genre, in: Culture, Medicine and Psychiatry 46 (2019), pp. 221–247, p. 221.

28 Cf. Angela McRobbie: Be Creative. Making a Living in the New Culture Industries, Cambridge 2015; see also Frances Williams: When was Arts in Health? A History of the Present, Singapore 2023; William Viney: What is a Medical Humanities Project?, in: The Polyphony, 18 June 2024. thepolyphony.org/2024/06/18/med-hums-projects/ (10.4.2025).

29 Cf. Eli Clare: Exile and Pride. Disability, Queerness and Liberation, Durham, NC 2015.

30 At the time of writing, social support for disabled people in the UK is under threat, and the policy arrangement discussed here cannot be taken for granted.

31 Tom Porter/Tom Shakespeare/Andrea Stöckl: Performance Management. A Qualitative Study of Relational Boundaries in Personal Assistance, in: Sociology of Health and Illness 42:1 (2020), pp. 191–206, p. 191.

32 Tom Shakespeare/Tom Porter/Andrea Stöckl: Personal Assistance Relationships. Power, Ethics and Emotions, Report for the Economic and Social Research Council 2017. www.sdsscotland.org.uk/wp-content/uploads/2017/07/PA-Relatiionship-Power-Ethics-EmotionsUAEJune-2017.pdf (10.4.2025), p. 33.

33 Cf. Porter/Shakespeare/Stöckl, Performance Management.

upskill themselves so that they know how to act as an employer. Furthermore, as Porter et al. note, a »striking feature of PA in the UK is the relative lack of regulation governing its organisation«,[34] enabling it to be deployed flexibly by different budget holders, but also allowing for ambiguity and lack of boundaries in terms of role definition.[35] In these contexts, disabled people thus end up ›representing‹ themselves for free. A model that is ostensibly empowering for disabled people implicitly makes a demand that the disabled person undertake work for free as a condition of accessing this empowerment and this ability to represent themselves.

## Disability as narrative prosthesis

In this complex ecology where emancipation works via subtle, or not so subtle, mechanisms of self-extraction and self-optimisation, and thus might be more accurately termed ›pseudo-emancipation‹, how can we think about the changing »representational fate« of disability as a stigmatised social category?[36] For Mitchell and Snyder, writing in 2000, disability is not just a stigmatised social category; it is *doing* something within narrative. From the Greek »placing + to add«, a prosthesis is a tool that supplements or even augments something – a body, or a narrative.[37] It is a tool that may serve to mask disability, and an instrument upon which a disabled person may rely to perform particular actions that bodies deemed ›normal‹ can perform without prosthesis. *Disability* as *narrative prosthesis*, then, is a concept that helps us to articulate the myriad ways that disability is called upon to do work that props up, generates and progresses the movement of narrative itself. Disability is *itself* a prosthetic device for narrative: it augments, it *enables* (paradoxically, perhaps).

Disability arrives in a story as a focus of inquiry and curiosity, inviting us to interpret. Mitchell and Snyder argue that it is a »stock feature of characterization« and an »opportunistic metaphorical device« in literature leading to an idea that literature ›depends‹ on disability to do narrative work – disability as *narrative's* crutch.[38] I think the crutch concept can still be widely

34 Ibid., p. 192.
35 Cf. ibid. and Porter/Shakespeare/Stöckl: Performance Management.
36 Mitchell/Snyder: Narrative Prosthesis, p. 6.
37 Oxford English Dictionary (2023) »prosthesis (n.), Etymology«, July 2023, doi.org/10.1093/OED/6876898764 (10.4.2025).
38 Mitchell/Snyder: Narrative Prosthesis, p. 48.

understood as animating contemporary Anglophone literary culture, although arguably it is a crutch that publishers have seized upon. What is different in contemporary memoirs of disability experience, in comparison with Mitchell and Snyder's historical archive, is that disability is no longer a ›stock feature of characterization‹. It is not used metaphorically or unwittingly in the present cultural context, and this of course can and should be understood as at least partly an outcome of twenty years of disability scholarship on Anglo-American cultural politics. Yet I will argue that one of the unintended, and under-explored, consequences of this progress is that *interpreting* disability as a literary *trope* has been replaced by *sharing* disability as a *lived experience* that accrues value for ›*me*‹. In the case of parental writing about raising disabled children, upon which I focus here, the practice of sharing seems to aim towards the recuperation of personhood for the child.[39]

You might ask: in making this claim about the movement from interpreting to sharing, am I confusing the job of the literary critic with the job of the writer herself? Surely, in conventional understanding at least, the former tends to do the *interpreting* and the latter the *sharing* – how can I say that the one activity has replaced the other if I am comparing practices that sit mainly within the remits of different professions? Yet, with the rise of ›autotheory‹, the boundaries between different disciplinary modes of writing have become blurred. Just as in the 2020s, the work of Public Relations is now something everyone can do for themselves, building a brand via a digital platform, so, with autotheory, the literary writer has become her own critical theorist. As Kornbluh argues – drawing on a 2015 interview with one of the figures who is considered to have founded autotheory, Maggie Nelson – we are now in a post-disciplinary moment in the academic humanities, where, in order to make oneself employable, flexibility across different disciplinary modes of writing is paramount.[40] Some of the most successful public intellectuals, such as Nelson, argue for a »lack of partition« between so-called ›creative‹ and ›critical‹ writing.[41] Indeed, literary critics may also be becoming more ›literary‹ in their writing.[42]

39 Cf. Amanda Apgar: The Disabled Child. Memoirs of a Normal Future, Ann Arbor 2023.

40 Kornbluh: Immediacy, p. 83; see also McCrary, Micah: Riding the Blinds, in: Los Angeles Review of Books, 26 April 2015. lareviewofbooks.org/article/riding-the-blinds/ (10.4.2025).

41 Ibid.

42 See Stephen Benson/Clare Conners: Introduction, in: Benson, Stephen/Conners, Clare (eds.): Creative Criticism. An Anthology and Guide, Edinburgh 2014, pp. 1–47.

While in this chapter I am focussed on ›memoir‹ as opposed to self-proclaimed ›auto-theoretical‹ writing, the memoir to which I now turn, *Raising Henry: A Memoir of Motherhood, Disability and Discovery*,[43] is written by a US disability studies academic, whose academic output engages with themes similar to those taken up in the memoir. While it was published in 2013 – prior to the popularisation of autotheory – and is formally akin to memoir in its adoption of a broadly chronological, non-experimental narrative, *Raising Henry* is not without allusion to disability as an academic and political issue, nor is Adams the only disability studies academic to venture towards a memoir recounting the experience of raising a disabled child. Earlier US examples of literary studies scholars who have crossed over to write a memoir for a general audience include Michael Bérubé, whose *Life as We Know It: A Father, a Family and an Exceptional Child* was published in 1996, and Ralph James Savarese, whose *Reasonable People: A Memoir of Autism and Adoption* was published in 2007. Indeed, Bérubé's work is discussed by Adams, who recounts her email exchange with Bérubé soon after Henry has been diagnosed. We can thus see that memoir operates as a site for working through the stigma of parenting a disabled child[44] and as a site of value-recuperation for parents with access to writing outlets.[45] This usage of the memoir form precedes the turn to autotheory. Indeed, the dual writing-identity occupied by such figures may in some ways foreshadow or enable the rise of autotheory. This is because the dual writing-identity highlights an opportunity available to academics working within the »identity knowledges« who wish to create audiences (and impact) for their thinking and their politics beyond academia.[46] In the era of the crisis of the humanities and long-term precarity in the academy, flexibility in terms of what one can write – and whom one can write for – is widely perceived as an advantage.[47] It is not coincidental that student numbers on creative writing programmes have exploded in recent years, as numbers have declined in other humanities subjects.[48] As Kornbluh puts it, »flexibility […]

43 Cf. Rachel Adams: Raising Henry. A Memoir of Motherhood, Disability and Discovery, New Haven and London 2013.

44 Harriet Cooper: Spoiled Identity and the Curated Self. Narrativising Stigma in Parents' Memoirs of Raising Disabled Children, in: Thomas, Gareth/Spratt, Tanisha/Williams, Oli/Chandler, Amy (eds.): Recalibrating Stigma. Sociological Perspectives on Health and Illness, Bristol (forthcoming).

45 Cf. Apgar: The Disabled Child.

46 Robyn Wiegman: Object Lessons, Durham, NC 2012, p. 5.

47 Cf. Kornbluh: Immediacy, p. 51.

48 Cf. ibid.; Cowan: Against Creative Writing.

has been the buzzword of circulation capitalism, often gilded with aesthetic cachet as a ›creative economy‹«.[49] Thus, being able to inhabit the role of the critic *and* the writer potentially opens doors to the monetising of the self. As such, it should not be a surprise, then, to discover that in the 2020s, the activities of interpreting and sharing come together in the single figure of the flexible writer and analyst of disability narratives.

It should be noted that Nelson explicitly distances *The Argonauts* from the category of memoir in the McCrary interview, observing that she is »always looking for terms that are not memoir«.[50] Implicitly, memoir is positioned here as a middlebrow cultural form, and one that is by-definition not experimental in the way that autofiction and autotheory supposedly are. However, the earlier memoir boom (and its connections with academia) is not, I think, incidental to the formation of new genres of self-writing that are pioneered by Maggie Nelson, Paul B. Preciado and others.

Before turning to Rachel Adams' memoir, it feels important to briefly note my discomfort with the work of ›critiquing‹ what a parental memoir is doing, as if I could somehow extricate myself from the capitalist relations of the creative economy that I discuss in relation to life-writing. In Cooper (forthcoming), a book chapter that also examines Adams' memoir, alongside another, I wrote:

> I write as someone who is myself drawn to life-writing and auto-ethnography as practices for exploring complex and reciprocal psychosocial relations – between the personal and the political, the individual and the collective, the psychic and the socio-cultural, the experiential and the representational. In *Critical Disability Studies and the Disabled Child: Unsettling Distinctions*, I used ›personal writing‹ as a method of working with and against academic writing, as a mode of unsettling an academic discourse that might otherwise proceed as if it could be ›sure of itself‹ and its mode of critique. […] I am ambivalent about the idea that my reading of these [memoirs] should take the form of an ›exposition‹, as if these texts do something that I – as literary critic – would not use writing to do. […] As someone who identifies both with the experience of having been a disabled child, and more recently with that of being a parent, the worlds of these memoirs are ones that are close to my life and to my heart.[51]

These words also apply here. The motive of wanting to recuperate value, or accrue value to the self, through writing is not something from which I am immune.

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49 Kornbluh: Immediacy, p. 85.
50 McCrary: Riding the Blinds, n. p.
51 Cooper: Spoiled Identity [forthcoming].

## Sharing disability's arrival

In this section I compare and contrast Mitchell and Snyder's (2000) work on the disability-as-that-which-produces-meaning-making with a notion of disability-as-that-which-is-to-be-shared by using the example of Rachel Adams' memoir. A common trope in the genre of parental memoirs is the sense that disability's arrival is a story-worthy event.[52] Indeed, for Mitchell and Snyder, disability also functions in this way, and, as a result, narrative has a »prosthetic relation to physical difference«.[53] However, the emphasis for Mitchell and Snyder is on *identifying narrative's reliance* on exceptionality and the sense in which narrative is not self-sufficient, but is instead incomplete without the very thing it posits as incomplete – the disabled body. By contrast, the emphasis in parental life-writing is (as we might also expect) on the *burdens* of exceptionality, which in this context lead the author towards forms of sharing via narrative.

In *Raising Henry*, Rachel Adams observes of her experience of mothering a child with Down syndrome: »We live in a world where a baby like Henry demands a story«.[54] The ›world‹ of this statement is one where, it is implied, disability's arrival is out of the ordinary, requiring explanation. Adams recounts that »more than one friend responded [to the news of Henry's diagnosis] by asking how this could have happened to me«.[55] There is incredulity that Adams did not have a pre-natal test; indeed one of the people who questions this decision is a disability studies professor, Adams tells the reader ruefully. This course of action, too, seems to demand a story. This account aligns with Mitchell and Snyder's observation that »[a] subject demands a story only in relation to the degree that it can establish its own extra-ordinary circumstances«.[56] Drawing on Puar's work, we can understand the relationship posited here between disability and narrative as one of ›representational politics‹.[57] Puar proposes that the primary framing of disability in the Anglo-American academy since 2000 is the lens whereby disability's visibility is tied to its exceptionality, which is problematic in terms of how we are then led to see others whose lives do not reach the threshold of visibility. In this chapter I am interested in asking how the cultural shifts of the last

52 Cf. Apgar: The Disabled Child; Cooper: Spoiled Identity; Couser: Signifying Bodies.
53 Mitchell/Snyder: Narrative Prosthesis, p. 54.
54 Adams: Raising Henry, p. 108.
55 Ibid., p. 107.
56 Mitchell/Snyder: Narrative Prosthesis, p. 54.
57 Cf. Puar: The Right to Maim.

twenty years make a difference to who is able to *make use* of this dominant framing of disability (and who, implicitly, is not), and why that matters.

The ›how could this have happened‹ question arises elsewhere in accounts of disability's arrival. Garland-Thomson writes movingly of her own experience of the »relentless ›What happened to you?‹« question, which was »asked sometimes with eyes and sometimes words« in the period before she discovered either feminism or disability studies.[58] Meanwhile, in her recent study of memoirs written by parents of disabled children, Apgar writes that »disability memoirs respond to a shared cultural understanding of disability as unexpected and in anticipation of the question, ›What happened to you?‹«.[59] Perhaps this question has long intruded into disabled people's lives in modernity and postmodernity, evidenced by the body of writing from the 1980s on the narrative work that disabled and chronically ill people found themselves doing to make sense of the »biographical disruption« that acquired impairment seemed to signify.[60] Yet, in the era prior to the curated self of platform capitalism, it was not so easy for the average person to ›respond‹ publicly to this interpellation, nor was the average person expected to respond or tell their story in quite the same way.

The ›what happened to you?‹ question interests and troubles Adams. She observes, rhetorically:

> Babies like Henry simply aren't born to successful, overeducated parents like us. Something must have gone terribly wrong. Many people seemed to believe that knowing what that something was would help to ensure it would never happen to them.[61]

The memoir unpicks the discourse of parental responsibility that has been folded into the naturalising of pre-natal testing for Down's syndrome in the Anglo-American context. Dominant cultural understandings that position Down Syndrome as, in Thomas' words, »worthy of detection and elimi-

58 Rosemarie Garland-Thomson: The Story of My Work. How I Became Disabled, in: Disability Studies Quarterly 34:2 (2010). dsq-sds.org/index.php/dsq/article/view/4254/3594 (10.4.2025).

59 Apgar: The Disabled Child, p. 16; Apgar cites Couser: Signifying Bodies, p. 16.

60 Cf. Mike Bury: Chronic Illness and Biographical Disruption, in: Sociology of Health and Illness 4:2 (1982), pp. 167–182; see also Kathy Charmaz: Loss of Self. A Fundamental Form of Suffering in the Chronically Ill, in: Sociology of Health and Illness, 5:2 (1983), pp. 168–195; Gareth Williams: The Genesis of Chronic Illness. Narrative Reconstruction, in: Sociology of Health and Illness 6:2 (1984), pp. 175–200.

61 Adams: Raising Henry, p. 108.

nation«, are in evidence in Adams' friends' surprise at her decision not to have a test.[62]

Accentuating the difference between her own memoir and others in this parental genre which might more readily use writing as a chance to respond directly to the ›what happened to you?‹ question, Adams instead seeks to *deconstruct* the question and query the assumptions underpinning it about the constitution of a good life. Yet, while developing a politics of parenting around the refusal to answer the ›what happened to you?‹ question straightforwardly in *Raising Henry*, Adams nonetheless also deploys life-narrative to tell a story about disability. In a way, then, the memoir confirms, by its very existence, the maxim that »everyone has a story to tell«.[63] It centres life narrative as a way of answering to the ›what happened to you?‹ question. If one cannot change the way the world is structured, one can at least mobilise one's story.

The very existence of this memoir is evidence that Adams is interpellated by the stigmatising question ›how could this happen?‹.[64] On the one hand, *Raising Henry* problematises the narrative of Henry's life as a tragedy or a »failure of medical science«.[65] Yet, on the other hand, Adams' statement about the *demand* for a story reveals the potent narrative relations within which the arrival of the disabled child is already entangled in this culture. This statement furthermore reveals the hegemony of what Kornbluh calls »memoirization« and the »elevation of the individual subject's lived experience to literary treatment«.[66] In the next section, I reflect on the consequences of this shift for the representation of disability.

## Naming disability

For Mitchell and Snyder (2000), the arrival of physical difference in fiction activates narration; it brings about the work of meaning-making. Mitchell and Snyder also allude to the way in which disability's arrival demands a story, but in contemporary self-representational practices, including the parental memoir, it is the *naming* of disability that comes first. Disability is named

62 Gareth M. Thomas: »We wouldn't change him for the world, but we'd change the world for him«. Parents, Disability, and the Cultivation of a Positive Imaginary, in: Current Anthropology 65:26 (2024), pp. S32–S54, p. S35.
63 Poletti: Coaxing an Intimate Life, p. 76.
64 Cf. Adams: Raising Henry, p. 107.
65 Ibid.
66 Kornbluh: Immediacy, p. 96.

in memoir titles and blurbs, setting up particular expectations for the type of story that will follow.[67] This latter state of affairs can give an unhelpful and artificial solidity to disability; it reifies it, by which I mean that it gives it a phantom objectivity, or thing-ness, to follow the Marxist literary theorist Georg Lukacs.[68] This process is arguably so widespread today that it is virtually imperceptible: we relate to ourselves as things because – as Hakim argues – we extract value from ourselves in the absence of other modes of value creation.[69] Social media platforms are spaces in which our very identities – our tastes, our beliefs, our ability to phrase something well – accrue value in the form of cultural capital. For memoir-writers who are in the ›nobody‹ category, to use Couser's nomenclature for the writer who is not widely known at the point of seeking to publish, access to the publishing industry may be conditional upon having cultivated a following on a dominant platform.[70] Kornbluh notes that »virtually all authors in the contemporary market-place – autofictionalists or not – must have social media ›presence‹ as a precondition of book contracts«.[71]

Disability, if reified as an identity category, has the potential to accrue value. Arguably, it is the very stigmatising social relations in which disability has historically been entangled that create the potential for value-extraction. As Chi-Chi Shi has argued in a fascinating article on the operations of contemporary identity politics, »today, it is the confession of trauma, of ›tragic drama‹ as ›grand truth‹ that is the mark of the authentic self«, such that »expressions of oppression are reified as authenticity«.[72] For Shi, the dominance of such a confessional-tragic mode reduces the possibility of *political change* to a discourse on morality. The invocation of ›the tragic‹ links us back to Mike Oliver's original objection to a so-called ›individual‹ model of disability, whereby a narrative of personal tragedy prevails.[73] Meanwhile, for Apgar, the

67 Cf. Apgar: The Disabled Child.
68 Cf. Georg Lukacs: Reification and the Consciousness of the Proletariat, in: Lukacs, Georg: History and Class Consciousness, London (1967 [1923]), n.p.: transcribed online by Andy Blunden and available at www.marxists.org/archive/lukacs/works/history/hcc05.htm (11.4.2025).
69 Cf. Hakim: Work That Body.
70 This point is made by Kornbluh: Immediacy, p. 91.
71 Ibid.
72 Chi-Chi Shi: Defining my Own Oppression. Neoliberalism and the Demands of Victimhood, in: Special Issue of Historical Materialism on Identity Politics 26:2 (2018), www.historicalmaterialism.org/special-issue/issue-262-identity-politics (10.4.2025).
73 Cf. Michael Oliver: Social Policy and Disability. Some Theoretical Issues, in: Disability, Handicap and Society 1:1 (1986), pp. 5–17.

form taken by parental memoirs about raising a disabled child is that of a progress narrative moving from »tragedy-to-acceptance«.[74] Apgar situates her analysis of this ›template‹ used by parent memoirists within an approach that centres the material context of memoir production, noting that »it is the very writing of the memoir, in addition to its narrative arc, that engages a neoliberal project of self-improvement«.[75] Such narratives are, for Apgar, »attempts to recuperate a disabled child's access to a meaningful and valued place in the social world«.[76] It is telling that, due to differential access to the means of literary production, not all children's lives can be retrieved and recuperated via the memoir form.

Whereas in the examples Mitchell and Snyder discuss, literary disability studies comes in after the fact and names ›disability‹ as the narrative supplement, I am suggesting that in memoir culture, disability is the starting point, it is the explicit subject and the thing that has to be shared, with the goal of *recuperating a life*. In parental memoirs, disability is thus not open to interpretation in the same way, it is not ›*hypersymbolic*‹ in Mitchell and Snyder's terms.[77] Apgar's notion of a ›template‹ tells us something important about how we are primed to attend to disability in the contemporary moment of sharing culture. It tells us something about the cultural imaginary of what it means for a life to unfold, and for that life to belong to an individual. It tells us something about how disability is the unexpected, the ›what-happened?‹, the story-worthy exception.

## The long life of disability exceptionalism

It can be argued that, formally, the parental memoir genre affords the potential to reinforce a notion of disability as exception, to draw on Puar's framing.[78] As the unexpected arrival into a context of (to a greater or lesser extent) social privilege in the Global North, the disabled child of parental memoir is comprehensible as an exceptional figure. Indeed, as Puar's acute and careful discussion shows, Anglo-American disability studies is founded upon an im-

74 Apgar: The Disabled Child, p. 41.
75 Ibid., p. 5.
76 Ibid.
77 Mitchell/Snyder: Narrative Prosthesis, p. 10.
78 Cf. Puar: The Right to Maim.

plicit, shared understanding of disability as exception. That is, the visibility of the individuated disabled body is predicated upon the backgrounding of un-narrated population-level states of debilitation and ›slow death‹.[79] Puar suggests that a focus on the politics of representation within disability studies sets up certain »assumed subjects of disability«.[80] Puar's paradigm-shifting analysis demonstrates how the assumed (privileged) subject of disability is always already assumed as the subject of rights, and as the subject of representation; indeed, this subject's very representation happens at the expense of debilitated populations. Debilitated populations cannot be thought of, or retrieved for rights, in the same way as the singular, exceptionalised disabled individual that is the object of disability studies in the Global North. Puar thus demonstrates how dominant liberal disability discourses matter and can be complicit in maintaining a material and economic *status quo*: they can simultaneously celebrate disabled people's empowerment via representation, even as they operate to uphold geopolitical and economic norms. They thus allow the disempowerment and debilitation of certain populations to continue in the way that it has always done.

For Puar, ›narrative prosthesis‹ functions as a technology for masking the debilitating operations of capital, in the sense that it allows a fiction of narrative resolution (rehabilitation) and closure to remain hegemonic in how we think about disability: »this model of narrative that climaxes with the resolution of the disabled body as banished or functionally restored works to proffer imminent rehabilitation for disability in one sense while masking the maintenance of debilitation as an endemic state on the other«.[81] Through narrative prosthesis, Puar argues, we gain »the cultural artifacts for the fantasy of resolution«, even as »economic structures manifest the proliferation of debilitation«.[82] Disability stories progress and resolve; debilitation continues without remark. That debilitation *can* continue without remark is directly entangled with the *progression and resolution of disability stories*, Puar contends. With this in mind, I move on, before concluding, to discuss the ideological apparatus through which some of us are interpellated to tell our stories; through which particular, individual disability stories are able to appear.

79 Cf. Berlant: The Female Complaint; Puar: The Right to Maim.
80 Ibid., p. 20.
81 Ibid., p. 86.
82 Ibid., p. 87.

## ›Everyone has a story to tell‹

For Poletti, a key part of the apparatus of contemporary life-writing is the ubiquitous idea that ›everyone has a story to tell‹.[83] There is something coercive in the celebratory and inclusive rhetoric of ›everyone‹, which suggests an inadequacy if one does not feel oneself to have a story. It recalls Galen Strawson's objection to the idea that narrative is a universal experience.[84] Who is outside of, beyond, unreached, by ›everyone‹? Does this interpellation then frame *not telling* as outside of the norm, as withholding, as secretive, and thus in some way as suspicious? The teller of the story is highly visible, but where is the interpreter?

Furthermore, how does this simple and innocuous idea that ›everyone has a story to tell‹ serve to erase the ways in which *access* to the means of literary and cultural production are differentially distributed? How does it elide the way in which not everyone's story will reach the threshold of appearing as a ›story‹, that some people's continuous experience of debilitation and slow death will be backgrounded, not reaching the threshold of narrative?[85] How does it fail to tell us that not everyone will have the cultural capital or the literary connections to write a memoir? How does ›everyone has a story to tell‹ create a »scene of the generally human«, to quote Berlant,[86] that obscures the way in which certain bodies appear, and others fail to do so? Its focus on self-representation obscures the ways in which some lives are lived in ways that do not constitute a story.

The phrase ›everyone has a story to tell‹ obfuscates the differently distributed experience of the ›confessional‹ demand as a technology of power. As Woods et al. have argued, in UK mental health service contexts, service users are invited to perform a certain sort of successful subjectivity by sharing a story of ›recovery‹ that conforms to the genre of the ›Recovery Narrative‹ by demonstrating ›insight‹ into aspects of one's mental health.[87] If we think of the Recovery Narrative as an example of auto-theory – albeit with its own norms that go beyond those generic to auto-theory – then we can think of it as a practice of making use of and re-signifying the stigmatised self via the

83 Cf. Poletti: Coaxing an Intimate Life.
84 Galen Strawson: Against Narrativity, in: Ratio 17 (2004), pp. 428–452; see also Angela Woods: The Limits of Narrative: Provocations for the Medical Humanities, in: BMJ Medical Humanities 37 (2011), pp. 73–78.
85 Cf. Berlant: The Female Complaint; Puar: The Right to Maim.
86 Berlant: The Female Complaint, p. 41.
87 Cf. Woods/Hart/Spandler: The Recovery Narrative.

public demonstration of reflexive self-awareness. Woods et al. observe that the Recovery Narrative tends to be instrumentalised in health service contexts to mobilise a particular kind of narrative about ›patient empowerment‹, about learning to live well with mental ill health, or about the successes of the service in question. The genre implicitly contains an imperative to positivity. For philosopher Byung-Chul Han, one of the distinctive psycho-political features of neoliberal society is an »excess of positivity, that is, not negation so much as the inability to say no«.[88] Why is it that the telling of one's story is hailed as courageous, if in fact it would be the *not-telling* that would perform some sort of refusal in the era of digital sharing?

## Concluding thoughts

In this chapter I have argued that in contemporary self-curatorial culture, sharing a story of disability (as long as it is an inspiring one) has become the dominant mode of engagement with disability, and that this has consequences for how disability is discussed and understood in literary studies contexts. If disability is still ›*hypersymbolic*‹ in Mitchell and Snyder's archive, this is much less the case in the arena of contemporary memoir culture. It is through *sharing* disability that value is extracted; indeed, in the sharing economy of social media the ›what‹ of sharing matters much less than the fact that sharing is happening.[89] This is also signalled in the language of the idea that ›everyone has a story to tell‹; the focus is much less on what that story is than the fact that the individual has one.

In calling attention to the arrival of the disabled child as ›demanding a story‹ and her own wish to deconstruct the ›what happened to you?‹ question, Rachel Adams purposefully subverts the narrative expectations of the parental memoir genre. Adams identifies the way in which she is interpellated by the expectation of a need to offer a story about disability's arrival, and she seeks to highlight this impulse itself. And yet, a narrative unfolds that is, nonetheless, about learning to live with disability. The memoir form permits the work of de-stigmatising a life, but in necessarily following the progress of a life, it gets caught up in certain ways with a tragedy-to-acceptance template.[90]

88 Byung-Chul Han: The Burnout Society, Stanford CA 2015, p. 41.
89 Cf. Jodi Dean: Blog Theory, Feedback and Capture in the Circuits of Drive, Cambridge 2010.
90 Cf. Apgar: The Disabled Child.

One of the affordances of life-narrative – its ability to portray human suffering at the level of the individual – is also a limitation in the sense that it operates on the terrain of the moral rather than the political[91] and that it cannot tell us about population-level experiences that should be visible and politicised, but are not understood via representational politics.[92]

The bland maxim that ›everyone has a story to tell‹ gives us a clue about the cultural interest in the status of the *teller* as opposed to the listener or interpreter. The voice of the sufferer – in this case the parent of a disabled child – sharing *their own ›authentic‹* story, offering *their own insights*, is what matters and is what generates value, via the act of sharing. Thus, while Rachel Adams may refute the terms of the question that gets posed interrogating her about ›what happened‹ opening out instead onto the terrain of histories of disability exclusion, that her refutation is enclosed within the form of the memoir limits it to ›a scene of the generally human‹ such that any re-signification of disability stays within this »ideology of true feeling«.[93] Our engagement with the story has made us feel something, and that somehow becomes enough. Within this context, I argue that there is a compulsion to ›share‹ disability stories, but how far do these stories continue to inaugurate the act of interpretation?

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91 Cf. Shi: Defining my Own Oppression; Berlant: The Female Complaint.
92 Cf. Puar: The Right to Maim.
93 Berlant: The Female Complaint, p. 41.

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