Klaus Birnstiel / Harriet Cooper /
Johannes Görbert (eds.)

Literary and Cultural Disability Studies

British and Continental Perspectives

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Johannes Görbert, on behalf of the editors

Literary and Cultural Disability Studies. British and Continental Perspectives. Introduction

The emergence of disability studies as a critical paradigm in the humanities and social sciences has fundamentally transformed scholarly approaches to embodied difference in literary and cultural texts.[1] This transformation extends beyond mere methodological innovation to encompass profound reconceptualisations of how bodily and cognitive difference function as sites of social signification and cultural interpretation. While Anglophone disability studies has established robust theoretical frameworks over several decades starting in the 1990s, including the social model of disability, cultural and identity-based approaches, Continental European scholarship of the twenty-first century increasingly contributes distinct intellectual traditions and methodological innovations that both challenge and enrich these well-known paradigms. These Continental approaches include phenomenologically-informed analyses of lived experience drawing on philosophical traditions from Husserl to Merleau-Ponty; critical engagements with biopolitical frameworks influenced by Foucauldian discourse analysis; applications of systems theory derived from Luhmannian sociology; and nuanced interrogations of institutional practices shaped by distinctive European welfare state histories and social policy contexts, for example in the Nordic countries. Such approaches have generated productive theoretical tensions with Anglophone paradigms while advancing distinctive conceptual vocabularies for analysing embodied difference.[2]

This edited collection, emerging from an international and interdisciplinary conference at the University of Fribourg, Switzerland, in November 2023, represents one of the first systematic attempts to facilitate substan-

1 This transformation builds on foundational work by scholars like Lennard J. Davis (Enforcing Normalcy, London, New York 1995) and Rosemarie Garland-Thomson (Extraordinary Bodies, New York 1997), who established disability as a critical category for literary and cultural analysis.

2 See Anne Waldschmidt: Disability Studies zur Einführung, Hamburg 2020 for a comprehensive overview that bridges German-language and international disability studies perspectives, and Dan Goodley: Disability Studies. An Interdisciplinary Introduction, London ^{3}2024 for a thorough introduction to Anglophone disability studies frameworks and methodologies.

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tive dialogue between these scholarly strands. The conference, organised through the Deutsche Forschungsgemeinschaft (DFG; German Research Foundation)-funded research network »Inclusive Philology: Literary Disability Studies in the German-Speaking Realm«, advances a dual intervention: it seeks to anchor disability studies approaches more firmly within German-language literary scholarship while simultaneously challenging the epistemological premises of national and disciplinary boundaries in disability studies research.[3]

The volume's transnational and translingual orientation reflects pivotal developments in contemporary disability studies scholarship. As researchers increasingly interrogate the boundaries of predominantly Anglophone frameworks, new theoretical possibilities emerge through sustained engagement with diverse intellectual traditions.[4] The methodological scope represented here – ranging from philosophical analysis to spatial theory, from narratological approaches to institutional critique – exemplifies not only the intellectual sophistication that emerges through transnational dialogue but also the transformative potential of interdisciplinary encounters. This theoretical heterogeneity enables multifaceted engagements with disability as a complex sociocultural phenomenon while fostering critical reflection on the situatedness of knowledge production itself.

The contributions of this volume intervene at an important moment in the field's evolution. As disability studies gains further prominence in Continental European academic institutions, the field's engagement with established Anglophone scholarship generates productive theoretical tensions while simultaneously advancing individual perspectives shared by distinct intellectual genealogies. These fusions are already evident in several significant scholarly interventions: Tobin Siebers' integration of Continental phenomenology with North American cultural disability studies in his concept of ›complex embodiment‹;[5] Robert McRuer's incorporation of Deleuzian theoretical frameworks within crip theory to analyse transnational disability

3 Cf. the network's website https://www.germanistik.uni-muenchen.de/forschung/proj_ndl_baukasten/inklusive_philologie/index.html (31.1.26) for an overview about its activities.

4 Recent work on transnational disability studies includes Sharon L. Snyder/David T. Mitchell (eds.): Cultural Locations of Disability, Chicago 2006 and Robert McRuer: Crip Times. Disability, Globalization, and Resistance, New York 2018. Cf. also Linda Leskau/Tanja Nusser/Katherine Sorrels (eds.): Disability in German-Speaking Europe. History, Memory, Culture, Rochester, NY 2022.

5 Cf. Tobin Siebers: Disability Theory, Ann Arbor 2008.

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formations;[6] Margrit Shildrick's synthesis of Derridean deconstruction with feminist disability studies to reconceptualise vulnerable embodiment;[7] and Dan Goodley's deployment of critical psychoanalytic approaches derived from Continental traditions to interrogate normative constructions of developmental difference.[8] Similarly, European disability scholars such as Anne Waldschmidt have engaged productively with Anglophone disability rights frameworks while maintaining distinctive Continental theoretical orientations rooted in Foucauldian discourse analysis and Bourdieusian concepts of symbolic power and social fields.[9] The volume thus instantiates how different scholarly traditions can mutually inform and transform theoretical paradigms. Perhaps most significantly, it delineates how rigorously contemporary literary and cultural disability studies has transcended traditional motif analysis to develop refined theoretical paradigms that profoundly reconceptualise questions of embodiment, representation, and social discourse.[10]

The volume's twelve contributions coalesce around four intersecting domains that characterise contemporary disability studies. These domains, although distinct in their methodological emphases, lay bare significant conceptual overlaps that bring to light the field's increasing theoretical sophistication and interdisciplinary reach.

Theoretical Foundations and Critical Frameworks

The analytical approaches deployed throughout these contributions demonstrate the productive dialogue between established disability studies paradigms and emerging theoretical innovations. This section examines fundamental epistemological interventions that are currently reshaping disability

6 Cf. Robert McRuer: Crip Theory. Cultural Signs of Queerness and Disability, New York 2006.

7 Cf. Margrit Shildrick: Dangerous Discourses of Disability, Subjectivity and Sexuality, New York 2012.

8 Cf. Dan Goodley: Dis/ability Studies: Theorising Disablism and Ableism, London 2014.

9 Cf. Anne Waldschmidt: Symbolische Gewalt, Normalisierungsdispositiv und/oder Stigma? Soziologie der Behinderung im Anschluss an Goffman, Foucault und Bourdieu, in: Österreichische Zeitschrift für Soziologie 36 (2011), pp. 89–106.

10 This evolution mirrors broader theoretical developments in disability studies in general, particularly the move from social model approaches toward more and divergent theoretical frameworks incorporating phenomenology, critical theory, and intersectional analysis. See, for example, Alison Kafer: Feminist, Queer, Crip, Bloomington 2013; Ellen Samuels: Fantasies of Identification. Disability, Gender, Race, New York 2014; and Tanya Titchkosky: Disability, Self, and Society, Toronto 2003.

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studies scholarship, with particular attention to how philosophical inquiry, interdisciplinary methodologies, and evolving disciplinary formations generate new conceptual possibilities. The contributions show how theoretical innovation emerges from the dialectical relationship between canonical scholarly traditions and emergent critical perspectives, particularly in the dynamic exchange between different national intellectual traditions and their distinct methodological genealogies. Of particular significance is how these developments reconceptualise not only the objects of analysis but also the methodological foundations of disability studies scholarship itself.

Tom Shakespeare's (London School of Hygiene and Tropical Medicine) opening contribution, »On Impairment and Disability« advances a nuanced critique of prevailing theoretical paradigms while developing innovative conceptual approaches for analysing embodied difference. Through sustained engagement with Elizabeth Barnes' influential work *The Minority Body* (2016), Shakespeare interrogates two dominant yet potentially limiting approaches: the social model's systematic elision of impairment's materiality and Barnes' »mere difference« conceptualisation of disability. His analysis deploys Wittgensteinian philosophical tools – particularly the concepts of family resemblance and rule-following – to sketch out a theoretical apparatus that synthesises embodied materiality with social constructivist perspectives. Especially crucial to his argument is Shakespeare's theorisation of what he terms the »apparent paradox« of disability: the complex dialectic between impairment's potential negative valence and the possibility of flourishing with impairment. His contribution thus offers analytical standpoints that transcend reductive binary dichotomies while maintaining crucial connections to embodied experience and social reality.

Stuart Murray's (University of Leeds) »Creating In/Disciplined Work in Medical Humanities and Disability Studies« focuses on the complex dialectic through which disciplinary boundaries simultaneously constitute and constrain critical engagements with health and disability. Mobilising Donna Haraway's theoretical concept of »staying with the trouble«, Murray develops his innovative methodological framework of »in/discipline« – a concept that facilitates both the recognition of disciplinary structures and sustained critical resistance to their epistemological limitations. His close analysis of Meri Nana-Ama Danquah's memoir *Willow Weep for Me* (1998) brings to light how attention to intersectional experiences of disability unearth the constraints inherent in established disciplinary paradigms. His analysis acquires special force through Murray's reflexive engagement with his personal experiences of epilepsy, mapping how embodied knowledge fundamentally disrupts and

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reconfigures conventional research approaches. Through this interweaving of theoretical analysis and experiential knowledge, Murray's contribution opens new possibilities for inhabiting interdisciplinary spaces as sites of both critical inquiry and theoretical innovation.

Klaus Birnstiel's (LMU Munich) »From *Motivgeschichte* to Cultural Studies and Beyond« presents a nuanced historiographical analysis of German literary studies' complex and often problematic engagement – or notable lack thereof – with disability as both a thematic *and* a formal category. Through meticulous attention to disciplinary genealogies and theoretical frameworks, Birnstiel traces how the field's historical emergence from nationalist *Kulturpolitik* and its subsequent methodological trajectories have systematically relegated disability to the level of thematic analysis, thereby overlooking its profound significance as an aesthetic force that shapes literary form itself. His contribution argues for innovative theoretical approaches for conceptualising the intricate relationship between disability and literary aesthetics, putting forward suggestions of how German studies might transcend its traditional methodological limitations. This historical-theoretical examination discloses how national scholarly traditions, shaped by their specific intellectual genealogies and organisational contexts, both generate and constrain modes of disability analysis.

Historical and Cultural Perspectives

The examination of disability's historical construction and cultural representation necessitates rigorous contextualisation within specific temporal, discursive, and sociocultural contexts. This section's contributions interrogate the complex processes through which disability has been negotiated across different historical eras and cultural environments, with particular attention to the dialectical relationships between medical epistemologies, aesthetic theories, and institutional power structures. Through careful historical analysis, these studies explain how understandings of disability emerge through the interplay of knowledge production and social figuration, while demonstrating how attention to specific national and cultural contexts unearths previously unexamined dimensions of disability discourse. These contributions thus advance our understanding of how disability functions as both an object of historical inquiry and a critical lens through which to examine broader sociocultural formations.

Martina King's (University of Fribourg) »›Many healthy children‹ or ›Mercy Killing‹? Eugenic Propaganda in NS Popular Fiction« offers a painstak-

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ing analysis of how the popular medical novel genre functioned as an instrument of ideological ›normalisation‹ during the German Nazi regime's barbaric policies against people with disabilities. Through close attention to narrative strategies and discursive formations in works like Bettina Ewerbeck's *Angela Koldewey* (1939) and Hellmuth Unger's *Sendung und Gewissen* (1936/41), King interrogates how seemingly peripheral literary genres participated in legitimising ›eugenic‹ violence through specific rhetorical and narratological mechanisms. Her examination delineates how these texts developed distinct literary conventions that transformed racial biopolitical policies into euphemistic narrative trajectories. Of particular significance is King's demonstration of how these discursive patterns persisted even beyond 1945, stressing once again the complex relationships between literary form, ideological normalisation, and cultural memory.

Evelyn Dueck's (University of Geneva) »›scandalum medicorum‹ – Taking Care of Your Eyes in the 18th Century« presents a nuanced investigation of how ophthalmological treatises functioned as critical sites for constructing new regimes of visual normativity in Enlightenment discourse. By carefully examining German-language medical texts published between 1724 and 1800, Dueck traces a crucial epistemological rupture: the transition from theological and physiological paradigms of blindness to a newly emergent social framework emphasising individual conduct and moral responsibility. This discursive transformation, as she lays bare, not only reflects broader cultural reconfigurations in conceptualising bodily difference during the Enlightenment but also anticipates later paradigms of corporeal self-optimisation. Her analysis thus elucidates how medical discourse participated in establishing new forms of disciplinary power while simultaneously generating influential models of embodied subjectivity that continue to shape contemporary understanding of visual impairment.

David Feeney's (independent scholar) »Beauty on Trust: Aesthetic Testimony, Verbal Description and the Impact of the ›Objectivity Imperative‹« investigates the complex intersection of aesthetic experience, disability, and institutional practice through rigorous philosophical and literary analysis. Through his reading of three pivotal Irish literary texts – Synge's *The Well of the Saints* (1905), Yeats's *On Baile's Strand* (1904), and Friel's *Molly Sweeney* (1994) – Feeney develops a refined critique of contemporary assumptions about aesthetic testimony and perception. Drawing on Barbara Herrnstein Smith's theorisation of contingent value, he charts how organisational insistence on ›pure‹ objectivity in verbal description fundamentally misconstrues the inherently interpretive nature of aesthetic experience. His analysis dis-

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closes how literary and cultural texts engage with and challenge normative conceptualisations of perception, while simultaneously tracing how art gallery practices can reinforce problematic assumptions about sensory hierarchies and aesthetic authority. His chapter culminates in a reconceptualisation of accessibility practices that acknowledges the fundamentally intersubjective nature of aesthetic experience. In this vein, Feeney's contribution advances both disability theory and museum studies toward a deeper understanding of embodied perception and artistic as well as visitor engagement.

Literary Form and Narrative Analysis

The formal analysis of literary texts proves essential for understanding how disability functions not merely as thematic content but as a constitutive element of textual structure and aesthetic organisation. This section maps various complex devices through which disability shapes narrative architecture, focusing particularly on questions of perspective, spatial configuration, and the intersection of various forms of embodied difference. Through close attention to formal literary elements, these contributions expose how textual structures themselves participate in constructing, negotiating, and potentially disrupting normative paradigms of corporeal experience. Especially striking is how different literary traditions have developed distinct formal strategies for representing embodied difference, hence demonstrating the intricate relationship between aesthetic form and cultural conceptualisations of disability. These analyses thus advance our understanding of how literary form itself can function as a critical site for examining and challenging dominant paradigms of bodily normativity.

Linda Leskau's (TU Dortmund) »Disability and Intersectionality: The Concept of ›Healing‹ in Johanna Spyri's *Heidi* Novels« analyses how nineteenth-century children's literature negotiates complex portrayals of embodied difference. Through a synthesis of narrative theory and disability studies approaches, Leskau shows how Spyri's texts (1880–81) construct multivalent conceptualisations of disability that transcend conventional binary categorisations. Her analysis critically examines two paradigmatic yet contrasting depictions: Klara Sesemann's paralysis and Peter's grandmother's blindness. While Klara's corporeal transformation initially appears to reinforce individual models of disability emphasising medical intervention and personal volition, Leskau's close reading shows how the text's narrative strategies simultaneously destabilise this framework through careful attention to environmental determinants and social conditions. The grandmother's metaphorical ›heal-

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ing‹ through religious engagement emerges as a particularly significant site of literary complexity, delineating how nineteenth-century texts could generate sophisticated negotiations between disability, spirituality, and social participation that resist reductive interpretation. This analysis thus shows how seemingly conventional children's literature can harbour complex theoretical engagements with questions of embodied difference and social integration.

Swaantje Otto's (BAdW Munich) »Wienke Haien and Her Environment: Perspectivisation in Theodor Storm's *Der Schimmelreiter*« puts forward a nuanced reinterpretation of Storm's canonical novella (1888) through comprehensive attention to narratological structures and perspectival modulations. Through scrupulous textual analysis, Otto explicates how the text's treatment of disability operates within a complex dialectic that both reinscribes and destabilises nineteenth-century normative paradigms. Her examination discloses how the character of Wienke functions as a critical nexus where supernatural and domestic-realist narrative modes converge, thereby bringing to light disability's central role in mediating between different aesthetic and generic conventions of the nineteenth century. Of particular significance is Otto's conceptualisation of the domestic sphere as a potential site of resistance to hegemonic disability discourse. Furthermore, her careful attention to narrative perspective traces how Storm's deployment of focalisation techniques generates previously unexamined possibilities for representing embodied difference. Otto's analysis thus maps how careful attention to formal literary devices can reveal complex negotiations between normative settings and counterdiscursive potential in nineteenth-century texts.

Johannes Görbert's (University of Fribourg) »From ›Vermin‹ to ›Superhero‹: Continuity and Change in Literary Representations of Disability« offers a comparative analysis of Franz Kafka's *Die Verwandlung* (1915) and its contemporary reimagining in disability culture, particularly in the work of the Swiss writer Christoph Keller. Drawing on Jürgen Link's normalisation theory, Görbert maps the transformation of cultural paradigms from ›protonormalistic‹ to ›flexible normalistic‹ environments in the portrayals of embodied difference in his text corpus. Görbert's analysis points out how Gregor Samsa's metamorphosis lays bare the violence of bourgeois normativity in the early twentieth century, while, in contrast, contemporary reinterpretations craft more liberatory visions of corporeal difference. Through this comparative lens, Görbert makes evident both persistent patterns and decisive shifts in literary disability figuration across temporal, cultural, and formal boundaries from the early twentieth to the twenty-first centuries.

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Contemporary Interventions and Life Writing

The final section examines how emerging theoretical paradigms and evolving literary genres in contemporary culture reconfigure the terrain of disability studies scholarship. Through critical engagements ranging from spatial theorisations of clinical environments to analyses of self-representation in the digital age, these contributions demonstrate the intricate nexus of systemic authority, lived experience, and narrative innovation. A special focus is put on how current modes of life writing and neurodiversity approaches challenge established conceptual boundaries while generating new methodological possibilities. These analyses show how shifting media environments and evolving forms of autobiographical and autofictional writing necessitate fresh analytical approaches that can account for the complex interplay between embodied experience, societal structures, and narrative authority.

Mona Baie's (University of Fribourg) »›A Featureless Landscape of Humiliation and Loss‹: Clinical Spaces and the Politics of Disability in Hilary Mantel's *Giving Up the Ghost* (2003)« develops an innovative conceptual framework for analysing clinical environments as crucial sites where disability emerges through organisational practices. Her interpretation discloses how Mantel's memoir articulates embodied difference not primarily through corporeal description but through intricate patterns of spatial and discursive power relations. Especially critical is Baie's formulation of »spatial narration« in clinical settings, which explains how hierarchical communication patterns – where physicians' authority manifests through speech while patients retreat into silence or internal reflection – constitute these medical spaces. This conceptualisation enriches spatial disability studies by explicating how literary texts can map the complex topographies of medical authority and patient experience, thus illuminating how organisational spaces shape both embodied experience and narrative possibility.

Jenny Bergenmar's (University of Gothenburg) »Neurodivergent Reading: Towards a Theoretical Framework« makes a significant intervention in literary and cultural disability studies by formulating interpretative practices that emerge from neurodivergent modes of engagement. Her analysis interweaves insights from neurodiversity studies, queer theory, and crip theory while remaining attentive to the cultural specificity of theoretical discourse. At the heart of her approach lies the concept of »neuroqueer worldmaking«, which she elaborates through critical dialogue with scholarship on community formation and historical consciousness. Her introduction of the Nordic concept »skev/skeiv« (meaning ›askew‹ or ›off kilter‹ and carry-

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ing connotations of non-normative positioning) proves particularly fruitful, as it both complements and productively complicates Anglophone formulations of »queer« and »neuroqueer«. This linguistic and conceptual expansion shows how attention to cultural specifics can generate new interpretive possibilities, while simultaneously bringing to light how different cultural traditions might inform more nuanced approaches to neurodivergent literary engagement.

Harriet Cooper's (University of East Anglia) »Represent Yourself! Disability, Interpretation and the Commodification of Experience« examines how digital cultures and contemporary memoir practices reshape figurations of corporeal variation. By engaging with Mitchell and Snyder's foundational concept of »narrative prosthesis«, Cooper traces how disability narratives have shifted from sites of interpretive multiplicity to marketable forms of experience within neoliberal frames of mind. Her incisive discussion of parental memoirs about disabled children points out how even politically astute writers who aim to contest stigmatising narratives find themselves enmeshed in memoir's generic constraints and the logics of neoliberal self-optimisation. Cooper thus elucidates how media environments in the digital and social media age reshape narrative possibilities while concurrently circumscribing them through market imperatives. Her chapter shows how contemporary modes of life writing negotiate the complex terrain between resistance and commodification.

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The contributions assembled in this volume underscore both the intellectual vitality of contemporary disability studies and the generative potential that emerges when Anglophone and Continental European scholarly traditions enter into sustained critical dialogue. Although preserving their distinct methodological genealogies, these diverse approaches divulge crucial points of convergence around fundamental questions of embodiment, representation, and social formation. The analyses collected here demonstrate how attention to different national and structural contexts can bring to fruition new interpretive possibilities while at the same time delineating persistent patterns in how literary texts negotiate questions of corporeal difference.

First, the contributions collectively demonstrate how disability functions not merely as thematic content but as a fundamental category of literary and cultural form, operating at both structural and semantic levels. This formal significance manifests in Birnstiel's examination of German literary studies'

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methodological apparatuses and their problematic historical relegation of disability to thematic analysis, Otto's investigation of how narrative perspective in Storm's *Der Schimmelreiter* simultaneously reinforces and subverts nineteenth-century normative backgrounds, and King's analysis of how the authors who created specific narrative strategies and generic conventions in Nazi medical novels actively participated in constructing and legitimising eugenic violence.

Second, the volume highlights the crucial role of intersectionality and theoretical synthesis in contemporary disability studies, demonstrating how different analytical tools can shed light on previously often neglected portrayals of embodied difference. Leskau's examination of Spyri's *Heidi* novels unwraps how disability intersects with age, class, gender, and religious discourse in complex ways that resist reductive interpretation, while Bergenmar's integration of neurodiversity paradigms with queer theory and Nordic terminological paradigms shows how different theoretical traditions can productively explain disability figuration in their fused form. Shakespeare's conceptional positionings further enrich such syntheses by acknowledging both the materiality of bodily difference and its social dimension through careful engagement with Wittgensteinian concepts.

Third, the contributions underscore the importance of historical contextualisation and structural critique even as they maintain a high level of theoretical complexity. Dueck's examination of Enlightenment ophthalmological discourse demonstrates how medical and literary discourses have historically shaped understandings of disability through new regimes of visual normativity, whereas Cooper's analysis of contemporary memoir culture accentuates how neoliberal surroundings condition current disability portrayals even within politically aware narratives. Görbert's analysis combines Link's normalisation theory with Mitchell and Snyder's concept of ›kill or cure‹ narratives to elucidate how literary texts negotiate disability across different historical epochs.

Fourth, questions of reflexivity, positionality, and the situatedness of knowledge production emerge as crucial methodological considerations across multiple contributions. Murray's advocacy for »in/disciplined« approaches productively destabilises disciplinary boundaries while remaining attentive to their real-world effects, whereas Baie's careful attention to her own scholarly positioning at the intersection of disability studies and medical humanities enables innovative theoretical insights about the cultural depiction of clinical spaces. Feeney's critique of museum practices, borne out of his own professional experiences, further unveils how scholarly self-reflexivity

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can generate more nuanced approaches to accessibility and aesthetic experience.

Looking forward, this volume suggests several promising directions for future research in literary and cultural disability studies. The productive tension between Anglo-American and Continental European approaches opens new possibilities for theoretical innovation and methodological development. Particularly significant is the potential for developing truly multilingual and multicultural approaches to disability phenomena. Several contributions show how different national intellectual traditions can generate innovative theoretical and methodical amalgamations in their approaches to institutional critique, artistic portrayals of embodied difference, and the relationship between literary form and disability representation. The volume's emphasis on interdisciplinary dialogue, for example with theoretical approaches from history, sociology, and philosophy, further suggests how literary and cultural disability studies might productively engage with adjacent fields, although maintaining their own critical edge. This cross-pollination of approaches suggests new possibilities for disability studies scholarship that move beyond geographic and linguistic boundaries while remaining attentive to specific cultural and historical contexts.

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The contributors' willingness to engage in sustained dialogue throughout the editorial process has significantly enhanced this volume's coherence while preserving the distinctive methodological approaches that make transnational scholarly exchange so valuable. Their commitment to advancing British and Continental literary and cultural disability studies scholarship through careful attention to both theoretical innovation and analytical precision reflects the field's continuing intellectual vitality.

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recognition of disability studies' crucial contribution to contemporary literary and cultural scholarship.

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Theoretical Foundations and Critical Frameworks

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Tom Shakespeare

On Impairment and Disability

To me, ›disability‹ encompasses physical impairment, sight loss, hearing loss, mental health conditions, intellectual impairments and neurodiversity. It is the term I use with reference to any lasting mental or physical health condition. Immediately, you can see that ›disability‹ is rather complex, because it is both multi-dimensional and scalar: it can be more or less significant in its impacts. However, both to make things simpler, and because this is what Elizabeth Barnes does in her book *The Minority Body. A Theory of Disability* (2016), and a key part of this paper is an examination of her work,[1] let me restrict ›disability‹ in what follows to impairments which are not primarily of the mind. In other words, let me bracket mental illness and intellectual impairment and neurodiversity and have you only consider physical impairments as ›disability‹.

Human beings are animals and we have bodies and minds which have evolved over millennia. In my view, while bodies and minds vary, there is a narrow band of ways of being which comprise evolved functioning for *homo sapiens* (cf. Christopher Boorse 1975).[2] Negative departures from that narrow band would be what I call illnesses and impairments. Of course, there are a few positive departures occasionally, for example optimal fitness or an amazing talent, but these are fewer and less interesting to me for the purposes of this paper.

I think human beings have these negative departures from species-typical functioning all the time, most of them minor. The body is mostly invisible, meaning we take it for granted, but sometimes it becomes visible, usually because of these departures. I am thinking of mouth ulcers and muscle strains and joint aches and influenza, and worse. None of us are free from these troubles. Social and economic disparities expose some of us to more of this.

However, some people have such major departures, such considerable predicaments that they become classed as disabled. Whereas illness and impairment could be seen as a natural kind, the classification as disabled

1 Elizabeth Barnes: The Minority Body. A Theory of Disability, Oxford 2016.
2 Christopher Boorse: On the Distinction between Disease and Illness, in: Philosophy and Public Affairs 5 (1975), pp. 49–68.

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is certainly a social and cultural artefact, which is different across time and place, depending on context, epistemology, welfare and politics. It is not automatic that you have a certain intensity of predicament and you become a disabled person, it depends on social and cultural factors.

To recap: to be embodied is to have impairments, from time to time, but to be disabled is to be socially classified as having a certain amount or intensity of impairments, such that someone is seen as being a disabled person. Mostly, people resist being classified as a disabled person because it is stigmatised as a pathological state.

Moreover, in society, there are stereotypes as to what disability is like, and who a disabled person is, and so despite functional difficulties, a person may not be seen as disabled, perhaps because they look ›normal‹, or because they are seen as a frail older person, not a disabled person.

I mentioned politics before, because this label which can be applied by a census or a social protection system can also become a badge, as people classified as disabled decide that this label has become their identity, and that they are going to gather with others on this basis and demand the right to be listened to.

This new social movement of disabled people, or people with disabilities – and that distinction itself connotes a particular ideological emphasis – this new political identity[3] has gone down a certain conceptual and political path, which I believe is mistaken. Whereas my account of impairment would emphasise that everyone's embodiment is vulnerable to frailty, illness and impairment, much of the new identity politics has sought to dislodge the connection between impairment and the state of being a disabled person. It has done so in a number of ways.

For example, the British social model approach makes a distinction between impairment and disability and has redefined the latter. People are disabled by society not by their bodies. Disability is the exclusionary relationship between people whose bodies or minds work in different – not inferior – ways, and a society which has grown up on the basis of that exclusion. Emancipatory disability research is about disabled people's groups researching exclusion, following the social model, and with the aim of promoting inclusion.

3 Cf. Ian Hacking: Making up people, in: Thomas C. Heller, Morton Sosna, David E. Wellbery (eds.): Reconstructing Individualism. Autonomy, Individuality, and the Self in Western Thought. Stanford 1986, pp. 222–236.

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In my work, particularly my book *Disability Rights and Wrongs*, I have tried to say that although discrimination and prejudice are a major part of the problem, we are wrong to deny or overlook the role of impairment, which itself is a problem (cf. Shakespeare 2006 and 2014).[4] So far, it has not been hard to show the contradictions or inaccuracies of the social model of disability. However, now a very rich philosophical account which revalidates impairment is available, in the form of the work of Elizabeth Barnes, and her abovementioned 2016 book *The Minority Body*. So I need now to demonstrate why this book is also wrong.

In *The Minority Body*, Barnes does two things. First, she redefines disability, so it is no longer rooted in impairment, but becomes those forms of life for which the disability rights movement should be trying to secure justice. Second, she describes disability as »Mere-Difference«, removing the association with negative forms of embodiment.[5] Barnes does not make the distinction I make between biological impairments and social disability. She uses one word, disability, to refer to everything. But what does she mean by it?

Barnes' first claim: what is disability?

Let me present how I understand Barnes' first claim. She makes much of the diversity of physical impairments, and says it makes up too many different phenomena to be a useful category, if it is based in bodily departures. She sees attempts to root disability in limitation of functioning, or departs from species typical functioning, or pain as incoherent. Moreover, she objects to accounts which see disability as intrinsically pathological, because she is trying to avoid normative judgements. Having rejected these attempts, as no doubt she would reject my account, she concludes:

> »Disability is all and only the things that the disability rights movement ought to consider as things they are promoting justice for […].«[6]

Note, this is not the actual things which any disability rights movement does, which may sometimes be mistaken or inconsistent. Barnes focuses on what a disability movement should do, actions which follow from the disability rights approach. Note also that this is an ingenious but also very unusual account.

4 Cf. Tom Shakespeare: Disability Rights and Wrongs, Abingdon 2006; idem: Disability Rights and Wrongs Revisited, London 2014.
5 Barnes: Minority Body, p. 7 passim.
6 Ibid., p. 46.

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It enables us to distinguish between positive talent, and negative limitation; it enables us to distinguish between a person who is naturally petite, and a person of short stature. It is not normative. It allows us to consider different eras of history, and construct a counterfactual account of what a disability rights response to a person's exclusion might have been. So as an approach, it has lots of strengths.

In response to Barnes, I think it is necessary to be clear-eyed about the disability rights movement, because it does a lot of heavy lifting in her argument. Our data suggests that worldwide, less than 10% of people with disabilities are in organisations of persons with disabilities. In Britain, far fewer people would be members, I doubt it is much different in America. Only 50% of people with rights under the former Disability Discrimination Act would even think of themselves as disabled.[7] In Britain, data suggests that 50% of disabled people are over 60[8] yet disabled people's organisations have traditionally been dominated by younger activists.

Moreover, I do not think that the movement always speaks for its members in the views it holds. One survey found that only 3% of disabled people had heard of the social model of disability.[9] Most disabled people consider that health issues are a major part of being disabled, even more so that non-disabled people.[10] Another survey found that a majority of disabled people supported assisted dying.[11] So disabled people's organisations and activists are perhaps out of touch as to what disability is. I am sceptical, for these and other reasons, as to whether Barnes' ingenious solution to defining disability in non-bodily terms survives cold reality.

As someone who broadly holds to a functioning or species-typical account of disability, I need to understand what she believes is wrong with defining disability in bodily terms? Barnes says:

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7 Cf. Department for Work and Pensions: Disabled for Life?, London 2023.

8 Cf. Office for National Statistics: Measuring Disability, 2019, www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/measuringdisabilitycomparingapproaches/2019-08-06#disability-prevalence-by-age (24.9.2024).

9 Andy Rickell: Key Notes, in: Disability Now, 20.1.2006.

10 Office of Disabled People, London: Public Perceptions of Disabled People. Evidence from the British Social Attitudes (2009), 2012, assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/325989/ppdp.pdf (24.9.2024).

11 Graham Box, and Kenneth Chambaere: Views of Disability Rights Organisations on Assisted Dying Legislation in England, Wales and Scotland. An Analysis of Position Statements, in: Journal of Medical Ethics (2021), 47:e64.

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> »There is nothing about what disabled bodies are like that *by itself* unifies or explains the category of disability.«[12]

Disability, as Barnes says, is a heterogeneous category. If one thinks about visible and invisible, congenital and acquired, and all the many types of impairment (achondroplasia, spinal cord injury, cerebral palsy, multiple sclerosis being just four of the major forms of impairment), we can see just how heterogeneous it is. This being so, there will always be debates about boundary cases: is overweight and obesity to count as disability? What if someone has a gene associated with impairment, but currently does not have symptoms of the condition? What if a person has an underlying health condition (for example epilepsy) but it is currently well controlled by medication?

But unlike Barnes, I do not think that this heterogeneity means that the concept itself is not helpful. I would turn to Wittgenstein's notion of family relationships in *Philosophical Investigations*. In paragraph 66, he writes about

> »a complicated network of similarities overlapping and criss-crossing: sometimes overall similarities«[13]

continuing in the following paragraph to suggest:

> »I can think of no better expression to characterize these similarities than ›family resemblances‹; for the various resemblances between members of a family: build, features, colour of eyes, gait, temperament, etc. etc. overlap and criss-cross in the same way.«[14]

It seems to me that the varieties of disability are exactly overlapping and criss-crossing in this way. I supplement this thought with reference to Peter Winch, where he talks about human behaviour following rules – in this case, the rule of understanding what we mean by disability.

> »I want to say that the test of whether a man's actions are the application of a rule is not whether he can formulate it but whether it makes sense to distinguish between a right and wrong way of doing things in connection with what he does.«[15]

Within a culture, there is often a broad agreement as to what to disability is, which is to say we know the rules: few people would have difficulty distinguishing between having restricted growth and simply being normally petite, to use Barnes' example. In other words, ›disability‹ is a helpful category,

12 Barnes: Minority Body, p. 23.
13 Ludwig Wittgenstein: Philosophical Investigations, Oxford 2009, p. 31.
14 Ibid., p. 32.
15 Peter Winch: The Idea of a Social Science and its Relation to Philosophy, Abingdon 2007, p. 58.

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which does not mean that there is complete agreement as to who counts as disabled: as Winch says, we have to have the possibility of being mistaken about applications of the rule as well.[16]

We say ›often‹ and ›mostly broad agreement‹, because there is not always consensus. Here we would introduce a key distinction which Barnes seems to side-step, which is the distinction between ›subjective‹ and ›objective‹ judgements as to what constitutes disability. A subjective judgement would be the belief of an individual about themselves, or about another individual or group of individuals. An objective judgement would be the application of a measure such as the Washington Group short set or long set of questions about disability, or the WHO World Health Survey or Multi-country Disability Survey, or the national equivalents, or else a clinical examination. There is a debate as to which approach is more precise, cost-effective, and as to who is left out from the category in each approach. There is a choice of which tool to use, showing that ›disability‹ definitions in practice are always the artefact arising from the social approach taken to define the category.

However, despite all the debate about definitions and tools, we still consider an objective approach to be preferable to a subjective approach, for several reasons. Because disability is so culturally stigmatised, many people are reluctant, if they are able to have a choice about the matter, to consider themselves disabled. Someone can have impairment to a considerable degree, but still not see themselves as a disabled person. If they have an invisible condition – such as a chronic illness – they may often claim to be non-disabled, even if the condition is very disabling to them. A related example is how rarely older people with impairments see themselves as disabled, despite their frailties: they will tend to say this is ›normal ageing‹, not least because they do not want to adopt the stigmatising description of ›disabled‹.[17]

Barnes' second claim: is disability ›mere difference‹?

As the title of her book highlights, for Elizabeth Barnes, to be a person with disability is not to be in a damaged or incomplete body, but is to be in a minority body. Note that she does not deny that persons with disabilities cannot do everything – it is obvious, for example, that many people with

16 Cf. ibid., p. 32.

17 Cf. Ann Leahy: Disability Identity in Older Age? Exploring Social Processes that Influence Disability Identification with Ageing, in: Disability Studies Quarterly 42 (2023), 3–4.

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hearing loss cannot enjoy music in the usual way, and many people with sight loss cannot appreciate many aspects of nature or visual art, and someone with my own combination of physical impairments will not be able to dance tango ordinarily or play conventional rugby. Barnes says:

> »The mere difference view need not deny that disabled people miss out on some intrinsically good abilities or experiences – it's just that they have access to other, different good things.«[18]

So overall, Barnes claims that disability is neutral with respect to well-being.

Note that Barnes is saying something a little more complex than a conventional social model approach. Let me take a quick detour. Empirically, it is evident that the lives of disabled people are often harder than those of the rest of the population. The Office for National Statistics found that working age disabled people's average well-being ratings in the UK were poorer than those for non-disabled people for happiness and life satisfaction measures, while average anxiety levels were higher for disabled people at 4.47 out of 10, compared with 2.91 out of 10 for non-disabled people. Disabled people over 16 were almost four times as likely to be lonely as non-disabled people. Half of working age disabled people were employed, on average, compared to four fifths of non-disabled people; only a fifth of autistic people were employed.[19]

However, a social model theorist would say that of course disabled people have a hard time in actuality, but that is due to disabling barriers, to discrimination, or to ableism. Eliminate the material barriers and negative attitudes that cause these problems, and it will be fine to have an impairment. But I think Barnes is saying more than the social model theorist would. Whereas the social modelist thinks that impairment is fine, Barnes is happy to concede that there are bad things about impairment. She just thinks that impairment overall is a Mere Difference, not a bad thing, because there are other aspects of impairment which are good.

Barnes contrasts her Mere Difference view with the conventional account, which she calls the Bad Difference view. The Bad Difference view is willing to accept that having an impairment may lead to good things, because it enables you to join a community, but that the impairment itself is not a good thing:

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18 Barnes: Minority Body, p. 58.

19 Cf. Office for National Statistics: Disability, Well-Being and Loneliness, 2019, www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilitywellbeingandlonelinessuk/2019 (9.1.2025).

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> »If she could keep her friends, her interests, and her community but lose her disability, most people would think she would be better off.«[20]

So she recognises that many would accept the instrumental benefits of having an impairment, even if they would not see impairment as neutral. Barnes is even willing to concede that impairment may have bad aspects, while still defending the Mere Difference view:

> »We can maintain that disability is mere difference without maintaining that everything about disability is perfectly fine and shouldn't be ameliorated.«[21]

For a Mere Difference like that of Barnes, it is necessary to say that on balance, impairment is not bad, even if some aspects of it might be difficult. She says that these would be local bads – such as not being able to see your baby's face – but do not add up to general bads.

After all, there are some benefits to having an impairment.[22] She is not taking what she calls the ›X Men view‹, that disabled people have compensating extra abilities. Instead she talks about how having an impairment might liberate you from beauty norms, or gender stereotypes, or provide perspective. Following Rosemarie Garland-Thompson, she argues that impairment can be a narrative resource or an epistemic resource. But it seems to me that many of these benefits to having an impairment could be had by anyone, without having to have an impairment, and indeed many people with impairments do not experience this perspective or liberation.

Barnes uses a string of what I consider questionable arguments to challenge the Bad Difference view. Let me mention a couple of these. For example, noting that the Mere Difference view is not the common-sense position, she rightly points out that common sense can often be wrong. Even the most rational people can be prejudiced and reflect their own times – she points out that Hume and Kant said things that were either racist or sexist. Yet while we should obviously be careful to examine our intuitions, that does not mean they are always wrong. The fact that Hume and Kant were wrong about race and gender does not mean we have to think differently about disability. Our common sense might be wrong – common sense has been wrong in the past, and often reflects cultural and historical contexts – but it might well not be wrong, just as Hume and Kant were arguably correct about many things despite some of their intuitions being wrong.

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20 Barnes: Minority Body, p. 65.
21 Ibid., p. 75.
22 Cf. Ibid., p. 96.

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Another argument relates one of the main reasons that disabled people find life difficult, which is pain, the symptom most commonly reported by disabled people. Barnes points out the known complexity of pain,[23] for example how men and women and different ethnicities report pain, concluding:

> »The assumption that physical pain is *neatly and directly* correlated with reduction in wellbeing is a crude oversimplification.«[24]

But pain remains a very difficult aspect of many illnesses and impairments, and one which cannot easily be eliminated by better medication or social conditions.[25] So while Barnes' argument is right, in terms of the complexity of pain; I think that she is wrong, in terms of the significance of many forms of pain to many people who experience it.

Barnes even accepts that some impairment can be a global bad for some people without maintaining that it is not bad simplicitur.[26] But why take that view, when it is more plausible that impairment is good for some people without being good simplicitur?

Importantly, Barnes also argues that we should listen to the perspectives of persons with disabilities, when they maintain that impairment is not a problem and they value their experience of it. She draws parallels with gay people and women and other minorities. It is not difficult to find disability activists maintaining that impairment is not a problem, at least in public. But while in general I think she should listen more to disabled people, I have some scepticism here, as I have suggested earlier.

For a start, I think the comparison with gay people, women and other minorities is a false analogy. In these other cases, there is usually nothing physically exceptional, overall, about being a member of this identity group. In the case of disability, there is often something different and difficult about having an impairment. In making this analogy, I think Barnes is assuming what she needs to prove. And she does it all the time, to argue that surely we would not attempt to change someone from being gay, for example, and therefore are we sure we are doing the right thing by assuming it is axiomatic that impairment should be prevented.

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23 Cf. Sarah E.E. Mills, Karen P. Nicolson, and Blair H. Smith: Chronic Pain: A Review of its Epidemiology and Associated Factors in Population-Based Studies, in: British Journal of Anaesthesia 123:2 (2019), e273–e283. doi.org/10.1016/j.bja.2019.03.023.

24 Barnes: Minority Body, p. 74 (emphasis in original).

25 Cf. William Raffaeli, and Elisa Arnaudo: Pain as a Disease: An Overview, in: Journal of Pain Research 10 (2017), pp. 2003–2008. doi.org/10.2147/JPR.S138864.

26 Cf. Barnes: Minority Body, p. 96.

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I think Barnes may be mistaken, because my experience of more than three decades of adult life is that many disabled people publicly state their faith in the social model, while in private acknowledge the difficulties of impairment. In the Twitter/X era, some publicly talk about the difficulties of impairment while simultaneously arguing that disability is all social barriers and oppression, and not at all health issues.

I think several things are going on here. First, disability is an example of identity politics, and this means ideologies can become dominant in a group, which are not necessarily true. Ask any disabled person whether they would mind if they were given a second impairment, or whether they would mind if their existing impairment got worse, or if their baby was born with an impairment. In fact, it is not just disabled people who value their own form of life, even if that life is very hard. Once you have an identity-forming experience, then you would not be celebrating you and valuing yourself, unless you also valued that experience.[27] At the same time, you might not wish that experience on others. Often, consistency breaks down at this point.

Second, as I suggested at the start of this paper, I think that the disability rights movement has gone down the wrong road in terms of impairment. Rather than acknowledging that impairment is a problem, but that everyone is at risk of impairment, and so we should be building a world in which impairment is not an issue, disability rights advocates have said that impairment is not a problem. Understandable, but ultimately unhelpful.

Because this is where I agree with the disability rights movement: people with impairment are not a problem. Disabled people are of equal moral worth to everyone else. You can lead just as good a life with impairment as you can without. But to me, that does not mean that impairment has to be a Mere Difference. Impairment can be bad, while life with impairment is good. It is an apparent paradox.

Let me give several other illustrations of this paradox. Barnes highlights people by whom impairment is celebrated, and to whom impairment means a lot. They certainly exist. But by analogy, we agree that poverty is bad. Yet remember Woody Guthrie, British and American folk music and all the other flowerings of the culture of disadvantaged people who celebrated their lives, which meant a lot to them, even while we do not want other people to have to live these lives, even knowing that without these experiences, we would not have the music or the brass bands or whatever. You could retort that might

27 Cf. Hartmann: Ethics.

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be an example of us benefitting from other people's hard lives, so we need to focus on them living that life and celebrating it. Cancer is bad, but people with cancer are not bad, and people who have had cancer may lead better lives subsequently. So these are examples of an individual themselves benefitting from a bad thing. By that might be an example of an instrumental benefit. We agree that divorce is bad, but people can be much better off as a result of divorce.

In the case of impairment, I think that people can adapt to impairment and lead good lives. Human beings are almost infinitely adaptable, to cancer, impairment, divorce, poverty. We cannot conclude from this empirical fact that impairment might be a Mere Difference, just as we cannot be blasé about poverty or divorce or any other bad thing. On balance, a world with less impairment in it is a better world than a world with more impairment in it.

Conclusion

To conclude by restating my view of disability. To be human is to be embodied. We all have transient illnesses and impairments. In a particular time and place, and when one has accumulated a certain number or intensity of conditions, one may come to be defined, or to see oneself, as disabled. This is a social and psychological process, it is not automatic and disability is not a natural kind. But, accepting that, I think having a very significant impairment, or a cluster of impairments, is difficult, and we should do what we can to avoid it.

Our options for decreasing disability are multiple. We can prevent people accumulating illnesses or impairments, or can offer rehabilitation or assistive devices to ensure that these impairments do not permanently affect functioning. We can offer counselling and other psychological inputs so that a person does not redefine themselves as disabled, or at least not as passive and non-functional. We can change the environment, through accessibility and reasonable adaptations so that fewer people encounter the mismatch between their abilities and the demands of the environment. We can change society, so there is more acceptance of different ways of functioning and different ways of being in the world. We can legislate for more inclusion and participation. In practice, in a high-income setting, we probably offer a range of these options, or all at once.

I do not think that the option of decoupling disability and negative forms of embodiment is promising. I think, if it discourages us from all or any of

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these ways I have listed of reducing disability, that would be unfortunate. The consequences of Mere Difference are broadly to inhibit disability prevention, which I would regret, although perhaps not as much as Guy Kahane and Julian Savulescu (2009) and the consequentialists.[28] I am not persuaded by either the social model of disability, or the Mere Difference account of disability. There are many intrinsic difficulties of impairment, and no amount of ingenuity can remove them. Elizabeth Barnes is a very good and ingenious philosopher, but I cannot accept her attempt to base disability in the efforts of the disability movement, nor to see impairment as neutral.

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28 Cf. Guy Kahane, and Julian Savulescu: The Welfarist Account of Disability, in: Brownlee, Kimberley, and Cureton, Adam (eds.): Disability and Disadvantage, Oxford 2009, pp. 14–53.

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Stuart Murray

Creating In/Disciplined Work in Medical Humanities and Disability Studies[1]

Shaping Disciplines

As with any other critical academic discipline, both Medical Humanities and Disability Studies have histories and trajectories, and knowledge of these can only add to a greater understanding of the critical developments each has made. At the same time, I concur with the editors of *The Edinburgh Companion to the Critical Medical Humanities* that the best way to approach that discipline is not through its history and identity, but rather its imaginary; the various scenes it unfolds (an observation also true for Disability Studies).[2] Even so, it is important to have a sense of how each operates. So, we might want to know some basics: What were the origins of the disciplines and how do they carry these legacies into their current work? Where are their boundaries? What is included and excluded? Who does the work? How does this scholarship overlap with other modes of critical enquiry (both old and new)? What kinds of spaces are made for the work to take place – within the academy, the wider intellectual community, and with the public? What feels important, and what is ephemeral?

One context for these questions might be to note that, relatively speaking, each discipline constitutes a highly specialised community, with a limited audience, and that these are unequal in size. Most people who work on literature and medicine, or the history of medicine (just to select two examples) do not identify as Medical Humanities scholars, and for all its profile, the discipline is undoubtedly niche in wider Humanities approaches to health. Disability Studies is more broadly established, with more scholarship having produced more publications and designated teaching programmes in academic institutions, but it is a subject absent from many universities and some other intellectual

1 This article is an excerpt from my book In/Disciplines. Medical Humanities and Disability Studies, London 2023, published with the kind permission of Bloomsbury Academic, an imprint of Bloomsbury Publishing Plc.

2 Cf. Anne Whitehead and Angela Woods: Introduction, in: Whitehead, Anne and Woods, Angela (eds.): The Edinburgh Companion to the Critical Medical Humanities, Edinburgh 2016, pp. 1–32, here: p. 2.

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approaches to disability and healthcare do not engage with its methodologies. In addition, for all that each discipline claims an inter- or multi-disciplinary approach to its subject matter, it can be argued that this is restricted in its reach, selecting some partners but dismissing others. Sometimes, these issues of scale and scope are ignored in discussions about how the disciplines function.

In this essay I want to argue that an idea of *indiscipline* (and specifically *In/Discipline*, a meeting of critical methods and disciplinary formations) offers a provocative and illuminating way to open up both the workings of Medical Humanities and Disability Studies as disciplines, and the connections between the two. I am drawn to it for a number of reasons: First, it allows for an obvious situating within discussions of the disciplinary concerns that necessarily speak of how academic scholarship works in institutional and intellectual spheres; second, it qualifies this location – messes it up – because of its clear suggested unruliness. It places disciplines in recognisable structures but then subjects them to the rule-breaking energy of nonconformity. This is my modest version of Donna Haraway's staying with the trouble, maybe, but, as Haraway has observed, to be in such a situation is not only to be oppositional, not only simply critical. Rather it heralds a positioning that inhabits spaces of both avoidance and adherence. Outlining her ideas of witnessing, Haraway tells us that her witness »is suspicious, implicated, knowing, ignorant, worried, and hopeful«, heir to the »cascading accounts« of configurations that write any topic or subject.[3] It is exactly through this kind of doubtful and/but generative lens that, in my research, I look at the scholarship that marks Disability Studies and Medical Humanities as critical modes.

As my own work on health and disability has developed, I have found that being indisciplined provides the clearest mode for the criticism I hope to write. This is true despite the apparent lack of clarity around the word itself (in English, ›indiscipline‹ is more common that ›undiscipline‹, but ›undisciplined‹ more in usage than ›indisciplined‹). It is important to stress that this adoption of the provisional and contingent does not detract from any desire to shed light on the workings of each discipline and write with clarity, however; it is a matter of how and where to start. From this position, I want to argue, it then becomes possible to attend to the gaps, pauses and vanishing points in both Medical Humanities and Disability Studies and to stress the indiscipline caused in the best work they produce. I want to avoid the insular-

3 Donna Haraway: Modest_Witness@Second_Millennium, FemaleMan©_Meets_OncoMouse™, London and New York 1997, p. 3 and p. 2.

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ity and parochial mood that can come with disciplines as they start to settle, whether within a model of disciplinary formation or taken-for-granted critical perspectives. The fact that at this current moment in time parts of academia choose to frame scholarship in medicine, health and disability within certain terms is a passing phase. It will change and develop in years to come. What won't change is the central role that medicine, health and disability have in people's lives and to the social and cultural formations that surround them. I understand it to be the job of both Disability Studies and Medical Humanities to respond to these issues, to be more than words that designate disciplines, subject areas, or the names of postgraduate courses and funding schemes. In fact, I value them precisely because I believe that they can do this. They bring philosophical concepts of selfhood into dialogue with personal experiences of bodily pain, for example, or theorise disabled embodiment as it helps inform systems of social health. To call this inter-, cross- or multi-disciplinary is fine, but only if those words are understood to come as a response to the work that finds formation in and around such headings. I agree with Felicity Callard and Des Fitzgerald's suspicions that these terms, for all that they wish to speak of collaboration and complexity, simply move the space of work out of the disciplinary to a place of ›between‹, ›over‹ or ›lots‹, and that these then perform their own version of stasis, assumed but often unexamined.[4] As ever, methodologies create their own shortcuts.

Trajectories

The relationship between medicine and the Arts is centuries old but Medical Humanities emerged as a distinct discipline in the US from the 1970s onwards as an additional element in the training of doctors and medical professionals. It brought discussions of literature, creative writing, anthropology, ethics and the visual arts in particular to give new perspectives on questions of (among others) patient experience and behaviour, empathy, professional bias, and cultural difference. The subject still functions primarily in this way in the US, with a strong presence in undergraduate and graduate teaching programmes within medical schools. The stress on ›additional‹ is central here, a word that has meant different things at different times. In their early presence in medical

4 Felicity Callard and Des Fitzgerald: Rethinking Interdisciplinarity across the Social Sciences and Neurosciences, Basingstoke 2015, pp. 80–81. As they also put it succinctly: »Interdisciplinarity is a term that everyone invokes and none understands« (ibid., p. 4).

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training, the Humanities offered humanist perspectives on clinical processes and opportunities to engage with alternative ways of talking about health. These were not without interest (sometimes significant) but largely peripheral and clearly a secondary set of perspectives.

The discipline has diversified in the last ten years in particular, developing wider interests and more sophisticated ideas of personal, historical, public, and social dimensions of health, and mobilising new critical approaches that address these. Much of this diversity, however, exists with the continuity of the older model. A read through of the website of the University of California San Francisco's comprehensive and influential *Perspectives in Medical Humanities* series showcases books, digital magazines and podcasts that focus on all manner of topics: from poetry and memoir to studies of cancer and climate change, histories of Obstetrics and Gynaecology, and the structures of medical research finance. The Press's mission statement makes clear, however, that the series invites »scholars from the humanities and health care professions to share narratives and analysis on health, healing, and the contexts of our beliefs and practices that impact biomedical inquiry«, an approach recognisable from the discipline's 1970s origins.[5] Similarly, Routledge's book series *Advances in the Medical Humanities* contains multiple titles – on Bioethics, Wellbeing, Palliative Care, Pain, Storytelling and Poetry – almost all of which are connected in same way to Medical Education and person-centred healthcare. It is instructive to note that 2016 saw the publication of both *The Edinburgh Companion to the Critical Medical Humanities*, mentioned above, and Alan Bleakley's *Medical Humanities and Medical Education: How the Medical Humanities can Shape Better Doctor*s, in the Routledge series. It would be different to imagine two more different books with the same central term in their title.

The Introduction to the *Edinburgh Companion* begins with a claim that, as a discipline, Medical Humanities »names a series of intersections, exchanges and entanglements«.[6] In so doing, the volume marked part of a major critical turn that reconfigured the subject not as an additional element or ›critical friend‹ to wider research in medicine and health, but as a seminal part of such approaches. It championed a sustained interdisciplinary inquiry that could not only bring new readings of health moments (of all kinds) but also enact structural change to research environments. What was before just the

5 See ›About Us‹, UCSF Medical Humanities. Available online: ucmedicalhumanitiespress.com/about-us (12.7.2022).

6 Whitehead and Woods: Introduction, p. 2.

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presence of other subject areas now became processes of critique, articulated through a variety of theoretical models and directed at the positions and presumptions of biomedical science, clinical practice, and healthcare more generally. The discipline's imaginary has become a force field of approaches to the full range of medical and health effects.

Like Medical Humanities, Disability Studies originated in the 1970s, led by activists in disability-rights movements and others who rejected the idea that disability should be seen predominantly as a medical issue. In place of this, they championed the rights of disabled people and stressed central social concepts – inclusion, equality, accessibility, discrimination – that marked day-to-day disability lives. Initially focused on physical impairment, the movement spread to include those with neurological conditions and learning disabilities and became characterised by a strong commitment to community, advocating affiliation in place of the estranging individualism frequently forced on disabled people within modes of medical assessment and healthcare. The social model of disability, with its the acknowledgement that it is social and environmental factors that disable, and not the difference of the disabled body, took specific institutional forms in the 1980s and remains one of the most powerful critical tools in the discipline.

Disability Studies has also had a critical turn, one (again, like Medical Humanities) marked by the advent of multiple theoretical perspectives and new subject methods. The central status of the social model, rooted in specifics of activism, social policy and law, has lessened, with the discipline broadening into fields of Cultural and Literary Studies, as well as Gender, Queer, and Critical Race Studies. This is not simply a case of scholars from the Humanities coming to a discipline based in the Social Sciences, but also academics within subject areas such as Sociology and Education continuing the engagement with (particularly) Philosophy and Critical Theory that has been part of their analysis of disability experiences for decades. Like Medical Humanities, in the last ten to twelve years Disability Studies has brought a greater multidisciplinary approach to focus on the concept of the ›human‹ that underpins so much thinking about disability and health, and both disciplines criss-cross the promise and problems of contemporary critical topics – such as care, dependency, contested identities, Posthumanism, digital societies – as they affect the lives of disabled people.

Whether through asserting agency or a commitment to complicating methodologies then, each discipline asserts the value of reading and championing difference. Medical Humanities wants to bring different critical perspectives to the study of medicine and health, and promote the value of

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partnerships beyond professional, healthcare and patient groups; Disability Studies stresses difference as well, working through the positive and generative nature of disability experience to provide theories and models of practice that centre around disability inclusion and the value of disabled lives. Scholars in each recognise that the ongoing complexities of health and disability need critical categories themselves capable of multiplicity. Recognising such a need for difference is one thing, however; practising it is something different altogether.

Thinking Differently

The above emphasis on difference prompts a question: What is the difference of difference? Or maybe it should be: What difference does difference make? Though it is clearly a knotty formation, I have found myself encountering this thought a lot as I have worked on disability especially over the years. I say ›encountering‹, with its slight stress on the provisional, because I suspect now that I have left the question too much at the edge of my mind, possibly not confident that I have skills to properly address its complexity. I use the term disabled difference a lot. ›It is when we use the insight derived from disabled difference…‹ is exactly the (clumsy) start of a sentence I might write. But what exactly do we mean when we talk about physical, disabled, cognitive, neurobehavioral difference? There are easy enough answers of course: A wheelchair experience is different from one that does not involve a wheelchair; seeing and encountering a space through OCD is different to doing the same without having the condition. But, while true, this has come to strike me as a pedantic statement of the position. Pedantry thrives on its presupposition of clarity, but frequently simplifies things in order to do so. The assumption that a wheelchair experience is predominantly oriented around a wheelchair, for example, is a simplification of a complex set of relationships in which the wheelchair itself is only one part. That it is the part that most signals difference should be an argument, not a given.

The academic world of Disability Studies often involves being inside this difference for most of the time. It stresses the complexities and inequities of being made peripheral (others, maybe yourself) while intellectually inhabiting and critically reassessing the very idea of periphery. Indeed, it stresses that it is precisely in learning about, reforming and reclaiming such space that various productive moments (progressive politics, intellectual insight and creativity, to name just some) become possible. Lennard J. Davis' seminal 1995

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text *Enforcing Normalcy: Disability, Deafness and the Body* is a classic example of this, identifying the ableist properties of the category of ›normal‹ as it has functioned in the modern period, but also noting that »a society of disabled people can and does easily survive and renders ›normal‹ people outsiders«.[7] Being without allows for the perspective that can critique within, a tactic common in academic methodologies that advocate for social change.

My claim, however, is that at times in Disability Studies the assertion of such difference arguably stops being different and instead becomes a location of assumed knowledge and confident critical superiority. How much is really at stake when an academic professes that disabled difference changes the world? Especially when that academic is almost always implicated in the complex location of the kind of institution which has a problematic relationship with its disabled staff and students (I have not ever known an exception to this). It is not that academics do not realise this, and much excellent work has been produced on what Sharon Snyder and David Mitchell term the often-precarious »cultural locations« of disability, both physical and intellectual; but at the same time the world of Disability Studies can become a space in which to say ›disabled difference‹ is to invoke a go-to statement free from risk, a comforting assertion of progressive liberalism.[8]

This has not always been the case. In the late 1990s, Simi Linton noted how the emergence of Disability Studies worked as a »strategic endeavour«, a corrective to »the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry«.[9] Here, the work was that of interlopers, the proud carriers of freak flags with PhDs and the forthright energy to ask questions about curricula and systemic exclusion in and beyond the academy. To think about the 25 years since is to highlight the complex consequences of the success that (first) Disability Studies and (then) Medical Humanities have achieved as disciplines, especially in the US and UK. The process of bringing into critical focus that which has been misunderstood and excluded, and revising the working methods of older disciplines by suggesting new approaches, is clearly a necessity. Likewise, rethinking research topics and methodologies through diversity and inclusion is essential. But equally, there are dangers that come with such innovation. In terms of new disciplines, innovation can become credentials in showcasing academic relevance, allow-

7 Cf. Lennard J. Davis: Enforcing Normalcy: Disability, Deafness and the Body, London and New York 1995, p. 22.
8 Cf. Sharon L. Snyder and David T. Mitchell: Cultural Locations of Disability, Chicago 2005.
9 Simi Linton: Claiming Disability, New York 1998, p. 2.

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ing for the jumping of the queue in seeking resources: jobs, funding, and institutional opportunities more generally. These processes may wear the clothes of difference, may be firmly committed to it, but paradoxically they can often become a new wave of the same.

This is a point about structures, of course. As a scholar in English Studies committed to interdisciplinary work, I still feel that (in my case) creative texts carry the power of critique, but that both critical thinking (theorising, conferences) and institutionalisation (syllabi, curricula, the racial makeup of staff and wider [non]opportunities for career progression) can create a quietude that stifles the emergence of so-called ›new‹ disciplines. The thought that lingers with me is whether, in its continued success, Disability Studies especially might follow a similar trajectory to other disciplines (such as Post-colonial Studies) founded through processes of productive troubling, that we might be in a moment when Linton's agitators become standard equality curriculum-reform memos. And when I say ›we‹ I again acknowledge that I am speaking of myself: someone directly involved in the institutional structures mentioned here.

At the same time, it can be simple to characterise agitation and the championing of difference as straightforward forms of an uninterrogated critical force for good. It is common to end an academic event or argument with a call for more radical thinking, as if that was something agreed and understood as opposed to an admission that this is an incredibly difficult process or fanciful wish. Radical agitation can be as closed and blinkered as the causes it seeks to oppose, another version of the same. In today's social media saturated world, where a Tweet can make anyone a pariah, disability itself is one of the subjects that nudges close to the you-cannot-say-that third rail of self-appointed progressivism that marks academic and public social discourse, with its firm sense of what constitutes justice and demand for appropriate experiential expertise when approaching the topic. Outrage is pervasive on such platforms, and prejudice against disabled people common, but this does not mean that the disability-positive version of such commentary should be excused its no-exceptions intolerance. There is a lot of claiming around as to who can and cannot speak on what topic and while there are countless vital and progressive arguments that have been possible through claims articulated in this way, particularly by those who lack access to more mainstream media outlets, it is clear that numerous debates are in fact typified by the shared intolerance of the antagonists. Entitlement takes many forms and those who want to propound difference can easily end up enacting the same.

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There are any number of examples in academic discourse where difference can become same then. But there are more important and complex manifestations of disability/same continuities. For many disabled people, many activities – studying, getting a job, having a partner, starting a family – are part of the fabric of all sorts of lives. Equally, many disabilities can be understood as a same: those with congenital conditions have never known lives without the body they have. Here, we can see that Linton's assertion of the right to claim is not only a claim to the status of being disabled and the power of that difference; it is also another format of claiming sameness, that which is unique in the everyday and mundane, the ordinary stuff of life.

This kind of disability same is everywhere, but a complexity, even a tautology, kicks in here. It is precisely a demand for ›same‹ in disability encounters that underpins ableism. In this formation, same is active in repressing disability meaning in that it enacts a retreat from difference to ignorance and intolerance. Here then is a challenge for disability scholarship's use of difference, one where the very idea begins to creak under the pressure of the work it is doing. As the above anecdote demonstrates, disabled difference folds into and around, but does not necessarily replicate, how any body and mind might work in the world. Collapsing disability into a wider idea of ›bodily difference‹ is a dangerous relativism that misunderstands how power works. But at the same time, there is an interweaving of difference/same through disabled and non-disabled experience, the naming of which can only help in expressions of disability recognition and justice. Lennard J. Davis speaks to this in his collection of essays *Bending Over Backwards*, where he asserts in the title of the book's Introduction that »People With Disability: They are You«, an argument about same he develops with reference to an increasingly ageing global population for which disability will become a fact of life. At the same time, Davis embraces disability as an unstable »difficult position« (a term in his book's subtitle) precisely because of the difference it produces. Such ›difficulty‹, he asserts, could provide both a new ethics of the body and an identity position that can be a link between others (he mentions race, gender and sexual orientation) in a fully multicultural patterning. This is, Davis acknowledges, highly ambitious, but is nevertheless an example of what he believes that a critical mobilisation of disabled difference could do.[10]

Michele Friedner is even more explicit about the interconnections between different and same in her study *Valuing Deaf Worlds in Urban India*, which

10 Lennard J. Davis: Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions, New York 2002, pp. 13–14 and pp. 22–23.

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analyses deaf communities in Bangalore. Friedner notes that a common greeting between deaf people in the city is »deaf deaf same«, a phrase that means »I am deaf, you are deaf, we are the same«. »Deaf deaf same«, she notes, is »a common sentiment and statement in Bangalore's deaf worlds, and it is a way of expressing deaf similitude or a shared language of being in the world based on common sensorial experience, use of sign language, and an awareness that structural barriers exist for deaf people«. A feeling of »deaf deaf same«, she continues, interacts with deaf people's circulation through space and locations to produce what she terms »deaf turns«. At the same time, Friedner develops an idea of »deaf development« that is geared towards a drive for social equality, something that »will result in deaf people's becoming equal to normal people–though it will not result in their becoming the same«.[11] Difference and same are held in a complex interrelationship here, one where the concepts of development and turn mark movements in how each operates (I especially like the suggestion of turning towards/away/between different and same). And crucially the idea is disability led, in that »deaf deaf same« is the origin (Friedner employs it at the very start of the book) of the development that reaches out for equality, and therefore justice. This careful charting of the interweaving of difference and same gives a depth of meaning to each as well as the relationship between the two.

We can learn much from these examples then, and avoid falling into the flat uselessness of saying that all bodies are the same because they are different in some way, or that our ›common humanity‹ means we are all the same despite what are obviously vast differences in experiencing the world. We can learn to respect the particularities of disability and ill health without pushing (or pulling) these so far away that they become fearful or exotic. They can be recognizable, from within and without, even as they weave within and without together.

A notion of difference/same and the ways they are expressed in both the experiences of lives lived in health and disability and the new academic disciplines that have come to coalesce around them are, I want to argue, major elements in how we might think about the relationship between Medical Humanities and Disability Studies. They speak to and of the multiple poles/not poles, dualisms/not dualisms that shift and oppose, complement and contradict, inform and challenge our efforts to make sense of what these essential labels – medicine, disability, health – mean when we come to speak

11 Michelle Friedner: Valuing Deaf Worlds in Urban India, New Brunswick, NJ 2015, p. 3.

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and write them. In the light of this, my arguments here about the workings of the two disciplines are attempts to specify methods and offer interventions, knowing that these lie over the missing words of each related topic, the indisciplined and palimpsestic presences that inform understanding but also always suggest possible erasure, helpful signposts and challenging shadows. Aiming to provoke in this context involves finding fluid intersections even while admitting that these might also be powerful oppositions: and wanting to do justice to both in their full manifestations.

Critically, there is nothing new in observing that dualities have unstable poles and work as continuums as much as contraries; it is a mode that drives theoretical framing and works to recognise nuance and sophistication. But to assert an indisciplined approach to disability and medical contexts of difference/same is to engage with a different critical process, one that is not only a critical paradigm but addresses vital and sensitive elements of health, agency and personhood. After all, there is significant space between a health condition designated as clearly ›different‹ to the majority of the population and a health status figured as the same as, or consistent with, that majority. With disability, this is equally acute: Here, difference is an essential category for multiple reasons, whether in terms of self-image and agency, (non-)acceptance by others, or access to benefits and allowances. For health and wider state bureaucracies, if a disabled person is deemed to be the same as others, their very status in society can be called into question. Equally, public perception of such a person is unlikely to register their disability experience. Here, to be the same is not to be disabled.

It is an act of indiscipline, then, to argue for a greater interweaving of difference and same. It is a provocation to assert that ill health should not always be understood to be a medical outlier, or that disability is not difference. I want to argue for the specific forms this takes when the topics are not only medicine and disability, but also Medical Humanities and Disability Studies. Most stories of health lives and their contexts never come near academic disciplines, but the latter claim a stake to discuss the former and uses complex critical tools that make this happen. To argue for disability same is to confront some of the politics of identity positioning Disability Studies holds dear; to do something similar with health is to contest one of the very premises of treatment. But, I would claim, ways that health services treat difference are themselves frequently problematic; and academic study of disability is (surprisingly) often less open and tolerant than might be expected.

Following these trajectories in my own work has led me to a series of indisciplined encounters that produce new provocations: On the complexities

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of claiming; the critical power of cynicism and anger; the prevalence of sneering condescension; the limitations of theory; the structures of listening; and the shortcomings of what might appear to be critical acuity and disciplinary success. To take one of these as an example: listening. Especially in the critical communities in which I find myself, listening presumes the value of a process that extends from the assessment of any given situation or experience to the delivery of what that assessment means. Listening – to a patient or a disabled person – is a good, a foundational element in Medical Humanities and Disability Studies scholarship. Yet frequently such an assessment is inattentive to exactly how structures obfuscate the very idea of such ›delivery‹ and here listening can become a gesture, an act that does not move on from its initial, well-intentioned, formation. I am as pleased as anyone who lives with or cares about disability that we talk more about it in the (UK) culture in which I live, that there are more disabled people on television and children's books and that as a result we, as societies and cultures, reach out, listen and try to understand disabled lives. Equally, I welcome any initiative to talk more, and better, about mental health (especially as someone who teaches young people). And yet, the systems of the worlds in which many of us reside continue to disempower those whose bodies or minds signal alternative ways of being in or experiencing the world. Demands to be a certain kind of individual, to move at a certain pace and produce in certain kinds of ways, are as pervasive as ever and to fall ill, have or acquire a disability is to be placed outside of what are incredibly powerful and seemingly unstoppable narratives of personal and communal worth. What spaces are there for those who face a future in which acceptance appears to be welcomed but who are excluded by structures? At times, this feels more insidious than blatant ignorance because it creates what appears to be an attitude of care. Often, cruelly, it can begin with listening.

The offer of the same then, of inclusion, understanding, and welcoming, masks what in fact is frequently an ongoing stress on the kind of difference that is intolerant, that excludes and (at worst) actively punishes. Individuals might be championed, but categories and populations are allowed to fall away. In social and political contexts, these latter remain under-resourced, with care budgets and community services always high on any list of austerity cuts. Likewise the presence of (for example) mental ill-health as a subject of agreed social concern does not translate into meaningful support for those whose health is so affected. What, put bluntly, can Medical Humanities and Disability Studies do about this? Do they, indeed, want to work with these subjects in mind? Maybe to even ask this is to misunderstand the trajectories

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of their disciplinary concerns as they are manifest in those who work under their umbrellas. It would be cruel to find that the disciplines themselves are examples of the welcoming/exclusion dyad.

Indisciplined Lives

In my own research on disability and health memoir and life writing, I have tried to follow the consequences of thinking about indisciplined and provocative difference/same through the ideas I discuss above. As my thoughts about listening might suggest, my suspicion of individualism and humanism means that I do not read life writing because it is the product of singular viewpoints, but rather because it is structural and enacts the *naming of a world*. In my view, the best life stories do not claim to supply a veracity of individual experience but work through the recognition of systems and sly mechanics of fabrication and editing, often taking the individual self out of truth and breaking down its centrality as the agent of worth. If this sounds counterintuitive, then I would note that it is not only an assertion I might make: It is there in the content and indeed the very titles of some of the best books that discuss disability and ill-health. Lauren Slater's self-styled »metaphorical memoir« *Lying* is, she tells the reader, »a slippery, playful, impish, exasperating text, shaped, if it could be, like a question mark«,[12] while Bassey Ikpi's collection of essays on her experience of being Bipolar, *I'm Telling the Truth, but I'm Lying*, captures the same logic. The titular tension here includes not only Ikpi's disjointed immersion into mental ill-health, but also the inherent contradiction in any claim that writing of such an experience offers a truth-telling clarity. As she says, »Lying is how I survive this […] I lie to control the narrative«. What she terms »parceling truth« is the survival mechanism that lets her »walk though this world vacillating between existing and not existing«.[13]

In the memoir of her depression, *Willow Weep for Me*, published in 1998, Meri Nana-Ama Danquah makes precisely this point about world naming when she observes the ways in which Black women are subject to specific structural stigmas in relation to mental health:

> Stereotypes and clichés about mental illness are as pervasive as thought about race. I have noticed that the mental illness that affects white men is often characterized, if not glamorized, as a sign of genius, a burden of cerebral superiority, artistic

12 Lauren Slater: Lying: A Metaphorical Memoir, New York and London 2001, p. 221.
13 Bassey Ikpi: I'm Telling the Truth but I'm Lying, New York 2019, p. 49.

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> eccentricity – as if their depression is somehow heroic. White women who suffer from mental illness are depicted as idle, spoiled, or just plain hysterical. Black men are demonized and pathologized. Black women with psychological problems are certainly not seen as geniuses; we are generally not labelled ›hysterical‹ or ›eccentric‹ or even ›pathological‹. When a black woman suffers from a mental disorder, the overwhelming opinion is that she is weak. And weakness in black women is intolerable.[14]

Facing her own illness, Danquah saw structure everywhere. No part of her depression escaped the fact she was Black. Even the central metaphors given to medical illness' manifestations–»A black hole; an enveloping darkness; a dismal existence through which no light shines; the black dog«–became markers of race. »But«, she adds »what does darkness mean to me, a woman who has spent her life surrounded by it? The darkness of my skin; the darkness of my friends and family«. For Danquah, »Depression offers layers, textures, noises« but it is not constituted through blackness: »It is loud and dizzying, inviting the tenors and screeching sopranos of thought, unrelenting sadness, and the sense of impending doom. Depression is all of these things to me– but darkness, it is not«. Later in her memoir she writes: »I despise the way blackness, in the English language, symbolizes death and negativity. Because I believe that the absorption of these connotations contributes to self-hate, I avoid them at all cost«.[15] Compare this to one of the most famous memoirs of depression, novelist William Styron's *Darkness Visible* (written in 1990, just a few years before *Willow Weep for Me*) which charts a journey from darkness into light, from »hell's black depths« to the »shining world« of health.[16]

Stryon's book is firmly focused on an idea of self, detailing the terror that comes when it is lost, and the power of the individual to reclaim it. Danquah complicates all this: she tells her readers that »Many names and skins have been shed in order for me to evolve into the person I now am«.[17] Born Mildred Nana-Ama Boakyewaa Brobby in Ghana, and called Nana-Ama as a child, she became Mildred Brobby after moving to the US. »In the face of people who were not part of the culture that I had come to know as my own«, she writes, »my public name and, ultimately, my public persona became Mildred, the English name I was given at birth [...] It hung strangely on my bones, but it was what was given to me so I took it and absorbed

14 Meri Nana-Ama Danquah: Willow Weep for Me: A Black Woman's Journey Through Depression, New York and London 1998, p. 20.
15 Ibid., p. 22 and p. 182.
16 William Styron: Darkness Visible, London 2004, p. 84.
17 Danquah: Willow Weep For Me, p. 103.

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all that it was until even my flesh became redolent of its ugliness«.[18] But Mildred transformed into Mary when Danquah was still a child, because »I convinced myself that only a plain, simple ›American‹ name could provide me with what I wanted most desperately: the luxury of slipping into a void of invisibility«.[19] As a student, Danquah changed her name again when Mary felt unsatisfactory: »I didn't want to be bland and anonymous anymore. I wanted to be myself–whatever that was. I toyed with the name, exchanging letters here and there, until I arrived at Meri. When I looked at the name Meri Danquah, something inside clicked. I felt as if I already owned it«. Reworking her first name and taking her mother's maiden name, after twenty years Danquah found a name that »wasn't a persona. It was me, who I had been all along«.[20]

Name changes such as these are not unusual in immigrant families. They often signal issues of race, ethnicity or nationality and how these are adjusted following a move to societies unsettled by difference (hence Danquah's reference to skins and the internalised ugliness produced by systemic racism). But, as she makes clear in the discussion of her name, Danquah associates this with her depression and the ways in which it created a disassociation of selfhood – the ›void of invisibility‹ – that affected both mind and body. In her book, she mentions the name changes near the start of a section entitled ›Ghosts at the Edge of a Swamp‹, which details a return to the neighbourhood in which she grew up. Ghosts, and especially haunting oneself, occur frequently in women's memoirs about their health; for Danquah they are manifestations of the »uncertainty and self-hatred« she experienced on her arrival in the US, experiences that she links explicitly to her depression.[21]

Danquah's testimony is another example of the difference of difference (here, the way in which the structural dynamics of understanding mental illness are so often exclusionary of specific experiences) but also difference as same (the way that illness is, for Danquah, always framed within the endlessly repeating tropes of stereotypes about being Black; racism means that her difference is nothing like Styron's). It is the figuration of her depression that speaks to and informs the realities of her Blackness, and vice versa, and this then spills out into the world she names in her memoir. When she reads in a newspaper that a significant number of Black people suffer from depression, she immediately counters: ›But why wouldn't there be?‹, continuing:

18 Ibid., pp. 103–104.
19 Ibid., p. 108.
20 Ibid., p. 130.
21 Ibid., p. 104.

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> Depressive disorders do not discriminate along color lines, people do. People determine what is publically acceptable and what is not, who may behave in what way at which time and under which circumstances; and these social mores spill into our private lives, into the images we create. White people take prescription drugs with gentle, melodic names; they go to therapy once or twice a week in nice, paneled offices. Black people take illicit drugs with names as harsh as the streets on which they are bought. We build churches and sing songs that tell us to »Go Tell It on the Mountain.« Either that or we march. Left, right, left, from city to city, for justice and for peace. We are the walking wounded. And we suffer alone because we don't know that there are others like us.[22]

The social mores that spill into private lives are a stark signpost to the structures that create and sustain mental ill-health. Recognising this helps explain how Styron (and others like him) can present their depression in terms of a humanist selfhood precisely because of the social space and capital he accrues as a privileged (and here, white) novelist. Because she is Black, Danquah is denied such security and community. The ghosts of her depression are interwoven with those built into her experiences of race.

In looking at work such as Danquah's, I find what I see as the fault lines and test limits of Medical Humanities and Disability Studies' status as disciplinary approaches, where the inevitable interweaving of life and health becomes a topic of critical enquiry. Such interweaving provokes an obvious question: why should we keep health and disability separate in ways that, as terms, Medical Humanities and Disability Studies clearly indicate? One answer is that, of course, this does not happen and that recognition of the overlappings of race, class, sexuality, gender, embodiment and others takes place all the time in intersectional work. But the disciplines' titles aren't meaningless, and their differing priorities and distinctions they create aren't simply products of academic legacies and institutional flag-waving. Disciplinary differences themselves become constitutive of how health and disability become understood in the social imaginary. They funnel into media, for example, whether through journalism or the siren status of social media, and they inform political opinions. Medical Humanities and Disability Studies scholars are vehemently opposed to any allegations that their work is in any way part of an ivory-tower-research-for-its-own-sake paradigm (activism and teaching are prime examples of engaged commitment). Well, fine. But if this is the case, we have to be attuned to how the critical parameters of our engaged

22 Ibid., p. 184.

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work might inform debates surrounding health in ways that might actually be counterproductive.

Writing like Danquah's helps me make sense of this. Because they are Black, writers such as Danquah and Ikpi provide complex interrogations of stigma not found in other life stories of mental ill-health. They invoke communal understandings of health and as such are practitioners of the kinds of indisciplined world naming I discuss above. The fact that both are women has also been a vital guide to my own work. As might be expected, there is a considerable amount of life writing by men that discusses ill-health, but (as with Styron) it is often shaped by the power of the personal, a centrality that clusters around the individual expressed (obviously) in terms of patriarchal entitlement in one form or another. In my research I have read much of this but – put bluntly – do not find it useful in putting forward the arguments about Medical Humanities and Disability Studies that I found to be the most vital to address. I have come to realise that the reason for this is simple: Women's stories provide the best ways to analyse the disciplines because they are the most complex. They give the best critical insight into topics like disability/same and they do so with the kinds of indisciplined reasoning that signifies the most provocative (and therefore the most useful) modes of health telling.

Conclusion: Disciplines Again

As a discipline, Medical Humanities is successful in many ways because it functions as a broad network of connected approaches across and through multiple subjects. It is through a synthesis of these, one imagined as much as actually theorised, that it lays claim to a critical power. In so doing, it self-consciously aspires to greater sophistication and has moved from deterministic models of instruction and listening (teaching doctors and consulting patients) to critical modes of entanglement and discipline crossing that ultimately are acts of complex reading. Disability Studies builds sophistication into highly complex theoretical frames that host critical projects of advocacy and interrogations of social and cultural activities; it is wary of structures that discriminate and committed to the project of championing disabled presence and forms of knowing the world. In contrast, Medical Humanities still positions itself so as to carry the authority of the category of ›Medicine‹ (even as it critiques it) and, as a result, inevitably operates with some of the legitimacy the word accrues – I find this to especially be true at an institutional level. Through the use of a complex grid of enquiry it seeks to organise better,

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to challenge, and provide improved critical insight into how medicine and health work. Disability Studies is more interrogative of structures and the rethinking of space and time, more committed to activity and organised change. Because of its history as a subject that argues for the need to use the arts in health and to respect the personal voices in patients, Medical Humanities still works through processes of enlightenment, an unveiling that demands more complexity as it asserts its place at the health and medicine table. In the ways in which Medical Humanities pushes to be more than a critical friend to clinical/academic conceptions of health, more than a recourse to humanist modes of understanding experience, for example, or a flat model of therapy, it has successfully argued – especially at levels of theory – for a need for interweaving, uncertainly and greater sophistication in seeing what health is. But arguably it does so through the addition of perspectives, even as its most critically complex. Disability Studies more fully names a recognisable and critical world, even in its sometimes contradictory and exasperated forms.

At the same time, Medical Humanities aims for greater critical inclusivity and can push back against many of the uninterrogated assertions made by Disability Studies and the assumptions inherent in its affirmative modes of counter narratives. I have long found the argument that the ›medical model‹ of minds and bodies underpins misunderstanding of disabled bodies and minds to be frustrating (and this is even if such a model is not seen as that practised by medical specialists but rather a public understanding of this practice). Do processes of medicine cause such problems because of their structures? Of course (think of the incredibly reductive nature of pain scales). Do they do so through recourse to an overarching and coherent model that guides this? Clearly not. Critical Disability thinking grounded in such a viewpoint can simplify the complexities of medicine and the arguments and tensions between different approaches to health and treatment: Health system officials insisting on discharging a patient from hospital, for example, set against rehabilitation experts who know that the person requires additional care; or a surgeon deeming an operation a success, when other doctors know complications are inevitable and will have to deal with patient and family confusion about the future. I once heard a psychiatrist lament wearily that they felt the idea of a medical model was a construction by social scientists (especially) and cultural theorists that licensed dismissive straw man arguments about medical practice, and I confess sympathy for that view. Disability Studies sometimes does the same with ›clinical‹ and ›biological‹ science (I have been guilty of the former). If critical work on disability can demand rightly that subtlety and nuance are essential to understanding

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its multiple manifestations, it is hardly reciprocal to resort to attacks on something called ›science‹ as a way of doing this.

In part, this problem arises because Disability Studies, understood here in its systemic disciplinary formations, is not always good at being inclusive. Scholars in the separate subject areas that contribute to research on disability believe rightly that their work is often vital in addressing issues that affect the lives of disabled people. Working to reduce prejudice, institutional exclusion and systemic discrimination, or understanding cultural narratives, questions of representation and issues of gender (just to give some examples) is enough to take up the most of any working day and there is not necessarily a need (or a desire) to attend to alternative ways of approaching disability experience. Many who work predominantly in Social Studies harbour suspicion towards the theoretical frameworks of Cultural Studies methods, while Critical Disability Studies may aim to build community, and so reaches out to engage with the thinking of others – gender/queer/race – because an alignment of methods can open new doors, but the results can be mixed. At its best, these processes are energising, bringing rich discoveries to ongoing work. But they can be dismissive of research located in specific disciplinary approaches and also produce a lazy intersectionality that lines up critical approaches without thought and actually collapses the specificity of each. Similarly, a commitment to provocative engagement can assume that counter narratives to ableism are de facto good simply by existing in opposition. I often feel that the tendency of Critical Disability scholars to claim the moral high ground through an assertion of wide-ranging inclusion to be something that needs investigation and revision, because it all too often simplifies complexities of disability lives. I find more tolerance in Medical Humanities approaches to critical methods, possibly because the subject acknowledges that it does not have the same kind of foundational core subject (the disabled person, for example) as other disciplines. It knows that it needs to know more.

In much disability theory, assumptions are made about what disabled people are or what they want and even if these come within a language of inclusion that suggests variety, they can be remarkably inflexible. The sometime-stereotyping of the disabled person or consensus about what disability is and how it functions evident in much disability scholarship can be off-putting, especially when the desire is to champion the diversity of disabled lives. The settled agreement that sometimes results can easily become self-righteous. A consensus needs troubling if it becomes in danger of telling people how to think and what to do.

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I am aware that I have possibly been drawn into the position of choosing sides in the ways that I have structured the above, but I hope that it can be seen to be more than this. Putting different elements of the two disciplines in conversation and opposition is not about deciding that one is superior to the other; rather it admits that, like all critical approaches, they have strengths and weaknesses. I am an optimist, and as such I see them as provocative possibilities, ways of making interventions in the critical work that both Medical Humanities and Disability Studies undertake and therefore ways of better understanding medicine, health and disability across the wide range of their manifestations.

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Klaus Birnstiel

From ›Motivgeschichte‹ (›History of Literary Motifs‹) to Cultural Studies and Beyond: Literary Disability Studies in ›Germanistik‹ and German Literary Studies

Ever since the days of Jacob and Wilhelm Grimm, literary studies in Germany and the German-speaking world have taken on a variety of issues and methodologies. Having started as an inquiry into the history of Germanic law and literature, ›Germanistik‹ has seen the rise of interest in the medieval sources and heritage of older German literature as well as the constant praise of Goethe and his time (›Goethezeit‹ or ›Kunstperiode‹, that is, ›epoch of art‹) in the second half of the 19th century, the reassessment of German and European intellectual history (›Geistesgeschichte‹) after the turn of the century, the consideration of the social history of literature since the 1960s and the various undertakings following the ›cultural turn‹ since the late 1980s.[1] However, it has only recently turned to the issues of disability, its representation, and aesthetic significance in German literature, with initially manageable results. In contrast to other national philologies, ›Germanistik‹ widely ignored the subject for a long time. In 2019, Matthias Luserke-Jaqui, professor of German literature at Technische Universität Darmstadt and himself being affected by disability, made a sweeping attack not only on the problem of inclusion at German universities, but also on the state of research on disability within ›Germanistik‹:

> This [the apparent lack of inclusion at German universities, K.B.] directed my scholarly attention to the question of how people with disabilities are actually treated in literature? What cultural and societal notions of disability are conveyed in literature, and with what consequences? When one turns to these questions, one inevitably encounters nothing in my field. No work could even remotely be considered paradigmatic for Disability Studies.[2]

1 On the specifics of a cultural turn in German academia, see Doris Bachmann-Medick: Cultural Turns. Neuorientierungen in den Kulturwissenschaften, Reinbek bei Hamburg 2006.

2 »Das lenkte meinen Wissenschaftler-Blick auf die Frage, wie geht man eigentlich mit Behinderten in der Literatur um? Welche kulturellen und gesellschaftlichen Vorstellungen von Behinderung werden in der Literatur transportiert, mit welchen Folgen? Man stößt, wenn man sich diesen Fragestellungen zuwendet, in meinem Fach zwangsläufig auf - nichts. Es gibt keine Arbeit, die auch nur ansatzweise als paradigmatisch für die Disability Studies gelten könnte.« Matthias Luserke-Jaqui: Thomas Bernhard *Ein Fest für Boris* (1970). Behinderung

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As will be shown here, Luserke's harsh assessment is not only missing some crucial details. It also misrepresents the complicated history of the development of Germanistik as an academic discipline. Research on disability in German literature has existed since at least the 1980s and has expanded significantly since 2000. More recent publications make explicit use of theoretical insights from Disability Studies and Literary Disability Studies. However, the general impression that older research on German literature did not adequately consider disability or ideas from a Disability Studies perspective can hardly be disputed. This article aims to provide explanations for the apparent lack of attention to issues concerning disability in German literature within literary studies by reevaluating the historical origins of ›Germanistik‹ as an academic discipline and its development over time. However, it will also aim to unveil the hidden history of research on disability within Germanistik. At least four constellations in the history of Germanistik (and/or German Literary Studies) shall be considered: i. the ›heroic‹ beginnings of the discipline, 1800 to 1880; ii. the positivist turn in the early 20th century; iii. the brief reign of ›social history‹, around 1965 to 1985; iv. the cultural turn, 1985 to present, and the current and coming situation.

It should be taken into consideration that this undertaking requires some scrutiny regarding the levels of semantics and the lexicon: as for ›disability‹, the use of the German word ›Behinderung‹, implicitly referring to an individual or a rehabilitationist concept, is of relatively recent origin, dating back to the times of the Great War and only being used as the predominant designation of the phenomenon since the 1970s.[3] Historical inquiry thus has to follow other concepts and semantics of disability (see below). As a national philology, ›Germanistik‹ is a disciplinary concept dating back to the time of German Romanticism; as an academic discipline bearing various social responsibilities, ›Germanistik‹ in our time remains responsible for educating the nation's school teachers (albeit at the level of the federal states). In both respects (and some others), ›Germanistik‹ is not to be confused with German Studies, a term mostly but not only reserved for ›Germanistik‹ in foreign countries (the so-called ›Auslandsgermanistik‹, or, ›foreign German-

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als kulturelles Deutungsmuster in Literatur und Literaturwissenschaft?, in: Luserke-Jaqui, Matthias (ed.): Literary Disability Studies. Theorie und Praxis in der Literaturwissenschaft, Würzburg 2019, pp. 85–113, pp. 85–86 (translation mine).

3 Hans-Walter Schmuhl: Exklusion und Inklusion durch Sprache. Zur Geschichte des Begriffs Behinderung. Berlin 2010; cf., with an emphasis on special education, Helmut Bernsmeier: Untersuchung zum sprachlichen Gebrauch der Begriffe Krüppel und Körperbehinderter, in: Heilpädagogische Forschung 8 (1979), pp. 235–244.

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istik‹). While there are other terms for the inquiry into German-language literatures even in the ›mainland‹, they also do not precisely match Germanistik: The term ›Deutsche Philologie‹ (German philology), as the discipline is found to be labelled at many German, Austrian and Swiss universities, does not bear the same tonality as Germanistik; neither does ›deutsche Literaturwissenschaft‹, a term almost not rebuildable in English (›‹science‹ of German, or German-language, literature‹). On the following pages, I will focus on the development of ›mainland‹ Germanistik. However, it will be shown that the influx of external ideas, that is, from international disability studies and theorizing as well as from international German studies, has been decisive in transforming the field.

i. An ableist philology for a self-enabling nation: the ›heroic‹ beginnings of ›Germanistik‹, 1800 to 1880

The emergence of Germanistik as a national philology and an academic discipline in the 19th century is an interesting case that has garnered considerable scholarly attention.[4] As mentioned above, its foundations were laid around 1800, before and during German Romanticism, and in the works of the Brothers Grimm and others. Although intellectuals like Justus Möser and Johann Gottfried Herder had already promoted inquiry into the history of the German language and literature in the last decades of the Enlightenment, it is only after the turn of the century that this research began to take on a more specific form.[5] Historical circumstances were decisive here. Napoleonic troops had defeated Austrian and Russian forces at Austerlitz in December 1805 and Prussia in October 1806 in the battle of Jena and Auerstedt.[6] After the French occupation of territories on the left bank of the Rhine and the French-backed

4 Historic inquiry into the discipline's origins is abundant, but English-language publications are scarce. See Tuska Benes: In Babel's Shadow. Language, Philology, and the Nation in Nineteenth-Century Germany, Detroit/MI 2008, and also Jakob Norberg: German Literary Studies and the Nation, in: The German Quarterly 91 (2018), pp. 1–17. For a short (but somewhat dated) overview in German, see Jost Hermand: Geschichte der Germanistik, Reinbek 1994. Books by Klaus Weimar and Jürgen Fohrmann offer a more detailed picture; see Klaus Weimar: Geschichte der deutschen Literaturwissenschaft bis zum Ende des 19. Jahrhunderts, München 1989, and Jürgen Fohrmann: Das Projekt der deutschen Literaturgeschichte, Stuttgart 1989. Parts of this section of my paper rely on Klaus F. Gille: Germanistik and Nation in the 19th Century, in: Yearbook of European Studies 12 (1999): Nation Building and Writing Literary History, pp. 27–55; Gille also works through the research mentioned above.

5 Gille: Germanistik and Nation in the 19th Century, p. 29.

6 Gille: Germanistik and Nation in the 19th Century, p. 28.

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exit of several southern and western German principalities such as Bavaria, Wurttemberg and Baden, the Holy Roman Empire of the German Nation was dissolved in 1806. As a central political body for the nation had ceased to exist and as vast parts of the German territories were either occupied by France or had become under French political control, calls for national unification seemed to have no prospect in the political realm.

Reflecting the loss of the over-arching political, cultural and ›national‹ integration of the Holy Roman Empire and the humiliating experience of the Napoleonic Wars, proponents of national unity such as Ernst Moritz Arndt, Ludwig Tieck, Ludwig Uhland, Joseph Görres and even Friedrich Ludwig Jahn, widely known as Germany's ›Turnvater‹ (›father of gymnastics‹), advocated for a view of German culture as a suitable foundation for endeavours in political unification.[7] Scholars such as August Wilhelm Schlegel, Jacob and Wilhelm Grimm, Friedrich Benecke, and Karl Lachmann provided for that. In these early days, Germanistik was part of a much broader ›Kulturpolitik‹, a cultural politics aimed at fostering German national identity through the means of language, literature and their history.[8] National identity was conceived through cultural identity, which was constructed by linking the ›Volk‹ (›the people‹) to its language and literature. In his *Reden an die Deutsche Nation* (*Addresses to the German Nation*), philosopher Johann Gottlieb Fichte in 1808 argued that the exceptionality of German culture was based on the preservation of its language since ancient times. In Fichte's historical imagination, the ›Volk‹ had held sacred the German language and the values of German culture, and the language and its literary uses had shaped the national character.[9] Regaining access to the legal, mythological, linguistic, and literary sources of the German nation and feeding those findings into the cultural and political debates of the hour was the mission then. Somewhat ironically, while at times interfering with the non-national politics pursued by the German principalities and kingdoms of the day, ›Germanistik‹, comprising both philology and literary history, was begun and saw itself as a national undertaking. Being a rather minoritarian enterprise pursued by poorly secured academics and intellectuals, its interests were not concerned with minorities. Instead, the nation was central to its endeavour. As Jakob

7 Gille: Germanistik and Nation in the 19th Century, p. 35.

8 On the notion of »Kulturpolitik« after 1800, especially in German romanticism, see Till Dembeck: Kulturpolitik und Totalitarismus, in: Merkur 66 (2012), No. 2, p. 170–176.

9 [Johann Gottlieb] Fichte: Addresses to the German Nation, ed. by Gregory Moore, Cambridge 2008; cf. Gille: Germanistik and Nation, pp. 32–33.

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Norberg puts it, the evolution and establishment of ›Germanistik‹ is not to be seen as a project entangled with nationalism. Rather, it is nationalism itself:

> It would not be quite accurate to say that nationalism began to shape or influence German literary studies in the early nineteenth century, when the field was first coming into being. Instead, German literary studies, or *Germanistik*, was a form of nationalism in itself; it articulated, supported, and sought to substantiate nationalist ideas. Linguists, editors, critics, folklorists, legal historians, and ethnographers retrieved and restored Germanic texts, mapped out the grammars of Germanic languages, constructed a German canon, told histories of German literature, and collected information about Germanic customs and traditions—all efforts dedicated to the delineation of a German culture worthy of preservation and reverent attention. The project of the early Germanists was to allow the nation to appear, to reveal its historical depth, represent its particular character, and convey its authentic voice. In this sense, early Germanistik was the quintessential nationalist enterprise.[10]

The scope of philological work of the time was both broad and narrow. In the preface to the 1815 edition of the second volume of German fairy tales, the acclaimed *Kinder- und Hausmärchen* (›Children's and Household Tales‹, but commonly referred to as *Grimms' Fairy Tales*), Jacob and Wilhelm Grimm linked the fairy tale of *Dornröschen*, the sleeping beauty, back to the medieval Brünhild from the *Nibelungenlied* (*Song of the Nibelungs*), seemingly opting for a transhistorical and even transnational approach.[11] But the ultimate goal of this research was to regain access to the »essentially German myth« (»urdeutscher Mythus«).[12] The Grimms provided their readers with short annotations, thus opening up the sprawling inquiry into the history of the ›raw material‹ and the ›motifs‹ of German literature. Although the term »Motivgeschichte« (»history of literary motifs«) itself was coined only at the beginning of the 20th century, collecting, classifying, and describing motifs was part of German philological scholarship from its very beginning in the early 1800s.[13] This kind of research repeatedly had to address the semantics of disability, albeit under different lexemes and morphemes. As mentioned above, the modern notion of ›disability‹ and its morphological

10 Norberg: German Literary Studies and the Nation, p. 1.

11 [Jacob Grimm, Wilhelm Grimm:] Vorrede, in: Jacob Grimm, Wilhelm Grimm (eds.): Kinder- und Haus-Märchen. Zweiter Band, Berlin 1815, pp. iii-xii, p. vi.

12 [Jacob Grimm, Wilhelm Grimm:] Vorrede, p. vii.

13 Rudolf Drux: Motivgeschichte, in: Harald Fricke et al. (eds.): Reallexikon der deutschen Literaturwissenschaft. Band II H-O, Berlin/New York 2000, pp. 641–643, p. 642. For a critical revision of the history of »Motivgeschichte«, cf. Hans-Jakob Werlen: Stoff- und Motivanalyse, in: Jost Schneider (ed.): Methodengeschichte der Germanistik, Berlin/New York 2009, pp. 661–677.

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manifestation, ›Behinderung‹, did not come to see the light of day before the early 20th century. Instead, philology, lexicography, and literary studies during the 19th century had been treating ›Zwerge‹ [›dwarfs‹] and ›Krüppel‹ [›cripples‹], as well as ›Missgeburten‹ [›monstrosities‹] and the like.[14] A rich tradition of inquiry into issues of disability in research on folk poetry and fairy tales, albeit under different names, has emerged from this.[15] Philology and the critical edition of ancient sources were indeed driven by national and nationalist energies. However, the philological enterprise within Germanistik opted out of the project of ›nation-building‹ (Gille) in the 1830s and 40s. Karl Lachmann, who held a chair at the university of Berlin since 1827, and his successor Moriz Haupt, both notable for producing the first critical edition of medieval ›Minnesang‹ (minnesong), set high professional standards in preserving and commenting on literary sources – standards that were too high to serve the cause of ›Volksbildung‹ (›education of the people‹). In this sense, professionalization of Germanistik came along with some depoliticisation: although literature and literary education was still seen as a privileged means of forging the nation, this task was assigned not to the academic discipline of Germanistik in the sense of critical edition and philology, but rather to its historical branch, and to popular editions and primers gleefully neglecting the standards of scholarship.[16]

For scholars of the German language and literature, rigorous philology was certainly one path to follow. Writing the literary history of the nation offered another option, serving the outlined cultural-political cause. But within the national and even nationalist framework with its normative prescriptions, writing a literary history of disability was of no concern. Instead, a heroic pattern of literary history aimed at consoling the nation over its political problems. Looking back at the times of the Napoleonic Wars and reflecting

14 As Klaus-Dieter Thomann has shown, even ›Krüppel‹ (›cripple‹), nowadays widely seen as predecessor to the modern ›Behinderter‹ (›person with disabilities‹), was not in use throughout the 19th century as a whole, making lexicography and semantics even more difficult. Cf. Klaus-Dieter Thomann: Der »Krüppel«. Entstehen und Verschwinden eines Kampfbegriffs. In: Medizinhistorisches Journal 27 (1992), pp. 221–271.

15 Using the word »Behinderte« (›people with disabilities‹) in the title of his 1981 book on myth and folk poetry, Hans-Jörg Uther could draw on an impressive research tradition, spanning from the late 19th century to present times: Hans-Jörg Uther: Behinderte in populären Erzählungen. Studien zur historischen und vergleichenden Erzählforschung, 1981. De Gruyter. But Uther's work is situated much more in »Komparatistik« (comparative literature) than in Germanistik. Its scope and zeal are international, not national, and even anthropological.

16 Gille: Germanistik and Nation, pp. 40–42.

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on his own times, the mid-1830s, literary historian Georg Gottfried Gervinus declared that it had been impossible to engage in fruitful political history then and now. Instead, turning to the history of German literature would offer a more hopeful outlook.[17] Trying to come to terms with literary history, ›Germanistik‹ did not relinquish its political core. Telling the story of the greatness of German literature at least from the early Middle Ages to Goethe, reminding readers of the cultural heritage of the nation, and also, securing its place at the banquet of European nations was the mission of this strain of ›Germanistik‹, turning away from the micro-problems of philology and painting the broader picture of literary history instead. The monumental literary histories that emerged in and after the formative phase of Germanistik as an academic discipline and especially between the failed revolution of 1848 and the foundation of the Second German Empire (Kaiserreich) in 1871 are known to tell the story of the development of German national literature primarily through great authors and works and to classify them in overarching schemes of heyday and decline, thus paradoxically combining an older ›theory of literary waves‹ already established since the 17th century with a grand national-teleological design for 19th-century political purposes.[18] Georg Gottfried Gervinus' *Geschichte der Deutschen Dichtung* (1835–1842) or August Friedrich Christian Vilmar's *Geschichte der deutschen National-Literatur* (1845) proceed in this way, and even the first ›positivist‹ turn in literary history brought about by Wilhelm Scherer (*Geschichte der Deutschen Litteratur*, 1883) does nothing to change this.[19] The development of German literature is seen as a process of

17 Georg Gottfried Gervinus. Translated by Gille: Germanistik and Nation, p. 43. With regard to actual politics, Germanistik of the 1830s and 1840s had a national and a liberal edge to it, thus being put in a counterposition against the forces of repression and conservative restoration of the loosely-connected states of the Deutscher Bund (German Confederation) founded in 1815. As members of the Göttinger Sieben (Göttingen Seven), Gervinus and the Grimms were fired from their professorships at university of Göttingen by the king of Hanover in 1837. The Göttingen Seven had protested against the revocation of the constitution by Ernst August I. Their story became a legend to liberals in the 19th century. For a critical revision of the history and the legend, see Klaus von See: Die Göttinger Sieben. Kritik einer Legende, Heidelberg 1997.

18 Jürgen Fohrmann: Das Projekt der deutschen Literaturgeschichte. Entstehung und Scheitern einer nationalen Poesiegeschichtsschreibung zwischen Humanismus und Deutschem Kaiserreich. Stuttgart 1989, pp. 8, 132.

19 Vilmar's book was first published as August Friedrich Christian Vilmar: Vorlesungen über die Geschichte der deutschen National-Literatur, Marburg 1845; Gervinus' work saw several reeditions, with the final title being established by the edition of 1853: Georg Gottfried Gervinus: Geschichte der Deutschen Dichtung. Five vols., Leipzig 1853. Scherer's literary history, which became quite popular, was published as Wilhelm Scherer: Geschichte der

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unfolding its inner greatness through time and finding its definitive form around 1800. As Jürgen Fohrmann puts it, the project of literary history pursued in the 19th century since its theoretical beginnings with Johann Gottfried Herder many decades earlier focused on »a kind of historical entelechy perspective«.[20] In this sense and, again, in the words of Gervinus, writing the nation's literary history means taking into account the obstacles and adversaries of German poetry, its struggles and shortcomings, and ultimately, its outstanding success: »A single painting will attempt to vividly depict the fates it [she] suffered, the obstacles it [she] encountered, how it [she] endured some and overcame others, how it [she] grew stronger internally, what promoted it [her] externally, and what ultimately earned it [her] unique value, recognition, and dominance.«[21] Gervinus, as many others to come during the 19th century, sees the climax and provisional end point of the entelechy of German literature around 1800: »The goal in the history of our German poetry, to which I alluded, lies at the cusp of the last centuries; thus, my narrative had to reach that point. This goal is not one artificially created by me, one adapted and substituted for my own purposes, but one rooted in the very nature of the matter.«[22] Histories of German literature stayed true to these convictions throughout the 19th century. Written by professionals in the field but also directed at a broader public, they maintained these ideas together with claims of ultimate superiority over other European literatures. As late as 1883, after the founding of the Kaiserreich under Prussian leadership, Wilhelm Scherer could claim that most prominent writers of the 18th century

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deutschen Literatur. Berlin 1883. ›Literaturgeschichte‹ (›literary history‹) in the German sense, both as a concept and a genre, is a difficult case. For a comprehensive overview for the English reader, albeit lacking analytical depth, see Michael S. Batts: A History of Histories of German literature, 1835–1914, Montreal 1993.

20 Fohrmann: Das Projekt der deutschen Literaturgeschichte, p. 31 (translation mine).

21 As »Dichtung« (»poetry«) is feminine in German, Gervinus refers to it as a »sie« (»she/her«): »Welche Schicksale sie litt, welche Hemmungen ihr entgegentraten, wie sie die einen ertrug, die anderen überwand, wie sie innerlich erstarkte, was sie äußerlich förderte, was ihr endlich eigentümlichen Wert, Anerkennung und Herrschaft erwarb, soll ein einziges Gemälde anschaulich zu machen versuchen.« Georg Gottfried Gervinus: Geschichte der poetischen National-Literatur der Deutschen. Erster Theil, Leipzig 1835, p. 1 (translation mine).

22 »Das Ziel in der Geschichte unserer deutschen Dichtkunst, auf das ich hindeutete, liegt bei der Scheide der letzten Jahrhunderte; bis dorthin mußte also meine Erzählung vordringen. Dieses Ziel ist nicht ein künstlich von mir geschaffenes, ein zu meinen Zwecken zugerichtetes und untergeschobenes, sondern ein in der Natur der Sache begründetes;« Gervinus: Geschichte der poetischen National-Literatur der Deutschen. Erster Theil, p. 8 (translation mine).

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such as Gotthold Ephraim Lessing had already participated in the entelechy of the Prusso-German state of the late 19th century.[23]

Within this framework, the dismissal of 17th century ›baroque‹ blocked deeper insight into the many literary embodiments of disability e.g. in the epoch of the Thirty Years' War or in Romanticism, and as contemporary literature did not come under consideration generally, the exhaustive engagement with disability in late 19th literary Realism could also not be commented on. And even with regard to the so much revered ›classic‹ 18th century literature, disability was nowhere to be seen: Lessing's *Minna von Barnhelm* (1767) does not only ponder questions of honour. Major Tellheim's arm is paralyzed by gunshot, but literary historian Wilhelm Scherer depicts the play's characters as »all capable and lovable patriotic figures«.[24] Johann Wolfgang Goethe's *Götz von Berlichingen* (1774), featuring a knight with a crippled hand, was commented on in terms of fight and struggle, not injury and survival. Georg Gottfried Gervinus makes no mention of his impairment. Instead, he praises Goethe for picking the historical Götz as an epitome of German national values.[25] Franz von Moor, the envious brother in Schiller's *Die Räuber* (1782) is depicted as ugly and deformed and obsessively describes himself as disadvantaged by nature. But August Friedrich Christian Vilmar interprets the play solely as a staging of the social and political turmoil of its time, no matter the detailed corporeal discourse.[26]

Under the auspices of cultural and national pride in and qua literature, disability is not discussed in older research for conceptual and semantic reasons only, but for normative reasons. Ideas of the history of German literature as a sign for the higher glory of the nation make it difficult to imagine assigning a place to the deviant, especially since literary histories of this kind are consistently characterized by strict value judgments that more or less obviously follow the semantics of Goethe's unfortunate remarks on the healthy and the sick in German literature. Looking at disability seemingly could not contribute anything useful to this robust version of literary history. What was needed here is literary heroes, not crips – men, proficient and capable, perhaps with a slight leaning to the mystical like a certain Mr. Faust,

23 Scherer: Geschichte der deutschen Literatur, p. 449; see Gille: Germanistik and Nation, pp. 48–51.

24 »[L]auter tüchtige und liebenswerthe vaterländische Gestalten«: Scherer: Geschichte der deutschen Literatur, p. 449.

25 Georg Gottfried Gervinus: Neuere Geschichte der poetischen National-Literatur der Deutschen, Erster Theil, 3rd edition, Leipzig 1851, p. 506.

26 Vilmar: Vorlesungen über die Geschichte der deutschen National-Literatur, pp. 377–378.

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but able-bodied, able-minded, and able in every sense.[27] The outlined idea of a national entelechy of German literature, with its ideas of cultural heritage, the parallel coming-to-itself of literature and the nation and the admiration of artistic excellence in the so-called ›Kunstperiode‹, is ableist in its entirety, and to this day, this concept persistently resists disabling it. Aside from the margins of ›Motivgeschichte‹, disability was a non-topic, and thus, 19th century Germanistik does not know of any valid overall descriptions of the subject in question in terms of literary history. Even with regard to the literature of Romanticism, which was a matter of dispute in general, no literary history of ›the other‹ developed. The Hegelian Karl Rosenkranz's call for an aesthetics of the ugly, which *en passant* polemicizes »the making fit« of literary history »for girls' boarding schools and upper-class girls' schools«, met with no response, at least not in the emerging field of ›Germanistik‹.[28] Synthesizing literary-historical reconstructions of the subject matter can neither be found in the national philology of the 19th century nor in the literary studies of the early 20th century. Indeed, the new strain of ›Geistesgeschichte‹ (›intellectual history‹, but ›Geist‹ leaning much more to metaphysical ›spirit‹) brought forward by scholars such as Fritz Strich (*Deutsche Klassik und Romantik*, 1922), Paul Kluckhohn (*Die Auffassung der Liebe in der Literatur des 18. Jahrhunderts und der Romantik*, 1922), and Hermann August Korff (*Der Geist der Goethezeit*, 1923–53) focused on big ideas and the ›Zeitgeist‹ of certain epochs, and not on corporealities.[29]

ii. Outside inquiry as happy list-making: the ›positivist turn‹ in the early 20th century

On the margins of the field, things started to change after 1900, or rather, after the Great War. As Urte Helduser has shown, amateur researchers began to engage with disability through an inventory of plot, a list of literary characters

27 Note the shift of heroism from object to subject here: many of the literary historians of these days do not only conceive of the national literary history of Germany as heroic. In mastering its vast material, they very often refer to themselves as heroic German characters.

28 Karl Rosenkranz: Ästhetik des Häßlichen, Königsberg 1853, p. XI (translation mine).

29 Fritz Strich: Deutsche Klassik und Romantik, München 1922; Paul Kluckhohn: Die Auffassung der Liebe in der Literatur des 18. Jahrhunderts und der Romantik, Halle/Saale 1922; Hermann August Korff: Der Geist der Goethezeit, 4 vols. , Leipzig 1923–53.

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and, again, a history of literary motifs.[30] The most prominent example is the work of Hans Würtz (1875–1958), an outsider to any kind of philology. Fairly recently, German philosophical writer Peter Sloterdijk (*You Must Change Your Life*) has devoted some attention to him.[31] As deputy director of the Oskar-Helene-Heim in Berlin, an institution devoted to rehabilitating people with disabilities, Würtz not only argued for a special »Krüppelpädagogik« (»cripple pedagogy«) in the interwar period. He also put together a huge collection of works of art depicting people with disabilities. The objects were on display in an exhibition in 1932.[32] In that very same year, his book *Zerbrecht die Krücken* (»Break the Crutches«) presented an exhaustive list of people, artists, and authors affected by disability in some way or the other.[33] It listed works of German literature dealing with disability ranging from Friedrich Schiller's *Die Räuber* (*The Robbers*) to Theodor Storm's *Der Schimmelreiter* (*The Rider on the White Horse*), and it also featured contemporary literature, with Alfred Döblin's *Berlin Alexanderplatz* (known under the same title in English) being the most prominent example. Würtz, as an amateur researcher, aimed at mapping the unexplored territories of disability in German literature for the uses of his »Krüppelpädagogik« and not for Germanistik. The same applies to an entry in the *Enzyklopädie der Heilpädagogik* (›Encyclopedia of Special Education‹) by Friedrich Pagel in 1934.[34] Not devoted to the uses of special education any more, it is a somewhat ironic fact that this happy list-making, or, to use a phrase ascribed to Michel Foucault, this ›happy positivism‹ still is

30 Urte Helduser: Literatur- und Sprachwissenschaften in den Disability Studies, in: Waldschmidt, Anne (ed.): Handbuch Disability Studies, Wiesbaden 2022, pp. 219–233, pp. 221–222.

31 Peter Sloterdijk: You Must Change Your Life. On Anthropotechnics, Cambridge 2013, pp. 48–57, passim. Sloterdijk's reading situates Würtz' work in the context of Nietzscheanism, an issue which cannot be explored here.

32 On Würtz' biography and work cf. Oliver Musenberg: »Das Material ist völlig unbefangen gesammelt« – der Pädagoge Hans Würtz und seine »Krüppelbilder- und Plastiksammlung«, in: Musenberg, Oliver (ed.): Kultur – Geschichte – Behinderung. Die kulturwissenschaftliche Historisierung von Behinderung, Opladen 2013, pp. 183–205. A joint British-German research project, led by Oliver Musenberg and Simon McKeown, explores the history and implications of Würtz' collection: cf. https://gepris.dfg.de/gepris/projekt/468465125?language=en .

33 Hans Würtz: Zerbrecht die Krücken. Krüppel-Probleme der Menschheit, Leipzig 1932. The double entry of the Nazi propaganda minister Joseph Goebbels for his »Klumpfuß« (»clubfoot«) in the directory, in conjunction with other accusations, earned Würtz a prison sentence; after serving it, he left Berlin and only returned to the city after the war: Musenberg: Hans Würtz, pp. 191–192.

34 Friedrich Pagel: Der Abnorme in der schönen Literatur. In: Adolf Dannemann et al. (eds.): Enzyklopädisches Handbuch der Heilpädagogik, Halle/Saale 1934, cc. 1602–1626.

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part of the discussion on disability and German-language literature today, be it scholarly or more oriented towards the broader public.[35] Würtz' controversial positions on the ›cripple problem‹ cannot be described in detail here, and as his taxonomies themselves are quite dubious, I will refrain from exploring them in depth. Furthermore, the work of Würtz and Pagel did not have any impact on ›Germanistik‹ of these times itself. Although there was a lot of newspaper discussion on disability issues and also on contemporary literature on disability after the Great War, the literary histories of Germany written in the 1920s and early 30s do not deal with disability. Instead, the rise of Nazism promoted an overtly nationalist and chauvinist re-writing of literary history, with Josef Nadler's *Literaturgeschichte der deutschen Stämme und Landschaften* being the most shameful example of collaboration with National Socialism in Germanistik.[36]

iii. The short reign of ›social history‹, 1965 to 1985

The end of literary history's overly close ties to national or even nationalistic paradigms and the tendency to formalize the discipline after the Second World War did not fill the research gap on all things disability. Even the ambitious research program of a ›Sozialgeschichte‹ (›social history‹) of German-language literature brought forward from the late 1960s onwards and during the 1970s has produced remarkably few relevant works. The mid and late 1960s had seen the belated denazification of universities and scholarly bookshelves in a way unprecedented in Germany, or at least Western Germany. A generation of liberal or mildly social democratic scholars had pushed out the older generation; the ›Germanistentage‹, the profession's biggest gatherings, in Munich (1966) and West-Berlin (1968) had been core events in this process.[37] Moreover, the aftermath of the so-called student revolt of 1968 saw a huge expansion of university teaching, filling the demand for German teach-

35 Cf. Christian Mürner: Erfundene Behinderungen. Bibliothek behinderter Figuren, Neu-Ulm 2010.

36 Josef Nadler: Literaturgeschichte der deutschen Stämme und Landschaften, 3 vols., Regensburg 1912–1918; revised, with an overtly national socialist tendency, as Josef Nadler: Literaturgeschichte des deutschen Volkes. Dichtung und Schrifttum der deutschen Stämme und Landschaften, 4 vols., Berlin 1938–1941.

37 Cf. Eberhard Lämmert: Germanistik - eine deutsche Wissenschaft. In: Germanistik - eine deutsche Wissenschaft. Beiträge von Eberhard Lämmert, Walther Killy, Karl Otto Conrady und Peter v. Polenz, Frankfurt/Main 1967, pp. 7–41.

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ers, and it also saw a scholarly turn towards social issues. Within the field, student protesters inspired by Marxism were shouting slogans as »Schlagt die Germanistik tot. Macht die blaue Blume rot« (roughly: ›Kill Germanistik. Make the blue flower red‹).[38] However, in accordance to German academic customs, dying the blue flower red only resulted in establishing a very lightly red research paradigm. Within this framework, literary scholars queried content and modes of literary representation – and underrepresentation: women, the working class, and Jewish people became objects of literary history (though, generally speaking, mostly not subjects). But the two major socio-historical undertakings that came to see the light of day, *Hansers Sozialgeschichte der Literatur*, edited by Rolf Grimminger, and Horst Albert Glaser's *Deutsche Literatur. Eine Sozialgeschichte* reconstruct literary history primarily as a social communication context and refrain from drilling deep into content or vaulting over the history of discourse.[39] Disability plays no special role here either. At the moment these extensive volumes appeared, the theoretical framework of ›Sozialgeschichte‹ already had come under fierce criticism, losing credibility among scholars and students.[40] During the 1980s, its Marxist foundations were reworked in the style of Niklas Luhmann's influential theory of social systems, a much more abstract way of reflecting social change. And even in its earlier, Marxist incarnation, one could say with some polemical acuity, literary studies with a social-historical orientation seem to neglect disability as a secondary contradiction, and this also stays true for the more liberal (or ›bourgeois‹) version of the project.

Inspired by these scientific contexts and under a climate of heightened social awareness, some direct scholarly engagement with disability can be seen at last, but only some, and it worked within positivist frameworks established (and dismissed) much earlier. A study by Helmut Bernsmeier, *Das Bild des Körperbehinderten in der deutschsprachigen Literatur des 19. und 20. Jahrhunderts* (»The Image of the Physically Disabled in German Literature of the 19th

38 Cf. Thomas Anz: »Schlagt die Germanistik tot ... «. Kontroversen zur Literaturwissenschaft um 1968 und ihre Folgen, in: Martina Knopf, Sascha Seiler (eds.): Die 1968er Jahre. Utopie und Desillusion in Literatur, Film und Musik, Heidelberg 2023, pp. 17–27. The blue flower is a key concept of German Romanticism, most prominently used by the poet Novalis (Friedrich von Hardenberg).

39 Horst Albert Glaser (ed.): Deutsche Literatur. Eine Sozialgeschichte. 10 vols., Reinbek 1980–1991.
Rolf Grimminger (ed.): Hansers Sozialgeschichte der deutschen Literatur. 12 vols., München 1980–1999.

40 Gerhard Sauder: »Sozialgeschichte der Literatur«: Ein gescheitertes Experiment? In: KulturPoetik 10 (2010), pp. 250–263.

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and 20th Centuries«), published in 1980 stands out here as a special case.[41] Bernsmeier's work is based on sociological studies dealing with historical and contemporary attitudes towards people with disabilities. Setting out from the observation that society and its structures underwent profound change during the 19th century, Bernsmeier expects change also in attitudes towards disability. But the diachronic examination of literary texts since around 1800 that deal with disabilities and social perceptions leads to the somewhat discouraging insight that during the course of time, attitudes within society and their literary representation have not changed much. Heavily relying on paradigms of sociology and special education, of the history of changing mentalities and of cultural narratology, the book combs through an impressively wide range of German literary texts spanning from the early 1800s to the 1970s. It considers works by authors such as Gerhart Hauptmann, Frank Wedekind and Thomas Mann. Bernsmeier's book aims at tackling disability issues in society via a reconsideration of literature. Its sophisticated theoretical framework allows for a cross-mapping of historical developments in society and the evolution of literature. However, its actual engagement with literary texts as such comes down to the insertion of small summaries and interpretative rediscription in bleak sociological and historical terms. Apparently, the book has not gained significant attention within Germanistik.[42]

Until the last two decades of the twentieth century, the history of research on disability in Germanistik can therefore hardly be told in any other way than as a series of negative findings, rare exemptions included: during the 1980s, scholarship in the German Democratic Republic also started to engage with disability, focussing on contemporary literature.[43] As has been the case with the paradigm of social history, this is not only a story of lacunae and neglect, but also one of missed opportunities: neither research on ›outsiders‹ (Hans Mayer) nor on ›normalism‹ (Jürgen Link) has inspired corresponding work on disability. Hans Mayer, a Cologne-born German Jew who had been exiled during the times of the Third Reich, went to the GDR after the war and left for the West in 1963, earned a lot of attention for his

41 Helmut Bernsmeier: Das Bild des Körperbehinderten in der deutschsprachigen Literatur des 19. und 20. Jahrhunderts, Frankfurt/Main 1980.

42 The book was reviewed in *Sprachspiegel*, the journal of the then-*Deutschschweizerischer Sprachverein*: Sprachspiegel 39 (1983), No. 4, p. 126. The leading journals within Germanistik did not review it.

43 Gudrun F. Klatt: Literatur als Organ sozialer Kommunikation - Behinderte in der neuesten DDR-Literatur, in: Rönisch, Siegfried (ed.): DDR-Literatur '84 im Gespräch, Berlin, Weimar 1985, pp. 46–52.

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1975 book on *Außenseiter* (›outsiders‹) in the history of German literature.[44] However, his version of the history of German literature from the Enlightenment onwards did cover the exclusion of women, Jews and homosexuals – but not of the working class, and not of the disabled.[45] Twenty years later, Jürgen Link's work on normalism and normalisation did touch on discourses of disability, but it did not inspire further research in that direction, at least not initially. However, it gained significant importance for disability theory in a sociological context.[46]

iv. The cultural turn, 1985 to present – and the current situation

It is only against this background that the ›cultural turn‹ in Germanistik, as can be observed in singular approaches since the mid-1980s and on a broader front since the 1990s and 2000s, can be adequately assessed in terms of its significance for the examination of the complex of literature and disability.[47] In the various studies that open up the German-language field of research, first, a more focused attention for the subject in question and then a tightening connection to the theoretical paradigms of Disability Studies can be observed. The clearest focus on ›disability‹ as subject matter is initially found in contributions to children's and young adults' literature, focusing on thematic, social and pedagogic aspects.[48] Since, as described above, the lexeme ›Behin-

44 On Mayer's eventful and dramatic life, cf. Klaus Pezold: Hans Mayer, in: König, Christoph (ed.): Internationales Germanistenlexikon 1800–1950. Vol. 2: H–Q, Berlin / New York 2003, pp. 1181–1184.

45 Hans Mayer: Außenseiter, Frankfurt/Main 1975.

46 Jürgen Link: Versuch über den Normalismus, Opladen 1996, p. 148–155; cf. Anne Waldschmidt: Die Flexibilisierung der »Behinderung« - Anmerkungen aus normalismustheoretischer Sicht, unter besonderer Berücksichtigung der »International Classification of Functioning, Disability and Health« (ICF), in: Ethik in der Medizin, 15 (2003), pp. 191–202.

47 The ›cultural turn‹ of literary scholarship and Germanistik was widely discussed in the late 1990s and after. See, among others, Claudia Benthien, Hans Rudolf Velten (eds.): Germanistik als Kulturwissenschaft. Eine Einführung in neue Theoriekonzepte, Reinbek 2002; Ansgar Nünning, Roy Sommer (eds.): Kulturwissenschaftliche Literaturwissenschaft. Disziplinäre Ansätze – Theoretische Positionen – Transdisziplinäre Perspektiven, Tübingen 2004; for a more critical perspective, see Jörg Schönert: Literaturwissenschaft – Kulturwissenschaft – Medienkulturwissenschaft: Probleme der Wissenschaftsentwicklung, in: Renate Glaser, Matthias Luserke (eds.): Literaturwissenschaft – Kulturwissenschaft: Positionen, Themen, Perspektiven, Opladen 1996, pp. 192–208.

48 Rosmarie Zimmermann: Behinderte in der Kinder- und Jugendliteratur, Berlin 1982; also see Gabriele von Glasenapp, Simple Stories? Die Darstellung von Behinderung in der Kinder- und Jugendliteratur. kjl&m – Forschung.Schule.Bibliothek, 14 (2014), 3, pp. 3–15.

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derung‹ for ›disability‹ established itself comparatively late as a collective term for the semantics discussed here, inquiry into the history of German literature inspired by the cultural turn had to search for cripples, monsters, the disabled and other deviant figures and did so with increasing success since the 1990s. Achim Hölter's work on war invalids, *Die Invaliden. Die vergessene Geschichte der Kriegskrüppel in der europäischen Literatur bis zum 19. Jahrhundert* (»The Invalids: The Forgotten History of War Cripples in European Literature up to the 19th Century«, 1995) dwells on an exhaustive list of sources from European literature. Focusing especially on German-language texts, its range extends from Grimmelshausen to Lessing and beyond.[49] Hölter's inquiry not only drives home the message that injured people populate literature throughout these times. It also shows that disabled people in a broader understanding are a constant topic across all genres, from nursery rhymes and mocking verses to high-brow literature. Irmela Krüger-Fürhoff's book *Der versehrte Körper. Revisionen des klassizistischen Schönheitsideals* (»The damaged body. Revisions of the classicist ideal of beauty«, 2001) reconsiders aesthetic considerations in the 18th century by Johann Joachim Winckelmann, Johann Gottfried Herder, Karl Philipp Moritz, Goethe, Kleist, and others.[50] Contrary to assumptions about classicist aesthetics only being based on ideas of wholeness and bodily perfection, Krüger-Fürhoff's work shows that German writers of the time engaged with phenomena of deformation and dismemberment, autopsy and plastic surgery as well. The analysis proves that bodily disfigurement served a double purpose here. Being excluded from aesthetic dogma on its surface, it nonetheless provided for its very constitution. Reconsidering the literary presence of monsters and the monstrous, Urte Helduser's book *Imaginationen des Monströsen. Wissen, Literatur und Poetik der »Missgeburt« 1600–1835* (»Imaginaries of the Monstrous. Knowledge, Literature and Poetics of ›Monstrosity‹ 1600–1835«, 2016) makes use of insights and theories from disability studies even more explicitly.[51] Setting out from philosophical and literary discourse of the 17th and 18th century, Helduser reconsiders the monstrous in its scientific and aesthetic ambivalence. While Enlightenment authors worked against assumptions on the monstrous as superstition, literature explored

49 Achim Hölter: Die Invaliden. Die vergessene Geschichte der Kriegskrüppel in der europäischen Literatur bis zum 19. Jahrhundert, Stuttgart 1995.

50 Irmela Marei Krüger-Fürhoff: Der versehrte Körper. Revisionen des klassizistischen Schönheitsideals, Göttingen 2001.

51 Urte Helduser: Imaginationen des Monströsen. Wissen, Literatur und Poetik der »Missgeburt« 1600–1835, Göttingen 2016.

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and exploited its visual, dramatic and narrative qualities. As Helduser shows, Romanticism reserved a special place for the monstrous after Enlightenment. Highlighting epistemic ambivalence or even contradiction, monsters and the monstrous thus feature prominently in the work of E.T.A. Hoffmann, Clemens Brentano, Ludwig Tieck, and others. Reading literary monsters via the means of disability studies, the book effectively reclaims their significance in discourses on disability. On the other hand, it also allows for a poetological revaluation of the monstrosity of literary texts themselves. Krüger-Fürhoff's and Helduser's work shed light on literary history since the 17th and 18th century and lend historical depth to literary disability studies. In contrast to the often strong, albeit not exclusive, attachment to Foucauldian paradigms, especially in US-American research, Germanistik follows its own path here, emphasizing not only the historical specificity of development in the German-speaking world, but also referring to its own disciplinary background and tradition.

In the recent past and in the present, Literary Disability Studies are taking more and more shape both as a ›field‹ and as a ›method‹, and thus, they generate output. A predominantly social science-oriented handbook edited by Anne Waldschmidt and another one focusing more on cultural and literary studies edited by Susanne Hartwig appeared in 2020 and 2022; a slim but programmatic collection of studies in Germanistik edited by Matthias Luserke-Jaqui (2019) bears *Disability Studies* in its title.[52] International German studies are still driving the change: special issues of journals and anthologies produced either outside the ›mainland‹ or as international collaborations shed light on the literature and culture of disability especially during the times of the Weimar Republic (edited by Eleoma Joshua and Michael Schillmeier in 2010), the history and memory of disability in German-speaking Europe (edited by Linda Leskau, Tanja Nusser and Katherine Sorrels in 2022) and a broad selection of German literature from the perspective of literary disability studies (edited by Habib Tekin and Leyla Coşan in 2024).[53] Two

52 Anne Waldschmidt: Handbuch Disability Studies, Wiesbaden 2022; Susanne Hartwig: Behinderung. Kulturwissenschaftliches Handbuch, Stuttgart 2020; Matthias Luserke-Jaqui (ed.): Literary Disability Studies. Theorie und Praxis in der Literaturwissenschaft, Würzburg 2019.

53 Eleoma Joshua/ Michael Schillmeier (eds.): Edinburgh German Yearbook 4 (2010): Disability in German Literature, Film, and Theater, Rochester/NY 2010; Linda, Leskau, Tanja Nusser, Katherine Sorrels (eds.): Disability in German-Speaking Europe. History, Memory, Culture, Rochester 2022; Habib Tekin, Leyla Coşan (eds.): Behinderung in der deutschsprachigen Literatur, Lausanne 2024.

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book series, »Disability Studies. Körper – Macht – Differenz« (»Disability Studies. Bodies – Power – Difference«, published with transcript academic publishers since 2007) and »Behinderung – Literatur – Kultur« (»Disability – Literature – Culture«, published with Rombach since 2026) promote academic exchange.[54] As a collaborative initiative, bringing together international scholars from Germanistik, German studies and neighbouring philologies, the research network *Inclusive Philology: Literary Disability Studies in the German-Speaking Realm* strives to coordinate further research and increase its visibility in the discourse in German studies and neighbouring philologies.[55] Panels on disability and literature are now regularly part of the program of the *Deutscher Germanistentag* or the conferences of the *Internationale Vereinigung für Germanistik* (International Association for German Studies). However, as for the institutional development of Literary Disability Studies within Germanistik and German academia, stumbling blocks do remain. The inter- and transdisciplinary and often intersectional approach of Disability Studies, highly necessary for this type of inquiry, seems to make its institutionalisation difficult, especially in literary studies: although there are professorships with a disability denomination in sociology, special education and similar fields in German-speaking countries, there have not yet been any in Germanistik and literary studies.

In the last fifteen to twenty years, the ways in which Germanistik reads disability have changed profoundly. In most recent scholarship, the impact of American and British disability studies and literary disability studies is clearly visible. Relations of knowledge and power, intersections of disability and ›race‹, class and gender have come to attention. In many ways, the history of the establishing of disability theory and Disability Studies within Germanistik thus resembles the history of Gender Studies, Postcolonial Studies and other inquiry into marginalizing discourses within Germanistik. There has been and still is a strong feminist strand in Germanistik. Scholars have thought about alterity and identity in a national and post-national context, and they even have begun to consider disability issues *avant la lettre*. But in all the areas mentioned, the influx of theory from outside of Germanistik and from outside of Germany has been decisive, and so is the case with disability. This, of course, is not a matter of ›us‹ and ›them‹; rather, it can raise

54 This book is the first volume published in the series at Rombach.

55 For a brief description of the project, see https://gepris.dfg.de/gepris/projekt/509035805?context=projekt&task=showDetail&id=509035805& .

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questions on how to further shape Literary Disability Studies in Germanistik, German Literary studies and the German-speaking realm.

Conclusions and outlook: enabling literary disability studies in Germanistik

As has been shown here, it is not the case that Germanistik has and has had nothing to do with disability. Stepping out of the large-looming shadows of 19th century literary history, the picture has changed profoundly. As shown above, Literary Disability Studies are currently experiencing a clearly recognizable upswing in the German-speaking context. But while the national ›project‹ of literary history has rightly fallen into disrepute in recent decades and thus has been replaced by other forms of inquiry and criticism, the substantial research gap concerning matters of disability in German-language literature still remains a cause for lament. Reconsidering the ground-breaking work that has been done in the course of the cultural turn and the present state of research, one might still think about what Disability Studies within Germanistik (and German studies) can do in the future. Since the 1980s, many observers of the development of Germanistik and Literary Studies have described the working conditions of the field as theoretical and methodical pluralism, or even eclecticism.[56] Bringing to attention social and individual issues of disability as cultural issues seem to be paradigmatic for the moment, although the preponderance of ›culture‹ in certain areas of literary studies remains a matter of debate. To the somewhat cautious observer, it seems that the cultural turn in Literary Studies, and in Literary Disability Studies especially, has left open some questions: the question of the social, the question of the ›thickness‹ of symbolic constructions, the question of our own scientific responsibilities and of activism, and the question of the identities of our own discipline. Contrary to the Anglophone discussion, where Literary Disability Studies are constantly being productively challenged by Medical Humanities, the emerging ›culturalist‹ framework of Literary Disability Studies within Germanistik and its increasingly intersectional approach has not become a subject of critical discussion yet.[57] Neither has the question of activism within the discipline.

56 Ulrich Charpa: Methodologie der Wissenschaft: Theorie literaturwissenschaftlicher Praxis? Hildesheim 1983, pp. 12–13.

57 For the discussion on Disability Studies and Medical Humanities, see Stuart Murray in this volume.

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On the levels of philology and literary history, a comprehensive history of German literature and disability is yet to be written. But were it only to recollect the material in a positivist manner, its purpose would be limited. It is not sufficient to retell the contents of representation, to summarize stories and look out for disabled protagonists. Instead, Germanistik must take seriously the idea that working on disability in literature can itself be a way to reinvoke the powers of philology, and even more importantly, to redescribe the workings and reworkings of literary form.[58] To that end, it must attempt to adopt the theoretical inspirations from the Anglophone discussion for a critical revision of the history of German literature as a whole, adequately considering its historical, content-related and formal peculiarities. To name but a few, narratological and aesthetic approaches to disability in literature such as the concept of »narrative prosthesis« outlined by American scholars David T. Mitchell and Sharon L. Snyder or the idea of an »aesthetic nervousness« brought about by Ato Quayson offer further insight and are yet to be considered thoroughly.[59] And if the goal here really is to rewrite the history and theory of German literature by using the toolbox of literary disability studies, there are more theoretical paths to follow. Considerations of genre, metaphor, figural language and narratology would not only allow for a more adequate way of dealing with disability in and as literature. Rethinking disability at the level of literary form could also sharpen our philological tools and productively challenge our fragile critical and scholarly identity. In an increasingly complex cultural environment, it would also help to shape the future of Germanistik and German Studies as an empowering mode of literary inquiry, philologically self-conscious and socially aware, relevant not only to our own community of scholars but also to society itself. Thus, enabling disability studies in Germanistik and German literary studies not only might undo some of the more sinister elements of the history of our discipline. It also could provide for substantial change in scholarship and teaching, and, ultimately, in society.

58 For a broad take on these »powers«, cf. Hans Ulrich Gumbrecht: The Powers of Philology. Dynamics of Textual Scholarship, Urbana/Chicago 2003. Progressive politics is not included in this list.

59 David T. Mitchell, Sharon L. Snyder: Narrative Prosthesis. Disability and the Dependencies of Discourse, Ann Arbor 2000; Ato Quayson: Aesthetic Nervousness. Disability and the Crisis of Representation, New York 2007.

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Martina King

»Many healthy children« or »Mercy Killing«? Eugenic Propaganda in NS Popular Fiction

1 Introduction: classifying mental impairment in the NS era

This article is about the most horrendous episode in the history of disability and about the role that literary fiction played here: the NS-dictatorship between 1933 and 1945. Historians of medicine agree that the NS regime should be called a biomedical dictatorship – it was built and consequently operated by physicians.[1] And it showed its worst side, among others, in the violent atrocities against people with mental impairments; this had started with the sterilization law from 1933 and culminated in the industrial mass killings between 1939 and 1941, the infamous ›Aktion T4‹.[2] Its potential future victims had been classified by the sterilization law under heterogenous arbitrary sub-categories such as ›hereditary cretinism‹, ›schizophrenia‹, ›manic-depressive insanity‹, ›hereditary epilepsy‹, ›hereditary Chorea‹, ›hereditary blindness‹, ›hereditary deafness‹ (Fig. 1).[3]

Of course, the Nazis were immensely keen on objectifying classes of mental impairments in order to declare them all as organic and therefore hereditary; their classification system was deeply naturalistic and essentialist, but it was also an open system with porous boundaries. In other words: it would easily expand to absorb on the one hand new categories; on the other hand, the initially hereditary categories would turn gradually into more universal ones. In the infamous leaflet of 1939 that accompanied the registration form (›Meldebogen‹) for the mass killings, new categories appear such as ›all patients kept as criminally mentally ill‹, ›all patients who suffer from encephalitis‹, ›all patients who have been in an asylum for at least 5 years‹ and ›all patients with senile illnesses‹. Apart from that, ›hereditary cretinism‹ has now turned into ›cretinism of any sort‹, ›hereditary Chorea Huntington‹ into ›Huntington and other neurological end-stage conditions‹ (Fig. 2).

1 See Wolfgang Uwe Eckart: Medizin in der NS-Diktatur. Ideologie, Praxis, Folgen, Cologne, Weimar, Vienna 2012, pp. 11–20.

2 The term ›Aktion T4‹ became common only after 1945 and refers to the address of the planning authority for the mass killings in Berlin, Tiergartenstrasse 4.

3 All translations of German sources, if not otherwise indicated, are by Martina King.

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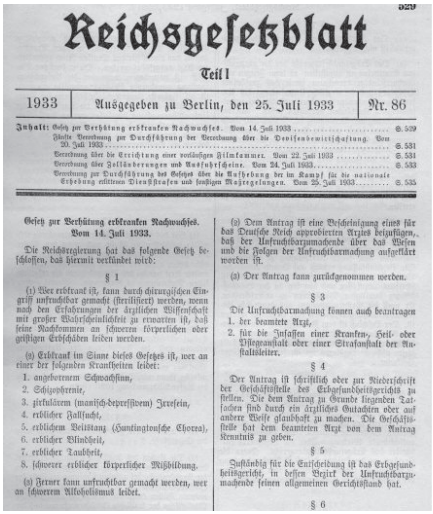

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Verordnung zur Durchführung des Gesetzes über die Aufhebung der im Kampf für die nationale Erhebung erlittenen Disziplinstrafen und sonstigen Maßregelungen. Vom 25. Juli 1933 ... S. 535

Gesetz zur Verhütung erbkranken Nachwuchses.
Vom 14. Juli 1933.

Die Reichsregierung hat das folgende Gesetz beschlossen, das hiermit verkündet wird:

§ 1

(1) Wer erbkrank ist, kann durch chirurgischen Eingriff unfruchtbar gemacht (sterilisiert) werden, wenn nach den Erfahrungen der ärztlichen Wissenschaft mit großer Wahrscheinlichkeit zu erwarten ist, daß seine Nachkommen an schweren körperlichen oder geistigen Erbschäden leiden werden.

(2) Erbkrank im Sinne dieses Gesetzes ist, wer an einer der folgenden Krankheiten leidet:
1. angeborenem Schwachsinn,
2. Schizophrenie,
3. zirkulärem (manisch-depressivem) Irresein,
4. erblicher Fallsucht,
5. erblicher Veitstanz (Huntingtonsche Chorea),
6. erblicher Blindheit,
7. erblicher Taubheit,
8. schwerer erblicher körperlicher Mißbildung.

(3) Ferner kann unfruchtbar gemacht werden, wer an schwerem Alkoholismus leidet.

(4) Dem Antrag ist eine Bescheinigung eines für das Deutsche Reich approbierten Arztes beizufügen, daß der Unfruchtbarmachende über das Wesen und die Folgen der Unfruchtbarmachung aufgeklärt worden ist.

(5) Der Antrag kann zurückgenommen werden.

§ 3

Die Unfruchtbarmachung können auch beantragen
1. der beamtete Arzt,
2. für die Insassen einer Kranken-, Heil- oder Pflegeanstalt oder einer Strafanstalt der Anstaltsleiter.

§ 4

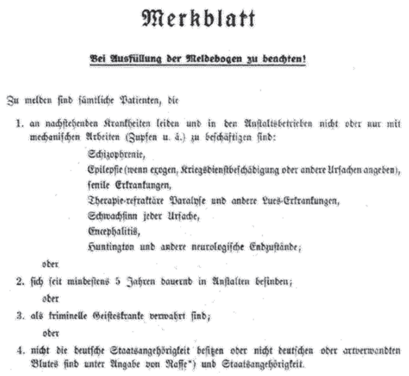
Der Antrag ist schriftlich oder zur Niederschrift der Geschäftsstelle des Erbgesundheitsgerichts zu stellen. Die dem Antrag zu Grunde liegenden Tatsachen sind durch ein ärztliches Gutachten oder auf andere Weise glaubhaft zu machen. Die Geschäftsstelle hat dem beamteten Arzt von dem Antrag Kenntnis zu geben.

§ 5

Zuständig für die Entscheidung ist das Erbgesundheitsgericht, in dessen Bezirk der Unfruchtbarzumachende seinen allgemeinen Gerichtsstand hat.

§ 6

Fig. 1 Announcement of sterilization law 1933[4]



Merkblatt

Bei Ausfüllung der Meldebogen zu beachten!

Zu melden sind sämtliche Patienten, die

1. an nachstehenden Krankheiten leiden und in den Anstaltsbetrieben nicht oder nur mit mechanischen Arbeiten (Zupfen u. ä.) zu beschäftigen sind:
   Schizophrenie,
   Epilepsie (wenn exogen, Kriegsdienstbeschädigung oder andere Ursachen angeben),
   senile Erkrankungen,
   Therapie-refraktäre Paralyse und andere Lues-Erkrankungen,
   Schwachsinn jeder Ursache,
   Encephalitis,
   Huntington und andere neurologische Endzustände;
   oder
2. sich seit mindestens 5 Jahren dauernd in Anstalten befinden;
   oder
3. als kriminelle Geisteskranke verwahrt sind;
   oder
4. nicht die deutsche Staatsangehörigkeit besitzen oder nicht deutschen oder artverwandten Blutes sind unter Angabe von Rasse*) und Staatsangehörigkeit.

Fig. 2 Leaflet, with registration form, 1939[5]

While the aspect of heredity still dominates in the legal text from 1933, the leaflet of 1939 leaves this restriction behind. Like a manual, it somehow orchestrates the actual practice of killing an inhomogeneous group of people all subsumed as mentally disabled in asylums and psychiatric hospitals (›Heil- und Pflegeanstalten‹). And in doing so, it opens up for simply everybody who, first, behaves differently than the normal individual—another vague, undefined biosocial category; and, second, for all those who are already kept in one of these institutions.

In accordance with the leading biomedical doctrine, the mentally ill were considered as ›unworthy lives‹ that weakened the collective body (›Volkskörper‹); their removal from the gene pool would lead to racial enhancement.[6] Hence, about 400,000 people underwent coercive sterilization after 1933 and

4 Reichsgesetzblatt: Gesetz zur Verhütung erbkranken Nachwuchses vom 25. Juli 1933, in: Wikipedia, de.wikipedia.org/w/index.php?title=Gesetz_zur_Verh%C3%BCtung_erbkranken_Nachwuchses&oldid=253231972 (02.03.2025).

5 Merkblatt zum Meldebogen, Landeszentrale für politische Bildung Baden-Württemberg (M17): Euthanasie im NS-Staat: Grafeneck im Jahr 1940 – Baustein, www.lpb-bw.de/publikationen/euthana/euthana34.htm (02.03.2025).

6 See Jürgen Peter: Einleitung, in: Public Health, Eugenik und Rassenhygiene in der Weimarer Republik und im Nationalsozialismus. Gesundheit und Krankheit als Vision der Volksgemeinschaft, Frankfurt/Main 2018, pp. 7–24, here p. 7f.

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6,000 lost their lives during the sterilization process; in January 1934, the *Law for the Prevention of Genetically Diseased Offspring*, in short: sterilization law, had come into force which regulated this practice until 1945. The next step of escalation was the ›Aktion T4‹: following an informal decree of Hitler, addressed to the physicians Philip Bouhler and Karl Brandt,[7] 80,000 people were killed between 1939 and 1941 in special institutions, mainly psychiatric hospitals and asylums—by gas poisoning, sleeping drugs or starvation, among them about 5,000 children.[8]

Now this is not only the darkest chapter in the history of disability; it is also the darkest chapter in the history of German literature. I will argue that literature, precisely popular fiction, played a substantial part here. It pushed the general public to accept this new, brutalized NS-world where disabled people had no right to live by systematically euphemizing and embellishing the principle of eugenic purification. Central to this process was a newly emerging, highly popular genre: the medical novel (›Arztroman‹). It became a major propaganda tool for eugenic doctrines, their ›legal‹ foundations and

7 See Gerrit Hohendorf: Ideengeschichte und Realgeschichte der nationalsozialistischen »Euthanasie« im Überblick, in: Fuchs, Petra/Rotzoll, Maike/Müller, Ulrich/ Richter, Paul/ Hohendorf, Gerrit (eds.): Das Vergessen der Vernichtung ist Teil der Vernichtung selbst. Lebensgeschichten von Opfern der nationalsozialistischen »Euthanasie«, Göttingen 2007, pp. 36–52, here pp. 39f.; Andreas Frewer: »Schiefe Ebene«, Zensur und Selbstzensur: Zur Geschichte der Sterbehilfe-Debatte in der Zeitschrift Ethik, in: Medizinhistorisches Journal 35 (2000), pp. 335–360, here p. 335.

8 The research literature is vast, therefore just some seminal works: Götz Aly: Aktion T4 1939–1945. Die ›Euthanasie‹-Zentrale in der Tiergartenstraße 4, 2nd ed., Berlin 1989; Ernst Klee: Was sie taten – was sie wurden. Ärzte, Juristen und andere Beteiligte am Kranken- oder Judenmord, Frankfurt/Main 1990; Maike Rotzoll /Gerrit Hohendorf/Petra Fuchs/Paul Richter/Wolfgang Uwe Eckart (eds.): Die nationalsozialistische ›Euthanasie‹-Aktion T4 und ihre Opfer. Geschichte und ethische Konsequenzen für die Gegenwart, Paderborn 2010; Thomas Beddies: Im Gedenken der Kinder. Die Kinderärzte und die Verbrechen an Kindern in der NS-Zeit, Berlin 2012; Margret Hamm: »Lebensunwert«: Zerstörte Leben. Zwangssterilisation und »Euthanasie«, Frankfurt/Main 2005; Christof Beyer/Petra Fuchs/Anette Hinz-Wessels/Gerrit Hohendorf/Maike Rotzoll/Hedwig Thelen/Jens Thiel (eds.): Tiergartenstraße 4. Memorial and Information Point for the Victims of National Socialist ›Euthanasia‹ Killings, Berlin 2016. For significant contributions from Anglo-American disability studies that examine the discursive and cultural dimensions of Nazi euthanasia policies, see: Emmeline Burdett: Disability, Nazi Euthanasia, and the Legacy of the Nuremberg Medical Trial, Boulder, CO 2023; Sharon L. Snyder/David T. Mitchell: Cultural Locations of Disability, Chicago 2006 (Chapter 3: »The Eugenic Atlantic«); and Harold Braswell: »Euthanasia«, in: Adams, Rachel/ Reiss, Benjamin/Serlin, David (eds.): Keywords for Disability Studies, New York 2015, pp. 79–81. These Anglo-American perspectives offer critical analyses of the rhetorical strategies and cultural contexts that enabled eugenic ideologies, complementing the historical research tradition predominant in German scholarship.

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practical consequences, in other words for the public acceptance of coercive sterilization and mass killing; and it did so by offering thrilling plots, soft entertainment, distraction and finally a happy new world.[9] Now if we want to understand how all this came about, how literary fiction and criminal practices worked hand in hand, we have to start at the interwar period.

2 Preconditions in the interwar period

What were the preconditions in the Weimar Republic for the ensuing systematic violence against the mentally disabled? In the years after the treatise of Versailles, mass poverty and economic crisis – 1922, 1929 – dominated the young republic. In this context, thousands of people in the overcrowded mental asylums were considered as socioeconomical burden: unwanted, useless eaters, social parasites, ›human ballast‹.[10] Many people, politicians, doctors, lawyers, thought that paying for their living costs in the asylums was something that the economically wretched Weimar state could not afford. These economic arguments met with eugenic ones, both converged perfectly well.[11] The pioneering Swiss psychiatrist Eugen Bleuler for example believed that all sorts of mental diseases, especially schizophrenia, were hereditary and would weaken the ›Volkskörper‹. In 1922, in the fourth edition of his famous *Textbook of psychiatry*, he writes the following phrases:

> If we do nothing but make mental and physical cripples capable of propagating themselves, and the healthy stocks have to limit the number of their children because so much has to be done for the maintenance of others, if natural selection

9 See Martina King: Helden, Heilige, Menschenzüchter: NS-Arztroman und biopolitische Diktatur, in: Weindling, Paul/Brandt, Christina/Fangerau, Heiner/Meinel, Christoph (eds.): NS Medicine: Cultures, Structures, Personal Histories. NAL Historica. Wissenschaftshistorische und wissenschaftstheoretische Schriftenreihe der Leopoldina, Halle 2026.

10 Cf. Dirk Blasius: »Einfache Seelenstörung«. Geschichte der deutschen Psychiatrie 1800–1945, Frankfurt/Main 1994; Heinz Faulstich: Hungersterben in der Psychiatrie 1914–1949. Mit einer Topographie der NS-Psychiatrie, Freiburg im Breisgau 1998, pp. 69–101; Stephanie Neuner: Politik und Psychiatrie. Die staatliche Versorgung psychisch kriegsbeschädigter nach dem Ersten Weltkrieg in Deutschland 1920–1939, Göttingen 2011.

11 Gerhard Baader: Rassenhygiene und Eugenik. Vorbedingungen für die Vernichtungsstrategien gegen sogenannte ›Minderwertige‹ im Nationalsozialismus, in: Peter, Jürgen (ed.): Public Health, Eugenik und Rassenhygiene in der Weimarer Republik und im Nationalsozialismus. Gesundheit und Krankheit als Vision der Volksgemeinschaft, Frankfurt/Main 2018, pp. 119–129.

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> is generally suppressed, then unless we will get new measures our race must rapidly deteriorate.[12]

With ›mental cripples‹, Bleuler meant already both the inborn ›idiots‹ and the ›mentally insane‹ – he considered the two classes both as genetically inferior, in historical semantics ›a life unworthy of life‹. Now within the rigid logic of eugenics, one had two possibilities to deal with Bleuler's ›mental cripples‹: either one prevented them from reproducing or one extinguished them. The first idea, mass sterilization, was widely popular in the Weimar Republic, supported by officials, theologians, lawyers and doctors; Bleuler is a prominent example. So even coercive measures, in other words violence seemed acceptable.

However, the second idea, extinction by euthanasia, was still very unpopular in the interwar period; but it had already come up in a notorious book. In 1920, the lawyer Karl Binding and the psychiatrist Alfred Hoche published their infamous treatise *Allowing the Destruction of Life Unworthy of Life* [*Die Freigabe der Vernichtung unwerten Lebens*].[13] Here, the authors describe mentally disabled people as »human lives that are not only absolutely worthless but have a negative value.«[14] The paragraph continues:

> There cannot be any doubt that there are human lives whose death would be redemption for themselves; likewise, it would free society and in particular the state from a burden which is of no use at all, apart from the one to be an example of utmost selflessness.[15]

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12 Eugen Bleuler: Textbook of Psychiatry, Translated by A.A., New York 1934, p. 214. Following the fourth German edition: Eugen Bleuler: Lehrbuch der Psychiatrie, 4th ed., Berlin 1922, p. 160: »Aber wenn wir nichts tun, als die geistigen und körperlichen Krüppel fortpflanzungsfähig zu machen, und die tüchtigen Stämme ihre Kinderzahl beschränken müssen, weil man so viel für die Erhaltung der anderen zu tun hat, wenn man überhaupt die natürliche Auslese unterdrückt, muß es ohne neue Maßregeln mit unserem Geschlecht rasch rückwärts gehen«.

13 Karl Binding/Alfred Hoche: Die Freigabe der Vernichtung lebensunwerten Lebens. Ihr Maß und ihre Form [1920], 2nd ed., Leipzig 1922. Contemporary English translation: Allowing the Destruction of Life Unworthy of Life. Its Measure and Form, translated by Cristina Modak, Greenwood 2012. Since there is no authorized scholarly translation, the quotes are translated by Martina King.

14 Ibid., p. 27, the whole paragraph goes like this: »Denkt man sich gleichzeitig ein Schlachtfeld bedeckt mit Tausenden toter Jugend […] und stellt man in Gedanken unsere Idioteninstitute mit ihrer Sorgfalt für ihre lebenden Insassen daneben—und man ist auf das Tiefste erschüttert von diesem grellen Missklang zwischen der Opferung des teuersten Gutes der Menschheit im grössten Massstabe auf der einen und der grössten Pflege nicht nur absolut wertloser sondern negativ zu wertender Existenzen auf der anderen Seite«.

15 Ibid., p. 28: »Dass es lebende Menschen gibt, deren Tod für sie eine Erlösung und zugleich für die Gesellschaft und den Staat insbesondere eine Befreiung von einer Last ist, deren

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Binding and Hoche again, in their radically utilitarian argument, include both innate disability and acquired mental disorder. Initially, they bring up two groups of people who legitimate the legalization of euthanasia. The first one: those with mortal physical conditions, end-stage cancer or deadly wounds on the battlefield who intentionally wish to die. The main target, however, is the second group which

> consists of the uncurable idiots—no matter if they have been borne or become like this, such as the paralytics [tertiary syphilis, MK] in the last stage of their illness. They have neither the will to live nor to die. Hence, one doesn't need, on the one side, consider consent on their side in being killed; on the other hand, the killing doesn't meet any will to live which would first have to be broken.[16]

Those »incurable idiots« for whom it doesn't make any difference if they are alive or dead, would just give rise to the emergence of a new profession, the carers in the asylums. This new profession has its only aim in maintaining the ›unworthy lives‹ for years and decades.[17] The rhetoric of Binding and Hoche, stating that the mentally disabled are far below the ›normal‹ human existence, without self-consciousness and hence unable to wish to live or to die, is so cynical, so striking and simplifying that the idea of legalized killing almost automatically emerges in this text. That in turn implies the infamous epithet, the ›beautiful death‹, euthanasia or ›mercy killing‹; it equally predominates Binding's and Hoche's rhetoric:

> The most suitable means in these cases – which have to be decided individually – would then be euthanasia, since redemption must come painless at any rate and only an expert would be entitled to use this means.[18]

»Painless redemption at any rate«: One can see that the fatal euphemism ›euthanasia‹ carries all sorts of religious subtexts. ›Erlösung‹ in German can mean release from the earthy burden (of ›unworthy life‹); but it can also mean

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Tragung ausser dem einen, ein Vorbild grösster Selbstlosigkeit zu sein, nicht den kleinsten Nutzen stiftet, lässt sich in keiner Hinsicht bezweifeln«.

16 Ibid., p. 31: »Die zweite Gruppe besteht aus den unheilbar Blödsinnigen—einerlei ob sie so geboren oder etwa wie die Paralytiker im letzten Stadium ihres Leidens so geworden sind. Sie haben weder den Willen zu leben noch zu sterben. So gibt es ihrerseits keine beachtliche Einwilligung in die Tötung, andererseits stösst diese auf keinen Lebenswillen der gebrochen werden müsste«.

17 Ibid., p. 31f.

18 Ibid., p. 37: »Es dürfte sich empfehlen, im Anschluss an den Befund des Einzelfalls das in diesem Fall geeignetste Mittel der Euthanasie zu bezeichnen. Denn unbedingt schmerzlos muss die Erlösung erfolgen, und nur ein Sachverständiger wäre zur Anwendung des Mittels berechtigt«.

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redemption or even salvation, it is polysemic and I translate it with ›redemption‹. However, as stated above, Binding and Hoche were not well received and could not gather much ground. The Weimar republic was still openly hostile to the idea of legalizing euthanasia; the influence of social democratic forces and Christian churches was still too strong. So why bother with Binding and Hoche? Because of their striking style which marks a threshold. We see a certain rhetoric of extremes coming up, precisely of extreme contrasts – mainly of darkness and light, misery and happiness, suffering and redemption. On the one hand, there is the darkness of the asylum, the poor dark creatures living a dark life of unworthiness: ›mentally dead‹, ›human ballast‹, ›empty shells of human beings‹. On the other hand, there is euthanasia – implying brightness and happiness, a happy society, happy caregivers, happy relatives and a soft, painless release from earthy burdens. What follows almost without saying from these dichotomic extremes: mercy killing can either happen on demand or without demand, if the person is unable for rational consent.[19] Hence this type of contrastive, black-and-white representation is catchy, easy to remember, will stick in people's mind.

3 Eugenic propaganda after 1933 – the NS media dictatorship

Why is this so important? Because the contrastive image of the disabled person as dark ›unworthy life‹ reappeared and remained after 1933 – and became a major propaganda tool for the crimes and atrocities against those considered inferior. We must not forget that the Nazi regime is considered both a biomedical dictatorship *and* a media dictatorship (›Mediendiktatur‹)[20] that worked and could only work with a huge, bureaucratically complex propaganda machinery, divided in many sub-institutions. On the state side, there was the Ministry of Propaganda, and furthermore the *Reich Chamber of Culture* (›Reichskulturkammer‹) with its many sub-divisions; on the party side, there was the *Rosenberg Office* (›Amt Rosenberg‹), a complex body of

19 See ibid.

20 See Erhard Schütz: ›Das Dritte Reich‹ als Mediendiktatur: Medienpolitik und Modernisierung in Deutschland 1933 bis 1945, in: Monatshefte für deutschen Unterricht, deutsche Sprache und Literatur 87 (1995), pp. 129–150; Bernd Sösemann/Marius Lange: Propaganda. Medien und Öffentlichkeit in der NS-Diktatur. Vol. 2, Stuttgart 2011. For the literary market see also the seminal book of Jean-Pieter Barbian: Literaturpolitik im »Dritten Reich«. Institutionen, Kompetenzen, Betätigungsfelder. Überarb. u. aktual. Ausg., Munich 1995.

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cultural surveillance. Finally, the Office of Racial Policy (›Rassepolitisches Amt der NSDAP‹) must be mentioned. It was founded by medical men with the purpose of education and dissemination; speakers were trained here, the Office ran a journal – *Neues Volk*[21] – and commissioned films for disseminating biomedical doctrines such as inherited racial or constitutional inferiority. This multifaceted, decentralized propaganda machinery would permanently infuse ideological content in didactic or entertaining, soothing or polarizing wrappings into society, such as UFA films, weekly broadcasts, documentaries, posters, novels, picture books etc. An important example is the propaganda film *Erbkrank* from 1936, produced by the Office of Racial Policy and its leading official for press and media, Hellmuth Unger[22] (see below), and directed by Walter Gross. It was mainly used for didactic purposes within the party, but also presented to the greater public in cinemas as educational film;[23] and it shows the universality of the category ›mentally disabled‹.

Fig. 3: screenshots from propaganda film *Erbkrank*[24]

21 Neues Volk. Blätter des rassepolitischen Amtes der NSDAP (Verlag der Deutschen Ärzteschaft), founded in 1933 by Hellmuth Unger, broadly received by NS physicians.

22 See Thomas Werther: Fleckfieberforschung im Deutschen Reich 1914–1945. Untersuchungen zur Beziehung zwischen Wissenschaft, Industrie und Politik unter besonderer Berücksichtigung der IG Farben, Marburg 2004, p. 167, FN 628.

23 See Petra Zimmermann: Der ›Kampf ums Dasein‹. Eugenik, Rassismus und Antisemitismus, in: Zimmermann, Petra/Hoffmann, Kay (eds.): Geschichte des dokumentarischen Films in Deutschland 3. ›Drittes Reich‹ 1933–1945, Stuttgart 2005, pp. 505–529 & 554–567; Ulf Schmidt: Medical Films, Ethics and Euthanasia in Nazi Germany. The History of Medical Research and Teaching Films of the Reich Office for Educational Films/Reich Institute for Films in Science and Education 1933–1945, Husum 2002.

24 Silent film, Rassenpolitisches Amt der NSDAP, 23m 40s, 352x288, 1935/36, Erbkrank|Filmportal.De, www.filmportal.de/film/erbkrank_4bc08ccca3da41b89c4a691f80a71ae1 (02.03.2025); see also Deutsches Filmportal (Deutsches Filminstitut und Filmmuseum DFF), www.filmportal.de/film/erbkrank_4bc08ccca3da41b89c4a691f80a71ae1 (02.03.2025).

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A large and intentionally unsystematic variety of people, children, adolescents, young women, old women, young men, old men, pass by in front of the camera very quickly, mostly in split seconds; but they are always depicted in a humiliating way, improperly dressed, sometimes half naked or in straitjackets, obviously vulnerable.

And they have, as far as one can see, very little in common, suffer from all sorts of heterogenous handicaps: neurological and physical illnesses, spastic paresis, ataxia, osteochondrodysplasia, Down syndrome, extrapyramidal disorders, limb amputations, behavioral disturbances, blindness, stereotypical movements, just to mention a few. However, inserted texts declare them without exception as ›madmen‹ or ›idiots‹ and offer arbitrary, astronomical statistics – their number having increased by 450% over the last 70 years, the general population only by 50%. These quick film sequences sum up to a panorama of monstrosities that should apparently shock people and frame the opinions of party physicians and party speakers about this new, universal class ›inherited insanity‹. The latter must not be passed on, as inserted texts repeat over and over again, since many of these ›idiots‹ are the offspring of criminals, vagabonds and alcoholics and stand now – at the end of the chain of degeneration – far below the animal. However, they are kept in luxurious homes by healthy staff, a complete waste of resources; inserted texts present again astronomical, five-figure costs for exemplary individuals after decades in asylums. The argument made for coercive mass sterilization is so strong that Goebbels was thrilled by the propagandist value of these pictures. In December 1936, he wrote in his diary: »[…] then a film from the asylums, for justification of the sterilization law. Horrible material. With great pictures. Makes one's blood freeze while watching. Sterilization then comes as a blessing«.[25]

While the film is a good example for the universalist scope of the category ›mentally disabled‹ – being at work in both dictatorial health policy and educational propaganda – the following picture from the same institutional source, the Office of Racial Policy, shows how eugenic propaganda works with defined iconographies of contrast. It was published in 1934 in the Journal *Neues Volk* and we see the contrastive constructions in both text and image (left side):

25 Diary entry 04.12.1936, quoted after Felix Moeller: Der Filmminister. Goebbels und der Film im Dritten Reich, Berlin 1998, p. 359: »Dann einen Film aus Irrenanstalten zur Begründung des Sterilisationsgesetzes. Grauenhaftes Material. Mit tollen Aufnahmen. Das Blut gefriert einem bloß beim Anschauen. Da ist die Unfruchtbarmachung nur ein Segen«.

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Fig. 4: Foto, Journal *Neues Volk*, 1934[26]

Fig. 5: Poster, Publishing House *Neues Volk*, 1938

There is the disabled person, spatially inferior; sitting, in dark clothes, with a dark facial expression and unpleasant body language. Then we have the opposite, the caregiver: superior, standing, in white clothing, friendly, open expression, very good looking. And the caption suggests that all this superiority is wasted to maintain ›unworthy live‹. In 1938, the scope of this new, dichotomic iconography was widened: the image was reprinted as a poster, with a much more aggressive caption, and widely disseminated. However, it is a somehow negative message – firstly it might leave an uneasy feeling, even be perceived as a threat. Secondly, no reward is given, for example with a nice story; no distraction, no entertainment, no pleasure, no happy end. And this is the point where the medical novel comes to the fore, becomes almost necessary in the totalitarian media machinery: on the one hand, this genre again draws on the dichotomic image of the disabled and his/her healthy

26 Journal Neues Volk. Blätter des Aufklärungsamtes für Bevölkerungspolitik und Rassenpflege, Vol. 2:1 (1934), p. 16. The caption is »Dieser Pfleger, ein gesunder kraftvoller Mensch, ist nur dazu da, um diesen einen, gemeingefährlichen Irren zu betreuen. Müssen wir uns dieses Bildes nicht schämen?«.

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counterpart. On the other hand, the medical novel combines the underlying threat with the pleasure of simplistic, teleological storytelling.

4 The medical novel as propaganda tool for eugenic crimes

The rather new genre[27] saw a real boom between 1933 and 1945, where at least 30 medical novels flooded the controlled Nazi book market – many of them bestsellers that sold up to half a million copies and had many post war editions.[28] They were all trivial, entertaining and easy-to-read-stories of various traditional kinds – adventure novels, social novels, travel novels, love novels, pastoral novels; but they had one thing in common: a male or female physician as protagonist.[29] These texts distracted readers from the reality of violence, barbarism and finally war; by showing devoted, modest, heroic doctors who embodied German scientific progress. These fictional protagonists continuously fight for humanity and a better happy world without misery – in other words a eugenically purified world without miserable disabled people.

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27 As to the history of the medical novel – at least in the German world: it seems to emerge in the 1920s as part of a growing entertaining media market. There are some precursors in ›high literature‹ such as Jean Paul's *Dr. Katzenbergers Badereise,* Storm's *Ein Bekenntnis,* Zola's *Docteur Pascal,* Kafka's *Ein Landarzt,* Schnitzler's *Traumnovelle,* Benn's *Rönne-Zyklus,* and Ernst Weiß' later novels, which all tackle questions of physicianship such as identity, ethics, and epistemology. However, in the course of the 20th century, the topic is no longer of interest for avant-garde or experimental prose and somehow moves into the entertaining sector; see King: Helden, Heilige, Menschenzüchter, 2026 and Walter Müller-Seidel: Arztbilder im Wandel. Zum literarischen Werk Arthur Schnitzlers. Sitzungsberichte der Bayerischen Akademie der Wissenschaften, Heft 6, Munich 1997, p. 11.

28 As to numbers of editions and sold copies, see Rolf Düsterberg: Einleitung, in: Düsterberg, Rolf (ed.): Dichter für das »Dritte Reich«. Biografische Studien zum Verhältnis von Literatur und Ideologie, Bd. 3. 9 Autorenporträts und eine Skizze über das Deutsche Kulturwerk Europäischen Geistes, Bielefeld 2015, pp. 7–19, here p. 8.

29 Here is a selection of the most successful novels: Hans Dittmer: Der Arzt, der aus Gott ging, Göttingen 1937; Betina Ewerbeck: Angela Koldewey, Berlin 1939; Hans Hartmann: Vitamine, Stuttgart 1939; Max René Hesse: Morath verwirklicht einen Traum, Berlin 1934; Hans Hoster: Genesung in Graubünden, Berlin 1938; id.: Viele sind berufen, Leipzig 1933; Friedrich Klingler: Darfst du töten? Ein Gegenwartsroman, Stuttgart 1935; Hans Künkel: Ein Arzt sucht seinen Weg, Berlin 1939; Luz Lorentzen: Elke oder die Bewährung, Berlin 1939; Reinhold Conrad Muschler: Beata Diana, Berlin 1938; Florian Seidl: Das harte Ja, Berlin 1941; Hellmuth Unger: Robert Koch: Roman eines großen Lebens, Berlin 1936; id.: Sendung und Gewissen, Berlin 1936; id.: Unvergängliches Erbe. Das Leben Emil von Behrings, Oldenburg 1940; id.: Germanin. Geschichte einer deutschen Großtat, Berlin 1940; Karl Unselt: Der Arzt aus Leidenschaft, Berlin 1935; id.: Ein Arzt muss schweigen, Berlin 1941.

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In the novel *Consent to the greatest hardship* [*Das harte Ja,* 1941], a propaganda text for the sterilization law, a physician tells the protagonist: »Just because the Volk matters most to us, just because we want children, many healthy children, we have to act like this«.[30] What he means: the protagonist must give up his great love, must not marry and reproduce, since his mother suffered from schizophrenia and died in an asylum. Her illness is described by the sister of the protagonist in a vivid way:

> She tossed and turned in the bed, screamed, reared, ran out onto the road in her nightgown and screamed that the wall would crack. […] She often screamed in a horrible way, I took her head in my hands and kept her mouth shut with a cushion; since no one should hear that.[31]

With this frightening report of the mother's condition, the narrative logic becomes clear: the reader follows the protagonist's inner development towards heroic renunciation. It emerges almost automatically from the contrastive stereotypical image of the disabled person: screaming, suffering, insane, the horrible dark side of human existence; well established, initially by Binding and Hoche and then echoed and disseminated by the film *Erbkrank*. The contrastive, bright side is also there:

> He thinks about the singing and dancing girls he had seen then, he looks at Guta and thinks: ›You healthy, strong mothers of my Volk!‹ […] And he thinks: Renunciation! I must renunciate![32]

Therefore, no marriage, no reproduction: the heroic individual steps willingly back from personal happiness for the sake of collective happiness. And for those poor creatures who are shown by the film *Erbkrank* as having no reason and no decision-making faculty, coercive sterilization emerges as the only, unavoidable solution; the novel fosters public acceptance of this mass crime firstly by arising emotions with extreme black-and-white-contrasts, and secondly by creating an atmosphere of progress with scientific language. A doctor in the asylum tells the protagonist about the successes of the insulin

30 Seidl: Das harte Ja, p. 348: »Gerade weil uns das Volk über alles geht, gerade weil wir Kinder wollen, viele gesunde Kinder, müssen wir so handeln«.

31 Ibid., pp. 220f.: » Sie wälzte sich auf dem Bett, bäumte sich vor Entsetzen auf, schrie, wollte zum Fenster, fliehen […]. Sie lief im Hemd auf die Strasse, sie rief: Die Mauer stürzt ein […] Sie schrie oft schauerlich, ich nahm ihre Stirn in meine Hände. Ich hielt ihr auch den Mund mit einem Kissen zu, denn es durfte niemand hören«.

32 Ibid., pp. 355f.: »Er denkt an die tanzenden und singenden Mädchen, die er damals sah, blickt auf Guta und denkt: Ihr gesunden und kräftigen Mütter meines Volkes! […] und er denkt: Verzichten! Ich muss verzichten!«.

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treatment and he adds »of course, all those who are – by the sake of the insulin treatment – reintegrated into a normal working life, must undergo sterilization before discharge; they carry the seed of the illness«.[33]

We see how the novel *Consent to the greatest hardship* adds elements of pleasure and hope to the threatening iconographies of film and pictures. The reader is led through internal states of fictional characters who doubt, fear, tremble and finally experience utter satisfaction, even happiness when they have found out the truth: eugenic purification will lead to a better world without any misery.

This kind of maturation of fictional characters, in other words heroic renunciation of ›impure‹ marriage, is a pattern we find in other medical novels. An important example is *Angela Koldewey. Story of a young female physician* [*Angela Koldewey. Roman einer jungen Ärztin*], an immensely successful bestseller. Written by ambitious Nazi physician and author Betina Ewerbeck, it had two editions (1939, 1943) in the publishing house *Neues Volk* of the Office of Racial Policy and sold 240,000 copies until 1945. After the war, it had six further editions between 1949 and 1963 and sold all in all 500,000 copies.[34] In this novel, the protagonist finds out in a conversation with her fiancé that she can't marry him, he is genetically ›impure‹:

> ›Something that I never told you: my older brother has been suffering from bouts of severe insanity for years, has repeatedly tried to kill himself. We had to bring him to an asylum—and also my father had died in an asylum‹. Angela was terrified, she realized the severe hereditary disease. As if he had read her thoughts, Martin added quietly: ›I must renounce having children, Angela, so our future is in your hands‹.[35]

We have the same pattern: poor disabled creatures in the asylum—and voluntary heroic characters with genetic burdens that renounce love and reproduction. In this case, the reader is offered pleasure by the teleological plot itself, since the female medical protagonist finds a better suited partner; he is the embodiment of Aryan superiority: »She wanted to have a child – and

33 Ibid., pp. 157f.: »Selbstverständlich müssen auch alle, die durch die Insulinkur wieder dem Erwerbsleben zugeführt werden, vor ihrer Entlassung unfruchtbar gemacht werden, denn sie tragen den Keim der Krankheit ja in sich«.

34 See King: Helden, Heilige, Menschenzüchter.

35 Ewerbeck: Angela Koldewey, p. 212: »›Etwas, was ich dir bisher verschwiegen habe: mein älterer Bruder leidet seit Jahren an Zuständen von schwerer Geistesverwirrtheit. […] [Auch] mein Vater ist in einer Anstalt gestorben.‹ Angela war zutiefst erschrocken. Eine schwere Erbkrankheit, dachte sie voll Entsetzen. Als ob er ihre Gedankengänge gespürt hätte, fügte dann Martin still hinzu: ›Ich werde auf Kinder verzichten müssen, Angela. Die Entscheidung über unsere Zukunft liegt bei dir‹«.

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Hans von Dühren, so young, so healthy, so happy and fresh, with the most honorable character – he was the best she could wish«.[36]

So healthy, happy and fresh: breeding with the perfect Aryan partner brings the protagonist to her final destiny, happy motherhood – and it brings a happy ending to the reader; namely to thousands of readers who had to be distracted in the years of merciless violence and extermination.

Now we see the twofold function of the eugenic novels: concealment *of* the violent reality on the one hand, subtle propaganda *for* the new eugenic world. Both come hand in hand, brought about firstly by systematic euphemisms, embellishment, glorification; secondly by showing inner states of characters and commenting on them as moral maturation. As opposed to the threatening iconography of the documentary film and the propagandist pictures, these novels transmit a positive message. They promise a healthy and happy world of perfect Aryans, e.g. in *Angela Koldewey* – without any suffering, violence and coercion. And this, in return, must have worked as positive propaganda: it apparently increased the public's preparedness for the reality of eugenic purification.

5 Hellmuth Unger and his novel *Mission and Conscience* [*Sendung und Gewissen*], 1936[37]

The next step was, as already mentioned, the mass killing of the mentally disabled. It was already debated in 1936 in the inner circle of Reichsärzteführer Wagner and in the Office of Racial Policy;[38] the concrete, secret planning started in 1939 when a committee of 40 eminent physicians met in the *Chancellery of the Führer* in Tiergartenstrasse 4. However, it could not remain an absolute secret and it was clear that disabled people had an uncertain future from now on. Against this background, it is hardly surprising that this step was equally accompanied by literary fiction. In 1936, the physician and creative writer Hellmuth Unger published his infamous medical novel *Mission and conscience*, which is all about ›mercy killing‹. Unger, high rank medical officer, prolific bestseller writer and leading figure within the NS

36 Ibid., p. 221: »Sie wollte ein Kind haben—und Hans von Dühren, so jung, so gesund, so froh und frisch, in Gesinnung und Charakter anständig und ehrenhaft bis zum letzten, war der Beste, den sie sich nur wünschen konnte«.

37 Unger: Sendung und Gewissen, Berlin 1936. Second edition: Oldenburg 1941.

38 See Eckart: Medizin in der NS-Diktatur, p. 98.

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medical press,[39] presents in his triple role the link between the dictatorial media market and the dictatorial medical system. Having published successful medical novels already in the Weimar Republic, he starts working at the Office of Racial Policy in 1933, founds the Journal *Neues Volk*,[40] becomes press officer for the *Reichsärzteführer* Gerhard Wagner and in 1935, press officer for the *Reich physicians' chamber* (›Reichsärztekammer‹). From 1938 onwards, Unger is publishing director of the central publishing company that unites all local medical journals in NS Germany and after 1936, he is involved – even if historical details are unclear – in the planning of children's euthanasia.[41] As one of the most powerful actors between media and medicine, Unger had already co-produced the film *Erbkrank* in the same year,[42] and now complemented his efforts with this novel.

The book is – as opposed to the film that only implies euthanasia without mentioning it – pure, frank euthanasia propaganda; but it comes in a manipulative and suggestive form that uses literary techniques for soothing and pleasing the reader. A homodiegetic narrator, a doctor himself, tells us (in a series of fictitious letters to his wife) the story of his medical teacher who is a great surgeon. Again, the reader follows the inner development of a saintly protagonist, but this time not towards heroic renunciation but towards heroic mercy killing. This inner ›maturation‹ is strictly presented from the point of

39 Unger had published several medical novels already in the Weimar republic which sold 150,000 to 200,000 copies, see Walter Müller-Seidel: Euthanasie im nationalsozialistischen Staat. Hellmuth Ungers Roman *Sendung und Gewissen* und der Film *Ich klage an*, in: Anz, Thomas (ed.): Literatur und Medizin in Deutschland. Zur Geschichte des humanen Denkens im wissenschaftlichen Zeitalter (1795–1945), Marburg 2022, pp. 636–660, here pp. 643f. From 1929 onwards, Unger was the director of the press office of the association of German physicians [Verband der Aerzte Deutschlands], see Claudia Sybille Kiessling: Dr. med. Hellmuth Unger (1891–1953). Dichterarzt und ärztlicher Pressepolitiker in der Weimarer Republik und im Nationalsozialismus, Husum 1999; see also Roger Uhle: Neues Volk und reine Rasse. Walter Gross und das Rassenpolitische Amt der NSDAP (RPA), Aachen 1999; Eckart: Medizin in der NS-Diktatur, pp. 94–100.

40 Unger publishes in 1936 – again in *Neues Volk* – also his most successful propaganda novel *Robert Koch: Roman eines großen Lebens* which sells 300,000 copies and has many further editions: Berlin/Wien 1940, Leipzig 1942, Hamburg 1947, Hamburg 1948, Berlin 1961, see King: Helden, Heilige, Menschenzüchter.

41 Unger belonged to the committee of experts for the ›Reichsausschuss zur wissenschaftlichen Erfassung von erb- und anlagebedingten schweren Leiden‹ (with Karl Brandt, the pediatricians Ernst Wentzler and Werner Catel, and the psychiatrist Hans Heinze); see Udo Benzenhöfer: NS-»Kindereuthanasie«: »Ohne jede moralische Skrupel«, in: Deutsches Ärzteblatt 97:42 (2000), pp. 2766–2772; id.: Der Fall Leipzig (alias Fall »Kind Knauer«) und die Planung der NS-»Kindereuthanasie«, Münster 2008, p. 72.

42 See Werther: Fleckfieberforschung, p. 167.

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view of the protagonist, and filled with self-reflections, self-doubts, deeply moralistic considerations and emotions such as pity or sorrows; and it leads to euthanasia as the unavoidable, difficult path that requires a morally pure, superior character. However, as compared to *Angela Koldewey* and *Consent to the greatest hardship,* this process of psychic development is rather shown than told, almost without auctorial intrusion. At the beginning, the first-person narrator, in the frame narrative of letters to his wife, sometimes comments on the superiority of the medical protagonist whose story he is about to tell. However, later on, he merely quotes the self-critical monologues of this saintly character or long dialogues between himself and the latter:

> Now I asked about Sollwich […]
> ›Incurable?‹
> ›Yes, incurable.‹
> ›And what will happen?‹
> ›You know pretty well! […] He is a weak, wretched creature. Must one not have mercy here? He asks nothing and wishes nothing, he is already half beyond the threshold. No one will miss him. As long as he is without pain, we will certainly care for him. […] Even in half-consciousness, every day is a little present. But if deterioration starts, then…
> ›You grant him mercy killing?‹
> ›Yes‹
> ›If there is someone who deserves painless dying, then him, I think‹.[43]

»He asks nothing and wishes nothing«: obviously a case of unworthy life that requires mercy; but euthanasia is just presented as something that will happen in the future or that happened in the past of the fictional world. Hence, there is on the one hand very little narrative distance; the mimetic, showing mode predominates and promotes the immersion of the reader. On the other hand, there is hardly any action, let alone murderous action. The plot merely consists of quoted thoughts and quoted speech – reflection, conversation, monologue, dialogue. Euthanasia is never performed in the actual textual world of this novel which obviously refers to the German genre *Bildungsroman* and its long tradition. Between enlightenment and modernism,

43 Unger: Sendung und Gewissen, 2nd ed., p. 198: »Nun fragte ich noch nach Sollwich […] ›Unheilbar?‹ ›Ja, unheilbar‹. ›Und was wird sein?‹ Sie wissen es doch […] Er ist […] eine schwache Kreatur. Ein Wrack […]. Muss man da nicht gnädig sein? Er fragt nichts und wünscht nichts mehr, er ist schon halb jenseits der Schwelle. Keiner wird ihn vermissen. So lange er, wie augenblicklich, ohne Schmerzen ist, pflegen wir ihn. […] Auch im Nur-Dahindämmern ist ja jeder Tag ein kleines Geschenk. Wenn erst die Verschlimmerung einsetzt, dann…‹ ›Vergönnen Sie ihm den Gnadentod?‹ ›Ja‹. Wenn einer schmerzloses Sterben verdient hat, dann er, überlege ich«.

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the *Bildungsroman* presents complex life journeys from youth to adulthood, full of personal experiences, moral and intellectual maturation, failures and the overcoming of failures. Initially, its plots follow the pattern of Goethe's *Wilhelm Meisters Lehrjahre,* they are highly teleological and end harmoniously; from the late 19. century onwards, they tend to become negative, involving failure, inability and disillusionment.[44] Against this background, *Mission and Conscience* is clearly conceived as the positive version of the *Bildungsroman* with its harmonious end: a meaningful, satisfactory task in society that the protagonist takes over, for the sake of the common good; it works as an ethical reward for the reader. This *telos* is now obviously mercy killing, as the title *Mission* already suggests; the former appears as the main moral value of the fictional world and as the main social task the protagonist has to take over for the sake of collective happiness. »When the value and the importance of euthanasia will be accepted generally«, he states in a long monologue, »then everywhere new combatants will come up and fight for it—since it is for the sake of mankind, for every living being in the whole world without exception«.[45]

It is part of Unger's refined narrative strategy – the mimetic mode with direct speech, small distance and immediacy is combined with a hypothetical, detached way of tackling euthanasia – that mercy killing does not function as real event in the fictional world; just as thought event, a change of inner states of characters. In other words, it is talked through, remembered, put in prospect and reflected on by the protagonist and other doctors in many examples: killing of the terminally wounded friend on the battlefield, killing of the terminally ill mother, killing of the poor insane in the asylum, killing on demand or without; usually by ›soft‹ poisoning with morphine. This pulls the reader into this belief system without confronting him/her directly with actual occurrences and possibly unpleasant consequences. Conclusively, euthanasia appears as embodiment of humanitarianism, altruism, spiritual modesty and Unger refers widely to the dark-and-bright-rhetoric introduced by Binding and Hoche:

44 See Jürgen C. Jacobs: Bildungsroman, in: Lamping, Dieter (ed.): Handbuch der literarischen Gattungen, Stuttgart 2009, pp. 56–65.

45 Unger: Sendung und Gewissen, p. 265: »Wenn Wert und Wichtigkeit der Euthanasie erst allgemein anerkannt war, erstanden bestimmt überall und täglich neue Kämpfer genug, da sie doch zum Segen der Menschheit diente, für jedes Lebewesen ohne Ausnahme auf der ganzen Welt«.

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> […] There is so much that a doctor has to see in war! So much gruesome suffering, such horrible maddening pain, such misery of the cripples who became disabled through no fault of their own! And one is expected to help! There were days when we had more than a thousand wounded soldiers![46]

We have here the dark side of gruesome physical suffering and death; and the contrastive bright side is implied with the euphemism »one should help«. In the whole novel, the verb »killing« is systematically replaced by either »helping« or even »redeeming«; murder is thereby transformed into its semantic opposite, redemption and salvation. This utopian bright side of euthanasia is fully enfolded in the following passage when the protagonist reflects on its powers; note the superlative rhetoric of happiness, beauty and virtue:

> It is puzzling how the face of a dead person relaxes in incomprehensible beauty – even if he has gone through the most unbearable suffering before death.[…] At that time, I had said to myself: If you, as physician, had the will, the power and the energy to bring such a magic smile on the face of a dead person, what a good doctor you would be, how much happier and more satisfying it would be for you![47]

The function of this extremely contrastive language – misery versus beauty, suffering versus salvation – is clear: in tandem with the focalized representation of inner states, it pulls the reader, as already pointed out, into the thought system of euthanasia; just by transforming murder into redemption and the killing doctor into a supernatural hero. Part of this narrative strategy is that the real target group, the mentally disabled, is *not* at the center of the story; *rather at its very margins*. The mentally disabled are of course mentioned, stereotypically dark, poor, miserable, suffering. However, they are brought up not by the protagonist but by a side character during a long conversation, and they appear only as a side effect that emerges almost naturally from the beauties of mercy killing:

> Is there not enough unworthy life that just burdens the ›Volksgemeinschaft‹ [racial community] economically and that vegetates only for the sake of its own deep misery? You yourself said that we – as people who are knowing and who heard the calling – are much more responsible to our conscience than everybody else. Why

46 Ibid., p. 125: »[…] was ein Arzt im Krieg erleben muss! So viel Grausigkeit des Leidens, solchen Wahnwitz an Schmerzen, solches Elend unverschuldeten Krüppeltums! Und man soll helfen! An manchen Tagen gab es mehr als tausend Verwundete«.

47 Ibid., p. 86: »Es ist merkwürdig […], wie unbegreiflich schön sich das Gesicht eines Toten entspannt, mag er vorher noch so viel Unerträgliches erlitten haben. […] Wenn du als Arzt, so habe ich mir damals gesagt, den Willen, die Macht und die Kraft besäßest, über das Gesicht eines Toten solch ein Lächeln zu zaubern, welch ein guter Arzt müsstest du sein, wieviel beglückender und schöner wäre es für dich«.

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> shouldn't we then also help those miserable creatures who have nothing humaine any more? Shouldn't we spare them endless suffering? Are they not hopeless sufferers, too?[48]

»Nothing humaine anymore« and »hopeless sufferers«: this identification of any mental disorder with a non-human state, firstly, and a terminally ill state, secondly, comes in the guise of humanitarian pity; but it is a false claim and it shows how rhetoric concealment, euphemisms, glorification and narrative techniques work together in order to influence the mentality of the public.

Unger went actually quite far; too far for even the ministry of propaganda. Goebbels was deeply shocked by Unger's frankness and worried about public irritation and debate, especially in catholic circles; and he demanded immediately after the publication that *Mission and conscience* must neither be reviewed nor discussed in the press.[49] But too late, the novel was out, and Goebbels worried for no reason. *Mission and conscience* was broadly received and even adapted in 1941 for the cinema: the UFA film with the title *I accuse* (*Ich klage an*) became one of the most successful Nazi propaganda movies, had 15 million viewers, and gained many fascist prizes.[50] However,

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48 Ibid., p. 157: »Gibt es nun nicht überhaupt lebensunwertes Leben genug das eine Volksgemeinschaft wirtschaftlich nur belastet und das sich selbst zur Qual dahinvegetiert? Sie sagten selbst, dass wir als Wissende und Berufene viel mehr unserem Gewissen verantwortlich sind als jeder andere. Warum wollen wir dann nicht auch jenen armseligen Kreaturen helfen, die nichts Menschenähnliches mehr haben? Ihnen jahrelange Qualen ersparen? Sind sie nicht auch hoffnungslos Leidende?«.

49 See Press conference 24.11.36, quoted after Hans Bohrmann: Press Conference 24.11.36, in: NS-Presseanweisungen der Vorkriegszeit. Edition und Dokumentation, Vol. 4/I-IV Anhang 1936, Munich 1993, p. 1424: »Die ›Nachtausgabe‹ habe trotzdem einen Aufsatz gebracht. Man weise darauf hin, dass die Euthanasie ein sehr heikles Problem sei. Man muesse naemlich bedenken, dass in katholischen Kreisen die Ueberlegung angestellt werde, zuerst habe man die Sterilisation eingefuehrt und jetzt wolle man offenbar auch noch die Euthanasie beguenstigen. Es wuerden durch Artikel ueber dieses Thema unnoetigerweise Widerstaende geweckt und oeffentliche Interessen geschaedigt. Auch nicht im Zusammenhang mit einem Roman von Unger ›Sendung und Gewissen‹ soll die Euthanasie behandelt werden.« The ministry of propaganda held daily press conferences to which the leading media sent their representatives; the latter were given oral, confidential directives which new products on the book market should be reviewed; and which not. Journalists were forbidden to write these directives down but some of them did and the documents have survived, see Hans Bohrmann/Gabriele Toepser-Ziegert (eds.): NS-Presseanweisungen der Vorkriegszeit. Edition und Dokumentation. Vol. 1–7, bearb. von Bartels, Claudia/Fortmann-Petersen, Heike/Kohlmann-Viand, Doris/Peter, Karen/Toepser-Ziegert, Gabriele, Munich 1984–2001.

50 See Eckart: Medizin in der NS-Diktatur, p. 224–226; Michael Schwartz: »Euthanasie«-Debatten in Deutschland (1895–1945), in: Vierteljahreshefte für Zeitgeschichte 46 (1998), pp. 617–665, here pp. 640f.; Ulrike Reim: Der *Robert-Koch*-Film (1939) von Hans Steinhoff,

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the sentimental love story of a terminally ill woman and her husband who delivers euthanasia on demand is an embellished, profoundly changed version of the novel and it softens the radical content of the latter substantially. But the book gained a lot of attention, too; it had two further editions in 1941 and 1943 and a total edition of 45,000 copies.

I come to my conclusion. One must assume that the quoted novels, along with various others, influenced the public attitude towards eugenics substantially. Given their success on the controlled NS book market, they obviously contributed to the gradual brutalizing of German society. *Mission and conscience* in particular was a milestone on the path to industrial mass killing of disabled people. With claims such as »the face of a dead person relaxes in incomprehensible beauty – having gone through the most unbearable suffering before death«, the novel turned the murderous reality in its utopian contrary, helped paving the way in German public opinion and must be considered as murderous in itself.

How murderous in fact, becomes clear if one contrasts it with a totally different piece of euthanasia fiction that appeared only ten years later. In 1946, Alfred Döblin published his short prose text *The Journey into the Blue* [*Die Fahrt ins Blaue*],[51] a fictitious dialogue between a homodiegetic first-person-narrator and a former colleague who used to work in a psychiatric asylum during the war.[52] He tells the narrator what happened in asylums and ›care homes‹ and gives a contrastive, rather shocking version of the ›beautiful and happy death‹:

> The sick are alone. […] It starts rushing. Apparently, the showers are rushing. One, on the bench, lowers her head and thuds lifelessly on the flagstone floor. The one who was walking in circles looks up, bends her knees and collapses. On the bench,

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Kunst oder Propaganda?, in: Benzenhöfer, Udo/Eckart, Wolfgang U.: Medizin im Spielfilm des Nationalsozialismus, Tecklenburg 1990, pp. 22–33, here p. 22. The film was directed by Hans Steinhoff who was both famous and absolutely conformist, the actors were Emil Jannings and Werner Krauss; 4 million people watched it in only four weeks: »Der Film hatte in vier Wochen vier Millionen Zuschauer und wurde mit der Coppa Mussolini, dem großen Preis der Biennale von Venedig 1939, als bester ausländischer Film geehrt.« Ibid., p. 23.

51 Alfred Döblin: Die Fahrt ins Blaue, in: Althen, Christina (ed.): Leben und Werk in Erzählungen und Selbstzeugnissen, Düsseldorf 2006, pp. 193–198, [03.05.1946, *Badische Zeitung*].

52 There is very little secondary literature on this extraordinary text which deserves to be scholarly investigated, both with regards to its elaborate narrative structure and its relevance for the cultural history of eugenics. An exception is Susanne Knittel's careful analysis, in: S.K.: The Historical Uncanny: Disability, Ethnicity, and the Politics of Holocaust Memory, New York 2015, pp. 107–111.

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> they lean on one another, they slip down, two together and separately, they fall over each other. The ›showers‹ rush.[53]

›The sick thudding on the floor and falling over each other‹ versus ›a dying person relaxing in incomprehensible beauty‹: these fundamentally opposed textual images of the same criminal reality indicate that literature plays a substantial role in the cultural history of eugenics. Hence, it is also a precarious role. Fictional prose can obviously lead to memory-building in the best sense, as we see with Döblin; but it can also foster a barbarized society where killing is hailed as happiness. It should be mentioned that Hellmuth Unger was never put on trial or sentenced after the war. He could pursue both his medical and his literary career and published further successful medical novels – now on leading social democrats such as Rudolf Virchow.[54] Neither became his murderous role in promoting children's euthanasia part of the collective memory, nor was there a scholarly or public debate on the possible murderous effects of his book.[55] On the contrary: the novel *Sendung und Gewissen* is still available in the internet antiquarian bookshop *booklooker*,[56] without explanation of meaning and context; it has never been put on any index. Literary disability studies have a responsible task here: they can throw light on such underexplored, hidden spaces of cultural representations and orchestrate adequate memory building.

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53 »Die Kranken sind allein […] Da rauscht es. Es scheint, die Duschen gehen. Eine auf der Bank läßt den Kopf sinken und plumpst, ihrem Kopf nach, dumpf auf die Steinplatten. Die im Kreis gegangen war, blickt auf und sackt in den Knien zusammen. Auf der Bank lehen sie eine neben der andern, rutschen, zwei zusammen und einzeln, herunter, fallen übereinander. Die ›Duschen‹ rauschen.« ibid., p. 221.

54 Unger: Virchow, Hamburg 1953; see Paul Weindling: Health, Race and German Politics between National Unification and Nazism 1870–1945, Cambridge 1989, p. 547.

55 The book is usually considered as the literary basis for the film and not discussed independently; one exception is a short chapter in Grübler, Gerd: Euthanasie und Krankenmord in der Deutschen Literatur 1885–1936, Marburg 2011, pp. 182–191.

56 See Booklooker.de: Hellmuth Unger: *Sendung und Gewissen* – Bücher gebraucht, antiquarisch & neu kaufen, www.booklooker.de/B%C3%BCcher/Angebote/autor=Hellmuth+Unger&titel=Sendung+und+gewissen (02.03.2025).

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Evelyn Dueck

»scandalum medicorum« – Taking Care of Your Eyes in the 18th Century

The 18th century is haunted by a fear of blindness. While the Middle Ages and the Renaissance still celebrate the blind seer as a positive figure, the self-image of the Enlightenment is epistemically founded on the individual act of seeing.[1] The main purpose of the philosophers of the Enlightenment since the so-called ›Scientific Revolution‹ is to make people see, in a concrete as much as in a metaphorical sense. The instruments which serve as icons of this task are the telescope and the microscope.[2] A lot has been written in the last decades about the specificity of this ›enlightenment gaze‹. It has been characterized as cold, neutral, distant, and even oppressive by influential thinkers such as Michel Foucault or Jonathan Crary.[3] They describe what Martin Jay calls the ›cartesian ocularcentrism‹ as a ›model of perception‹ which widely neglects or even denigrates the other senses (hearing, smell, taste, and touch).[4] It is not until the 1800s, they argue, that this model of perception is questioned by the Romantics and the early critics of industrialization. Under their influence, the iconic instruments of the Enlightenment are replaced by the stereoscope and mesmerism, emphasizing the subjective and even magic aspects of seeing.

In my research, I have tried to show that this Enlightenment model of perception is not nearly as monolithic as we think, and that philosophers,

1 See Matthias Reiß: Blindheit, in: Hartwig, Susanne (ed.): Behinderung. Kulturwissenschaftliches Handbuch, Stuttgart 2020, pp. 195–200.

2 See Philippe Hamou: Voir et connaître à l'âge classique, Paris 2002; Ulrich Stadler: Der technisierte Blick. Optische Instrumente und der Status von Literatur. Ein kulturhistorisches Museum, Würzburg 2003; Stuart Clark: Vanities of the Eye. Vision in Early Modern European Culture, Oxford/New York 2007; Mark A. Smith: From Sight to Light. The Passage from Ancient to Modern Optics, Chicago/London 2015.

3 See Jonathan Crary: Modernizing Vision, in: Foster, Hal (ed.): Vision and Visuality, Seattle 1988, pp. 77–80; Michel Foucault: Les mots et les choses. Une archéologie des sciences humaines, Paris 1966.

4 See Martin Jay: Scopic Regimes of Modernity, in: Foster, Hal (ed.): Vision and Visuality, Seattle 1988, pp. 3–23; Martin Jay: Downcast Eyes. The Denigration of Vision in Twentieth-Century French Thought, Berkeley/Los Angeles/London 1993; Ulrike Hick: Geschichte der optischen Medien, München 1999; Ulrike Zeuch: Umkehr der Sinneshierarchie. Herder und die Aufwertung des Tastsinns seit der frühen Neuzeit, Tübingen 2000.

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physicians, and opticians in the 17th and 18th centuries are, on the contrary, very much aware of the imperfections of the human eyesight and their own lack of knowledge about the process of seeing and perceiving.[5] This paper explores an aspect of this topic that I have neglected so far: the 18th century remarkable increase in publications on how to take care of your eyes and avoid blindness.[6] These publications are mostly written in vernacular languages (and not in Latin as it is the case for most contemporary medical treatises) and are explicitly addressed to a large public of non-specialists. They can be understood as popular manuals offering advice, helping people to take care of their eyes and maintain a sound sense of seeing.[7] Yet, I would like to argue that the purposes of these treatises change slowly over the 18th century, as simple moral or medical advisories featuring recipes of ointments or instructions for eye surgeries become codes of practice which tend to regulate everyday life. Going blind or even becoming short-sighted is no longer seen as a result of the general corruption of mankind, a disease, or an accident, but rather as a ›medical scandal‹ caused by the misbehaviour of every single person concerned.[8] The corpus of my research is composed of around twenty books that focus exclusively on ophthalmology, and which were published in German between 1724 and 1800. The first part of my paper illustrates the fundamental importance of the sense of sight stressed by all these publications. The second part shows how the causes invoked for eye disease or for blindness change over the 18th century by putting more and more emphasis on individual behaviour and daily routine. I will demonstrate how this shift translates into a code of practice giving concrete instructions on, for example, how to read and where to sleep. While these treatises participate in the development of a medical and individual model of disability by stressing the social and

5 See Evelyn Dueck: Die »krumme Bahn der Sinnlichkeit«. Sehen und Wahrnehmen in Optik, Naturforschung und Ästhetik des 17. und 18. Jahrhunderts, Paderborn 2022.

6 »Zwischen 1780 und 1880 sind etwa 100 Monographien zur Hygiene des Auges verzeichnet.« Alexandra Hildebrandt: ›Lebwohl, du heiterer Schein!‹ Blindheit im Kontext der Romantik, Würzburg 2002, p. 60.

7 »So ist innerhalb der diätetischen Literatur, die einem antiken Konzept folgend Anleitungen für eine gesundheitsorientierte Lebensweise zu vermitteln suchte und die sich unter aufklärungsmedizinischen Vorzeichen zunehmend an breitere Bevölkerungsschichten richtete, eine Sensibilisierung für die Gesundheit der Augen festzustellen.« Irmtraut Sahmland: Blindheit und Sehbehinderung in der Zeit der Aufklärung: Diagnosen und Bewältigungsstrategien, in: Klettner, Alexa/Lingelbach, Gabriele (eds.): Blindheit in der Gesellschaft. Historischer Wandel und interdisziplinäre Zugänge, Frankfurt/New York 2018, pp. 65–95, here pp. 66-67.

8 The term »scandalum medicorum« is used by Abrahamson Meyer to designate amaurosis. Abrahamson Meyer: Abhandlungen und Beobachtungen über einige Krankheiten der Augen, Hamburg 1785, p. 1.

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intellectual harm of blindness, they can be more accurately described as part of a cultural model of disability which materializes – through different media of popularization – in a practical code of behaviour addressed to an entire society in which everyone might potentially become disabled overnight.[9]

The importance of sight

Georg Christoph Lichtenberg's (1742–1799) *Über einige Pflichten gegen die Augen* (1792) first published in the weekly journal *Göttinger Taschenkalender* 1791 is one of the few ophthalmological treatises widely known to scholars of German literature today. In his introduction, Lichtenberg imagines an alarming scenario of »thousands« of people going blind due to careless behaviour or a lack of instruction.[10] His treatise explicitly refers to the English optician and instrument maker George Adams the younger (1750–1795) who publishes his *Essay on Vision* (1789) two years earlier and dedicates it to »those whose eyes are weak or impaired: enabling them to form an accurate idea of the true state of their sight, [and] the means of preserving it«.[11] Published in German as early as 1794, the translation by Friedrich Kries, a teacher from Gotha, further underlines in his introduction the dangers to which the eyes are permanently exposed:

> Niemand verkennt den Werth eines gesunden Gesichts, wenige aber kennen die Gefahren, die dem feinen Organ desselben von allen Seiten drohen, und lassen den Besitz eines so unschätzbaren Guts sorglos vom Zufall abhängen, oder ziehen vielleicht ein Uebel herbey, indem sie es zu entfernen meinen, weil ihnen die rechten Mittel zur Abwendung desselben unbekannt sind. Die Vorschriften zur Erhaltung der Augen sind an sich so einfach, die Gründe, auf denen sie beruhen, so leicht zu

9 Chris Mounsey underlines that, in the 18th century, the term ›disability‹ has not been used to describe a permanent physical or mental condition. To be accurate, I will follow him in using ›blindness‹ or ›impairment‹ instead of ›disability‹ when referring to 18th century sources. See Chris Mounsey: Sight Correction. Vision and Blindness in Eighteenth-Century Britain, Charlottesville/London 2019, pp. 22–26. For the cultural model of disability, see Andrzej Twardowski: Cultural Model of Disability – Origins, Assumptions, Advantages, in: KIL Kultura i Edukacja (2022), pp. 48–61; Anne Waldschmidt: Disability – Culture – Society: Strengths and Weaknesses of a Cultural Model of Dis/ability, in: Alter (2018), pp. 65–78.

10 Georg Christoph Lichtenberg: Ueber einige Pflichten gegen die Augen, Wien 1792, p. 5.

11 George Adams: An Essay on Vision, Briefly Explaining the Fabric of the Eye and the Nature of Vision, London 1789, titlepage.

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> fassen, daß in der That nur die Unbekanntschaft mit denselben die Ursache seyn kann, warum man so wenig darauf achtet.[12]
>
> [No one underestimates the value of healthy eyesight, but few know the dangers that threaten its delicate organ from all sides and carelessly leave the possession of such an invaluable possession to chance or perhaps bring about an evil by thinking they remove it, because they do not know the right means to prevent it. The rules for preserving the eyes are so simple, the reasons on which they are based so easy to understand, that in fact only ignorance can be the reason why so little attention is paid to them.][13]

Lichtenberg likewise emphasizes this perception of an existential threat by designating the blind man as ›halfdead‹ and the health of one's eyes as the most crucial part of a sound body and mind.[14] His arguments are as much of a theological kind – not being able to see God's creation in the beauty of nature – as of a practical kind – not being able to travel, to communicate over large distances, or to overlook a landscape.[15]

This ›*visio horribilis*‹ should not be interpreted as just another symptom of Lichtenberg's hypochondria or be seen as a position unique to the German physicist and famous satirist.[16] In fact, most authors of treatises on ophthalmology in the 18th century stress the importance of sight and the concrete and metaphysical harm of blindness. The physician Abrahamson Meyer (1764–1817), for example, refers to ›numerous cases‹ where patients turn blind literally overnight, suggesting that this could happen to anyone at any moment – even to those who are still in good health.[17] Meyer describes blindness as the most pitiful condition to experience. He rejects the positive

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12 George Adams: Anweisung zur Erhaltung des Gesichts und zur Kenntniß der Natur des Sehens. Aus dem Englischen übersetzt, und mit Zusätzen und Anmerkungen versehen von Friedrich Kries, Lehrer an dem gothaischen Gymnasium, Gotha 1794, p. 7.

13 All translations from German into English are my own unless otherwise noted (with AI support).

14 Lichtenberg: Ueber einige Pflichten, p. 7.

15 See ibid., pp. 5–10.

16 The term ›*visio horribilis*‹ is used by Freiling in her book on Lichtenberg. She analyses in detail the rhetorical devices of the text without situating it in its historical context. See Ulrike Freiling: ›Ist denn Vergnügen der Sinne gar nichts?‹ Sinnlichkeit in den Schriften Georg Christoph Lichtenbergs, U. Freiling 2002, p. 24; Peter Bexte: Die weggeschnittenen Augenlider des Regulus. Zur verdeckten Antikenrezeption in einem Wort Heinrich von Kleists, in: Kleist-Jahrbuch (2008/2009), pp. 254–266, here: p. 263.

17 See Meyer: Abhandlungen und Beobachtungen, p. 2. Some of the treatises are composed mostly of case studies. See, for example, Giovanni Bortolazzi: Abhandlung über eine seltne Art von angebornem Staare bei einer blindgebornen Weibsperson, Leipzig 1784. On the importance of such case studies in the history of ophthalmology, see: Marie-Theres Federhofer: Der erzählende Patient. Narrative von Augenkranken in Aufklärungszeitschriften,

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figure of the blind poet attributed to John Milton and instead considers him as just another victim of the miserable state in which a blind person finds himself.[18] As a counterpart to these worrying scenarios, most of the treatises sing the eyes' praises, including Christian Gottlieb Meinig (1690–1760) in his *Der Augen-Doctor* (1741):

> Es ist das Auge, das erste, oberste und gröste Meister= und Kunst=Stück so die weise Hand Gottes an unsern Leibe geordnet, die Augen sind gleichsam die 2 unschätzbarsten Kleinodien welche die Natur in die Schatz=Kästlein der Augenlieder eingeleget, mit Crystallen=Glanz überzogen, mit Fittichen beschattet, und als 2 kostbare Edelgesteine verwahret. Sie sind der Spiegel der Natur und des Hertzens, die Zunge der Seelen, der Dollmetscher des Verstandes die offene Thüre zu allen unsern Geheimnissen, die Abbildung unsers Gemüths, der Erfinder aller Wissenschaften, der Richter der Schönheit, der Bohte der Liebe, die Quelle und Ursprung der Freuden, und der Thränen, die 2 erhabenen Wächter unsers Leibes welche denselben und alle dessen Glieder vorsichtig bewachen.[19]
>
> [The eye is the first, highest and greatest master- and artpiece that the wise hand of God has arranged to our body, the eyes are the two priceless treasures that nature has placed in the treasure chests of the eyelids, coated with crystal shine, shaded with wings and kept as two precious gems. They are the mirror of nature and the heart, the tongue of the soul, the interpreter of the mind, the open door to all our secrets, the image of our mind, the inventor of all sciences, the judge of beauty, the messenger of love, the source and origin of joy, and of tears, the two sublime guardians of our body, who carefully guard it and all its parts.]

This passage's baroque style can be partly explained as a mere effort to captivate the attention of the potential reader (and buyer), but it also illustrates the great importance which is given to the sense of sight throughout the 18th century. In 1725, the physician Johann Michael Lichtmann writes that having healthy eyes is more important than the condition of all other parts of the body:

> Denn ja unter der Sonnen nichts edlers und kostbares zu finden / auch uns Menschen am meisten erfreuen kan / als die Gesundheit; unter welcher die Gesundheit der Augen billich vor die alleredelste zu rechnen. Denn wann ein Mensch gleich alle Gesundheit des Leibes besitzet / und hat darneben Mangel an den Augen / so genüget ihm nichts; und wann er an allen Gliedmassen kranck darnieder lieget /

in: Berndt, Frauke/Fulda, Daniel (eds.): Die Erzählung der Aufklärung, Hamburg 2018, pp. 590–598.

18 Meyer: Abhandlungen und Beobachtungen, p. I.

19 Meninto (Pseud. Christian Gottlieb Meinig): Der Augen-Doctor, Hamburg 1741, p. 7.

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> doch aber nur sein Gesicht gebrauchen kan / so kan er seine Schmertzen noch viel leichter ertragen.[20]
>
> [For there is nothing more noble and precious to be found under the sun / that can also please us humans more / than health; among which the health of the eyes can easily be considered the most noble. For if a person has all the health of the body / and besides has sick eyes / then he has nothing; and when he lies ill in all his limbs / but can only use his eyes, he can bear his pain much more easily.]

This statement that the eyes are the most valuable part of the human body, and that blindness excludes one from the human society and even from practicing one's faith, is shared by most physicians throughout the century.[21] The urgency of this standpoint is further underlined by several treatises which denounce itinerant ophthalmologists as charlatans promising instant cures for all eye diseases through unnecessary and expensive surgeries or ineffective medication. In 1752, the physician Christian Ehrenfried Eschenbach (1712–1788) identifies the 18th century as the »Okulisten=seculum« because of the large number of oculists who take advantage of suffering patients by promising to heal even those in the most desperate conditions.[22] Georg Ziegenhagen, a physician from Strasbourg, calls those who offer their services mainly at county fairs »sogenannte[] Staar-Ritter[]« [so-called knights of the cataract].[23] The patient, he writes, »trauet den glatten worten des neuen arztes; bietet willigst eine ansehnliche portion seines vermögens zur belonung an (den was gibt der mensch nicht vor sein gesicht?) und hoffet nunmehr die so sehnlich verlangte hülfte gewis zu finden« [trusts the smooth words of the new doctor; willingly offers a considerable part of his fortune as a reward (for what does a person not give for his sight?) and now hopes to find the help he so desperately desires].[24]

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20 Johann Michael Lichtmann: Der geschickte Augen-Artzt. Oder Ausführliche Beschreibung des Starrs- und Hirn-Fells, Nürnberg 1725, p. 4.

21 See also Adams: Anweisung zur Erhaltung des Gesichts, pp. 12–13.

22 Christian Ehrenfried Eschenbach: Bericht von dem Erfolg der Operationen des Englischen Okulisten Ritter Taylors, in verschiedenen Städten Teutschlandes, besonders in Rostok, Rostok 1752, p. 3.

23 Emmanuel Alexander Ludovicus Brunner: Vom Staar und dessen Heilverfahren, der Niederdruckung sowohl als Ausziehung. Aus dem Lateinischen frey bearbeitet von D. G. Ziegenhagen, Straßburg 1788, p. 6.

24 Eschenbach: Bericht von dem Erfolg der Operationen, p. 8. His treatise targets the British oculist John Taylor (1703–1770) travelling through Europe in a coach painted with pictures of the human eye and performing injurious eye surgeries famously on Johann Sebastian Bach and Georg Friedrich Händel. In a treatise published in German in 1757, Taylor pretends having found an effective and simple way to heal amaurosis. Johann von Taylor: Neue

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A significant number of treatises on ophthalmology in the 18th century are thus addressed explicitly, in vernacular language, to a public of non-specialists, encompassing actual as well as potential patients.[25] Lichtmann, for example, dedicates his treatise to the »Hülffs=bedürfftige[] Leser« [needy reader][26], while Meinig similarly addresses his to the »arme einfältige, schwache und nothleidende Menschen« [poor, simple, weak and needy people].[27] By the end of the century, the editor of Lichtenberg's treatise still justifies the printing of the second edition by claiming that it needs to be made accessible to a larger public: »damit sie bey dem wohlfeilen Preise allgemeiner sollte bekannt und auch der Nutzen dadurch für den edelsten Theil des menschlichen Körpers sollte gestiftet werden« [it should be more widely known, and at a reasonable price, so that the benefit thereby for the noblest part of the human body should be provided].[28]

Causes and remedies of eye diseases and blindness

The almost unanimous consensus on the importance of vision which appears in these sources does not extend to the causes they invoke for eye disease, which change over the course of the 18th century. In 1725, in the introduction to his book focused on cataracts, *Der geschickte Augen-Arzt*, Lichtmann dedicates this publication to patients in need of help and expresses his Christian love and compassion.[29] As a disciple of the early Enlightenment, he denounces the belief that cataracts were caused by starling birds – the German word for cataract being 'star' – as a superstition: »Solches ist aber ein Aberglaube / und falscher Wahn.« [But this is superstition / and false delusion.][30] The real cause, he continues, is a slimy liquid that descends from the brain to the eye and covers it like a cobweb with a darkening veil. Besides this physical explanation (for which he later blames blood circulation and digestion), Lichtmann also makes a theological argument based on the sinfulness of humankind, for which blindness is a punishment from God, thus combining in one treatise the religious and the medical model of disability:

Augen-Erhaltungs-Kunst, zu allgemeinem Nutzen und Vortheil so Gelehrter als Ungelehrter abgefaßt, Frankfurt am Main 1757.

25 See Adams: Anweisung zur Erhaltung des Gesichts, pp. 4-5.
26 Lichtmann: Der geschickte Augen-Artzt, p. 1.
27 Meinig: Der Augen-Doctor, preface.
28 Lichtenberg: Ueber einige Pflichten, p. 4.
29 Lichtmann: Der geschickte Augen-Artzt, p. 4.
30 Ibid., p. 2.

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> Die vornehmste und wichtigste Ursache der Blindheit und aller Kranckheiten ist die Sünde der Menschen / die uns auch zu dem zeitlichen Todt des Leibes bringet / und wo nicht rechtschaffene Busse und Bekehrung ist / auch die ewige Blindheit / und Finsternuß der Seelen darauf folget.[31]
>
> [The first and most important cause of blindness and all diseases is the sinfulness of mankind / which also brings us to the early death of the body / and where there is no righteous repentance and conversion / also follows the eternal blindness / and darkness of the soul.]

Twenty years later, Meinig dedicates his *Augen-Doctor* ›with love and without greed‹ to those who suffer from eye diseases. His book includes recipes on how to produce different ointments, powders, and lotions to heal various eye diseases. Another physician, Hans Sloane, who publishes his treatise in 1745 under the title *Nachricht eines bewehrten Mittels vor Schmerzen, Blödigkeit und mancherley andere Krankheiten der Augen*, gives detailed instructions on how to produce an ointment from snake grease.[32] Other publications around 1750 focus on the cataract surgery and give advice on how to distinguish a good surgeon from a charlatan.[33]

However, in the second half of the 18th century, a shift can be observed in the causes of blindness and eye disease mentioned by these treatises. While there is still consideration for those who lose their sight due to an accident or an illness, most of the reasons given are now linked to the supposed imprudence, ignorance, and even foolishness of the patients:

> Bey weitem der größte Theil derer, die dieses Unglück erleiden, die diesen Halbtot, möchte ich sagen, sterben, sterben ihn freylich unverschuldet durch Zufälle; allein keine geringe Anzahl, und zwar gerade unter einer Classe von Menschen, von denen man es am wenigsten erwarten sollte, ich meine der sogenannten gebildeten höheren Classe erleiden ihn öfters durch Schuld, wo nicht wissentlich durch muthwilligen Leichtsinn, doch gewiß sehr oft aus einer Unwissenheit, die leicht zu überwinden gewesen wäre.[34]
>
> [By far the largest part of those who suffer this misfortune, who die this half-death, I would say, do so through no fault of their own, through accidents; however, a considerable number, and indeed among a class of people from whom one would at least expect it, I mean the so-called educated upper class, often suffer it through

31 Ibid., p. 3.
32 Hans Sloane: Nachricht eines bewehrten Mittels vor Schmerzen, Blödigkeit und mancherley andere Krankheiten der Augen. Nach dem Englischen Original übersetzt, Danzig 1745.
33 See Balthasar Heinrich Klinge: Sendschreiben, an einen alten erfahrnen Chirurgum in Strasburg, Leipzig 1748; Eschenbach: Bericht von dem Erfolg der Operationen.
34 Lichtenberg: Ueber einige Pflichten, pp. 7–8.

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guilt, if not knowingly through wilful recklessness, but certainly very often out of ignorance that could have been easily overcome.]

Some of the eye diseases or impairments are no longer seen as the result of an illness or the general sinfulness of mankind, but are instead linked to minor actions and decisions about one's daily routine:

> Blindheit oder wenigstens eine grosse Augenschwäche rührt sehr häufig von einer solchen dem Anschein nach ganz unbedeutenden Ursach her. Daher sollte ein jeder, besonders wenn er schwache Augen hat, auf Umstände dieser Art Achtung geben, denn es ist leicht, dem Uebel vorzubeugen, aber es zu heilen ist schwer, und bisweilen unmöglich.[35]
>
> [Blindness, or at least a severe weakness of the eyes, very often stems from such seemingly insignificant causes. Therefore, everyone, especially those with weak eyes, should pay attention to circumstances of this kind, for it is easy to prevent the disease, but to cure it is difficult, and sometimes impossible.]

John Taylor distinguishes between two types of eye diseases, one caused by an illness of the brain, the other by the habit of reading too much,[36] an argument also emphasized by Lichtenberg. By the end of the century, ophthalmologists focus not only on the duration of reading or the fact of reading in the evening,[37] but also on the precise position of the reader (and his eyes) relative to the light: »Man schreibe oder lese nie, wenn man es haben kann, in der Lage, daß ein helles Fenster gerade gegenüber so steht, daß jedesmahl das Licht in das aufgeschlagene Fenster fällt, sondern lasse das Licht von der Seite einfallen.« [Never write or read, if you can, in a position where a bright window is directly opposite so that the light constantly falls into the open window, but let the light fall from the side.][38]

Besides this more accurate description of positions and alignments, the treatises on ophthalmology published by the end of the 18th century give concrete advice »zur Erhaltung, zur Schonung, [...] zur Stärkung und Beßerung seiner Augen« [for the preservation, protection, [...] strengthening and im-

35 Adams: Anweisung zur Erhaltung des Gesichts, pp. 122–123.

36 Taylor: Neue Augen-Erhaltungs-Kunst, pp. 5–6; see George Chandler: Abhandlung über die Krankheiten des Auges und die dagegen anzuwendenden Heilmittel. Aus dem Englischen, mit zwey Kupern, Leipzig 1782, pp. 61–64.

37 See Lichtenberg: Ueber einige Pflichten, p. 20; Adams: Anweisung zur Erhaltung des Gesichts, p. 118.

38 Lichtenberg: Ueber einige Pflichten, p. 15–16; see Meyer: Abhandlungen und Beobachtungen, p. 33; Michel Jean Baptiste Wenzel: Abhandlung vom Staar. Aus dem Französischen, Nürnberg 1788, p. 5.

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provement of one's eyes].[39] One of the most frequently given pieces of advice has to do with the arrangement of the bedroom. The bed should not be placed next to a window because – as Lichtenberg argues – direct or even indirect exposure to daylight negatively affects vision.[40] This is particularly problematic, Lichtenberg continues, during travel because, when arriving at a hotel late in the evening, it is impossible to foresee if one's eyes will be exposed to daylight the next morning:

> Hierauf hat man besonders auf Reisen zu sehen, und wenn man des Abends spät ankommt, die Lage der Fenster- und die Beschaffenheit der Bettvorhänge zu untersuchen, damit man nicht auf eine unangenehme Weise des Morgens vom Tage, oder gar von der Sonne überfallen werde.[41]
>
> [This is something you should pay particular attention to when traveling, and if you arrive late in the evening, you should examine the position of the windows and the quality of the bed curtains so that you are not unpleasantly assaulted by the day or even the sun in the morning.]

The most dangerous moment of the day is the early morning when one's eyes might suddenly be exposed to broad daylight: »Man muß die Augen nicht auf glänzenden Gegenständen ruhen lassen, am wenigsten des Morgens beym ersten Erwachen. Das Schlafzimmer darf alsdann durchaus nicht von der Sonne beschienen werden, sondern nur eine mäßige Hellung haben.« [You should not let your eyes rest on shiny objects, especially when you first wake up in the morning. The bedroom should not be exposed to sunlight at all, but should only have moderate brightness.][42] Adams therefore recommends sleeping with closed shutters or having green bed curtains in order to shade the sunlight. Doing so both strengthens and calms the eyes, even when the eyelids are closed. Lichtenberg likewise recommends covering one's head with a green veil anytime one is unable to control the intensity of light. To illustrate this point, he gives the example of travelling in a coach, where a quick movement or a sharp bend might suddenly expose one's eyes to the light. These veils are more effective, according to Lichtenberg, than umbrellas, shutters, glasses, or curtains because they cover the whole face while simultaneously allowing fresh air to circulate.[43] In addition, situations in which the intensity of the

39 Lichtenberg: Ueber einige Pflichten, p. 3.
40 Ibid., p. 17.
41 Ibid.
42 Adams: Anweisung zur Erhaltung des Gesichts, p. 119.
43 Lichtenberg: Ueber einige Pflichten, pp. 17–19.

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light changes rapidly, such as going quickly from a bright to a dark room or *vice versa*, must be avoided:

> Man halte sich nie eine lange Zeit weder an einem ganz finstern, noch an einem solchen Orte auf, wo man einem blendenden Licht ausgesetzt ist. Die Gründe, worauf sich diese Regel stützt, beweisen, wie schädlich es sey, aus einem sehr dunkeln Zimmer schnell in ein sehr helles überzugehen, und umgekehrt; auch erhellet daraus, daß ein Zimmer, das gegen Mittag liegt, für Personen von einem schwachen Gesicht nicht taugt.[44]
>
> [Never stay for a long time in a completely dark place, nor in one where you are exposed to dazzling light. The reasons for this rule demonstrate how harmful it is to pass quickly from a very dark room to a very bright one, and vice versa; it also shows that a room facing south is unsuitable for people with weak eyesight.]

Brightness should neither be too strong nor too weak or, even worse, strong and weak at the same time, for example when reading at dusk with the help of an oil lamp or a candle. Even the mere fact of reading a book in front of a window might harm the eyes. Light intensity should always be kept steady and equal: »Man bemühe sich daher, soviel als möglich bey allen Verrichtungen ein gleichförmiges Licht zu erhalten, da wenigstens, wo es leicht angeht, und wir von uns abhängen.« [Therefore, we should strive to maintain a uniform light as much as possible in all operations, at least where it is easy to do and we depend on ourselves.][45]

With all this in mind, the task of protecting one's eyes from blindness seems to be rather demanding. Things get even more complicated when Lichtenberg recommends being mindful of the state of one's vision before looking at an object. Those who wish to preserve their sight need to take not only light intensity into account, but also time. One should not look at the same object or landscape for too long but change from time to time – but not too quickly: »Man muß den Augen nie mehr anmuthen, als sie vertragen können, und die Art, und die Zeit der Beschäftigung so viel möglich nach dem Zustande der Augen wählen.« [You should never ask your eyes to do more than they can bear, and choose the type and time of activity as much as possible according to the condition of your eyes.][46] Lichtenberg suggests reading one page of a book and then asking a friend to read the next page

44 Adams: Anweisung zur Erhaltung des Gesichts, pp. 117–118; see Lichtenberg: Ueber einige Pflichten, p. 13.
45 Ibid., p. 12.
46 Ibid., p. 28.

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aloud, or alternating between an hour of reading and an hour of walking.[47] The subtle shaking of the body while walking or riding, Lichtenberg adds, has a healing effect on the nervous system and thus on the optic nerves: »Reiten hat einen längst erkannten Nutzen für nervenschwache Augen, durch die heilsame Erschütterung der Nerven. Fahren, und Spatzierengehen haben ihn auch in dieser Rücksicht.« [Riding has long been recognized as beneficial for weak eyes, through the healing stimulation of the nerves. Driving and walking also have this effect.][48]

You must take care of your eyes

It may be possible that Lichtenberg and the other authors of these treatises really had the public's interest at heart. However, the impression which one gets from reading them is that every little gesture and movement can have dreadful consequences on vision. At the beginning of the 18th century, in contrast, eye disease or blindness was thought to have mainly physical, moral, or dietetic causes – for example eating too much garlic, radish, lobster, drinking too much alcohol or crying too often:[49]

> Diese doppelte Art der Entzündung, ist gemeiniglich der Grund und Quelle aller übrigen Augen=Gebrechen, und entstehet von vieler Traurigkeit und Weinen, vielen Wachen, Nachtsitzen, Lesung all zu kleiner Schrifften, all zu hellen Glantz und schauen ins Feuer, als wodurch die Schärffe der Augen allzusehr angestrenget und zusammengezogen werden, übermässigen Beyschlaff, unmässige Sauffen hitziger Getränke, ausgebliebenes Nasen=Bluten und Monathliche Zeit, Verstopffung des Leibes, zurückgeschlagenen Grind und Ausschlag des Gesichts, Blattern und derselben scharffe Materie, rauhe Nord=Lufft und viele Winde, Staub, scharffe beissende Dinge, hefftiger Rauch, und endlich das Alter, in welchen der Nerven=Geist geschwächt wird, und die nöthigen Feuchtigkeiten abzunehmen pflegen.[50]
>
> [This double kind of inflammation is usually the cause and source of all other eye diseases, and arises from much sadness and crying, insomnia, staying awake at night, reading too small writings, too bright shine and looking into the fire, which strains and contracts the sharpness of the eyes, excessive sexual intercourse, immoderate drinking of alcoholic drinks, missed nosebleeds and menstrual bleeding, constipation, recurrent scabies and facial eruption, smallpox and its sharp substances, harsh northern air and much wind, dust, sharp, acrid substances, heavy

47 Ibid., p. 30.
48 Ibid., p. 31.
49 Lichtmann: Der geschickte Augen-Arzt, p. 4.
50 Meinig: Der Augen-Doctor, pp. 13–14.

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> smoke, and finally age, in which the nervous spirit is weakened and the necessary moistures tend to decrease.]

Some decades later, it has become first and foremost the responsibility of every individual person to take care of their eyes, as well as to be aware of the permanent dangers to which they are exposed. It seems as if, to avoid blindness, one must respect what Adams calls »Regeln zur Erhaltung des Gesichts« [rules for preserving sight][51] and Lichtenberg the »Oekonomie beym Geschäfte des Sehens« [economy of the business of vision].[52] The treatises and books I have studied in this paper are not addressed to ophthalmologists or opticians but explicitly to a wider public. This implies both that everybody can, and must take care of their eyes, and that a change in behaviour might prevent many diseases:

> Glücklich sind die, welche diese Vorschrift bey Zeiten beobachten, und ihre Augen schonen, ehe sie durch Schmerzen dazu genöthigt werden. Der thörichte Geiz mit einer Viertelstunde des Abends, hat schon manchen den vollkommnen Gebrauch der Augen für viele Jahre gekostet. Das Uebel wird nach und nach und unmerklich bewirkt, aber es ist unvermeidlich.[53]
>
> [Happy are those who observe this rule in time and spare their eyes before they are forced to do so by pain. The foolish stinginess of a quarter of an hour in the evening has already cost many the full use of their eyes for many years. The harm is brought on gradually and imperceptibly, but it is unavoidable.]

In 1801, this outreach to a large public of non-specialists translates into a new medium with the publication of a household code by the physician Christian Friedrich Benedict Ettmüller (1773–1849) with instructions on how to preserve the health of one's eyes. The subtitle clearly points to the responsibility of everyone to respect the advice given: »Bemitleidenswerth ist der, welcher des Lichtes seiner Augen beraubt, in ewiger Finsternis seine Tage verleben muß; aber doppelt unglücklich muß er sich fühlen, wenn er diesen Verlust durch eigne Schuld sich zugezogen hat.« [Pitiable is he who, deprived of the light of his eyes, must spend his days in eternal darkness; but he must feel doubly unhappy if he has incurred this loss through his own fault.][54] The German term »Haustafel« is coined by Martin Luther and designates a summary

51 Adams: Anweisung zur Erhaltung des Gesichts, p. 117.
52 Lichtenberg: Ueber einige Pflichten, p. 54.
53 Adams: Anweisung zur Erhaltung des Gesichts, p. 118.
54 Christian Friedrich Benedict Ettmüller: Von den Mitteln die Gesundheit der Augen zu erhalten, ihren Krankheiten vorzubeugen und solche vernünftig zu behandeln. Eine Haustafel für alle Stände, Lübben 1801.

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of actions related to the New Testament which each member of a household is expected to perform. Ettmüller's one-page household code, which can conveniently be hung on a wall, is composed of a short first part that describes the anatomy of the eye, »die Werkstatt des Sehens« [the workshop of vision].[55] The second part is dedicated to the actions and means of preventing blindness. The link between the two parts is the religious assumption that the eyelids and the eyelashes reflect the will of God to protect the eyes and, consequently, it is the duty of everyone to do likewise. In 1801, Ettmüller's arguments reiterate the moral and religious reasons given for blindness at the beginning of the 18th century. He still recommends green veils and washing one's eyes frequently, but he primarily blames ›immoral‹ behaviour: »zu viele hitzige Getränke trinket, unmäßig im Beischlafe ist, (man hat Beispiele, daß auf unmäßigen Beischlaf Blindheit entstand) ziegellos tanzt, sich erkältet, der heut zu Tage so häufig zur Mode gewordene Misbrauch der Vergrößerungsgläser u.s.w.« [drinking too many alcoholic drinks, having excessive sexual intercourse (there are examples of blindness resulting from excessive sexual intercourse), dancing excessively, catching colds, the misuse of magnifying glasses, which has become so fashionable today, etc.][56]

Until around 1700, philosophers, natural scientists, and opticians often choose to justify their findings by pretending that an uneducated and thus unbiased and impartial spectator – a child or an illiterate person – confirmed their observations. However, with John Locke's *Essay Concerning Human Understanding* (1690), vision is no longer seen as a gift from God or nature, but rather as a capacity that must be learned and trained. According to him, the development of reason follows almost mathematically from the number and quality of images perceived. A lack of such images inevitably results in a lack of reason and thought. Consequently, by 1700, natural scientists begin to refute the use of an uneducated spectator, as such a person is no longer considered impartial but rather almost foolish. In a translation of Giovanni Bertolazzi's case study of a sixteen-year-old blind girl, he describes her as vivacious and timid, emphasizing that her perceived stupidity is a necessary result of her blindness. Later in the treatise, the translator compares her in a footnote to an orangutan unable to answer questions:[57] »Sie lebte stets einsam; aller Ideen beraubt aus Mangel des Gesichts, und der gesellschaftlichen Vergnügungen, gab sie nur Merkmale eines stumpfen Verstandes, der sich der

55 Ibid.
56 Ibid.
57 Bortolazzi: Abhandlung über eine seltne Art, p. 69.

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Dumheit näherte, von sich.« [She always lived solitarily; deprived of all ideas for lack of sight and of social pleasures, she gave off only the signs of a dull mind approaching stupidity.][58] To summarize more crudely: by the end of the 18th century, not only are blind or partially sighted people considered less intelligent and less educated, they are also held responsible for their condition. This forms a vicious circle: supposedly unenlightened behaviour leads to disability resulting in unenlightened behaviour, etc. In conclusion, the rise of the individual and medical model of disability in the 18th century appears to be, at least partly, constructed in and through culture and media in the very concrete sense of advice on gestures, postures and everyone's daily routine.

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58 Ibid., p. 17.

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David Feeney

Beauty on Trust: Aesthetic Testimony, Verbal Description and the Impact of the ›Objectivity Imperative‹

Concern for the limits of what we can learn from one another about beauty has recurred throughout the history of aesthetic theory. Dividing its attention between literary renderings of blindness and widely endorsed regulatory features of art access initiatives, this chapter positions an exploration of what the experiences of people with visual impairment might contribute to long-standing deliberations about the appropriate weighting of the degrees of epistemological credence afforded to aesthetic and non-aesthetic testimony within a history of philosophical debate from which their potentially instructive perspectives have been regrettably absent. After tracing aspects of the ›aesthetic testimony debate‹ through literary representations of blindness, the chapter shifts focus in order to contemplate potential applications of insights generated by the debate to a review of the potentially impoverishing impact of selected art access guidelines on the aesthetic experiences of gallery visitors with visual impairment. The ›objectivity imperative‹ that is a feature of established verbal description guidelines is accounted for in terms of an ill-supported and distinctly unhelpful suspicion of interactive or correlational hermeneutics within the domain of art access. Barbara Herrnstein Smith's delineation of the threads of mutual causation and justification that fuse experience, hermeneutics and evaluation within the ›psychological set‹ of art engagement is brought into service alongside an application of concerns that have recurred throughout the history of aesthetic theory as a means of challenging the logic and value of the repeated instructional mantra that describers of works of visual art for gallery visitors should merely ›say what they see‹.

Aesthetic testimony

Were it not for testimony, a lot of what we consider ourselves to know about the world would remain a closed book to us. Although daily news reports from far-flung corners of the earth indicate that testimony is clearly an indispensable source of knowledge, misgivings persist within the aesthetic sphere about testimonial justification. The aesthetic testimony debate is premised on

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the question of whether we can come to know the aesthetic value of a particular entity – for example whether it is beautiful, or more or less aesthetically impressive – on the basis of someone's say-so. Language and the inherent limitations of its capacity to do justice to beauty is another recurring concern within these debates, culminating, perhaps, in James Elkins' seminal account of pictures and the words that fail them.[1] Theorists who have contemplated the question of whether it is acceptable to form a belief about the excellence of a movie, a painting, a literary representation or the beauty of a sunset or a human countenance simply on the basis of someone else's say-so have tended to arrive at less than entirely optimistic verdicts. These aesthetic testimony pessimists can be said to fall broadly into two camps. *Unavailability* pessimists claim that testimony fails to make meaningful, reliable or appropriate forms of knowledge available to its recipient, who is therefore poorly positioned to arrive at aesthetic judgment or knowledge when testimony constitutes the sole source of insight at his/her disposal. *Unusability* pessimists concede that aesthetic testimony can, in certain circumstances, transmit knowledge; but that certain exacting and non-negotiable conditions of justified belief preclude the full assimilation of the aesthetic insights that have been verbally volunteered to us by another. The snag for pessimists of this ilk lies not in the unavailability of knowledge, but rather in the hermeneutic transgression entailed in availing of the learning opportunity presented by such knowledge.

Although the frequently asked question about whether testimony can generate knowledge or merely transmit it would appear to have an especially pertinent bearing on considerations of the shareability of aesthetic understanding amongst individuals with differing sensory configuration, such isolated and indirect instances as the published epistolary correspondence between Brian Magee and Martin Milligan,[2] Diderot's brief discussion of the theme in his *Letter on the Blind for the Use of those who can See* (1749),[3] and William Paulson's fleeting engagement with the issue in his study of blindness and the enlightenment.[4] Issues relating to the availability, usability and value of aesthetic testimony have largely evaded interrogation within the specific context of the aesthetic experiences of individuals with visual impairment. My

1 Cf. James Elkins: On Pictures and the Words that Fail Them, New York 1998.
2 Cf. Bryan Magee/Martin Milligan: Sight Unseen, London 1998, 1st pub. as On Blindness, Oxford 1995.
3 Cf. Margaret Jourdain (ed. & transl.): Diderot's Early Philosophical Works, Chicago and London 1916, pp. 68–141.
4 Cf. William R. Paulson: Enlightenment, Romanticism, and the Blind in France, Princeton, NJ 1987.

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endeavours within the fields of literary disability studies and museum and gallery access have generated concern for the aesthetic cost to individuals with visual impairment of the (seemingly unwitting) regulatory incorporation of the more pessimistic doctrines yielded by these fastidious philosophical ruminations by institutions which undertake art access initiatives. The first section of this chapter draws on literary representations as a means of illustrating these concerns.

Well of the Saints and the unreliability of aesthetic testimony

Martin and Mary Doul, two blind beggars living in a rural society in the west of Ireland, are the central protagonists of J.M. Synge's *The Well of the Saints* (1905).[5] They have been led by the lies of the townsfolk to believe that they are both exceptionally attractive. When a saint cures them of their blindness with water from a holy well, the disgust each feels for the other's appearance belies the assurances they have historically been given that their beauty is unrivalled in the village. The indirectness of the way in which Martin and Mary accumulate the information about the world that they take for »truth« is captured in the auxiliary construction »to hear tell,« which is often used to describe the process. Martin becomes aware of strange happenings in the village, such as the killing of an old man for his gold by »hearing tell« of them.[6] Likewise, Mary is told that »it's a great sight to see a man hanging by his neck«,[7] and is asked by Timmy if she has »heard tell« of the »grave of the four beautiful saints«.[8] In terms of communicable information, »hearing tell« of a phenomenon is regularly deemed to be an acceptable means of coming to know or understand it. It is regularly deemed otherwise, however, when reference is made to aesthetic properties of the phenomenon. In order to learn about visual beauty – and the pair have an insatiable appetite for knowledge relating to their own – they must subject themselves to the mediatory function of the verbal descriptions. Mary, for example, has »heard tell« that the »splendour« of her appearance is accountable for in terms of the wet south wind to which she has been exposed for so many years.[9] In Act

5 Cf. John Millington Synge: The Well of the Saints, ed. Nicholas Grene, Gerrards Cross 1982.
6 Ibid., p. 77.
7 Ibid.
8 Ibid., p. 79.
9 Ibid., p. 71.

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I, when Martin questions the beauty of Mary because of her cracked voice, Mary reminds him that he's heard Timmy the Smith, Mat Simon, »and a power besides« speaking appreciatively of the beauty of her face.[10] Martin's means of comparing the beauty of Molly, a local woman, to that of his wife is equally based on what he can garner from village gossip. Misgivings about the adequacy of hearsay as a source of aesthetic awareness underpin Martin's declaration: »I've heard him say a power of times it's nothing at all she is when you see her at the side of you, and yet I never heard any man's breath getting uneasy the time he'd be looking on yourself«.[11] Martin also remarks that although the girls of the village lack the courage to approach him, »they do be saying" that he is »a handsome man«.[12] Mary reminds Martin that he is married »with a woman he's heard called the wonder of the western world«.[13] Martin concedes that he's »heard tell her yellow hair, and her white skin, and her big eyes are a wonder surely«.[14] Toward the end of Act I, when Martin is trying to identify his wife after the restoration of his sight, the role previously played by mediation in his reception of her beauty is illustrated by his decision that he is married to Bride rather than Mary, on the grounds that she is »more the like of what they said«.[15] Beauty, the play appears to suggest, is not something to have on second-hand authority, especially not the eminently equivocal authority of individuals whose shared conception of fun is deliberate misinformation.

Aaron Meskin is one of several theorists to have argued that unlike non-aesthetic reports, we learn very rarely from the beauty reports of others.[16] His argument is grounded in a deeply held conviction about the innate unreliability of aesthetic testimony. Such testimony can fail the trustworthiness test in one of two ways: incompetence or insincerity. The majority of Meskin's thesis is dedicated to addressing the first of these two scenarios – if someone lacks authority on a subject matter, then his or her testimony should be received with scepticism – and most people do not have recourse

10 Ibid., p. 71–73.
11 Ibid., p. 75.
12 Ibid., p. 87.
13 Ibid.
14 Ibid.
15 Ibid., p. 95.
16 Cf. Aaron Meskin: Aesthetic Testimony: What Can We Learn from Others about Beauty and Art?, in: Philosophy and Phenomenological Research 69 (2004), pp. 65–91; Aaron Meskin: Solving the Puzzle of Aesthetic Testimony, in: McIver Lopes, Dominic/Kieran, Matthew (eds.): Knowing Art: Essays in Aesthetics and Epistemology, Dordrecht 2006, pp. 109–124.

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to the necessary expertise to make warranted aesthetic judgments. Meskin's treatment of dismissals of aesthetic testimony on the grounds of insincerity is not as expansive, but his reflections on this issue are expanded upon by Brian Laertz.[17]

It does happen that people are less than entirely genuine when relaying aesthetic testimony. We may feel compelled to tell a potential partner that an artwork or a movie towards which we feel ambivalent was utterly compelling, for example, because we happen to know that such a verdict aligns with their opinion and so may enhance the prospect of the emergence of a sympathetic connection. As a manifestation of the phenomenon known to reluctantly coerced clothes-shopping companions as the highly perilous ›does my ass look big in this?‹ quandary, our familiarity with the capacity of aesthetic judgments to generate personal upset amongst sensitive or particularly vain acquaintances can prompt us to approve of a radical makeover although we inwardly believe it to signal a marked disimprovement, or make us feel inclined to tell an ill friend that (s)he is looking well, even though their appearance has triggered an intensification of our concern for their wellbeing. Parents will be familiar with those scribbled wall hangings and with a reluctance to let a child know that their creative output is cherished on no other basis than sentiment. Young people might feign aesthetic appreciation, prompted by peer pressure to avow wildly affirmative evaluations of music that actually leaves them unmoved, while certain adults will employ a similar strategy in the belief that demonstrating appreciation for certain artworks will generate an impression of sophistication and discernment. However, although disingenuously volunteered aesthetic testimony and the various motivations that might prompt insincerity in this regard are not entirely unheard of, it is hard to countenance that it is such a persistent or significant occurrence as to have a meaningful bearing on the epistemic value of such testimony. Within a museum or gallery context, I would suggest, while concern about the competence or credentials of the member of the access team tasked with the challenge of describing paintings for visitors who cannot see them may represent a genuine concern, it is difficult to imagine how concerns about the honesty of a museum or gallery docent might account for the resistance to aesthetic testimony that continues to prevail within that domain. It seems noteworthy, in this and other regards, that existing critical engagement in Synge's play tends to dismiss Martin and Mary as ›dreamers‹ for investing

17 Cf. Brian Laertz: A Modest Defence of Aesthetic Testimony, in: The Journal of Aesthetics and Art Criticism 64:4 (2008), pp. 355–363.

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faith in anything other than the ›reality‹ that unfolds when their vision is restored by a wandering saint.

On Baile's Strand and the (old) acquaintance principle

Yeats's *On Baile's Strand*[18] might be said to represent an ableist reverse engineering of the literary tradition of ›romantic agony‹ documented by Mario Praz, Frank Kermode and others.[19] In his study of the »cult of isolated joy, « and the cost of the »Image,« for example, Kermode details the »sense of irreconcilable difference and precarious communication« and the ultimately unbearable torment of alienation imposed on the single beholder of the »romantic image«.[20] The emergence of this torment in the warrior Cuchulain is evidenced when his appeal to Conchubar, the High King of Ireland about the impact of the legendary beauty of Aoife is informed by a keen sense of the value of such an appeal when addressed to someone who has not witnessed this beauty at first hand:

> A fierce woman of the camp!
> But I am getting angry about nothing.
> You have never seen her. Ah! Conchubar, had you seen her,
> With that high, laughing, turbulent head of hers
> Thrown backward, and the bowstring at her ear,
> Or sitting at the fire with those grave eyes
> Full of good counsel as it were with wine,
> Or when love ran through all the lineaments
> Of her wild body – although she had no child,
> None other had all beauty, queen or lover,
> Or was so fitted to give birth to kings.[21]

What is most notable about Yeats's rendering of this phenomenon is that the only thing that threatens to save the fearless and otherwise invincible warrior Cuchulain from being undone by the »romantic isolation« traditionally the lot of the solitary witness of a site of visual beauty is that the play's Blind Man has encountered it too. The opportunity to spare himself a form of mania-in-

18 Cf. William Butler Yeats: The Variorum Edition of the Plays of William Butler Yeats, ed. Russell K. Alspach, London 1966, reprinted 1989, pp. 457–527.
19 Cf. Mario Praz: The Romantic Agony, New York 1993; Frank Kermode: Romantic Image, London 2001.
20 Kermode: Romantic Image, p. 9.
21 Yeats: The Variorum Edition, p. 487.

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ducing agony born of »the very costly matter of beatific imaging« and »the sacrifice of a thousand possible sympathies«[22] presents itself to Cuchulain only when he happens upon the unlikely solace of the company of Blind Man's who bore witness to Aoife's beauty before losing his vision. The representation of blindness primarily in terms of visual memory, as Yeats was also to do with Hanrahan in *The Tower*, is likely to be deemed problematic in many ways by literary disability studies scholars. Epitomising the concept of narrative prosthesis, Blind Man, an otherwise irreducibly peripheral figure, assumes an authority as a consequence of being able to alleviate the quarantined torment of the play's central protagonist – although the influence he commands is entirely uninformed by or indebted in any way to his contemporary sensory configuration. Blind Man assumes the substantial significance he comes to wield purely on the strength of what he has previously seen. The element of the aesthetic testimony debate to which the play seems to me to most directly relate is what has become known as the ›acquaintance principle‹. The ableism underpinning Yeats's rendering of blindness manifests in the apparent assumption that in instances of individuals who are adventitiously blind, the only acquaintance that is of any interest or value is old acquaintance.

Richard Wollheim explains the rationale underpinning his scepticism about the value and credence of aesthetic testimony in relation to the aforementioned Acquaintance Principle, which »insists that judgments of aesthetic value, unlike judgments of moral knowledge, must be based on first-hand experience of their objects and are not, except within very narrow limits, transmissible from one person to another«.[23] Positioning the issue inadvertently within a context that is more specifically aligned with our current focus, Alan Tormey contends: »[i]n art, unlike the law, we do not admit judgments in the absence of direct or immediate experience of the object of the judgment. We require critical judgments to be rooted in eye-witness encounters, and the epistemically indirect avenues of evidence, inference and authority that are permissible elsewhere are anathema here«.[24] Bertrand Russell's treatment, in 1910, of the distinction between knowledge by acquaintance and knowledge by description arguably remains the definitive one, although it has been very usefully complemented by Richard Fumerton.[25] Language and description

22 Kermode: Romantic Image, pp. 4–5.
23 Richard Wollheim: Art and Its Objects, 2nd ed, Cambridge 1980, p. 233.
24 Alan Tormey: Critical Judgments, in: Theoria 39 (1973), pp. 35–49, here: p. 39.
25 Cf. Bertrand Russell: Knowledge by Acquaintance and Knowledge by Description, in: Proceedings of the Aristotelian Society 11 (1910–11), pp. 108–128; Richard Fumerton: Knowl-

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assume a central importance within this element of the aesthetic testimony debate, as second-hand, verbal accounts of somebody else's direct experience with a site of beauty represent, for advocates of the acquaintance principle, a poor and misguided basis for aesthetic judgment.

Brian Laertz lists remembered acquaintance alongside photographic evidence of beauty and aesthetic engagement in recorded musical performance within a suite of aesthetic experiences which seem to cast into jeopardy the validity of the acquaintance principle's insistence that only direct forms of experiential engagement can warrant aesthetic judgments.[26] He concedes, however, that subscribers to the principle might, by means of a considered application of the ›transparency thesis‹ argue that engagement with the effectively diaphanous media of photography, audio recording and memory might constitute so slight a remove from immediate contact as to represent a negligible compromise of the rationale underpinning the acquaintance principle. From a purely philosophical perspective, acceptance of aesthetic knowledge via memory, as such acceptance pertains within the relationship between Cuchulain and Blind Man, represents a distinctive challenge to acquaintance principle advocates. Whether one deems remembering that something has an aesthetic quality to constitute direct experience of it, depends on whether the conditions of directness are deemed to be met by the fact that one was once acquainted with an entity. »Sometimes,« Laertz suggests, »our memories are so dim all we recollect is our assessment of a work but none of the details that compelled us to make it. We often decide to revisit a work, simply because we remember that it was good.«[27] Reflecting on this challenge within the context of the aesthetic experiences of individuals with acquired visual impairment generates even more intricate convolutions. Were an individual to resume, after losing their vision, engagement with an artwork to which they attributed significant aesthetic value as a fully sighted person in the past, there is no guarantee that the favourable verdict arrived at in the past would survive the transition to less ocularcentric forms of beholding. Were Blind Man to encounter Aoife in ›real time‹, the fate of her legendary beauty would be in the balance.

The assumption that the aesthetic sensibility of an individual with acquired visual impairment is inevitably or necessarily residual brings to mind Ray-

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edge by Acquaintance vs. Description, in: Stanford Encyclopedia of Philosophy (2008). plato.stanford.edu/entries/knowledge-acquaindescrip/ (22.10.2023).

26 Cf. Laertz: A Modest Defence, p. 357.

27 Ibid.

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mond Williams' treatment of the often-definitive influence wielded by historical lineaments over the transition from past to future cultures, and of the debilitating impact of tradition and long-won convention on the emergence of alternative or oppositional forms of cultural expression.[28] The hegemony afforded to residual convention can, according to Williams, »exert its pressure as a static and exclusionary prototype against which all real cultural progress is measured«, resulting in the advocacy of perspectives supportive of traditionally dominant practices and the exclusion of the marginally emergent.[29] Subordination happens, according to Williams, because the emergence of diverse perspectives is rarely accompanied by a corresponding emergence of accommodating infrastructures. Applying these sweeping epochal observations to Yeats's rendering of blindness yields insights into Yeats's apparent disregard for the capacities of individuals with acquired impairment to forge new standards of ontological, epistemological, and aesthetic value as they renegotiate their experiential contracts with the lived realities of their surroundings.

Questions relating to the perceived availability and usefulness of elements of an outlived sensorium also afford opportunities to reengage with central tenets of the aesthetic testimony debate. One of the instances identified by Jon Robson as representing grounds for aesthetic testimony optimism, for example, is when the beauty of an entity stands the test of time.[30] We can assure an acquaintance that Yeats was an exquisite poet, though a shockingly poor dramatist, because that consensus has persisted amongst learned scholars for a considerable period of time. If our approach to aesthetic value is more inclined towards conceptions of it being the product of the relationship between an entity and an individual sensibility, however, rather than being conceived of in terms of the cultivation of good taste by ushering aesthetic preference into contrived alignment with that commonly espoused by proven experts, the truth value of any endorsement by Blind Man of Cuchulain's affirmations of Aoife's beauty when that beauty has become, for the former, a remembered feature of an outlived sensorium, seems highly contestable.

David Bolt has commented on the tendency of blind characters to be represented as tolerating a »residual existence whose only pleasure is in the past«.[31]

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28 Cf. Raymond Williams: Marxism and Literature, Oxford 1977.

29 Ibid., p. 121.

30 Cf. Jon Robson: Aesthetic Testimony and the Test of Time, in: Philosophy and Phenomenological Research 96:3 (2018), pp. 729–748.

31 David Bolt: Cultural Disability Studies in Education: Interdisciplinary Navigations of the Normative Divide, London 2018, p. 8.

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Claire Penketh argues that ascription of an irreducibly retrospective aesthetic sensibility to those with acquired impairment is inevitably premised on the invalidation of an epistemology embedded in the lived contemporary realities of life with an impairment.[32] I have elsewhere identified at the core of a history of »visually-biased meta-narratives« of blindness a recurring assumption that, in the case of characters with acquired visual impairment, »the beautiful thing has always already been and gone«.[33] Disability studies scholars tend to be less interested than pure philosophers in the question of whether the epistemic value of reports of remembered beauty can be rationalised, being generally more inclined to concern themselves with the potentially debilitating impact of such rationalisations. My involvement in the domain of museum and gallery access provision, however, has prompted a certain tempering of my wariness of the perils inherent in indulging a residual aesthetic in a way that I am sure will frustrate or disappoint many of my colleagues in the field of critical disability studies. My work in that field generally brings me into regular contact with individuals with acquired visual impairment. Many of these individuals are artists. They are self-selecting gallery visitors, and retain an interest in, and usually a passion for, visual art. For these individuals, the suggestion that indulging a residual interest is not in keeping with the principles underpinning contemporary work in socially-oriented academic approaches to disability identity tends not to readily register itself as a pressing concern, as visual memory becomes one of several modalities exercised within their comprehensive and fervent engagement with exhibited artworks.

Molly Sweeney and the asymmetry thesis

Within philosophical treatments of the issue, the imbalance between willingness to believe, assimilate or epistemologically operationalise the yield of aesthetic and non-aesthetic testimony is often referred to in terms of an asymmetry thesis, which holds that aesthetic testimony is epistemically inferior to its non-aesthetic counterpart. This asymmetry is evidenced in the opening monologue of Friel's *Molly Sweeney*, where we gain an insight into the type

32 Cf. Claire Penketh: Special Educational Needs and Art and Design Education: Plural Perspectives on Exclusion, in: Journal of Education Policy 31:4 (2016), pp. 432–442.

33 David Feeney: Toward an Aesthetics of Blindness: An Interdisciplinary Response to Synge, Yeats and Friel, New York 2007, p. 279, p. 125.

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of tuition to which her father subjects Molly as a young girl.[34] It may be instructive, for our current purposes, to consider the patterns of distinction and attempted fusion that pertain between aesthetic and non-aesthetic elements of her father's pedagogical endeavours. Mr Sweeney tells Molly, for example, »at the bottom of the pedestal there is a circle of petunias. There are about twenty of them all huddled together in one bed. They are – what? – seven inches tall. Some of them are blue-and-white, and some of them are pink, and a few have big, red, cheeky faces«.[35] In the immediate aftermath of this tuition, the following test ensues:

> ›Now Molly. Tell me what you saw.‹
> ›Petunias.‹
> ›How many petunias did you see?‹
> ›Twenty.‹
> ›Colour?‹
> ›Blue-and-white and pink and red.‹
> ›Good. And what shape is their bed?‹
> ›It's a circle.‹
> ›Splendid. Passed with flying colours. You are a clever lady.‹[36]

Her father's methodology entails rewarding Molly with high praise for the memorizing and repetition of his descriptions of the visual features of the garden. Molly's capacity to produce what her father hails as ›excellent testimony‹ is where her education begins and ends.[37] It is also one element of Friel's exposition of the blindness that he appears, for all of his exquisite wordsmithery, to identify at the heart of language. Molly finds herself bound to the corrective and compensatory designs of another who instinctively attributes aesthetic frustrations to her condition and thereby creates them. As part of a misguided indoctrination into the formal domain of aesthetic appreciation, Mr Sweeney resolves to make his blind daughter a witness to all of the beauty he describes. Although Molly is encouraged to touch and smell the flowers, when their beauty is in question, all that she derives through these sensory channels is subordinated to or translated into the terms of her teacher's visual perspective. As Molly's education progresses, it becomes evident that the imparting of information about the features of the family garden is also intended as a component of her aesthetic education, which seems premised on an active

34 Cf. Brian Friel: Molly Sweeney, Oldcastle 1994.
35 Ibid., p. 14.
36 Ibid.
37 Ibid., p. 15.

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discouragement of the pupil's capacity to exercise or express preferences or forms of discernment that are aligned with her experience. »I know you can't see them«, Mr. Sweeney informs Molly about the nemophila, »but they have beautiful blue eyes. Just like you«.[38] When considered within the wider context of the play in its entirety, the scene juxtaposes conceptions of the purpose of aesthetic education as the cultivation of good or proper taste, with approaches underpinned by the recognition volunteered by Ralph Alexander Smith and other aesthetic theorists, that aesthetic value, like any other, is the product of the interface between an entity or phenomenon and a particular sensibility.[39] The lesson underscores the soundness of Santayana's argument:

> It is absurd to say that what is invisible to a given being *ought* to seem beautiful to him. Evidently this obligation of recognizing the same qualities is conditioned by the possession of the same faculties. But no two men have exactly the same faculties, nor can things have for any two exactly the same values.[40]

The shortcomings of testimony as a means of transmitting aesthetic value are further exposed later in the play, when Molly reflects on her own genuine aesthetic experience. In keeping with the play's recurring illustration of the limitations of verbal mediations of direct sensory experience, Molly is reconciled to the ineffability of the experience to which she endeavours to do descriptive justice:

> And how could I have told those other doctors how much pleasure my world offered me? From my work, from the radio, from walking, from music, from cycling. But especially from swimming. Oh, I can't tell you the joy I got from swimming. I used to think – and I know this sounds silly – but I really did believe I got more pleasure, more delight, from swimming than sighted people can ever get. Just offering yourself to the experience – every pore open and eager for that world of pure sensation, of sensation alone–sensation that could not have been enhanced by sight – experience that existed only by touch and feel; and moving swiftly and rhythmically through that enfolding world; and the sense of such assurance, such liberation, such concordance with it.... Oh, I can't tell you the joy swimming gave me. I used to think that the other people in the pool with me, the sighted people, that in some way their pleasure was actually diminished because they could see, because seeing in some way qualified the sensation; and that if they only knew how full, how total my pleasure was, I used to tell myself that they must, they really must envy me.[41]

38 Ibid., p. 14.
39 Cf. Ralph A. Smith: The Sense of Art, New York and London 1989.
40 George Santayana: The Sense of Beauty, New York 2005, 1st pub. 1896, pp. 19–20.
41 Friel: Molly Sweeney, p. 24.

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A rich history of aesthetic theorists, including Immanuel Kant,[42] Frank Sibley,[43] Mary Mothersill,[44] and Richard Wollheim,[45] have been reticent to attribute any epistemological value to aesthetic testimony on the general grounds that nothing can be learned from it. These arguments represent iterations of what is referred to in the literature as the asymmetry thesis – the contention that aesthetic testimony is epistemologically inferior to its non-aesthetic counterpart. Arguably the most robust slight against the epistemological credence of aesthetic testimony is ventured by those, such as Frank Sibley[46] and Alan Tormey[47] who hold that there is no such thing as aesthetic knowledge, thereby rendering anomalous the very idea of the generation or transmission of knowledge through aesthetic testimony. Related arguments amount to either a denial of the truth-aptness of aesthetic claims, or to an applied subscription to John Leslie Mackie's error theory, culminating in the contention that all aesthetic claims are necessarily false.[48] Others still fall short of denying the existence of ›aesthetic truth‹ but do deny that such truths can be known. In the course of these philosophical debates, the epistemological status of aesthetic testimony has been targeted on the grounds that aesthetic judgments are broadly perceptual, subjectively evaluative, or effective or attitudinal. Those few theorists, such as Brian Laertz,[49] Rachel McKinnon,[50] and Jon Robson,[51] whose interrogations of aesthetic testimony demonstrate a semblance of optimism, have suggested either that these misgivings do not represent grounds for a wholesale dismissal of aesthetic testimony as a source of knowledge or belief, or that as these characteristics are also regularly properties of non-aesthetic claims or concerns, their influence does not render aesthetic testimony uniquely problematic. Even these more optimistic theorists, however, tend to identify a unique set of challenges related to arrival at aesthetic understanding via testimonial means, their arguments often resting on resting on the reduction of complex epistemological questions to a series of purely semantic distinctions between the profound epistemological entities

42 Cf. Immanuel Kant: Critique of Judgment, trans. James Creed Meredith, Oxford 1998.
43 Cf. Frank Sibley: Aesthetic/Nonaesthetic, in: Philosophical Review 74 (1965), pp. 135–159.
44 Cf. Mary Mothersill: Beauty Restored, Oxford 1984.
45 Cf. Richard Wollheim: Art and Its Objects, 2nd ed, Cambridge 1980.
46 Cf. Sibley; Aesthetic/Nonaesthetic.
47 Cf. Tormey: Critical Judgments.
48 Cf. John Leslie Mackie: Ethics: Inventing Right and Wrong, Harmondsworth 1977.
49 Cf. Laertz: A Modest Defence.
50 Cf. Rachel McKinnon: How to be an Optimist about Aesthetic Testimony, in: Episteme 1:2 (2016), pp. 1–20.
51 Cf. Jon Robson: Aesthetic Testimony: An Optimistic Approach, Oxford 2022.

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of knowledge and belief, while also remaining embedded in quite a severely delimited set of circumstances within which transmissions of aesthetic judgment may secure a degree of epistemic purchase. As a fully-sighted Brian Friel devotee with a background in critical disability studies, I realise that Molly is spot-on when she suggests that it is beyond even her remarkable powers of description to do justice to richness of her aesthetic sensibility through words or to render through that medium the precise nature of her aesthetic experience available to me. As someone who is now very familiar with the play, however, I feel richer and even more knowledgeable, for the fact that she nevertheless endeavoured to communicate it.

The cost of aesthetic testimony scepticism within a gallery access context

The majority of existing audio description guidelines recommend a ›neutral‹ or ›objective‹ approach (ADC 2008; AENOR 2005; Salzhauer Axel, Hooper, et al. 2003; Snyder 2010).[52] Not only does the vehemence with which this specification is tirelessly commanded belie the thrust of a rich history of philosophical accounts of the nature of aesthetic experience, it remains at perplexing variance with the more elemental dimensionalities of practical viability and the avowed preferences of many gallery visitors with visual impairment. The first two stipulations outlined in the Audio Description Coalition's ›Standards for Audio Description‹ (third edition, 2009), for example, are ›Describe What You See‹ and ›Describe Objectively‹. The former stipulation, qualified by the directive »what you see is what you describe« is presented as »the first rule of description«.[53] One should never, access facil-

52 ADC (Audio Description Coalition): Standards for audio description and code of professional conduct for describers (2009) available at: www.perkins.org/wp-content/uploads/elearning-media/adc_standards.pdf (25.10.2024; AENOR: Norma Española UNE 153020: Audiodescripción para personas con discapacidad visual. Requisitos para la audiodescripción y elaboración de audioguías (2005). Available at www.en-standard.eu/une-153020-2005-audio-description-for-visually-impaired-people-guidelines-for-audio-description-procedures-and-for-the-preparation-of-audio-guides/?srsltid=AfmBOorbLJmB_8AiGqQ1nOz48pNYIgzdGQDNaNfRmRU4X2tBWLf-yIIh (29.12.2024); Elizabeth Axel Salzhauer/Virginia Hooper/Teresa Kardoulias: AEB's guidelines for verbal description, in: Salzhauer, Elizabeth Axel/Levent, Nina Sobol (eds.): Art Beyond Sight: A Resource Guide to Art, Creativity, and Visual Impairment. New York 2003, pp. 229–237; Joel Snyder (ed.): Audio Description Guidelines and Best Practices Version 3.1. American Council for the Blind Audio Description Project, 2010. adp.acb.org/docs/AD-ACB-ADP%20Guidelines%203.1.doc (27.10.2024).

53 ADC: Standards, p. 1.

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itators are cautioned, describe »what you think you see«. We do not see emotion, so we should concern ourselves only with descriptive accounts of the physical manifestation of emotion, rather than incorporating the naming of emotions within our access provision endeavours. To inform a listener that a character seems angry, for example, constitutes a reprehensible transgression. Joel Snyder takes this stipulation to an extreme by prohibiting the relaying of the information that a character is dead, on the grounds that doing so amounts to the casting of aspersions about the cognitive faculties of an individual with visual impairment.[54] Amidst this expansive array of prescriptive disallowances relating to when describers should not to say what they should not say, Snyder, without betraying the remotest recognition of the irony inherent in doing so, then proceeds to instruct the describer not to employ censorship.[55]

As part of the justification volunteered to support this objectivity decree, we are instructed to concentrate on that which is the most significant and to prioritise what is deemed to be ›essential‹[56]. The commanded cull of all things subjective and, by extension, superfluous, seems ordained by an objectivity fetish premised on convictions pertaining to a conception of experiential redundancy that seems decidedly unencumbered by any form of informed concern for the nature of aesthetic experience or art engagement. The ideal of descriptive impartiality should be further advanced, according to the ADC guidelines, by refraining from any form of interpretive activity when facilitating engagement with the artwork being described. »The best audio describers«, Snyder informs access practitioners, »objectively recount the visual aspects of an image«. »Subjective or qualitative judgments or comment«, he continues, »get in the way – they constitute an interpretation on the part of the describer and are unnecessary and unwanted«.[57] The imperious positing of this objectivity fixation remains at distinct odds with what I have personally been led by gallery visitors with visual impairment to believe about their access and aesthetic preferences, and, more significantly, with the findings of research conducted by the Royal National Institute for the Blind (RNIB) and VocalEyes, which suggest that more subjective descriptions are deemed by sig-

54 Snyder, Visual Made Verbal, p. 43.
55 Ibid., pp. 42–43.
56 Ibid., pp. 33–34.
57 ADC: Standards, p. 9.

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nificant sections of the population of gallery visitors with visual impairment to be conducive to a more meaningful and engaging gallery experience.[58]

Soler Gallego (2019) and María Colmenero (2024)[59] share my concern for the tendency of existing audio description guidelines to »recommend describing only that which is seen«, as a means of avoiding »subjective interpretations of the visual message«.[60] As part of her persuasive rejoinder to this prevalent stipulation, Soler Gallego's research evidences the preference for subjective description amongst many gallery visitors with visual impairment. The nature of art and art access, she contends, renders the incorporation of subjectivity within descriptions of selected artworks an inevitability. Rather than lamenting this fact, Soler Gallego's consultation with gallery visitors suggests that such subjectivity is the cornerstone of meaningful aesthetic experience within an art access context. Her empirical review of audio description guidelines in museums in France, Spain, UK and USA yielded the finding that the withholding of subjective elements from descriptions of artworks depletes aesthetic experience. The degree of this depletion was found to be directly correlated with the rigidity with which describers comply with audio description guidelines as they relate to the subjectivity/objectivity interface.

The ideal of objectivity upon which art access guidance tends to be premised seems as philosophically misguided and ill-informed as it is practically untenable. Consultation with an abundant history of insights into the nature of the objectivity-subjectivity interface within the domain of aesthetic experience might have prompted those who feel compelled to regulate the acceptable terms of art access provision to temper the categorical complexion of this directive or to at least soften the absolute terms in which it is so obstinately repeated throughout most available guidance on the issue. It would appear that the prohibition of all reference to emotion, interpretation or appraisal from endeavours to convey what Ralph Smith (1989)[61] has described as a ›sense of art‹ is stipulated on the grounds that the volunteering of such insights serves an editorial, analytical, elucidatory or explanatory function

58 RNIB and VocalEyes: Talking images guide. Museums, galleries and heritage site: Improving access for blind and partially sighted people, 2003, pp. 47–52. www.thetalkingwalls.co.uk/PDF/public_talkingimagesguide.pdf (25.11.2024).

59 María Olalla Luque Colmenero: Subjectivity and Creativity Versus Audio Description Guidelines, in: Marcus-Quinn, Ann/Krejtz, Krzysztof/Duarte, Carlos (eds.): Transforming Media Accessibility in Europe, Cham, 2024, pp. 39–52.

60 Soler Gallego: Defining Subjectivity, p. 708.

61 Ralph A. Smith: The Sense of Art: A Study in Aesthetic Education, New York and London 1989.

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that is deemed alternately as being be either ultimately unhelpful or all too helpful for the recipient.[62] The more salient of the misconceptions in which such guidance seems to be embedded arguably relate to the nature of the relationship between sensation and language and the nature of aesthetic agency. The first of these misconceptions might be accounted for in terms of conceptions of the nature of description in a museum or gallery context as a form of intersemiotic and multimodal translation.[63] If prescriptive guidelines are deemed necessary for the acceptable facilitation of such translation, those who undertake the formulation of these guidelines need to factor into their consequential reckonings the nature of the relationship between an irreducibly non-verbal source and the verbal output that is at the core of such cross-modal mediation. There is scant evidence in any of the existing guidelines that these intersemiotic and multi-modal features of verbal approaches to art access have been considered.

Although nothing more persuasively versed in these matters than meagerly supported dogmatic stricture is forthcoming in any of the existing guidelines, the implicit assumption would appear to be that avoidance of subjectivity on the part of the generator of the description bestows agency to its recipient, whose own inferential faculties are thereby compelled to intervene in order to decipher the aesthetic significance of the evocative narrative sketch of which they have taken delivery. The grasp of the phenomenon of aesthetic agency (Gorodeisky 2022, McIver Lopes 2018, Dammann & Schellekens 2021)[64] informing the unequivocal attribution of passivity to the reception of a subjective account of an artwork would appear to be rather slack. The conception of aesthetic agency underpinning Snyder's direction, for example, seems premised on an underestimation of the significance of the exercise of the type of discernment required to distinguish aesthetic from non-aesthetic and intrinsic from secondary qualities of an artwork. His regulatory principles also seem premised on an underestimation of the capacities and appetites of self-selecting gallery visitors for discerning forms of aesthetic engagement with descriptors. Only »adjectives and adverbs that do not offer value judgments«, according to Snyder, should feature in the verbal mediation of a visual

62 ADC: Standards, p. 3.

63 Soler Gallego: Defining Subjectivity, p. 727.

64 Keren Gorodeisky: Aesthetic agency, in: Ferrero, Luca (ed.): The Routledge Handbook of the Philosophy of Agency, Abington, Oxon 2022, pp. 456–466; Guy Dammann/Elisabeth Schellekens: Aesthetic understanding and epistemic agency in art, in: Disputatio 13:62 (2021), pp. 265–282.

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artwork.[65] The subsequent qualification that these selected parts of speech should »not themselves be subject to interpretation«[66] raises questions about the very existence of terminology that meets these exacting and seemingly spurious criteria. It is entirely conceivable that persuasive arguments might be developed in order to refute the suggestion that failure to incorporate subjective elements within art access facilitation represents a compromising of aesthetic value. For all of the fervor with which this contention is reversed within existing verbal description guidance, however, no compelling rationale for the reversal is anywhere advanced.

Furthermore, unless we are inclined to broadly dismiss what centuries of aesthetic theorists have suggested about the impossibly involved interplay between objectivity and subjectivity and language and sensation within aesthetic experience, the recommended reduction of art engagement to a deductive and propositionally articulated approach to the mediation of elements of the substance or value of artistic expression seems problematic. To insist on objectivity in the mediation of aesthetic value is to ride slipshod over a richly generative history of philosophical debate. Modern contributions to these protracted deliberations by such figures as Nelson Goodman (1968), Munroe Beardsley (1970), George Dickie (1964) and Frank Sibley (1968)[67] can be traced as far back as to ninth century reflections of John Scotus Eriugena and ultimately to Aristotle,[68] via the seminal ruminations of Edward Bullough (1912), George Santayana (1896), Frances Hutcheson (1726), Immanuel Kant (1789), and others.[69] Insistence that the formulation of a sense of art should only be attempted once the artwork being described has been purged of any semblance of subjectivity amounts to an ascetic form of aesthetic absti-

65 ADC: Standards, p. 2.

66 Ibid.

67 Nelson Goodman: Languages of Art, New York 1968; Munroe C. Beardsley: The Aesthetic Point of View, in: Kiefer, Howard/Munitz, Milton (eds.): Perspectives in Education, Religion, and the Arts, Albany, 1970, pp. 219–237; George Dickie: The Myth of the Aesthetic Attitude, in: American Philosophical Quarterly 1:1 (1964), pp. 56–65; Frank Sibley: Objectivity and Aesthetics, in: Benson, John/Redfern, Betty/Roxbee Cox, Jeremy (eds.), Approach to Aesthetics: Collected Papers on Philosophical Aesthetics, Oxford, 2001, pp. 71–87.

68 Johannes Scotus Erigena: De divisione naturae, trans J.J. O'Meara and I.P. Sheldon Williams, Scriptores Latini Hiberniae, vol 13, Dublin 1995; Aristotle, Poetics, Ingram Bywater (trans.), Oxford, 1920; reprinted in Cahn and Meskin (eds.) 2007, pp. 41–56.

69 Edward Bullough: ›Psychical distance‹ as a factor in art and an aesthetic principle, in: British Journal of Psychology 5 (1912), pp. 87–117; George Santayana: The Sense of Beauty, New York 1896; Frances Hutcheson: An Inquiry into the Original of Our Ideas of Beauty and Virtue, W. Leidhold (ed.), Indianapolis 1726 (2004); Immanuel Kant: Critique of Judgment, trans. James Creed Meredith, Oxford 1998.

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nence which, in turn, seems a rather unlikely communicative, interpretive or phenomenological basis for the (co-)construction of aesthetic value. Existing verbal description regulations, this is all to say, seem formulated to engender a surfeit of unnecessary penitence among those docents who instinctively align the focus of their descriptions with the spirit of what has been historically deemed to be an irreducibly subjective medium. That an apparent indifference to aesthetic theory renders the oxymoronic resonance of the hypothesis of an impartial aesthetic indiscernible to the generators of art access guidelines seems a dubious pretext for the unnecessary impoverishing of the richness of aesthetic experience that gallery visits are capable of yielding.

Guidelines for the generation of verbal descriptions have in this way historically emphasised the importance of refraining from the incorporation of any semblance of subjectivity within descriptions of artworks. Although a detailed rationale for this aversion has not been forthcoming, it would appear that the fixation on objectivity harboured by those who assume responsibility for the regulation of art access may be accounted for in terms of a combination of an intuitive, if unknowing adoption of aesthetic testimony scepticism, an unwarranted suspicion that gallery docents might for their own reasons have designs on the aesthetic inclinations, preferences and predilections of individuals with visual impairment, and a vague and misplaced instinct of protectiveness towards these visitors. Verbal description has become big business. Prohibitively expensive international workshops are facilitated on the cultivation of the capacity for objective description, promoted on the premise that anybody who does not facilitate access according to the objectivity imperative is doing it wrong by compromising the sanctity of a form of art engagement from which the self has somehow been extracted.[70] Josh Miele, a blind San Francisco-based scientist who has set up a freely accessible online audio-description platform as a means of democratising the domain of art access – thereby threatening the profit-making potential of the afore-mentioned initiatives – is included among the perpetrators of crimes against objectivity who get art access wrong by not prohibiting the incorporation of subjectivity within verbal descriptions.[71]

Although Joel Snyder's approach to verbal description – outlined with a certain authority in his treatise/training manual *The Visual Made Verbal* (2014) demonstrates an alignment with the various forms of aesthetic testimo-

70 Cf. Joel Snyder: The Visual Made Verbal, Arlington, VA 2014.

71 Cf. Georgina Kleege: More than Meets the Eye: What Blindness Brings to Art, New York 2018, p. 107.

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ny pessimism that recur through the philosophical literature, there is scant indication that he has familiarised himself with any of these abundant critical sources. Similarly, his insistence on the strict maintenance of objectivity when describing art for those who cannot see it very well demonstrates an apparent disregard for a rich history of philosophical rumination on the complex interplay between objectivity and subjectivity in the generation of aesthetic meaning. Snyder's antipathy towards the transmission of insights relating to the perceived aesthetic qualities of the artworks being described would appear to reflect a wider cultural affinity with one side of the aesthetic testimony debate. Malcolm Budd, for example, suggests that the paucity of existing philosophical justifications of the acquaintance principle belies how deeply entrenched it has traditionally been within and outside the rarefied domain of formal philosophical investigation.[72] There appears to be a prevailing innate scepticism towards aesthetic testimony, an intuitive disclination to afford to it the degree of trust that we more readily invest in examples of its non-aesthetic counterpart. Or, as Brian Laertz expresses it, the perceived inferiority of aesthetic testimony »seems to be a fixture of the folk theory of rationality, which underlies our doxastic practices«.[73] I would suggest that the widely corroborated common-sense diktat of aesthetic testimony pessimism also underlies traditional approaches to the regulation of art access initiatives for gallery visitors with visual impairment in a way that has an impoverishing effect on the depth, vigour and liveliness of the experiences such undertakings are capable of affording. Rather than subscribing to the historically accepted truism that, to use Laertz's expression, aesthetic reports are ›epistemologically handicapped‹,[74] the argument presented here is that the historically widespread inclination to give subjectivity a wide berth when facilitating art access actually adds yet another layer to the already multi-dimensional forms of disablement to which individuals with visual impairment are subjected when they endeavour to indulge their innate interest in art.

From experience, I would suggest that a standpoint of determined aesthetic ambivalence serves poorly as a starting point for discussion or experiential exchange within a museum or gallery access context. Alleviating such ambivalence by means of volunteering subjective opinions about the aesthetic merits or demerits of a particular painting can seem both an act of enlivening mercy

72 Cf. Malcom Budd: The Acquaintance Principle, in: British Journal of Aesthetics 43 (2003), pp. 386–392.
73 Laertz: A Modest Defence, p. 361.
74 Ibid., p. 355.

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towards an art access session that might otherwise die on its feet, and a useful portal through which participants with visual impairment can reflect on distinctive features of their own forms of aesthetic engagement with the exhibited artefacts. Thankfully, more recent scholarship in this area has challenged the feasibility, efficacy, and appropriateness of the strict maintenance of aesthetic objectivity within the art access domain. For one thing, the practical impossibility of observing the stipulation that describers be completely objective is undermined by the inevitable fact that in order to avoid generating descriptions of a length that render sustained attention challenging, these professionals have to select what they describe, and differences between components prioritised by different describers inevitably emerge. Similarly, as Floriane Bardini points out, differences in compositional styles are also likely to manifest a degree of inter-describer subjectivity.[75] Contemporary scholars have also begun to appreciate the extent to which the practice of purging all interpretive elements from description may prove counter-productive by precluding the vital element of imaginative or experiential connotation.[76] International divergences of convention in this regard have begun to emerge, as illustrated by Mazur and Schmiel's comparative review of the art access practices that prevail in the US and Europe.[77] European guidelines for audio description are increasingly inclined towards the conclusion that the historically practiced fetishization of objectivity can be both counter-productive and radically misaligned with the unapologetically subjective elements of creative expression.[78]

Although many of the most widely applied description guidelines continue to recommend describing only that which is seen as a means of avoiding

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75 Floriane Bardini: Audiovisual Translation for the Blind and Partially Sighted: Audio description, an indispensable access mode. Conference presentation: International Research-to-Practice Conference and Summer School of Audiovisual Translation 2016. www.researchgate.net/publication/323907256_Audiovisual_Translation_for_the_Blind_and_Partially_Sighted_Audio_description_an_indispensable_access_mode (25.10.2023).

76 Cf. e.g. Pilar Orero: Audio Description Behaviour: Universals, Regularities and Guidelines, in: International Journal of Humanities and Social Science 2 (2012), pp. 195–202; Floriane Bardini: Audio Description of Cinematic Language: A Comparative Study of Describers' Approaches. Conference presentation: Advanced Research Seminar on Audio Description 2013. www.researchgate.net/publication/301748125_Audio_Description_of_Cinematic_Language_A_Comparative_Study_of_Describers'_Approaches (25.10.2023).

77 Iwona Mazur/Agnieszka Schmiel: Towards Common European Audio Description Guidelines: Results of the Pear Tree Project, in: Perspectives 20:1 (2012), pp. 5–23.

78 Cf. Aline Remael/Nina Reviers/Gert Vercauteren: Pictures Painted in Words: ADLAB Audio Description Guidelines (2015). repository.uantwerpen.be/docman/irua/99e3cf/130865.pdf (3.8.2024); Louise Fryer: An Introduction to Audio Description, London 2016.

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subjective interpretations, evidence, such as that provided by Soler Gallego increasingly suggests that many people with visual impairments prefer more subjective descriptions.[79] Although Joel Snyder's forcibly volunteered recommendations demonstrate what might be argued to be a healthy and sensible disregard for philosophical hypotheses, as a fully sighted individual, he does claim to have consulted with individuals with visual impairment when formulating his guidelines. I can only say that my undertaking of such consultation has consistently yielded conflicting feedback. As part of their reflections on patterns of difference and similarity between the ways in which they receive aesthetic and non-aesthetic testimony within a gallery environment, these visitors told me that they enjoy receiving subjective insights from a describer, on the condition that these insights are not volunteered as matters of incontestable fact.[80] This finding chimes with those generated by research conducted by Orero, Bardini and Soler Gallego[81] which suggest that a total lack of subjective interpretation may actually impoverish the engagement of individuals with visual impairment in the artworks explored within gallery access sessions.

In her study of blindness and the visual arts, Georgina Kleege relays an anecdote that encapsulates the core of the argument presented here – that the fixation on objectivity within the development of guidelines for verbal description is representative of a wider tendency towards the unnecessary and counter-productive withholding of vital elements of aesthetic experience in the name of access.[82] Kleege describes her attendance of an accessible screening of Ben Lewin's film *The Sessions*, facilitated as part of a disabled student-led disability awareness initiative at Berkeley. During the screening, the captions and audio-description were turned on for the entire audience. The film is based on the autobiography of Mark O'Brian, a poet and journalist who became dependent on the artificial respiration administered by an iron lung after an accident in childhood left him paralyzed from the neck down. One of the scenes of the film involves Mark embarking on a shopping trip with one of his assistants in search of some new shirts. One of the garments selected was

79 Cf. Silvia Soler Gallego: Defining Subjectivity in Visual Art Audio Description, in: Meta 64:3 (2019), pp. 708–733.

80 Cf. David Feeney: A Modest Defence of Disability Simulation within an Arts Access Context, in: MuseumEdu: Education and Research in Cultural Environments 5 (2017), pp. 83–106.

81 Cf. Orero: Audio Description; Bardini: Audio Description; Soler Gallego: Defining Subjectivity.

82 Cf. Kleege: More than Meets the Eye.

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audio described as being »a dark paisley button up«. A student within earshot of Kleege took the initiative of supplementing the description provided with the hollered avowal »and it's really ugly«. The experience prompted Kleege to reflect on how this instance of faithful compliance with the established guidelines for effective audio description lead to an impoverishment of aesthetic engagement. In a later scene, Kleege tells us, Mark's newly acquired item of clothing is commented on by Cheryl, a sexual surrogate employed by Mark as part of his endeavour to lose his virginity at the age of thirty-eight. »Is it racy and sophisticated?«, Mark asks – to which Cheryl responds: »you took the words right out of my mouth«. At this point, Kleege notes, the relevance of the shirt-purchasing scene becomes clear. His feelings for Cheryl have prompted Mark to allow his resolve to make a striking impression to get the better of his customarily understated or under-developed sense of sartorial taste to hilarious effect. The »failure of the describer to make an aesthetic judgment about the paisley shirt,« Kleege observes, »made it hard to assess the characters' banter about it«.[83] Kleege's account of the failure of forms of access provision that are predicated on a slavish compliance with the maxim that facilitators should steer a wide berth of any avowals that bear a semblance of subjectivity or evaluation illustrate the wrong-headedness of regulating art access at a remove from informed reflection on the nature of artistic expression.

The dubious rationale underpinning verbal description guidelines

Among the most notable features of the verbal description guidelines in common usage is the dearth of sustained or critically informed rationalisation of normative directives relating to the verbal mediation of the impression generated by visual artefacts. In the absence of any discernible attempt to justify the recommended terms of art access provision, what appears to connect these guidelines with the misgivings about the epistemological credence of aesthetic testimony outlined above is the sense that both entities seem to be grounded in suspicion. In the case of verbal description guidelines, this suspicion would appear to manifest primarily in two ways: 1) A suspicion that a gallery docent might, for some reason, be inclined to dupe gallery visitors with visual impairments into some form of sightist aesthetic ideology; and 2) An unfounded conviction that these gallery visitors (most of whom are

83 Ibid., pp. 99–103.

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self-selecting and have an interest in art) are aesthetically inept in the sense of being incapable of receiving information about art in a suitably discerning fashion or exercising judgement in a manner that demonstrates an appreciation of the contingent nature of aesthetic value and its verbal transmission. In what remains of this article, I will endeavour to outline why elements of the forms of aesthetic impoverishment that contemporary theorists have begun to attribute to certain elements of institutionalised art access guidelines can be traced back to the ›bad faith‹ on which these guidelines appear to be predicated, while also indicating why the regulatory demarcation of art engagement as a hermeneutic-free zone seems predicated on a misguided conception of aesthetic experience.

Another notable feature of art access guidelines is a lack of specificity about their intended function. It is not clarified with any degree of precision, for example, either in Joel Snyder's audio description training manual,[84] nor in many of the extant institutional verbal description guidelines, whether the experiences afforded by compliance with these recommendations are intended to be formally educational, primarily sociological, aesthetic, or to serve a combination of these or other ends. Openness in relation to this issue is not necessarily regrettable. Whatever particular objectives are anticipated when verbal description training is delivered, one assumes that art access is facilitated with some form of aesthetic or experiential enrichment in mind, the realisation of which one would expect to be informed by a resolve to operationalise certain conditions for knowing and appreciating artworks as art. The wilful extraction of any semblance of subjectivity seems an unlikely condition of the realisation of a capacity for art appreciation, yet that is precisely the core edict upon which verbal description guidelines tend to be predicated. In place of sustained reflection on the modes of perception and forms of understanding entailed in art appreciation, those who devise and canvass verbal description guidelines offer little apart from the repetition of the brute sermonic mantra that describers should ›say what they see‹, accompanied, on occasion, by the supplementary directive that the describer should be the eyes, rather than the brain, of a gallery visitor with visual impairment. In this way, the architects of these guidelines behave as though they had somehow settled centuries of aesthetic debate without giving any indication that they have familiarised themselves with the sources of contention underpinning these complex deliberations. It seems likely, if not quite inconceivable, that this apparent lack of

84 Cf. Snyder: The Visual Made Verbal.

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concern for the nature of aesthetic experience is unrelated to the aesthetic impoverishment identified by several contemporary critiques of institutional approaches to verbal description.

It would be admittedly difficult to mount a credible defence of gallery docents who conceive of their purview as incorporating responsibility for the emancipation of the gallery visitor from ignorance while ushering them into a state of cultural erudition through the cultivation of good taste while also applying correctives to the artwork's obliviousness to its own meaning. In the absence of a volunteering of any credible form of justificatory rationale, it remains unclear whether a perceived alignment between the figure of the gallery docent and these critical portraits of the cultural analyst might constitute the precise foundation of the suspicion that has prompted the formulators of verbal description guidelines to supress interpretive discourse. My experience of working in the domain of art access suggests that the positing of such a performative coupling is extremely tenuous, and that gallery docents do not approach their roles in the grip of any preformulated designs on the aesthetic predilections of visitors with visual impairment. I have been repeatedly told by gallery visitors with visual impairments that art access sessions become most animated and engaging when differing opinions about the quality and significance of particular artworks are aired in ways that directly contravene verbal description guidelines.

The depletory impact of the objectivity imperative on approaches to art access

There is definitely something to be said for the maintenance of an objective approach to verbal description. The trouble, or at least part of the trouble, with the canvassing of such an approach by Joel Snyder and others is that they do not say it – or at least do not do so in a manner that is particularly persuasive.[85] Although Snyder's treatise on the issue is peppered with an obligatory array of isolated quotations from such celebrated thinkers as Ruskin, Goethe and Valery, there is little evidence that his a-contextual incorporation of a sporadic array of aphorised insights represents more than a superficial treatment of a long-debated and potentially vital issue. The proposition of objective modes of engagement and appraisal has certainly received a sufficient degree of critical attention since the introduction of aesthetics as a formal philosophical discipline in the eighteenth century to inform a compelling argument

85 Cf. ibid.

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for a considered rationing of subjective insight within art access provision. But the directive that we predicate access provision on a largely unjustified belief, however much that belief might happen to lend itself to potential rationalisation, seems less than entirely reasonable or satisfactory.

The most direct challenge to the logic and feasibility of the ›objectivity imperative‹ relates to the obvious impracticality of deciding, in the first instance, which artworks to describe if a wide berth of subjectivity is to be vigilantly steered. Related responsibilities, such as discerning which components of a selected artwork to emphasise within description, or formulating accounts of the nature of the impression generated by the internal relationships pertaining between selected components, seem equally dependent on subjective insight. Even the most rudimentary of trawls through the history of aesthetic theory reveals an assortment of subsidiary forms of aesthetic impoverishment generated by the imposition of strictly objective descriptive parameters. These poorly conceived and largely unjustified prohibitive stipulations obstruct several channels of potential aesthetic exploration and collective discovery that would otherwise be a valuable characteristic of encounters between people with differing sensory configurations within art access ventures. In this way, the prohibition of subjectivity effectively disqualifies the differential iterations of aesthetic experience the promotion of which art access initiatives are presumably designed to facilitate. In their apparent resolve to prevent the inequitable imposition of sighted criteria on the engagement of individuals with visual impairment with works of visual art, the guidelines serve to preclude the emergence of distinctive features of a differential aesthetic by disbarring aesthetically oriented forms of discursive and experiential exchange. In this way, dogged insistence that access facilitation is strictly beholden to an objectivity mandate serves primarily to render innately relative features of aesthetic value a closed book rather than a portal of reciprocal aesthetic discovery.

The aesthetic detriment caused by the purposeful elimination of subjectivity from aesthetic engagement within an art access context extends to the removal of the encounter between the aesthetic sensibilities of fully-sighted gallery docent and visitor with visual impairment from opportunities for forms of inter-cultural transfer that may otherwise be ideally primed for the cultivation of creativity. Citing Gertrude Stein's professed belief that creative writers need to reside in two countries, for example, Angela Ka-yee Leung and colleagues suggest that increased exposure to multi-cultural experience is positively related to such features of creative performance as the generation of insights and ideas and the capacity to conceive of remote associations

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that would be otherwise unlikely to occur.[86] Inter-cultural exposure was also found by these researchers to be positively related to the development of a tolerance for and capacity to assimilate unconventional forms of knowledge while expanding on creative ideas. Within the same study, the cultivation of these creative attributes was found to be contingent on an openness to foreign cultures found to prompt an imaginatively productive relaxation of instinctive determination to conclusively resolve existential concerns.

The conception of inter-cultural transfer underpinning the reflections presented here is informed by the work of a number of contemporary theorists. Laura Marks' (2008) appeal to the importance of factoring sense experience into elected modes of cultural analysis is a formative influence in this regard. If the notion of ›sensory culture‹ is entertained in alignment with Marks' compelling demarcation of that domain, and conceived as a decisive component of a differential aesthetic (Florence & Foster 2000),[87] the role of audio description as a portal of intercultural transfer becomes evident. According to Marks, the innate »affective dimension« of sensory experience serves as both the foundation of an »immanent epistemology« and as a vehicle for pluralistic conceptions and manifestations of beauty.[88] The account of cultural mediation volunteered by Mörsch and Chrusciel (n.d.)[89] and James Winchester's (2000, 2002)[90] reflections on the transmission of aesthetic value across cultural divisions also seem pertinent here. The former account presents a phenomenon which entails people receiving information about the arts, entering into an exchange about that information and reacting to it in ways that affirm, rather than problematize, difference. My personal experiences of access facilitation suggest that bilateral exploration of diverse partialities and

86 Cf. Angela Ka-Yee Leung/William W. Maddux, Adam D. Galinsky/Chi-yue Chiu: Multicultural Experience Enhances Creativity: The When and How, in: American Psychologist 63:3 (2008), pp. 169–181.

87 Penny Florence and Nicola Foster, eds.: Differential Aesthetics: Art Practices, Philosophy & Feminist Understandings. Aldershot, 2000.

88 Laura Marks: Thinking multisensory culture, in: Paragraph 31 (2) (2008), pp. 123–137, here p. 123.

89 Carmen Mörsch/Anna Chrusciel (eds.; for Pro Helvetia). Time for Cultural Mediation. Zurich: Institute for Art Education, Zurich University of the Arts (n.d.). Available at www.kultur-vermittlung.ch/zeit-fuer-vermittlung/download/pdf-e/TfCM_1.pdf (25.10.2024).

90 James J. Winchester: Understanding Aesthetic Judgments Across Cultural Borders: Bell Hooks, Kant, and Cornel West and the Understanding of Aesthetic Judgments of Others, in: The Southern Journal of Philosophy, Vol. XXXVIII (2000), pp. 499–525; James J. Winchester: Aesthetics Across the Color Line: Why Nietzsche (Sometimes) Can't Sing the Blues, Oxford, 2002.

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predilections represent the precise juncture at which art access sessions come to life. To prohibit such exploration in the name of objectivity is to impoverish the richness and depth of the aesthetic experiences that gallery visits are capable of affording.

Winchester (2000, 2002) contends that aesthetic understanding across cultural divides requires unrelenting and sensitive attentiveness to features of the worlds and experiences from which distinctive sensibilities emerge. If heeded within the context of Marks' plea, Winchester's insight, in its apparent alignment with the optimistic side of the aesthetic testimony debate, prompts us to question the wisdom of considering cultural situatedness without also contemplating sensory situatedness. The differences that are likely to emerge between the aesthetic preferences of individuals with visual impairment and their fully sighted counterparts should not, as Winchester expresses it, be posited as an excuse for a lack of communication.[91] Rather, were the fully sighted describer to share his/her experience of an artwork with a gallery visitor with visual impairment as sincerely and as entirely as possible, and then listen with all of the keenness, greenness and alertness of an apprentice when his/her counterpart reciprocates, the type of experiential impasse that verbal description guidelines seem designed to engender might be rewardingly negotiated to the considerable aesthetic benefit of both parties. The determined impressing on blind people of the irrelevance of the aesthetic predilections and partialities of their sighted counterparts seems an unlikely basis for the generation of the type of cross-cultural transaction advocated by Winchester. Such an approach seems embedded in scepticism, concerned with a needlessly depleted form of human interaction, and motivated by an unwarranted conviction that the fully sighted docent will somehow harbour wilful designs on the aesthetic predilections of gallery visitors with visual impairment. In addition to being predicated on a dubious conception of the nature of aesthetic experience, the deliberate purging of subjectivity from aesthetic encounters between fully and partially sighted participants in art access initiatives depletes opportunity for such collective inter-cultural fostering of creative approaches to the negotiation of any evaluative impasse that might be generated in the course of the collective engagement of individuals with differing sensory configurations in exhibited artworks. While fully-sighted access facilitators clearly need to remain vigilantly mindful of the aesthetic jeopardy that might be occasioned by the wilful imposition of exclusively visual crite-

91 Winchester: Aesthetics Across the Color Line, p. 9.

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ria,[92] operating on the assumption that aesthetic experience is an exclusively objective phenomenon seems an unlikely and inevitably counter-productive means of circumventing such ableist forms of aesthetic imperialism within an art access context.

The casualties of aesthetic experience generated by these guidelines are too extensive to be enumerated here. An indicative shortlist of ten issues whose pursuit might help to delineate the scope of the impoverishing impact of the prohibition of subjectivity from art access initiatives is presented below. As the objective here is to re-open the portals of inquiry that the objectivity imperative would appear to firmly close, these issues are formulated as open-ended questions rather than categorical indictments:

1) In what way is compulsion to proceed with verbal description as though artworks are bereft of such vital qualities as mood, attitude or tone, and to refrain from rendering the manifestation of these qualities discernible, compatible with mediation of a sense of art?
2) How is the mandated omission of insights into how a particular features of an artwork might lend themselves to appraisal reconcilable with the emergence of interactively generated insights into differential aesthetics?
3) In the absence of discursive facilitation of such forms of experiential exchange, how might we advance understanding about whether discrepancies in modes or quirks of aesthetic reception are primarily critical, affective, objective, etc in nature?
4) On what grounds are matters of aesthetic preference deemed to be irrelevant to art engagement?
5) How might one refute the claim that imposing a blanket veto on subjectivity precludes equitable exploration of dependent, emergent and tertiary qualities of artworks and mutually rewarding discussion of whether differences in perceived aesthetic value might be attributable to the artwork and/or the beholder?
6) When artworks are reduced to the status of quotidian objects purposively bereft of impression, how might enlivening insights emerge into distinctive features of the ways in which artworks are perceived and responded to by people with and without visual impairment?
7) In instances where the primary thematic content of a work stems from a congruence or incongruence of subject and design or form and content,

92 Cf. Feeney: A Modest Defence.

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how is this to be relayed when description is volunteered in the grip of a studied absence of subjectively evaluative insight?

8) If, as is widely believed to be the case, the aesthetic unity underpinning the impressions that paintings register on the understanding of their beholders entails more than the sum of the constituent elements of these paintings, how can the impact of painting be captured or communicated through a sequence of objective descriptive accounts of these components in isolation from one another?
9) How might a semblance of creativity be salvaged within art engagement processes if description is confined to the relaying of objectively verifiable information?
10) If subjectivity is outlawed within the domain of art access, how are fully sighted docents expected to learn from the experiences and preferences of gallery visitors with visual impairment?

Beauty on Trust

Informed reflection on the nature of the aesthetic experiences afforded by art engagement does not constitute the only reason to harbour misgivings about the repeated decree that subjectivity is to be stringently avoided when describing works of visual art for people with visual impairment. The relational nature of access provision constitutes equally compelling grounds for scepticism in relation to the logic and feasibility of this command. Contemplating verbal description in terms of the credibility of aesthetic testimony raises the issue of trust or ›good faith‹ as it pertains to the relationship that develops between the describer and the gallery visitor in art access scenarios. While this is clearly not the place to embark on an expansive exegesis on the richly researched phenomenon of trust, it is worth noting that many of the existing approaches to this concept emphasise both its interplay with risk perception and the innately subjective nature of the interface between these entities. Gambetta, for example, discusses trust in terms of subjective probability, asserting that »[w]hen we say we trust someone or that someone is trustworthy, we implicitly mean that the probability he will perform an action that is beneficial or at least not detrimental to us is high enough for us to consider engaging in some form of cooperation with him«.[93] When

93 Diego Gambetta: Can we trust?, in: Gambetta, Diego (Ed.): Trust: Making and Breaking Cooperative Relations, New York 1988, pp. 212–237, here: p. 217.

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considered in relation to a probabilistic conception of trust, risk – discussed by Fischhoff,[94] Luhmann[95] and others in terms of »calculated probabilities under conditions of uncertainty« (Das and Teng)[96] and its perceived role within an art access context suggests itself as a possible motive for the acute apprehension generated by subjectivity within an art access context.

Das and Teng outline the theoretical consensus that trust is »a perception about others in relation to oneself«,[97] describing how trust is earned by the trustee by virtue of demonstrations of characteristics such as responsibility, competence, goodwill and judgment that incite the confidence of the trusting party. Subjective trust therefore emerges as a feature of art access in the guise of the visitor's appraisal of the likelihood that a gallery docent might be inclined to act in any way other than one which serves his/her best interests. When considered in this context, regulatory insistence that art access should be purged of any semblance of subjectivity deprives gallery visitors with visual impairment of opportunities to make independent judgments about how any evaluative insights that might be volunteered by a fully-sighted describer might be optimally received, about the degree to which the describer should be trusted, and about whether subjecting oneself to the vagaries of the aesthetic preferences of a fully-sighted describer might constitute a risk that is worth taking. By depriving gallery visitors of self-determination in relation to judgments of risk and trust in terms of the anticipation of favourable or unfavourable hermeneutic outcomes, and of opportunities for discussion of how such a distinction might manifest in relation to aesthetic experience, the architects of verbal description guidelines are impoverishing the aesthetic experience that art engagement is capable of yielding in at least two ways. Their dubiously substantiated aesthetic strictures reduce the artefact to object while their presumptuous resolve to decide on behalf of gallery visitors with visual impairments that docents are not to be trusted to handle aesthetic value responsibly deprives these visitors of aesthetic agency by discounting their capacity for aesthetic discernment. In this way, verbal description guidelines contribute to a wider social tendency towards an ultimately inhibiting instinct

94 Cf. Baruch Fischhoff: Managing Risk Perceptions, in: Issues in Science and Technology 2:1 (1985), pp. 83–96.

95 Cf. Niklas Luhmann: Risk: A Sociological Theory, New York 1993.

96 T. K. Das/ Bing-Sheng Teng: The Risk-Based View of Trust: A Conceptual Framework, in: Journal of Business and Psychology 19:1 (2004), pp. 85–116, here: p. 98.

97 Ibid., p. 95/96.

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towards over-protectiveness with which many disabled people are all-too-familiar.

From a hermeneutics of suspicion to a suspicion of hermeneutics

Another dubious feature of widespread approaches to verbal description is the tendency of guidelines to collapse the distinction between a hermeneutics of faith and a hermeneutics of suspicion into what presents as an uncannily visceral suspicion of hermeneutics. It would be understandable were the wariness of interpretation that has been persuasively articulated by several cultural theorists in exasperated response to postmodern critical tendencies to command a certain empathy among architects of verbal description guidelines. The suspicion that appears to underpin their approach of the authorities who have assumed responsibility for the regulation of art access, however, bears scant indication of having been influenced by these critical debates. It is conceivable, for example, that Susan Sontag's celebrated take on the impoverishing and depleting impact of interpretation on the world, for example, her treatment of interpretation as the revenge of the intellect upon art, and her appeal to the need to replace hermeneutical exegesis with an erotics of art, might have been brought into service to support an argument that interpretation should be beyond the brief of a verbal describer.[98] Rita Felski's reworking of Sontag's misgivings might also have been appealed to as a point of supportive reference. Drawing most fundamentally on Paul Ricoeur's concept of a hermeneutics of suspicion, Felski's misgivings about contemporary cultural analysis highlight several ways in which the distrustful nature of contemporary approaches to critical interpretation, born of an ostensibly suspicious or resentful attitude towards creative expression, has an impoverishing impact on art engagement.[99] Equally intolerant of ambiguity and mystery, the role assumed by the contemporary critic, as Felski sees it, is as the ultimate arbiter of aesthetic axiology, a figure of authority who knows an artwork more intimately than it can possibly know itself. The task undertaken by these self-appointed cultural connoisseurs is to demystify an artwork by resolving for

98 Cf. Susan Sontag: Against Interpretation and Other Essays, New York 1966.

99 Cf. Rita Felski: After Suspicion, in: Profession 1 (2009), pp. 28–35; Rita Felski: Critique and the Hermeneutics of Suspicion, in: M/C Journal 15:1 (2011a). doi.org/10.5204/mcj.431 (3.8.2024); Rita Felski: Suspicious Minds, in: Poetics Today 32.2 (2011b), pp. 215–234; Rita Felski: The Limits of Critique, Chicago 2015.

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the uninitiated its internal and often unwitting contradictions and disclosing its guilefully cloaked truths in the manner, as Terry Eagleton expresses it, of a »seasoned cop browbeating a shifty suspect«.[100]

It would be admittedly difficult to mount a credible defence of gallery docents who conceive of their purview as incorporating responsibility for the emancipation of the gallery visitor from ignorance while ushering them into a state of cultural erudition through the cultivation of good taste while also applying correctives to the artwork's obliviousness to its own meaning. In the absence of a volunteering of any credible form of justificatory rationale, it remains unclear whether a perceived alignment between the figure of the gallery docent and these critical portraits of the cultural analyst might constitute the precise foundation of the suspicion that has prompted the formulators of verbal description guidelines to supress interpretive discourse. My experience of working in the domain of art access suggests that the positing of such a performative coupling is extremely tenuous, and that gallery docents do not approach their roles in the grip of any preformulated designs on the aesthetic predilections of visitors with visual impairment.

The folly of requirements to purge art access facilitation of any semblance of interpretation and of all perspectives that are other than entirely objective can be revealed by contemplating these directives in the context of Barbara Herrnstein Smith's treatment of the inescapable contingency of aesthetic value.[101] In the course of her reflections on this issue, a number of conditions under which certain potential meanings and values of artworks become more or less realisable are delineated. Primarily addressing literary works in a way that seems applicable to artworks more generally, Herrnstein Smith suggests that interpretation of a work is an inextricable component of our experience of it, and that hermeneutics and evaluation are two »interloping« circles.[102] Presenting experience and interpretation as mutually dependent components of the »psychological set« of our encounters with artworks, she contends that the nature of art is such that our assumptions, expectations, capacities and interests cannot be extricated from our experiences of art. In this way, experience, interpretation and evaluation cause and justify themselves and one

100 Terry Eagleton: Not just anybody, in: London Review of Books 39:1 (2017). www.lrb.co.uk/the-paper/v39/n01/terry-eagleton/not-just-anybody (30.7.2024).

101 Barbara Herrnstein Smith: Fixed Marks and Variable Constancies: A Parable of Literary Value, in: Poetics Today 1:1/2 (1979). Special Issue – Literature, Interpretation, Communication, pp. 7–22; Barbara Herrnstein Smith: Contingencies of Value: Alternative Perspectives for Critical Theory, Cambridge 1991.

102 Herrnstein Smith: Fixed Marks, p. 16.

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another. The pertinence of Herrnstein Smith's treatment of these issues to the rationale underpinning verbal description guidelines become most apparent when she attests:

> While these circles are no doubt logically vicious or at least epistemologically compromising, they are also … both psychologically inevitable and experientially benign. Undue distress at their philosophic status coupled with a failure to appreciate their inevitability will produce misguided and futile attempts to escape from them, as reflected in the familiar searches for »true« or objective value and for uniquely »correct« interpretations or determinate meanings. There is, however, no way out of these circles for the individual reader: only the recognition of their existence and, of course, the pleasure and interest of the particular experiences they yield – and, for the theorist, the possibility of describing and explaining the dynamics of their interrelation.[103]

Herrnstein Smith prefers to discuss aesthetic experience in relation to its relativity, contingency or variability, rather than in relation to the concept of subjectivity which appears to strike such terror in the hearts of those who assume responsibility for devising guidelines for verbal description. Her preference is informed by a critical tendency whereby fixation on subjectivity firmly closes doors of inquiry rather than opening them. She accounts for her weariness of the history of concern for subjectivity within aesthetic contexts in terms of the epistemological and experiential stalemates to which the pursuit of such concern inevitably leads. Critical consensus about subjectivity invariably assumes one of two forms – either the blanket contention that individual taste is indisputable or the misguided conviction that there exists a converse to subjective value – an objective value that must somehow be unearthed by those with the appropriate aesthetic expertise. Within the context of art engagement, Herrnstein Smith believes the concept of objectivity to be a vacuous one, although she is at pains to emphasise that the contention that aesthetic value is entirely dictated by the whims and predilections of individual subjects is not the logical corollary of this belief.

Granting to these reflections the degree of extended reflection they merit would entail positioning existing verbal description guidelines within an expansive framework of aesthetic axiology of a scale that is unfeasible here. In place of such a substantial project, I suggest here only that, provided it is undertaken as part of an equitable experiential exchange,[104] the incorporation of insights that are not entirely objective within the verbal transmission of

103 Ibid., p. 17,
104 Cf. Feeney: A Modest Defence.

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information about works of visual art is not the calamity that Joel Snyder and other advocates of an exclusively dispassionate approach to description appear to take it to be. I would suggest, on the contrary, that the affordance of mutually enriching experiences of art engagement to fully and partially sighted participants in access initiatives is contingent on a creative transgression of the objectivity-fixated regulations outlined in verbal description guidelines. Such a transgression can be accommodated by displacing the suspicion of hermeneutics that appears to underpin access guidelines by a more trusting regulatory disposition.

Concluding reflections

Autarchic determinations of apposite distinctions between forms of art engagement that can be legitimately pursued from those deemed to lie unequivocally out of bounds seem a dubious basis for the facilitation of absorbing aesthetic experience within a gallery environment. The imposition of a wholesale injunction against subjectivity, combined with the decree that any aesthetic elements that the entity being described may possess must remain unspoken, appear to be measures designed to withhold any sense that the entity being described is a humanly fashioned artefact that has amongst its characteristics a capacity to occasion in interested percipients a degree of aesthetic experience. On these grounds, it might be argued that verbal description guidelines can, as a potentially debilitating form of aesthetic gatekeeping, be added to a substantial list of normalising myths about aesthetic experience that have historically impeded or delegitimised the emergence of a differential aesthetic amongst individuals with visual impairment.[105] For all of Joel Snyder's denunciation of the verbal transmission of subjective interpretations of aesthetic value, nowhere in his various pontifications on the subject does one encounter a persuasive argument that the prohibition of such practice is either the logical or the optimum practical corollary of any belief one might be inclined to invest in the dictum that no visual rendering of creative expression that can be described with exhaustive precision warrants the denotation of beauty.

For all of their canvassing of disinterest, the tendency of the architects of description guidelines appear to ride slipshod over a rich history of aesthetic debate about such issues as perception, attitude, gratification, judgement, experience, justice, opportunity, skills, understanding, value, wealth and welfare

105 Cf. Feeney: Toward an Aesthetics of Blindness.

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in a way that appears to have been designed precisely with the promotion and nurturing of their own interests in mind. Snyder's dismissal of Josh Miele's attempt to democratise the domain of access provision[106] seems born of an anxiety about the potentially catastrophic consequences for an industry that feeds on the purposeful screening behind a paywall – that can be permeated only by individuals who are prepared to purchase a book or attend a prohibitively expensive training course – of resources designed to initiate these paying customers in the mastery of the only access-facilitation interventions that Snyder deems to be acceptable. A minority of authors on aesthetic testimony have suggested that there is reason to be optimistic about the human capacity to learn from one another about beauty.[107] Regardless of whether one shares the enthusiasm of these authors in relation to the feasibility of the verbal transmission of aesthetic qualities, a defence of the incorporation of evaluative elements within the verbal description of artworks might be persuasively developed in relation to the twofold compulsion to circumvent the double standards underpinning the art access industry while avoiding the unjustified embedding of art access in a groundless and distinctly unhelpful suspicion of interpretation. Whether such practice is discussed in terms of subjectivity or relativity, prevailing insistence that art description should essentially be a hermeneutic-free zone can be countered by more compelling and research-informed appeals to the inextricable fusion of experience, interpretation and evaluation within the 'psychological set' of art engagement.

An interdisciplinary fusion of histories of imaginative renderings of visual impairment and aesthetic theory illustrates the pertinence to the aesthetic experiences of people with visual impairment of such entities as notions of (un)trustworthiness, the acquaintance principle and the asymmetry thesis. If re-framed in a more considered and critically informed manner, the verbal description guidelines scrutinized above might be presented as an imaginative hermeneutic process of ›de-arting‹ in order to facilitate a subsequent ›re-arting‹ after a provisional reduction of artefacts to a series of verbal propositions. While such an approach might represent an intriguing attempt to circumvent potential for the dominant imposition of the predilections of a describer on the recipient of a description, the array of aesthetic consequences inherent in such a strategy warrants much deeper and more comprehensive reflection than appears to have been afforded by the generators of these prescriptive standards of inclusive practice. Factoring the diverse perspectives incorp-

106 Cf. Kleege: More than Meets the Eye.
107 Cf. McKinnon: How to be an Optimist; Robson: Aesthetic Testimony.

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orated within the history of the aesthetic testimony debate represents one way in which we might optimize the likelihood that these consequences might be acknowledged and contended with in considered and creative ways that are more dispositionally aligned than existing guidelines with the imaginative sensibility that underpins artistic expression.

In the preceding reflections I have outlined a richly complex history of aesthetic debate with a delineative nonchalance that admittedly belies the exasperation I expressed at the apparent indifference towards this history betrayed by those who have taken it upon themselves to regulate the domain of verbal description. Their inescapable imprecision notwithstanding, the ultimate objective of these reflections has been less to generate a definitive account of this history, than to suggest that this history needs to be reckoned with, less to conclusively resolve the debate about the credibility of claims that words are entirely capable of doing justice to beauty, than to suggest that the domain of art access would be enriched were verbal describers, whatever beliefs they might happen to harbour in relation to this dispute, were to volunteer their small contribution to the facilitation of an engaging gallery experience as provisional agents of the optimistic faction of the aesthetic testimony debate. It is only once the exploratory reticence of prevalent verbal description guidelines has been displaced by the aesthetic enthusiasm of this position that fully sighted access facilitators can truly apprentice themselves to the defiantly subjective expertise of gallery visitors with visual impairment in ways that can begin to affirm anything other than a fully sighted aesthetic and make tentative inroads into the vital task of challenging the experiential power imbalances that have historically characterised the domain of art access.

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Literary Form and Narrative Analysis

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Linda Leskau

Disability and Intersectionality: The Concepts of ›Healing‹ in Johanna Spyri's *Heidi* Novels

Part of the canon of Western children's and young adult literature, the story of the child Heidi details her life with her grandfather in the Swiss mountains and how she is brought to the city of Frankfurt to live as a playmate of the bourgeois girl Klara. Johanna Spyri's two novels *Heidi's Lehr- und Wanderjahre* (1880; *Heidi: Her Years of Wandering and Learning*) and *Heidi kann brauchen, was es gelernt hat* (1881; *Heidi: How She Used What She Learned*) have been translated into over 70 languages and have been adapted into numerous media formats, including movies, anime, comics, musicals, and more. They are by far the Swiss author's most successful books.[1]

Jean-Michel Wissmer emphasizes that when it comes to the story of Heidi, we often only remember her life in the mountains with her grandfather, her friend Peter, and the goats.[2] However, this idyllic landscape is contrasted to the city of Frankfurt in Germany. Embedded in this constellation is a second juxtaposition that decisively characterizes the novels: disabled and non-disabled. By introducing Klara Sesemann as a character with disabilities – her legs are paralyzed, and she uses a wheelchair – the novels follow a typical narrative structure of literary representations of disability, one that David T. Mitchell and Sharon L. Snyder have referred to as ›narrative prosthesis‹: The ›problem‹ of disability is introduced and demands an explanation, placing disability at the centre of the story, only to be ›solved‹ at the end – by compensating or overcoming the disability or even by eradicating the character with disabilities.[3] Accordingly, Klara is healed at the end of the second novel; she overcomes her paralysis and begins to walk.

1 Cf. Linda Leskau/Sigrid Nieberle: Kanonisierung/Popularisierung. Johanna Spyris *Heidi*-Romane, in: Wernli, Martina/Klimek, Sonja (eds.): Heidi und mehr. Neue Studien zu Johanna Spyris Werken, Berlin 2026 (in print).

2 Cf. Jean-Michel Wissmer: Heidi. Ein Schweizer Mythos erobert die Welt, Basel 2014, p. 19.

3 Cf. David T. Mitchell/Sharon L. Snyder: Narrative Prosthesis. Disability and the Dependencies of Discourse, Ann Arbor 2000, pp. 53f.

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Thus, the *Heidi* novels can be identified as a form of supercrip narrative.[4] Supercrip narratives are, as Sami Schalk argues, »stereotypical representation[s] of disability« that »rely on concepts of overcoming, heroism, inspiration, and the extraordinary«, »making it seem as if all effects of disability can be erased if one merely works hard enough«.[5] Even if in disability studies, supercrip narratives are often problematized, this almost unanimous criticism in academic discourse is, as Schalk stresses, offset by the narrative's high popularity – as can be seen in the reception of the *Heidi* novels. Without denying that supercrip narratives can indeed reproduce problematic stereotypes of disability, Schalk demands we »open up disability studies to increased engagement with mainstream genres that are often dismissed as too normative, regressive, or uncomplicated« in order to »demonstrate that rather than having one self-evident meaning, supercrip actually encompasses a large body of representations«.[6]

Both agreeing with and extending Schalk's call for a methodological, theoretical, and cultural-historical analysis of supercrip narratives, the aim of my article is to show how the *Heidi* novels ultimately reject a one-dimensional representation of disability. Instead, I argue that disability cannot be read separately from other categories such as age, class, gender, and religion.[7] In the following, I will therefore first outline some central concepts in literary disability studies and then employ these together with intersectional narrative theory to examine the various ›healing processes‹ of disability present in the *Heidi* novels.

4 Johanna Spyri's *Heidi* novels were published in the late 19th century (1880 and 1881). Sami Schalk explicitly draws attention to the fact that supercrip narratives are not only a current phenomenon, but that the »discursive use of supercrip narratives (without the actual label of supercrip)« can be traced back to around 1900, cf. Sami Schalk: Reevaluating the Supercrip, in: Journal of Literary & Cultural Disability Studies 10:1 (2016), p. 73.

5 Ibid., pp. 72f.

6 Ibid., pp. 71f.

7 Cf. Linda Leskau/Sigrid Nieberle: Wiedersehen mit Heidi. Zur Einführung, in: Leskau, Linda/Nieberle, Sigrid (eds.): Wiedersehen mit Heidi. Polyperspektivische Lektüren der Heidi-Romane von Johanna Spyri, Bielefeld 2023, pp. 9–24; Victoria Gutsche: Das kranke Töchterlein. Behinderung und Krankheit in den *Heidi*-Romanen Johanna Spyris, in: ibid., pp. 217–229.

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Narrating Disability

In their article »Representation and Its Discontents«, David T. Mitchell and Sharon L. Snyder provide an overview of various tendencies in disability studies' engagement with literary texts. They divide the development of literary disability studies into different historical phases, starting in the 1980s.[8] The so-called early phase – the ›Negative Imagery School‹ and the ›Social Realism‹ – is based on a mimetic understanding of literature, in which literature should reflect reality as authentically as possible because a causal relationship is assumed between literature and society. The assumption is that negative or stereotypical images of disability in literature and discrimination against people with disabilities in society are mutually dependent. Consequently, the task of literary disability studies is to critically expose negative images and to demand positive or realistic representations of disability.

However, this early phase is criticized for neglecting the historical context of disability and literary texts. As a result, researchers employing a historicist approach focused their attention on the reciprocal interactions between literature and historical reality. The inclusion of the historical-cultural context through the ›New Historicism of Disability Representations‹ brought authorship into focus. ›Biographical Criticism‹ departs from the assumption that disability influences literary writing and vice versa and centers primarily on criticism and revision of the hegemonic canon that excludes authors with disabilities. The final phase Mitchell and Snyder mention is called ›Transgressive Resignifications‹: »Rather than rail against or bemoan the unjust social exclusion of cripples, scholars have begun to attend to the subversive potential of the hyperbolic meanings invested in disabled figures«.[9] Counteracting the medical and individual perspectives on embodied difference, this theoretical direction offers a plurality of perspectives regarding the historical category of disability.

Despite the differences discussed, these theoretical directions share a focus on the extra-literary potential of literature. Each supports a socio-political perspective that is fundamental to disability studies. However, I argue that this perspective can sometimes lead to the neglect of both literary and rhetorical

8 Cf. David T. Mitchell/Sharon L. Snyder: Representation and Its Discontents. The Uneasy Home of Disability in Literature and Film, in: Albrecht, Gary L./Seelman, Katherine D./Bury, Michael (eds.): Handbook of Disability Studies, Thousand Oaks/London/New Delhi 2001, pp. 195–218. The following explanations of the phases are based on this article, cf. ibid., pp. 196–212.

9 Ibid., p. 208.

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aspects of the texts discussed. The use of disability metaphors can serve as an illustrative example. They are often used in literary texts either for the purpose of characterization or to refer to more general issues:

> Blindness may represent the incapacity of humanity to see into the future; lameness can designate the crippling effects of social ideologies; physical deformity may symbolize corrupt corporate policies; deafness may represent a refusal of leaders to listen to their constituencies; diabetes might conjure up images of gluttonous commodity culture; amputation can provide evidence of an unchecked medical industry; and so on.[10]

In the *Heidi* novels, Klara's paralysis can be interpreted as a criticism of the 19th-century bourgeois upbringing of girls, who were only allowed to leave the house when accompanied by someone, if at all.[11] They did not learn, to use another metaphor, to stand on their own two feet. Such use of disability metaphors is criticized in disability studies, but, as Michael Bérubé points out, there is a catch:

> One of the tasks undertaken by disability studies so far has been to point out these tropes and these characters, and to critique them for their failure to do justice to the actual lived experiences of people with disabilities. That project is long overdue and still needed; yet it sometimes proceeds as if characters in literary texts could be read simply as representations of real people. At the risk of sounding polemical, I want to stress how counterintuitive this should be for literary critics. If there's one thing we're all trained to do, it's to read things in terms of other things – whether the »other things« be the deep structure of human thought, the workings of the unconscious, the inscription of gender difference, the determination of cultural forms by the material base, the contradiction between literal and rhetorical senses of language, the trace of hybridity, or the homo-hetero divide that has guided so much binary thought in the past century or so. It is altogether queer that disability studies might suggest that the literary representation of disability *not* be read as the site of the figural.[12]

The inextricable link between literariness and extra-literary potential that Michael Bérubé emphasizes is crucial. Only by analyzing the literariness of texts and their genre-specific characteristics can we explore non-literary functions. Clare Barker and Stuart Murray also emphasize this:

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10 David T. Mitchell: Narrative Prosthesis and the Materiality of Metaphor, in: Snyder, Sharon L./Brueggemann, Brenda Jo/Garland-Thomson, Rosemarie (eds.): Disability Studies. Enabling the Humanities, New York 2002, p. 25.

11 Cf. Anna-Katharina Gisbertz: Gehen, um frei zu sein. Zu den Lehren der Aufklärung in *Heidi*, in: Leskau, Linda/Nieberle, Sigrid (eds.): Wiedersehen mit Heidi. Polyperspektivische Lektüren der Heidi-Romane von Johanna Spyri, Bielefeld 2023, pp. 27–42.

12 Michael Bérubé: Disability and Narrative, in: PMLA 120:2 (2005), p. 570.

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> The relationship between the aesthetic, the political, and the ethical implications of disability representation is an ongoing concern within literary and cultural disability studies, but such work on aesthetics and narrative theory has pushed the field beyond making distinctions between »positive« and »negative« representations toward a better understanding of the complex nature of many disability narratives.[13]

In what follows, I unpack the »complex nature« of the *Heidi* novels by drawing on methods from narrative theory and using intersectionality as an analytical tool. I focus on two characters with disabilities – the young girl Klara Sesemann from Frankfurt and Peter's grandmother on the mountain pasture – to analyze how the novels narrate different concepts of ›healing‹.

The *Heidi* novels are told by an authorial, heterodiegetic narrator, who makes no explicit statements about themself. Therefore, it is not possible to ›determine‹ the narrator's social and political identities. In narrative theory, this has often resulted in either considering the categorization of the narrator as irrelevant or in the unquestioned identification of the narrator as male, heterosexual, non-disabled, middle class, middle aged etc. Feminist narratology has criticized such generalizations for not doing justice to the complexity and plurality of narratives. Consequently, scholars are calling for the inclusion of intersectionality as an analytical tool in narrative theory.[14] According to Patricia Hill Collins and Sirma Bilge,

> [i]ntersectionality investigates how intersecting power relations influence social relations across diverse societies as well as individual experiences in everyday life. As an analytical tool, intersectionality views categories of race, class, gender, sexuality, class, nation, ability, ethnicity, and age – among others – as interrelated and mutually shaping one another. Intersectionality is a way of understanding and explaining complexity in the world, in people, and in human experiences.[15]

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13 Clare Barker/Stuart Murray: Introduction. On Reading Disability in Literature, in: Barker, Clare/Murray, Stuart (eds.): The Cambridge Companion to Literature and Disability, Cambridge 2018, p. 5.

14 Cf. Sigrid Nieberle: Gender Studies und Literatur. Eine Einführung, Darmstadt 2013, pp. 108–110; Vera Nünning/Ansgar Nünning: ›Gender‹-orientierte Erzähltextanalyse als Modell für die Schnittstelle von Narratologie und intersektioneller Forschung? Wissenschaftsgeschichtliche Entwicklung, Schlüsselkonzepte und Anwendungsperspektiven, in: Klein, Christian/Schnicke, Falko (eds.): Intersektionalität und Narratologie. Methoden – Konzepte – Analysen, Trier 2014, pp. 33–60; Eva Blome: Erzählte Interdependenzen. Überlegungen zu einer kulturwissenschaftlichen Intersektionalitätsforschung, in: Pohl, Peter C./Siebenpfeiffer, Hania (eds.): Diversity Trouble. Vielfalt – Gender – Gegenwartskultur, Berlin 2016, pp. 45–67.

15 Patricia Hill Collins/Sirma Bilge (eds.): Intersectionality, 2nd ed., Cambridge 2020, p. 2.

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An intersectional assessment helps us to consider the interplay of these different categories not as additive but rather as interdependent. When focusing on the *Heidi* novels, the perspective of intersectional narrative theory can assist in drawing conclusions about the narrator based on the way in which the story is told. As such, we find that the narrator uses the demarcation between healthy and sick in the introduction of the main characters Heidi and Klara. Moreover, this demarcation is also tied to specific spaces: outside and inside, countryside and city, Switzerland and Germany. On the one hand, we have Heidi, the »kräftig«[16] (strong[17]) looking girl with the glowing cheeks,[18] who runs and jumps around on the mountain pasture with her friend Peter and his goats. On the other hand, we have Klara, the »kranke«[19] (sick) and »lahm[e]«[20] (lame) girl with a »blasse[n], schmale[n] Gesichtchen«[21] (pale, narrow face), who sits in a wheelchair and never leaves her house in Frankfurt.

The narrator introduces Klara as follows: »[D]as [Töchterlein] müsse immer im Rollstuhl sitzen, denn es sei auf einer Seite lahm und sonst nicht gesund, und so sei es fast immer allein [...].«[22] And further: »Im Hause des Herrn Sesemann in Frankfurt lag das kranke Töchterlein, Klara, in dem bequemen Rollstuhl, in welchem es den ganzen Tag sich aufhielt und von einem Zimmer in's andere gestoßen wurde.«[23] The text constructs a causal relationship between impairment and disability: Klara's impairment causes her social isolation. This is indicated by the two conjunctions »denn« (because) as well as »und so« (and so) being used in the sentences. Furthermore, the narrator speaks about Klara using the diminutives »Töchterlein« and »Töchterchen« (little daughter) and the hypocorism »Klärchen« for her. These belittlements, which appear over 40 times in the novels, have

16 Johanna Spyri: Heidi's Lehr- und Wanderjahre, Gotha 1880, p. 1.
17 Unless otherwise noted, all translations in this chapter are mine.
18 Cf. Spyri: Heidi's Lehr- und Wanderjahre, p. 1.
19 Ibid., p. 89.
20 Ibid., p. 79.
21 Ibid., p. 89.
22 Ibid., p. 79. Translation: »[O]ne daughter, who was ill, and obliged to remain all the time in a rolling-chair, because she was paralyzed on one side. This girl was almost always alone [...]«. Johanna Spyri: Heidi: Her Years of Wandering and Learning, Boston 1885, p. 138. The translations by Louise Brooks are provided to support understanding, however, since they differ greatly from the original, my analysis is based exclusively on the German version.
23 Spyri: Heidi's Lehr- und Wanderjahre, p. 89. Translation: »In the house of Mr. Sesemann, in Frankfort, lay his little sick daughter, in the comfortable armchair in which she reclined all day, and was rolled from one room to another.« Spyri: Heidi: Her Years of Wandering and Learning, p. 153.

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an affective function, they convey the impression of closeness and empathy between the narrator and Klara. The narrator seems to take pity on the girl with disabilities because they assess disability as an individual and tragical fate that leads to social exclusion and dependence. Based on these observations, I argue that the narrator speaks from a non-disabled positionality.

Moreover, I presume that the narrator, like the Sesemanns, belongs to the Bildungsbürgertum (highly educated middle classes) since the narrator positively highlights the different types of rooms in the Sesemann household – for example, the »Studierzimmer« with a »großen, schönen Bücherschrank mit den Glasthüren« and the »Eßstube« where »vielerlei Geräthschaften herumstanden und lagen, die das Zimmer wohnlich machten und zeigten, daß man hier gewöhnlich sich aufhielt«.[24] The aforementioned adjective »bequem« (comfortable) that the narrator uses to describe Klara's wheelchair is also intended to make clear that Klara receives what the father and medical institutions imagine to be the best possible care. Against the background of the sheltered environment and care for Klara, the slightly violent expression »gestoßen wurde« (was pushed) that the narrator uses to describe Klara's movement in her wheelchair comes as a surprise. In German, the verb ›schieben‹ (to push) is usually used to describe the movement of a wheelchair by another person not inhabiting it.[25] The difference between ›schieben‹ and ›stoßen‹ is the amount of pressure exerted to cause the movement. ›Schieben‹ entails light, continuous, and even pressure, whereas ›stoßen‹ connotes a rough and strong, momentous push that lacks continuity. As such, ›stoßen‹ is more aggressive than ›schieben‹ and points to a movement that is defined by continuous (inter)ruptions. By attributing this aggressive treatment of Klara to her servants, the narrator does not negate the previous laudatory description of her surroundings but does call it into question. It also establishes a hierarchy of care and sends an implicit message: While Klara's family cares and wants the best for her, the people working for the Sesemann family perceive it as tied to their employment. Furthermore, the passive construction ›gestoßen wurde‹ (was pushed) makes clear that Klara's

24 Spyri: Heidi's Lehr- und Wanderjahre, p. 89. Translation: For example the »study« with a »large, handsome bookcase with glass doors« and the »dining-room« where »all sorts of pretty things were arranged and disposed in such a way as to make it look attractive, and prove that it was the place where the family usually lived.« Spyri: Heidi: Her Years of Wandering and Learning, p. 153.

25 In Swiss German, the verbs ›stoßen‹ and ›schieben‹ are often used synonymously for the movement of a wheelchair by another person – nevertheless, the more vehement aspect of the verb ›stoßen‹ remains.

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wheelchair – despite the existence of wheelchairs in the late 19th century that allowed self-determined movement indoors[26] – was not designed or intended to be used for independent mobility. To be more precise, the narrator reduces Klara to an object in need of care.

To illustrate this point further, I turn to Klara's healing at the end of the second novel, in which Klara visits Heidi in Switzerland and is on the mountain pasture for the first time. After taking a few steps, the narrator says: »Gewiß kannte sie gar kein größeres Glück auf der Welt, als auch einmal gesund zu sein und herumgehen zu können, wie die anderen Menschen, und nicht mehr elend die ganzen Tage lang in den Krankensessel gebannt zu sein.«[27] Once more, the narrator structures and evaluates Klara's happiness based on the constructed opposition between healthy and sick (or disabled). On the one hand, we have Klara associated with misery, dependency, and limitation while using a wheelchair. On the other hand, we have all »die anderen Menschen« (the other people). They are positioned as healthy and ›normal‹ and thus associated with happiness and independence. The adverb »[g]ewiß« (certainly) that introduces the sentence is also linked to the expressions »größeres Glück« (greater happiness) and »gesund« (healthy) via the letter ›g‹. The alliteration leaves no room for doubt as to the hierarchical opposition operating linguistically between healthy and sick (disabled).

In his reflections on border crossings in narratives, Jurij M. Lotman argues that transgressions can both consolidate and subvert borders.[28] When it comes to Klara, the focus remains on the former. After Klara overcomes her disability and switches sides in the disabled/non-disabled paradigm, the narrator clearly distances themself from the wheelchair as a symbol of Klara's former disability. While the wheelchair was initially described as »bequem« (comfortable) it is now devalued – for the first time – as »Krankensessel« (sick chair). The re- and devaluation of the wheelchair supports the line being drawn between disabled and non-disabled, sick and healthy, and marks Klara's progression towards becoming a full member of society.

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26 Cf. Nick Watson/Brian Woods: History of the wheelchair, in: Encyclopaedia Britannica, 2015, www.britannica.com/technology/history-of-the-wheelchair (28.03.2024).

27 Johanna Spyri: Heidi kann brauchen, was es gelernt hat, Gotha 1881, pp. 131f. Translation: »Certainly there could be not greater happiness in the world than to feel strong, and able to go about like other people, and not lie suffering all day long in a sick-chair.« Johanna Spyri: Heidi: How She Used What She Learned, Boston 1885, p. 200.

28 Cf. Jurij M. Lotman: Die Struktur literarischer Texte, München 1972.

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Such an impression is confirmed when we examine the intersectionality of disability, age, class, and gender. After Klara's healing, significant changes to her previous life and social position transpire:

> Herr Sesemann hatte sich vorgenommen, mit seiner Mutter eine kleine Reise durch die Schweiz zu machen und erst zu sehen, ob sein Klärchen im Stande sei, eine kurze Strecke mit zu reisen. Nun war es so gekommen, daß er die genußreichste Reise in Gesellschaft seiner Tochter vor sich sah, und nun wollte er auch gleich diese schönen Spätsommertage dazu benutzen.[29]

Through linguistic means the two sentences convey Klara's transgression. In the first sentence, which refers to the time before the healing, the narrator uses the hypocorism »Klärchen« and tells of Mr. Sesemann's doubts about the possibility of a long journey due to Klara's physical impairment. The second sentence refers to the time after the healing and uses the term »Tochter« (daughter) removing the belittlement. The young and disabled »Töchterchen«, »Töchterlein«, or »Klärchen« (little daughter) has become the adult, non-disabled daughter with whom her father plans to go on a journey. Furthermore, when Klara's father sees her walking for the first time, he remembers his late wife.[30] This suggests that Klara, having overcome her disability, is finally ready to take on the role of a woman in the Bildungsbürgertum (highly educated middle classes) at the end of the 19th century; she will leave her father's house (the journey is a first step) and, now looking like Mrs. Sesemann, will become a married woman and mother.

However, this traditional, bourgeois ending of the Sesemann family is contrasted with Heidi's non-traditional ending. As Heidi Schlipphacke has argued, Heidi lives in a queer family at the end of the second novel consisting of herself and two old men, her grandfather Öhi and Klara's doctor from Frankfurt:[31]

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29 Spyri: Heidi kann brauchen, was es gelernt hat, p. 169. Translation: »Mr. Sesemann had proposed to travel a little with his mother through Switzerland, and to see if Klara were strong enough to make a short distance with them. Now, it was all so different; he could have the most delightfully interesting trip with his daughter, and he would make use of these beautiful late summer days for that purpose.« Spyri: Heidi: How She Used What She Learned, pp. 256f.

30 Cf. Spyri: Heidi kann brauchen, was es gelernt hat, p. 153.

31 Cf. Heidi Schlipphacke: Zur Temporalität von Bildung. Traumatisierte Männerseelen und das queere Prinzip ›Heidi‹ in Johanna Spyris *Heidi*-Romanen, in: Leskau, Linda/Nieberle, Sigrid (eds.): Wiedersehen mit Heidi. Polyperspektivische Lektüren der Heidi-Romane von Johanna Spyri, Bielefeld 2023, pp. 67–81.

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> Der Herr Doktor und der Almöhi werden täglich bessere Freunde, und wenn sie zusammen auf dem Gemäuer herumsteigen, um den Fortgang des Baues zu besichtigen, kommen ihre Gedanken meistens auf das Heidi, denn Beiden ist die Hauptfreude an dem Hause, daß sie mit ihrem fröhlichen Kinde hier einziehen werden.[32]

In contrast to the previous past tense, when describing the queer family, the narrator uses the present tense; the queer mountain pasture is presented as an »ewige Gegenwart«[33] (eternal present). This diverges from Klara's story in both its division into before and after the healing and its trajectory aimed toward the future of the next generation of the Sesemanns.

Klara Sesemann, who has been my focus of attention so far, is not the only character with disabilities in the *Heidi* novels. From the very first mentioning of Peter's grandmother, the narrator introduces her as a character with disabilities, assigning her the adjective ›blind‹ without going into further detail about the disability.[34] The grandmother's blindness is discussed for the first time after more than 60 pages in a conversation between herself and Heidi. The grandmother mourns her blindness: »›Ach Kind, ich kann sie nie mehr sehen, die feurigen Berge und die goldenen Blümlein droben, es wird mir nie mehr hell auf Erden, nie mehr.‹«[35] The grandmother's direct speech begins with an interjection, the exclamation »[a]ch«, which strengthens both the oral nature and the intense emotionality of the statement. The triple repetition of »nie mehr« (never again) reinforces the emotional statement; blindness is thus presented as a tragic condition. The grandmother's recounting of what

32 Spyri: Heidi kann brauchen, was es gelernt hat, p. 176. Translation: »The doctor and the Alm uncle are daily more and more intimate, and as they walk about inspecting the progress of the building in Dörfli, their talk falls mostly upon Heidi, for their greatest pleasure in the new dwelling is that the happy child will here live with them.« Spyri: Heidi: How She Used What She Learned, p. 267. However, Eva Blome emphasizes that this alternative family structure goes hand in hand with Heidi's commitment to care work for the two old men. Gender norms are thus partially reaffirmed and reproduced, cf. Eva Blome: Zwischen Alp und Alphabetisierung. Spyris Heidi als *transclasse*-Figur, in: Leskau, Linda/Nieberle, Sigrid (eds.): Wiedersehen mit Heidi. Polyperspektivische Lektüren der Heidi-Romane von Johanna Spyri, Bielefeld 2023, pp. 211–213.

33 Schlipphacke: Zur Temporalität von Bildung, p. 76.

34 Cf. Spyri: Heidi's Lehr- und Wanderjahre, p. 12. In addition to Peter's grandmother, Peter himself has been examined in the context of disability, cf. Grit Dommes: »Hoffentlich […] nicht normal«: Behinderung als Thema der deutschsprachigen Kinder- und Jugendliteratur, in: Luserke-Jaqui, Matthias (ed.): Literary Disability Studies. Theorie und Praxis in der Literaturwissenschaft, Würzburg 2019, pp. 54–56.

35 Spyri: Heidi's Lehr- und Wanderjahre, p. 62. Translation: »›My child, I cannot see the fiery mountains nor the golden flowers. It will never be light for me on the earth, never again.‹« Spyri: Heidi: Her Years of Wandering and Learning, p. 108.

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she can no longer see supports this evaluation: »die feurigen Berge und die goldenen Blümlein« (the fiery mountains and the golden flowers). In doing so, she names the very natural objects that so enthused Heidi on her first day on the mountain pasture.[36] Peter O. Büttner and Hans-Heino Ewers emphasize that the mountain pasture functions as a *locus amoenus* for Heidi, as an idyllic place of happiness.[37] This experience of happiness in or through nature is linked to visual perception: »Heidi wurde niemals unglücklich, denn es sah immer irgend etwas Erfreuliches vor sich […].«[38] Since Heidi's happiness is tied to the constant (»immer«) visual experience of her surroundings in the Swiss mountains, she reacts to the grandmother's blindness by crying.

In contrast to Heidi, who wants to heal the grandmother's blindness, the other characters – including the grandfather, Peter, and his mother – do not view the disability as necessitating a cure or as a lack needing remedied. However, the approach to female disability is completely different in the grandmother's context than it is presented in Klara's case. Here, it is not only Heidi, but also the grandfather who believes in the need to overcome the disability and repeatedly urges Klara to walk.[39] This stance towards Klara's disability is reinforced by the narrator who hints the possibility of Klara's paralysis to be overcome through her own willpower.[40] The different ways in which the characters and the narrator approach female disability can be explained by taking the categories of age and class into account. The aged grandmother is no longer an active, reproductive, and economically significant contributor to the village community. Moreover, the link between disability and old age leads to a normalization of disability and opens up the possibility of establishing blindness within a model of compensation.

The compensation narrated in the novels is based on one stereotype associated with blindness, in which blindness is conceptualized as a loss of access to the outside world. Primarily, this is due to the primary positioning of the

36 Cf. Spyri: Heidi's Lehr- und Wanderjahre, pp. 33–37, 45f., 48.
37 Cf. Peter O. Büttner/Hans-Heino Ewers: Arkadien in bedrohlicher Landschaft. Die Mehrfachcodierung der Schweizer Berge in Johanna Spyris *Heidi*-Romanen (1880/81), in: Bialek, Edward/Pacholski, Jan (eds.): »Über allen Gipfeln…« Bergmotive in der deutschsprachigen Literatur des 18. bis 21. Jahrhunderts, Dresden/Wroclaw 2008, pp. 14–22.
38 Spyri: Heidi's Lehr- und Wanderjahre, p. 52. Translation: »Heidi, for her part, was never unhappy. There was always something that interested and amused her.« Spyri: Heidi: Her Years of Wandering and Learning, p. 90.
39 Cf. Spyri: Heidi kann brauchen, was es gelernt hat, p. 114.
40 Cf. ibid., p. 126.

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sense of sight over other senses since antiquity.[41] When taking the loss of the outside world into account, the light-and-dark-metaphor the grandmother uses becomes relevant. She describes blindness as a state of darkness: »›Laß mich nur sitzen, du gutes Kind, es bleibt doch dunkel bei mir, auch im Schnee und in der Helle, sie dringt nicht mehr in meine Augen.‹«[42] This metaphor is taken up in another encounter between Heidi and the grandmother after Heidi has returned from Frankfurt and has learned to read. Heidi reads parts of the Lutheran hymn »Die güldene Sonne voll Freud und Wonne« (The golden sun full of joy and delight) by Paul Gerhardt, a German theologian and hymnist, to the grandmother:

> Die güldne Sonne
> Voll Freud' und Wonne
> Bringt unsern Gränzen
> Mit ihrem Glänzen
> Ein herzerquickendes, liebliches Licht.
>
> Mein Haupt und Glieder
> Die lagen darnieder;
> Aber nun steh' ich,
> Bin munter und fröhlich,
> Schaue den Himmel mit meinem Gesicht.
>
> Mein Auge schauet,
> Was Gott gebauet
> Zu seinen Ehren,
> Und uns zu lehren,
> Wie sein Vermögen sei mächtig und groß.[43]

In the hymn, the lyrical subject cites the »herzerquickende[], liebliche[] Licht« (heartwarming, lovely light) of the sun, which opens up a view into the afterlife. The grandmother reacts to the religious hymn through an adoption

41 Cf. Georgina Kleege: Introduction: Blindness and Literature, in: Journal of Literary & Cultural Disability Studies 3:2 (2009), pp. 113–114.

42 Spyri: Heidi's Lehr- und Wanderjahre, p. 61. Translation: »›Let me sit here quietly, you good little child. It will always remain dark for me, in snow and in sunshine. The light can never pierce my eyeballs again.‹« Spyri: Heidi: Her Years of Wandering and Learning, p. 107.

43 Spyri: Heidi's Lehr- und Wanderjahre, pp. 222f. Translation: »The sun's orb of gold / Brings joys untold; / Brings us the showers, / And the shining hours, / Brings heartfelt rejoicing and beautiful light. // Heavy of heart, / I languished apart; / Now again I am strong, / Now I raise my loud song, / Praising the Lord with my strength and my might. // I see, up above, / What God in his love / Has made to teach men, / Again and again, / How strong and how great is his kingdom on high. // […]« Spyri: Heidi: Her Years of Wandering and Learning, pp. 370f.

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of the metaphor; she speaks of the brightness of the heart: »›O Heidi, das macht hell! das macht so hell im Herzen! […]‹«[44] The narrator continues the alignment of the grandmother's life with the hymn in the following passage:

> Heidi strahlte vor Glück und mußte sie nur immer ansehen, denn so hatte es die Großmutter nie gesehen. Sie hatte gar nicht mehr das alte, trübselige Gesicht, sondern schaute so freudig und dankend aus, als sähe sie schon mit neuen, hellen Augen in den schönen himmlischen Garten hinein.[45]

The change from dark to light, from blindness to ›seeing‹ occurs through this reading of a religious hymn. This is no coincidence. The contrast between light and dark and the overcoming of darkness by light is a common metaphor in Christianity.[46] This transition from dark to light is staged as a kind of ›metaphorical healing‹ for the grandmother. This is reflected in the absence of and the replacement of the adjective ›blind‹ through which the grandmother has received »neue, helle Augen« (new, bright eyes). It is as if she now sees. Since blindness is understood as a loss of access to the outside world, the compensation for blindness often takes place through an inward turn – here in the sense of a religious, inner contemplation – that opens new horizons. In the process, it substitutes the outer world for an inner vision. This supplants the worldly restrained view with a wider, more heavenly view of life.

Conclusion – Concepts of ›Healing‹

I would like to emphasize that in the novels *Heidi's Lehr- und Wanderjahre* and *Heidi kann brauchen, was es gelernt hat* we have not just one, but at least two healing stories that follow the basic organizing principle of a supercrip narrative: overcoming and/or compensating. Whereas Klara overcomes her disability, the grandmother compensates it. However, the grandmother's metaphorical healing in the form of an inner sight that is independent of seeing, opens up the possibility of interpreting it within the second model of

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44 Spyri: Heidi's Lehr- und Wanderjahre, p. 224. Translation: »›That makes it light for me, my child. That makes it light in my heart. […]‹« Spyri: Heidi: Her Years of Wandering and Learning, p. 374.

45 Spyri: Heidi's Lehr- und Wanderjahre, p. 225. Translation: »The face of little Heidi was irradiated with pure pleasure as the grandmother thus spoke, for the grandmother's countenance seemed as if the blind woman really saw the heavenly peace that awaited her.« Spyri: Heidi: Her Years of Wandering and Learning, p. 374.

46 Cf. Gerhard Härle: Die Alm als pädagogische Provinz – oder: Versuch über Johanna Spyris *Heidi*, in: Rank, Bernhard (ed.): Erfolgreiche Kinder- und Jugendbücher: Was macht Lust auf Lesen?, Baltmannsweiler 1999, p. 75.

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Jurij M. Lotman's conceptualization of border crossings I mentioned above: the questioning of fixed categorizations.

Nevertheless, despite the religious context, the grandmother's inner contemplation is not a divine gift. Rather, the narrator clearly attributes this »sakrale Leistung«[47] (sacred achievement) to Heidi. The ›religious healing‹ is thus somewhat profaned; for it is the social act of reading that ›heals‹ the grandmother. Therefore, the compensation of the grandmother's disability takes place through social interaction. While her sensory impairment remains unchanged, the limitation of her opportunities to participate in religious and social life changed significantly. Within a disability studies framework, this can be understood in terms of the social model of disability. However, ›healing‹ in the form of social participation is also part of the novel's comprehensive normalization strategies that not only apply to figures with disabilities but also to ›outsiders‹ in general. The villagers speak of Heidi's grandfather as a man who lives on the fringes of the community not just in spatial terms, but also in social and religious ones:

> »Es weiß ja kein Mensch, was mit dem Alten da oben ist! Mit keinem Menschen will er Etwas zu thun haben, Jahr aus Jahr ein setzt er keinen Fuß in eine Kirche, und wenn er mit seinem dicken Stock im Jahr einmal herunterkommt, so weicht ihm Alles aus und muß sich vor ihm fürchten. […]«[48]

After her return from Frankfurt, Heidi reads the grandfather the parable of the prodigal son, in which a long-lost son returns to his father. As in the case of the grandmother, the story is aligned with the grandfather's life and the same metaphor already encountered during the grandmother's ›healing‹ is used for the grandfather's reintegration process: The grandfather sees the world with »hellen Augen«[49] (bright eyes) and finally returns to his place in the social and religious structures of the village.

Certainly, Klara's healing is also part of the novel's normalization strategies that level out differences. Her healing shares many similarities with supercrip narratives; above all, the focus on the individual perspective of disability, i.e.

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47 Volker Mergenthaler: Woher das Licht kommt. Sakralisierungsstrategien in *Heidi's Lehr- und Wanderjahren*, in: Thums, Barbara/Mergenthaler, Volker/Kaminski, Nicola/Bischoff, Doerte (eds.): Herkünfte. Historisch, ästhetisch, kulturell, Heidelberg 2004, p. 355.

48 Spyri: Heidi's Lehr- und Wanderjahre, p. 4. Translation: »›No one knows how he lives up there. He will have nothing to do with other people, year in year out. He never sets foot in a church; and when he comes down here once a year, with his thick stick, every one avoids him, and is afraid. […]‹« Spyri: Heidi: Her Years of Wandering and Learning, p. 10.

49 Spyri: Heidi's Lehr- und Wanderjahre, p. 231.

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on »individual attitude, work, and perseverance«.[50] Klara overcomes her disability through her willpower. Shortly before Klara begins to walk for the first time, the narrator mentions Klara's desire for independence: »[E]in großer Wunsch stieg auf in ihr, auch einmal ihr eigener Herr zu sein und einem Anderen helfen zu können und nicht nur immer sich von allen Anderen helfen lassen zu müssen.«[51] Because she no longer wants to be dependent on other people and wants to help people as they helped her, she starts to walk. However, this individual perspective on disability, which assumes that the cause and responsibility for disability are situated in the individual and their body, is called into question over the course of the novel. The narrator states several times that the healing is influenced by both the change of location and the changed social environment. Klara's healing is the product of the good air,[52] the sun,[53] the food[54] (especially the goat's milk[55]), and the care of Heidi's grandfather.[56] Thus, the *Heidi* novels are part of a discourse that conceptualizes the mountain pasture as a »Therapielandschaft«[57] (therapeutic landscape).[58] I do not mean to imply that the individual perspective has disappeared at the end of the novels. Rather, the non-disabled narrator's references to social aspects in relation to the construction of disability become more prevalent.

To summarize, different concepts of ›healing‹ are presented in the *Heidi* novels, all of which ultimately aim at the social reintegration of the characters. In the end, they all find their place in society, be it in the bourgeois nuclear family (Klara), in a queer family (grandfather), or in the religious community (grandmother). Nevertheless, to be part of these social units, the characters have to overcome or compensate for their disabilities. The different concepts of ›healing‹ – physical (Klara) and religious/social (grandmother) – can be

50 Schalk: Reevaluating the Supercrip, p. 73.
51 Spyri: Heidi kann brauchen, was es gelernt hat, p. 126. Translation: »[A] greater desire arose in the girl's heart than she had ever yet experienced, to be for once mistress of herself, and to be able to help others, and not always be waited on and tended.« Spyri: Heidi: How She Used What She Learned, p. 192.
52 Cf. Spyri: Heidi kann brauchen, was es gelernt hat, pp. 98, 105, 111.
53 Cf. ibid., pp. 105, 133.
54 Cf. ibid., pp. 94, 111f., 140f.
55 Cf. ibid., pp. 106, 110f., 114, 141.
56 Cf. ibid., pp. 89f., 103f., 113f.
57 Büttner/Ewers: Arkadien in bedrohlicher Landschaft, p. 14.
58 As early as 1762, Jean-Jacques Rousseau praises the benefits of country air in contrast to the harmful air in the city in *Emile oder Über die Erziehung* (*Emile, or On Education*), cf. Jean-Jacques Rousseau: Emile oder Über die Erziehung, (ed.) Zumhof, Tim, Stuttgart 2019, pp. 54f.

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explained through the interdependence of disability, age, class, gender, and religion as well as through a shift in emphasis in the novels, one that manifests not only in the individual but also vis-à-vis the social perspective on disability. The *Heidi* novels, albeit presenting normalizing and uncomplicated supercrip narratives, represent disability as an intersectional category with multiple forms of representation.

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Swaantje Otto

Wienke Haien and Her Environment: Perspectivisation in Theodor Storm's *Der Schimmelreiter (Rider on the White Horse)* in Light of Literary Disability Studies

This article examines the literary construction of the disability of the character Wienke Haien in Theodor Storm's novella *Der Schimmelreiter* (1888). It outlines whether the character might be a genre-typical disability icon following Ria Cheyne,[1] thus seeking to describe both the role disability plays in the plot and the perspectivisations of disability that can be identified at different narrative levels. Building on this, it discusses whether the diversity of perspectivisations and Wienke Haien's role in the embedded narrative undermine the demonstrably normative character of the frame narrative, thus confronting the reader with potentially opposing constructions of disability.[2] These questions may seem surprising, given that the work is known to have been appropriated in 1934 by National Socialist cultural propaganda, with its intolerance and hostility to disability, and that, independently of this propagandistic appropriation, the text itself continuously presents the reader with stereotyped gender roles[3] and a racist focus on ethnicity.[4] In light of

1 With reference to Ria Cheyne: Disability, Literature, Genre. Representation and Affect in Contemporary Fiction, Liverpool 2019.

2 This question is rooted in Mitchell and Snyder's fundamental hypothesis of a ›narrative prosthesis‹, that a narrative »issues to resolve or correct […] a deviance marked as improper to a social context«. (David T. Mitchell/Sharon L. Snyder: Narrative Prosthesis. Disability and the Dependencies of Discourse, Ann Arbor 2014, p. 53).

3 Theodor Storm: Der Schimmelreiter, Stuttgart 2012, pp. 36, 42, 53, 82, passim. All translations from German into English from this edition are my own.

4 Ibid. pp. 9, 44, 58, 63. »[…] Ihr hörtet wohl schon, Herr, die Friesen rechnen gut« (I dare say you have heard, sir, that the Frisians are good at arithmetic); »[…] die grauen Augen sahen aus dem langen Friesengesicht vorwärts […]« (the grey eyes in his long Frisian face were looking ahead); »Der kluge Friese besann sich doch noch ein paar Augenblicke.« (Clever Frisian though he was, he nevertheless had to stop and think a few seconds); »[…] die lange Friesengestalt mit den klugen grauen Augen neben der hageren Nase und den zwei Schädelwölbungen darüber!« (the long Frisian over there with the keen grey eyes, the bony nose and the high, projecting forehead!).
Of course, immanent politicisation must also always be considered in the context of the emergence of Schleswig-Holstein's independence efforts under Prussian foreign rule at the end of the 19th century; cf. Birgit Althans: Storms Schimmelreiter. Das Töten als Initiation ins Soziale, in: Paragrana 20 (2011), No. 1, pp. 328–347, p. 330.

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its enduring popularity, especially as assigned reading in German-speaking schools, it seems all the more urgent to discuss an interpretation that raises the question of whether it communicates a future-oriented image of society and, at the same time, critically scrutinises its problematic contents.

In the research conducted so far, the character of Wienke Haien in *Der Schimmelreiter* has been analysed as an element in a literary-symbolic system.[5] There is one contribution written from a medical perspective that proposes a diagnosis of her condition.[6] In the novella, the term ›disability‹ is not used. Instead, we find discriminatory, normative attributions that suggest a form of pervasive developmental disorder.

In the article, I would like to show that research on the narrative scope and potential meaning of this character could benefit from insights provided by literary disability studies and, in doing so, address genre-related aspects of disability in Gothic fiction.[7] The methodological and theoretical foundation for this article is provided by Ria Cheyne's work on the narrativization of disability in genre,[8] along with David Mitchell and Sharon Snyder's concept of ›narrative prosthesis‹.[9] Cheyne's identification of disability icons that are characteristic to certain genres and their embedding within familiar narratives are of central importance to this study. In particular, it seeks to connect

5 Cf. Ian Findlay: Myth and Redemption in Theodor Storm's Der Schimmelreiter, in: Papers on Language & Literature 11:4 (1975), pp. 397–403; Andrew Webber: The Uncanny rides again. Theodor Storm's Double Vision, in: The Modern Language Review 84 (1989), No. 4, pp. 860–873; Wiebke Strehl: Heredity and Environment. The Child Motif in the Novellas of Theodor Storm, 1992, www.proquest.com/dissertations-theses/heredity-environment-child-motif-novellas-theodor/docview/303988590/se-2 (11.06.2024); Althans: Storms Schimmelreiter.

6 Cf. Maik Urban/Alexa Nieschlag: The Enigma of the Old Poet. Did the Child Wienke in Theodor Storm's Novella Der Schimmelreiter (1888) have Phenylketonuria?, in: American Journal of Medical Genetics 104:2 (2001), pp. 174–178. The proposed diagnosis concerns the metabolic disorder phenylketonuria. The authors speak of a »probable case« (p. 174). This author finds the descriptions in the novel too vague to follow a medical diagnosis of Wienke's diversity.

7 From the perspective of literary history, *Der Schimmelreiter* is classified as a work of literary realism. In terms of its structure and motifs, the novella can also be identified as Gothic fiction, more precisely a Gothic realism novella (»Schauerliteratur« – the German- and English-language exemplars are difficult to distinguish) (Jürgen Vierig: Schauerroman, in: Braungart, Georg/Fricke, Harald/Grubmüller, Klaus/Müller, Jan-Dirk/Vollhardt, Friedrich/Weimar, Klaus (eds.): Reallexikon der deutschen Literaturwissenschaft: Neubearbeitung des Reallexikons der deutschen Literaturgeschichte. Vol. III, Berlin 2007, pp. 365–368, pp. 365f.).

8 Although Cheyne's studies focus on contemporary literature, her methods and results can be applied to the historical example of Gothic fiction, as the structures typical of this genre can be compared with the cases analysed by Cheyne.

9 Mitchell/Snyder: Narrative Prosthesis, p. 49.

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these icons from diverse genres examined by Cheyne with the potentially contradictory aspects of disability embodied in the figure of Wienke Haien. It is in this contradictoriness, if anywhere, that we can find a way of representing disability that is distinctive to the Gothic-realist novella. The disability icons in question are ›the needy disabled child‹, from romance,[10] and ›the disabled prophetess‹, modifying Cheyne's disability icons in fantasy.[11] Alongside the symbolic level, the text develops a literary construction of disability as an experience with a social dimension regarding both marginalization and inclusiveness.[12] This interconnectedness also seems to be specific to the genre.

With regard to the classification of the genre, the following can be said: *Der Schimmelreiter* is structured as an artful scheme of frame and core narratives. In his childhood, the anonymous frame narrator, to whom the author gives autobiographical traits, comes across a story in a magazine, which, as an elderly man, he reconstructs from memory decades later, at the end of the 19th century. This outermost frame remains open at the end of the narrative. The story in the magazine is, for its part, composed as an autobiographical account by an unnamed man who travelled through North Frisia, on the west coast of Germany, in around 1830. While riding along the dike during a heavy coastal storm, he encounters a ghostly rider on a white horse. Afterwards, he stops off at an inn, where the schoolmaster of a nearby village tells him the story of the life and death of Hauke Haien and his family, said to have taken place some 100 years earlier. According to the schoolmaster and others present, the ghostly rider is a spectral figure, whose appearance in a storm foretells an impending dike breach and whose existence, as later becomes clear, can be traced back to Hauke Haien. The embedded narrative about Hauke Haien takes up the lion's share of the novella. This structure makes the text a typical representative of its genre.[13] Disability is only thematised in

10 Cheyne: Disability, Literature, Genre, p. 11, 137f.

11 Ibid. p. 114f. Referring to »some iconic figures, such as the blind wizard, wise man, or seer, an icon that gains its force from the assumed contradiction.«

12 Cf. Mitchell/Snyder: Narrative Prosthesis, p. 48; Anna-Rebecca Nowicki: Raus aus der semiotischen Falle. Die Herausforderungen und Potenziale einer Disability Studies-Perspektive in der Germanistik, in: Luserke-Jaqui, Matthias (ed.): Literary Disability Studies. Theorie und Praxis in der Literaturwissenschaft, Würzburg 2019, pp. 9–44, p. 17.

13 Cf. Horst Thomé/Winfried Wehle: Novelle, in: Braungart, Georg/Fricke, Harald/Grubmüller, Klaus/Müller, Jan-Dirk/Vollhardt, Friedrich/Weimar, Klaus (eds.): Reallexikon der deutschen Literaturwissenschaft: Neubearbeitung des Reallexikons der deutschen Literaturgeschichte. Vol. II, Berlin 2007, pp. 725–731, pp. 726, 728; Vierig: Schauerroman, p. 366; Ian Cooper: Theodor Storm and Disenchantment, in: German Life and Letters 68:4 (2015), pp. 584–597, p. 593.

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the core plot of the innermost narrative and the first frame narrative, meaning it is embedded in the perspectives of the frames. The oft-studied, polarising leitmotifs of the novella are, on the one hand, science, progress, and enlightenment and, on the other, the uncanny, superstition, and magical thinking.[14] Plot lines, characters, spaces and objects in the fictional world have opened up hermeneutic possibilities in light of one or the other of these two poles. The existence of a supernatural, uncanny entity is to some extent questioned at the narrative level of the schoolmaster,[15] but it is confirmed by the nameless author of the autobiographical narrative in the journal and not commented on by the anonymous frame narrator.[16] In virtue of the discontinuities in its perspectivisation of the uncanny, *Der Schimmelreiter* can be classified within the genre of Gothic fiction, and, more specifically, the subgenre of the Gothic-realist novella.[17]

Intertwined with this irresolvable perspectivisation of the uncanny, a similarly contradictory perspectivisation of disability can potentially be observed in the character of Wienke Haien. The narrative voice of the schoolmaster, who is, from a modern perspective, a regressive advocate of enlightenment values is dominated by an ableist perspective that defines disability as a deficiency.[18] However, in the characters of Hauke Haien, his wife Elke, and their daughter Wienke, the text constructs opposing ideological perspectivisations that stand in contradiction to those of other figures in the embedded narrative, as well as the narrative of the schoolmaster, but are also ambiguous in themselves. In order to show the contradictions and ambiguities of the novella's perspectivisation, I will focus on analysing the plot and character development in the embedded narrative: The protagonist Hauke Haien is

14 Cf. Lothar Köhn: Dialektik der Aufklärung in der deutschen Novelle, in: Deutsche Vierteljahrsschrift für Literaturwissenschaft und Geistesgeschichte 51:3 (1977), pp. 436–458, pp. 438f.; Wolfgang Tschorn: Idylle und Verfall. Die Realität der Familie im Werk Theodor Storms, Bonn 1978, pp. 168f.; Webber: The Uncanny rides again; Beata Kołodziejczyk-Mróz: Das Verhältnis zwischen Rationalem und Irrationalem im Schimmelreiter von Theodor Storm, in: Roczniki humanistyczne 57:5 (2009), pp. 67–95, pp. 75f.; Althans: Storms Schimmelreiter, p. 331; Cooper: Theodor Storm and Disenchantment, p. 587.

15 However, this is not clear; cf. Storm: Der Schimmelreiter, p. 16.

16 Cf. Köhn: Dialektik der Aufklärung, p. 440; Thomas Heine: Der Schimmelreiter: An Analysis of the Narrative Structure, in: The German Quarterly 55:4 (1982), pp. 554–564, pp. 554, 558. On the fact that the contradiction is irresolvable, cf. the contributions in note 14.

17 Cf. note 7; Catherine Delyfer: Lucas Malet's Subversive Late-Gothic. Humanizing the Monster in The History of Sir Richard Calmady, in: Bienstock Anolik, Ruth (ed.): Demons of the Body and Mind: Essays on Disability in Gothic Literature, Jefferson 2010, p. 2, pp. 80–96. pp. 85–87.

18 Cf. Storm: Der Schimmelreiter, p. 16, 114f.

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an only child, an intelligent autodidact, gifted in language and construction, and a patient, farsighted empiricist.[19] Described as an outsider from early in his life, Hauke's ambivalent development in adolescence is characterised by irascibility[20] and an interest in the macabre.[21] The schoolmaster's descriptions of Wienke's father and main caregiver are in many ways constitutive of Gothic-realist novella:[22] The ambiguity of his initial character traits, torn between rational and magical, and sometimes uncanny actions hint at the development of his character, as well as of the narrative. Within the perspectivisation of the schoolmaster, this development is marked from the beginning by a conventionalist power of failure, which, according to the symbolic logic of the plot, can in extension be attributed to his daughter.

Thanks to a profitable love match with Elke Volkerts, daughter of the incumbent dike-warden, an expansion of his holdings, and his own talent and ability, Hauke himself becomes dike-warden in a district of North Frisia, which makes him responsible for the construction and maintenance of the dikes there. In this role, he initiates and oversees the construction of a new, safer and considerably more expensive dike. However, Hauke's social advancement and engineering innovations alongside authoritarian leadership are enmeshed with social conflicts that drive him into isolation from the world outside his small family and farm.[23] This defensive isolation brings out negatively marked personality traits and behaviours, such as greed, harshness and authoritarian aggression, which are emphasised by the narrator's perspectivisation.[24] These traits stand in contrast to Hauke's behaviour as a husband and father, which is characterised by kindness, empathy, affection

19 Cf. ibid. pp. 9–11.

20 Cf. ibid. One day, when the beloved cat of a lonely woman, who is described as witch-like, snatches a bird Hauke had caught while out hunting, he kills the cat in a brutal overreaction and the woman curses him. The narrative suggests at several points that his life is influenced by the curse.

21 Cf. ibid. p. 15.

22 Cf. Thomé/Wehle: Novelle, p. 726, Vierig: Schauerroman, p. 366.

23 Cf. Storm: Der Schimmelreiter, p. 111.

24 Ibid. p. 101: »Es war doch trotz aller lebendigen Arbeit eine Einsamkeit um ihn, und in seinem Herzen nistete sich ein Trotz und ein abgeschlossenes Wesen gegen andere Menschen ein. (But in spite of all the lively work, a loneliness had spread round him, and in his heart nestled a stubbornness and a reserved manner toward other people.) […] Gegen Gesinde und Arbeiter aber wurde er strenger, (Towards servants and workmen, however, he grew more severe) […] die Ungeschickten und Fahrlässigen […] wurden jetzt durch hartes Anfahren aufgeschreckt (the clumsy and careless ones […] were now startled by his harsh address).«

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and solidarity.[25] Elke Haien, née Volkerts, is introduced in the first third of the novel. As the only child of the incumbent dike-warden, she initially enjoys a higher social status than her husband. She is characterised as a serious and mathematically gifted woman,[26] who is just as taciturn as Hauke. Their Frisian ›ethnicity‹ is repeatedly emphasised and valorised, which reads strangely from a modern-day perspective.[27] The similarities between them as social ›misfits‹ have led some interpreters to the conclusion, in line with the conventions of the genre, that, within the narrative logic of the novella, their offspring is the product of spiritual incest[28] and therefore cannot endure. This interpretation sees Wienke as a character in the sense of ›narrative prosthesis‹, according to which her »extermination« would be considered a »purification of the social body«.[29] At the same time and in an ambiguous way, according to the racist focus on ethnicity in the text, the suggested ›abnormality‹ and racialised excellence of the two parents allow us to anticipate ›abnormal‹ and excellent offspring. The text thus projects the contradictory iconisation of Wienke who will arrive later in the narrative.

Despite Hauke's advocacy of enlightenment and progress, superstition and occult practices are very important in marshland society,[30] where stories[31] and supposed eyewitness accounts of mysterious apparitions also circulate.[32] A number of incidents reveal that even Hauke and his wife are affected by the uncanny: as a teenager, Hauke is cursed by the witch-like Trien' Jans,[33] after killing her white tomcat.[34] Later, when she is an old woman, she lives on Hauke's farm, where she becomes close friends with his daughter Wienke and gives her an animal companion.[35] Here, too, through its structure and

25 Cf. ibid. pp. 36, 57, 101.
26 Ibid. p. 24: »[…] aber seine Tochter Elke, die kann rechnen!« (but his daughter Elke, she can calculate!).
27 Cf. note 2.
28 Cf. Strehl: Heredity and environment, p. 209; Urban/Nieschlag: The enigma of the old poet, p. 177.
29 Mitchell/Snyder: Narrative Prosthesis, p. 54.
30 Cf. Storm: Der Schimmelreiter, pp. 7, 14, 15, 61, 72, 106, etc. Beliefs in ghost riders, sea devils, spirits of the drowned, the importance of hanging up of mirrors when someone dies, entombing sacrificial victims in buildings (in the best case a child), and many more.
31 Cf. ibid. pp. 119f. e.g. Trien' Jans' tale of the mermaid.
32 Cf. ibid. pp. 78–80.
33 Cf. Kołodziejczyk-Mróz: Das Verhältnis zwischen Rationalem und Irrationalem, p. 91.
34 Cf. ibid. pp. 18f.; 130.
35 Ibid. p. 113: »Dann hob sie das Kind […] und setzte es derb auf den Schemel [Stool covered with the fur of her tomcat, which Hauke killed, S.O.] nieder. Da es aber stumm und unbeweglich sitzen blieb und sie immer nur ansah, begann sie mit dem Kopfe zu schütteln. »Du

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narrative form, the text creates an ambiguity, as it is simultaneously suggested that Trien' Jans has a socially positive influence on Hauke's needy, impaired child, while simultaneously suggesting the opposite through Jans' derogatory judgement and abuse, as well as hinting at the uncanny draw that she exercises on Wienke.[36]

During his rise to the position of dike-warden Hauke buys a white horse from a stranger with demonic features.[37] However, several observant farmers claim that it is actually an undead horse carcass that had disappeared from the desolate land between the dike and the sea. The schoolmaster, who repeats the tale, considers it a ghost story[38] maliciously spread by Hauke Haien's opponents.[39] The narrative leaves it uncertain whether the undead horse carcass actually exists. However, the horse exhibits a distinctive behaviour and, after it is domesticated by the paterfamilias Hauke, allows only him to ride it, with the exception of his daughter, whom he leads around on it.[40]

Already before Wienke is born, characters and objects associated with the occult are gradually introduced, with which she later develops a close relationship and which confer on her an aura of the uncanny and magical. In this way, the text lays the groundwork for aspects of the disability icon distinctive of fantasy, namely the disabled prophetess.[41]

Elke is the first to bring up the tradition of entombing sacrificial victims during the construction of a dike, albeit in an ironic context.[42] With this remark, which is referenced numerous times in the course of the plot, the death of the family is hinted at for the first time, as I will show in more detail below. While in labour, Elke has visions of her own death, as she suffers from a severe

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strafst ihn, Gott der Herr! Ja, ja, Du strafst ihn!« […] aber ein Erbarmen mit dem Kinde schien sie doch zu überkommen; ihre knöcherne Hand strich über das dürftige Haar desselben, und aus den Augen der Kleinen kam es, als ob ihr damit wohl geschehe.« (Then she lifted up the child […] and set it down roughly on the stool. But when it remained sitting there, silent and motionless and only kept looking at her, she began to shake her head. »Thou art punishing him, Lord God! Yes, yes, Thou art punishing him!« […] but pity for the child seemed to come over her; she stroked its scanty hair with her bony hand, and the eyes of the little girl seemed to show that this did her good.)

36 Cf. pp. 8f.; Storm: Der Schimmelreiter, p. 114.

37 Cf. ibid. The uncanny nature of the figure is also marked by ethnic, potentially racist categorisation.

38 Cf. ibid. pp. 74–80.

39 Cf. ibid. p. 100.

40 Cf. ibid. p. 103; cf. p. 13.

41 Cf. Cheyne: Disability, Literature, Genre, p. 114.

42 Cf. ibid. p. 72.

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fever.[43] During her vision, Elke herself can be read as a disabled prophetess. Her disability does not consist in a chronic, physical impairment, but in a lack of awareness about her own prophecies due to the constricting circumstances of the birth and serious puerperal fever, a gender-specific vulnerability.[44]

If we adopt a semiotic reading proper to the genre, the text generally conveys that the future of the parents is baleful,[45] which has led many to the conclusion that, in the narrative logic, Wienke is supposed to be the ultimate result of their flaws and wrongdoings,[46] or even their incestuous relationship.[47] Hauke and Elke remain childless for a relatively long time, leading Elke to develop severe feelings of guilt, from which Hauke must absolve her.[48] Then, »in the ninth year of marriage« (»im neunten Ehejahre«),[49] their daughter Wienke Haien is born. She is thus, quantitatively speaking, a minor character, who is only introduced two-thirds of the way through the story. At first, only a single reference is made to her later existence, one that is inserted proleptically and whose context is explained below. The narrator describes the child as »feeble-minded« (blöde) and a God-given burden.[50] Despite its diverse meanings in contemporary interpretations, »blöde« is to be interpreted negatively here, in the sense of dull-witted or feeble-minded.[51] The presence of disability is hinted at from her birth: Elke's midwife worries about the newborn's crying, which sounds »strangely muffled« (wunderlich verhohlen).[52] In infancy, she does not react to attempts to entertain her and,

43 Cf. Storm: Der Schimmelreiter, p. 97f.

44 Cf. Cheyne: Disability, Literature, Genre, p. 114.

45 Cf. Findlay: Myth and Redemption, p. 401; Köhn: Dialektik der Aufklärung, p. 442; Tschorn: Idylle und Verfall, p. 169.

46 Cf. Tschorn: Idylle und Verfall; Heine: Narrative Structure; Webber: The Uncanny rides again; Strehl: Heredity and environment; Urban/Nieschlag: The enigma of the old poet; Althans: Storms Schimmelreiter.

47 Cf. note 28.

48 Storm: Der Schimmelreiter, p. 82: »Du müsstest denn ein ander Weib nehmen; ich bring dir keine Kinder.« (You would have to take another wife then; I shall bring you no children.) »[…] Das überlassen wir dem Herrgott (We'll leave that to the Lord) […] jetzt aber, und auch dann noch sind wir jung genug, um uns der Früchte unserer Arbeit selbst zu freuen. ([…] but now and at that time too, we are young enough to have joy for ourselves in the fruits of our labors).«

49 Ibid. p. 97.

50 Ibid. pp. 16, 117.

51 (Art.) blöde, in: Deutsches Wörterbuch von Jacob Grimm und Wilhelm Grimm, Vol. 2, Leipzig (1854–1971), col. 139–140, www.woerterbuchnetz.de/DWB (12.02.25), col. 139–140; (Art.) blöde, in: Grammatisch-Kritisches Wörterbuch der Hochdeutschen Mundart, Vol. 1 (1811), col. 1082–1086, woerterbuchnetz.de/Adelung (12.02.25), col. 1082–1086.

52 Storm: Der Schimmelreiter, p. 98.

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in contrast to another infant character, she is described as facing delays in linguistic, cognitive and motor development. The descriptions remain vague, making a specific diagnosis difficult.[53] Her disability only becomes evident through normative descriptions of how she is different, both those mentioned above and others.[54] Another element that offers a premonition of the child's otherness is that she is born in the ninth year of her parents' marriage, which, in keeping with the genre, symbolises an uncanny extension of the nine months of pregnancy.

Elke is the first character in the embedded narrative to notice Wienke's divergences from a norm established by the characters and narrator and to judge them negatively at first.[55] Meanwhile, Wienke does have a happy childhood, as the text repeatedly emphasises. At a very young age, she owns a dog[56] – a sacrificial victim that her father rescued from a superstitious custom, which serves to connect Elke's earlier mention of the sacrificial burial of animals underneath new dikes with the subsequent fate of her family. As mentioned above, she is friends with a seagull[57] and the sinister Trien' Jans, whose friendliness seems to be driven by both pity and an uncanny interest in the child.[58] Thus, Trien' Jans, as a character who embodies the uncanny, displays hostility towards the disabled, as shown above, and is assigned to a similar group as Wienke. This exemplifies the genre's association between the uncanny and the disabled, as suggested by the genre. The narrator comments on the foursome:

> When by chance Hauke's or Elke's eyes fell upon this strange four-leaf clover which, as it were, was held to the same stem only by the same defect – then they cast tender glances upon their child. But when they had turned away, there remained on their faces only the pain that each carried away alone, for the saving word had not yet been spoken between them.[59]

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53 As mentioned above, Urban/Nieschlag diagnose her with phenylketonuria, cf. note 6.

54 Cf. Storm: Der Schimmelreiter, p. 117, 114, 120, passim.

55 Ibid. p. 103: »[…] Elke […] sagte mitunter schmerzlich: »Das Meine ist noch nicht so weit wie deines, Stina!« (Elke […] sometimes said with regret: »Mine isn't as far on as yours yet, Trina.«)

56 Cf. ibid. pp. 108, 111.

57 Cf. ibid. p. 111.

58 Cf. note 35.

59 Storm: Der Schimmelreiter, p. 114f. »Fielen zufällig Haukes oder Elkes Augen auf dies wunderliche Vierblatt, das nur durch einen gleichen Mangel am Stängel festgehalten wurde, dann flog wohl ein zärtlicher Blick auf ihr Kind; hatten sie sich gewandt, so blieb nur noch der Schmerz auf ihrem Antlitz, den jedes einsam mit sich von dannen trug; denn das erlösende Wort war zwischen ihnen noch nicht gesprochen worden.«

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In other words, the narrator presents Wienke's disability as a deficiency that primarily causes her parents grief, even though they conceal it from her.[60] In this way, his perspective is shown to not be any more differentiated than that of Trien' Jans. Although he describes the parents' interaction with the child as loving, despite their perception of otherness, and empathically addresses a realistic problem of parenthood in the couple's unspoken self-reproaches, the lack of agency implied by the metaphor of the four-leaf clover disparages her ability to create a community. Initially, therefore, the narrator and the characters' behaviour contribute to a consistently negative construction of disability. At the level of the embedded plot, the fact that her only friends are an old woman and animals, with whom she cannot interact as equals, is not problematised in itself.[61]

So far then, the narrative primarily constructs disability as a failure and exploitatively casts the social response to disability purely as a challenge to be overcome, rather than as the circumstance that constructs disability in the first place.[62] Once again, the text constructs a genre-specific ambiguity: In the face of Hauke Haien's ambitious attempt to secure his legacy through the new dike, on a symbolic-ableist reading his daughter appears to represent a countervailing element that threatens to invalidate this progressive accomplishment. Within the framework of Mitchell and Snyder's scheme of narrative structure, this antithesis seems to mark a step in the narrative where the »deviance is brought from the periphery of concerns to the centre of the story to come«.[63] It is in this centrality that a contradictory iconisation emerges: As the needy disabled child, Wienke receives empathy and care from her parents, and the text attempts to arouse the empathy of the reader – which is an exploitative narrative strategy, but at the same time has a potential

60 A perspective that has been reproduced in research. Cf. Heine: Narrative Structure, p. 564; Webber: The Uncanny rides again, p. 872; Strehl: Heredity and environment, pp. V, 159; Althans: Storms Schimmelreiter, p. 344. Köhn: Dialektik der Aufklärung, p. 442, speaks of an »ethical problem«, assigning the topic of disability to the broad theme of the novella, man's confrontation with nature.

61 Even if it is possible to draw parallels with other characters in Storm's late works on the basis of their friendship with animals, in the case of Wienke in the *Schimmelreiter* »isolation« (Tschorn: Idylle und Verfall, p. 145) – if we accept it as a theme – seems to be a problem caused by society.

62 The narrator reproduces disability as an absolute category, produced by an ableist society (cf. Davis, Lennard J.: Enforcing Normalcy: Disability, Deafness, and the Body. London 1995, p. 24f.).

63 Mitchell/Snyder: Narrative Prosthesis, p. 53.

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to influence a more accepting and diversity-friendly attitude of readers.[64] At the same time, the schoolmaster's perspective conveys mistrust vis-à-vis the uncanniness that both surrounds the child and emanates from her, an uncanniness which, on a symbolic reading, gives her power, albeit one that is not to be identified here with empowerment. The latter is only to be found in the form of a judgement-free perspective on the freedom to shape social relationships to other characters, where the text (contradicting the schoolmaster's perspective) attributes the capacity to act to the character.

One day, Hauke takes his daughter to the sea on the white horse, accompanied by the incomprehensible »mumbling« of Trien' Jans. At the sight of the sea, a fearful Wienke speaks incoherently and abruptly: »Father, [...] you can do that. Can't you do everything?« and »It's not doing anything to me [...] no, tell it not to do anything to us; you can do that, and then it won't do anything to us!«[65] Back home, in answer to her mother's question as to whether she likes the sea, she declares: »It talks [...] Wienke is afraid!«[66] During a visit to the dike years later, Wienke is once again overcome by fear and seems to see »into an abyss«.[67] Just like her mother before her, she appears to have a vision of her own death.[68] This vision is to be situated in the long literary tradition involving a purely symbolic interpretation of disability, i.e. that her disability is equated with a supernatural gift.[69] In addition, it seems to reflect an ongoing suggestion that there exists a connection between disability, prophetic power and femininity, in which Wienke and her mother participate, although Wienke does so to a higher degree and more permanently. They both fulfil Cheyne's additional criterion of vulnerability for the disabled prophet.[70] Since women have an educational disadvantage over men in a literary-historical context and are also depicted in the novella as propagators of superstition,[71] it is quite possible to suspect a pejorative

64 Wienke might count as a reflexive representation of disability; cf. Cheyne: Disability, Literature, Genre, p. 162.

65 Storm: Der Schimmelreiter, p. 115f. »Vater […], du kannst das doch! Kannst du nicht alles? « and »Es tut mir nichts […] nein, sag, dass es uns nichts tun soll; du kannst das, und dann tut es uns auch nichts.«

66 Ibid. p. 117: »Es spricht […] Wienke ist bange!«.

67 Ibid. p. 121: »es war, als sähe sie erschrocken in einen Abgrund«.

68 Cf. Kołodziejczyk-Mróz: Das Verhältnis zwischen Rationalem und Irrationalem, p. 91f.

69 Cf. Davis: Enforcing Normalcy, p. 100ff.; Cheyne: Disability, Literature, Genre, p. 133f.

70 Cf. p. 7; Cheyne: Disability, Literature, Genre, p. 29.

71 See also Christoph D. Weber: Deichbau und Selbstopfer. Der Katastrophendiskurs in Theodor Storms Der Schimmelreiter, in: Deutsche Vierteljahrsschrift für Literaturwissenschaft und Geistesgeschichte 90:1 (2016), pp. 109–133, p. 121.

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attitude of the text here. However, this can be attributed to the schoolmaster and the space of ›society‹.[72] There is no judgement at the level of the plot or in the ›family‹ space. In any case, Wienke's function as an ambiguous disability icon seems evident by this point.

Hauke's and Wienke's second visit to the dike occurs at the site of the narrator's prolepsis at the beginning of the story, when the teenaged Hauke wanders further and further out onto the dikes. One February, corpses start washing up on the frozen sea. Their appearance is described as unappetising and they are compared to »sea devils«.[73] Hauke Haien immediately seeks out the place where they were found: »Nobody knew whether he wanted to look for more dead, or if he was drawn to the places now deserted by the horror that still clung to them.«[74] The impression made by the frozen marshes, dikes and mudflats is described in the following terms: »it seemed as if the whole world lay in a white death«.[75] Hauke is standing on the dike looking out over the surroundings, when he notices a ghostly mass of figures emerging from between the ice floes. On his way home, he continues to be enveloped by eerie sensations:

> [...] Yet he is said to have told neither his father nor anyone else about it. But many years later he took his feeble-minded little girl, with whom the Lord had later burdened him, out onto the dike with him at the same time of day and year, and the same riot is said to have appeared then out on the sand flats; but he told her not to be afraid, it was just the herons and crows, that seemed so big and horrible, and that they were getting fish out of the open cracks.[76]

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72 Tschorn (Idylle und Verfall, p. 167) distinguishes between »work« and »privacy«.

73 A reference to superstition later repeated by Wienke under Trien' Jans' influence. Storm: Der Schimmelreiter, p. 14: »Glaubt nicht, dass sie wie Menschen aussahen […] nein, wie die Seeteufel! So große Köpfe […] gnidderschwarz und blank, wie frisch gebacken Brot!«. (Don't you believe they looked like people! […] no, like sea devils! Heads as big as this […] coal-black and shiny, like freshly baked bread!).

74 Ibid. pp. 14–16. »Es war nicht zu sagen, wollte er noch nach weiteren Toten suchen, oder zog ihn nur das Grauen, das noch auf den jetzt verlassenen Stellen brüten musste.«

75 Ibid. p. 15: »Es war, als liege die ganze Welt in weissem Tod.«

76 Ibid. p. 16: »[…] niemals soll er seinem Vater oder einem anderen davon erzählt haben. Erst viele Jahre später hat er sein blödes Mädchen, womit später der Herrgott ihn belastete, um dieselbe Tages- und Jahreszeit mit sich auf den Deich hinausgenommen, und dasselbe Wesen soll sich derzeit draussen auf den Watten gezeigt haben; aber er hat ihr gesagt, sie solle sich nicht fürchten, das seien nur die Fischreiher und die Krähen, die im Nebel so groß und fürchterlich erschienen; die holten sich die Fische aus den offenen Spalten.«
The listeners then look out the window of the inn and, under the impression that the Schimmelreiter has just ridden by, the dike-warden interrupts the schoolmaster's narrative, out of fear that the story has provoked the ghostly figure.

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While the existence of the uncanny is suggested, even if the schoolmaster urges his listeners to be reasonable, Hauke Haien is clearly sceptical and seems to view this attitude as a pedagogical mission. No mention is made of Wienke's vision here, although it plays an essential role in the resumption of the prolepsis later in the story. However, long before she surfaces in the narrative, her character is presented as a burden. At the same time, Wienke is the only character in the narrative who is entrusted with knowledge of an early childhood experience that terrified her father, even as a teenager, and that must also be considered a liminal experience, due to the poetic, death-related context. According to the father's scientific approach to explanation, the education of reason in the face of overpowering superstition is of central importance. The father's actions resemble a rite of passage, revealing a divergence between the narrator's perspective and Hauke's and Wienke's actions: The former constructs disability as a harmful deviance, whereas the latter depicts Wienke as a person in her own right, and with her own sense of agency. This divergence grows larger as the plot progresses. For the narrator, there exists only an ideologising perspective, but within the framework of the plot, disability plays no role at significant points in the narrative. Instead, the focus lies on an active subject, a friend, a prophetess, and daughter, which together constitute a unique, genre-specific disability icon.

After Wienke, who was terrified by the second visit to the dike, has run off to see Trien' Jans, her parents enter into a discussion, during which she is labelled »schwachsinnig« (feeble-minded).[77] Elke proclaims: »So we are left alone after all« (So sind wir denn doch allein geblieben).[78] She sees her behaviour as the cause of Wienke's disability, which she interprets as a punishment, while Hauke shows understanding and tries to convey acceptance.[79] Elke's statement about being alone does not negate the presence of the child, but rather scathingly addresses the mother's perceived lack of a relationship with her daughter and thus stresses the loneliness of the parents. Simultane-

77 Storm: Der Schimmelreiter, p. 117. From this point onwards, this adjective is used repeatedly, e.g. p. 120.

78 Ibid. p. 117.

79 Ibid. p. 117f.: »I love her, and she throws her little arms round me and presses herself close to my breast; for all the treasures of the world I wouldn't want to miss that!« (Ich hab sie lieb, und sie schlägt ihre Ärmchen um mich und drückt sich fest an meine Brust; um alle Schätze wollt ich das nicht missen!) »But why? […] what have I, poor mother, done?« (Aber warum? […], was hab ich arme Mutter denn verschuldet?) – »Yes, Elke, that I have asked, too, of Him who alone can know […]« (Ja, Elke, das hab ich freilich auch gefragt; den, der allein es wissen kann […]).

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ously, it expresses her concerns and doubts about the continuation of the family through the daughter, well prepared by the narrative structure of the genre's exemplar as shown above.

Only after Hauke reassures her and makes his central declaration in the text – »Don't let yourself be kept from loving your child as you do; be sure it understands that.«[80] – is Elke able to turn to her child, which she does with fervour. In other words, her husband must take the initiative before she is able to free herself from shame and feelings of guilt and live out a healthy relationship with her child.[81] This is followed by a new paragraph: »Thus the people on the dike-warden's farm lived together quietly; if the child had not been there, much would have been wanting.«[82]

This line makes clear that the family can be regarded as a safe space and that Wienke is an indispensable part of it. It is only hinted at that this represents a familial deconstruction of the interpretation of her disability that was previously understood as a deficiency and as an absolute category. The fact that they live together »quietly« suggests that the family does not and will not adhere to the socially acceptable norms and thus evades normative discrimination, whose very existence it nevertheless needs to take into account. Furthermore, in accordance with the plot and the narrator's comments, the retreat could also be attributed to Hauke and how he is perceived publicly as a result of negative behaviour, which is to be distinguished from the inclusive appreciation found in the family space. Although the text subtly calls into question the necessity of the family's withdrawal and thus the reasons for it, the withdrawal is also presented as beneficial and as a solution for the family. On the whole, this retreat functions as an exploitative ›narrative prosthesis‹ that counteracts the structure of the embedded narrative. The question of whether the text thus presents itself as a critique of the anti-disability environment of the 19th-century period, which the text depicts requires further analysis, possibly involving comparisons with contemporary literature.

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80 Ibid. p. 118: »Lass dich nicht irren, dein Kind, wie du es tust, zu lieben; sei sicher, das versteht es!«.

81 Elke's painful confession and the ensuing dynamic call to mind Garland-Thompson's remark on the potential of disability to foster integration: »Telling one's disability story is an antidote to disability disqualification, to the social banishment and apartness of the sick role and the stranger-making function of disability stigma. Making disability narrative integrates one into the human community […]« (Rosemarie Garland-Thomson: Building a World with Disability in It, in: Waldschmidt, Anne (ed.): Culture - Theory – Disability, Bielefeld 2017, pp. 51–62, p. 56).

82 Storm: Der Schimmelreiter, p. 118, »So lebten die Menschen auf dem Deichgrafshofe still beisammen; wäre das Kind nicht da gewesen, es hätte viel gefehlt.«

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Thus, while Wienke's shortcomings are initially recognised by various characters, as well as by the narrator himself, there are other indications that the character can be read without reference to a normative perspective, especially in the ›family‹ space, such as the fact that Hauke repeatedly draws strength from his interactions with his daughter.[83] As mentioned above, Wienke is the only person other than her father to ride the supposedly demonic white horse, which emphasises both her own abilities and the uncanniness she shares with her father.[84] Furthermore, she is described in terms of the same (rather limited) number of physical features as her parents.[85] While, as shown above, normative discrimination plays a role in the description of the character's behaviour, even in these cases the context points to a family's engagement in day-to-day life with progressive, inclusive approaches. Overall, it is possible to observe the character's subjectivity, dissociating it from symbolic meaning, but this remains in the background, as, in quantitative terms, it makes up a very small portion of the plot.

The non-normative aspects of Wienke's actions are inexplicably linked to the uncanny: the white horse is something that should not be ridden, and having Trien' Jans and animals as friends arouses suspicion, as does the gift of foresight. Further discrimination appears to result from the imposition of the narrator's perspective, from which readers must actively emancipate themselves by adopting Hauke Haien's point of view. That said, the empathy centred on the ›family‹ space provides a strong incentive to identify with the protagonist and his perspective. It stands in contrast to the inexplicable and ominous horror, while at the same time being linked to it, creating a unique bond, in which Wienke, as a disability icon of the Gothic-realist novella, thrives in an ambiguous way, making the degree of exploitation within the framework of the concept of ›narrative prosthesis‹ difficult to assess.

At this stage, there is an important conceptual observation to be made regarding the restriction of the theme of disability to the core narrative and the embedding of this narrative within the perspectivisations of the frame stories, as discussed above. The figurative parallel of powerlessness produced by marginalization, which both Wienke and Hauke are exposed to during

83 Ibid. p. 101: »[…] and every evening and every morning he knelt at the cradle of his child as if there he could find the place of his eternal salvation.« ([…] und an der Wiege seines Kindes lag er abends und morgens auf den Knieen, als sei dort die Stätte seines ewigen Heils).

84 Cf. ibid. p. 103.

85 Cf. ibid. pp. 103, 111, 113, 119. She has pale blue eyes, pale blonde hair and an enigmatic facial expression.

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their lifetimes and which is emphasised in the narrative by the schoolmaster, is reflected in the very structure of the novella. In this way, the form of the work itself reflects an immanent critique of hostility towards its diverse characters, without resolving the ambiguity inherent in the genre. This reading is affirmed above all at the end of the novella:

Hauke Haien, debilitated by social opposition and illness, makes an irresponsible decision to secure an old dike. On a stormy night before All Saints' Day, he rides out on his white horse to inspect both the old dike and the new one. His wife Elke brings their daughter Wienke and the dog, who had been saved from becoming a sacrificial victim, to see him. However, the worst possible scenario comes true and the old dike breaks. The reclaimed land of the new koog[86] remains unharmed, but the old, inhabited koog is swamped by a storm surge, along with the dwellings it contains. Hauke's family perishes before his eyes and Hauke throws himself and his horse into the flood, pleading to God to spare his family in return for his death.[87] The novella then concludes with a few paragraphs from the frame story in the inn set in 1830, in which a distant dike breach is reported, which the acting dike-warden insistently links with the appearance of the rider.

The aborted sacrifice from earlier in the narrative, which Hauke vainly attempted to forestall through his own self-sacrifice, is now completed. Through the extermination of the deviant a purification is carried out. But the final motif of the embedded narrative is the existential threat of losing one's family. The annihilation of the family, the protagonists of the central narrative, is naturally irreversible, but it is also incomplete, insofar as the central project of the new dike, Hauke's life's work, and whose construction the father, mother and daughter fundamentally accompanied, remains standing.

Does *Der Schimmelreiter* challenge the assumption that ableist perspectives are preferable or is the presentation of Wienke simply exploitative of disability for the sake of suspense? A reading of disability in *Der Schimmelreiter* that is limited to a semiotic understanding of the Gothic-realist novella as a subgenre has proven to be insufficient. The findings above illustrate that an inherently problematic representation does not prohibit the creation of a »reflexive representation«[88] of disability in the novella. Using the central figures of Hauke

86 A type of polder specific to the North Western German coast, protected by embankments known as dikes enclosing the land to form arable marshland.

87 Storm: Der Schimmelreiter, p. 143: »Lord, take me instead, spare the others!« (Herr Gott, nimm mich; verschon die andern!).

88 Cf. note 64.

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Haien, his wife Elke and their daughter Wienke Haien, the text constructs ideological perspectivisations that stand in contradiction to those of other figures in the internal narrative, as well as that of the schoolmaster:

As we have seen, a countervailing perspective and narrative construction emerges in the embedded narrative, which seems to be abruptly subverted at the end, in a way that fundamentally aligns with the contradictory nature both of the genre in general and of Storm's text in particular. I have laid out how ›society‹ is constructed in this embedded narrative as a dangerous space, in which discrimination is the rule and Wienke serves as a symbol of improper deviance. The space of the ›family‹, in contrast, passes through various stages of discrimination before ultimately resulting in the acceptance and inclusion of Wienke as an influential subject capable of action. It is only at this narrative level that a diversity-friendly viewpoint can be constructed to stand in internal contradiction to the narrative figure of the schoolmaster and his ableist assumptions. This does not, however, undermine Wienke's construction as an ambiguous disability icon.

In the end, it seems that the uncanny prevails: the absurd tragedy of the conclusion, which lies above all in the fact that the progressive, pious protagonist, who rejects all superstition, ends up as a ghostly figure, has been emphasised many times.[89] But in his attitude towards his daughter, Hauke shows himself to be ahead of his wife, his environment and his time, which he is able to influence to a greater or lesser extent. Within the framework of the schoolmaster's ableist perspectivisation, it is Hauke's behaviour that allows a reader to understand his daughter's disability not as a burden on the family, but as a natural manifestation of human diversity, and as a challenge to the emphasis on the homogeneity that the other characters establish as the norm.

The embedded narrative suggests that overcoming this prejudice is a task for society, but in the concrete case narrated here, it is the family's achievement and not a matter of social debate. Within the interpretative framework of the Gothic-realist novella, the imperfection of Hauke Haien's life and its guilt-ridden end, as well as the uncanny acquisition of the white horse, are brought together in the ghostly afterlife. There are also uncanny details, such as his saving the dog from sacrifice, only for it to come to pass anyway. The Old Koog, which in the semiotic reading stands for superstition, tradition, backwardness and hostility to the disabled, is flooded. Conversely, the

89 Cf. Findlay: Myth and Redemption, p. 400; John Hamilton: Rahmen, Küsten und Nachhaltigkeiten in Theodor Storms Der Schimmelreiter, in: Weimarer Beiträge: Zeitschrift für Literaturwissenschaft, Ästhetik und Kulturwissenschaften 61:2 (2015), pp. 165–180, p. 178.

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progressive work, the new dike, is preserved. At the same time, the ghostly figure of the rider is to be understood as an uncanny reference to Hauke's Cassandra-like prophecies during his lifetime. The survival of the new dike transforms Hauke Haien's spirit of innovation into a force that influences the present of the second narrative level and symbolises the perseverance of a progressive attitude in the face of regressive hostility.

Wienke does share in her father's tragic heroism to a large extent: she is a child, first and foremost there to be protected. Ultimately, her disability scarcely plays a role in the advancement of the plot, since adults steer the action in the novella and Wienke's young age leaves her in a comparatively passive position. However, she does have a strong influence on her father, representing a source of strength and sharing in some of his formative experiences. Neither Wienke nor her mother, who are both able to make Cassandra-like prophecies, return as apparitions, since neither of them shares responsibility for the disaster, but the collective demise of the family symbolises their togetherness. The novella's final image of Hauke's dike lends substance to the professional and social progressiveness of his character, which is evident in his rejection of an ableist perspective on his daughter, but also to the uncanny, with the ambiguity of the ghostly figure.

Whereas in the beginning of the novella the genre-specific symbolism presents disability itself as a facet of the uncanny and some characters' perspectives on it as running counter to this, the focus shifts as the narrative takes its course. Within the novella's narrative construction, it is possible to integrate a progressive reading drawn from disability studies, in which disability is a bearer of meaning that informs the characters' actions, into the semiotic level of interpretation particular to the genre as a whole.

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Johannes Görbert

From ›Vermin‹ to ›Superhero‹: Continuity and Change in Literary Representations of Disability – Using the Example of Franz Kafka's *The Metamorphosis* and its Literary Reception in Contemporary Disability Culture in Works by Christoph Keller[1]

1. *The Metamorphosis* from a literary and cultural disability studies point of view

Franz Kafka's *The Metamorphosis* [*Die Verwandlung*] (1915)[2] has been interpreted in a number of ways, including biographically, psychoanalytically, morally, ethically, economically, socio-historically, and in terms of genre theory, to name but a few frequently recurring readings.[3] The following article presents another type of interpretation, whose potential from a literary and cultural studies perspective seems far from exhausted. The intent is to read this highly canonical narrative through the terms of disability and with key questions from literary disability studies in mind. This field has recently started gaining traction in German-speaking countries.[4] In this context, the article also looks beyond the text of *The Metamorphosis* itself to the reception of Kafka in contemporary disability culture. To this end, the books *The Best Dancer* [*Der beste Tänzer*] (2003) and *Every Cripple a Superhero* [*Jeder*

1 This article is a translated, edited and abridged version of Johannes Görbert: Vom »Ungeziefer« zum »Superhelden«. Kontinuität und Wandel literarischer Darstellungen von Behinderung – am Beispiel von Franz Kafkas *Die Verwandlung* und ihrer literarischen Rezeption in der Disability Culture der Gegenwart bei Christoph Keller, in: KulturPoetik 24:1 (2024), pp. 22–53. The references for the Kafka and Keller editions in English that I have used are given below. All other translations (especially from research literature on Kafka in German) are my own. For the original German quotes, please refer to the article in KulturPoetik.

2 All quotes from the story are taken from Franz Kafka: The Metamorphosis. A New Translation. Texts and Contexts. Criticism. Transl. by Susan Bernofsky, ed. by Mark M. Anderson, New York, London 2016. In the following I quote passages from this edition with the page number in brackets in the body of the text.

3 Cf. the research report by Sandra Poppe: Die Verwandlung, in: Engel, Manfred/Auerochs, Bernd (eds.): Kafka-Handbuch. Leben – Werk – Wirkung. Stuttgart 2010, pp. 164–174 as well as the interpretations presented in Ulf Abraham: Franz Kafka: Die Verwandlung, in: Schneider, Sabine (ed.): Lektüren für das 21. Jahrhundert, Würzburg 2005, pp. 18–36.

4 Cf. for example the activities of the German Research Foundation (DFG) network »Inclusive Philology. Literary Disability Studies in the German-Speaking Realm«, gepris-extern.dfg.de/gepris/projekt/509035805?language=en (6.9.2024).

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Krüppel ein Superheld] (2020) by the contemporary Swiss author Christoph Keller (born 1963) are explored.[5] The guiding consideration is, firstly, that Kafka's story and its protagonist Gregor Samsa continue to offer considerable potential for being connected with the concerns of disabled people right up to the present day. Secondly, the comparison between the hypotext and Keller's hypertexts, understood overall as a critical homage to Kafka, exemplifies processes of change related to the (artistic) evaluation of disability, shifting from dominant protonormalistic to more flexible normalistic approaches in the terminology of Jürgen Link's theory of normalism.[6] While in Kafka's narrative deviations from societal norms, as embodied by its protagonist, are sharply sanctioned, Keller, specifically through his own fictional text, titled »Bug Story« [»Wanzengeschichte«], presents a literary response to *The Metamorphosis* in which forms of an extraordinary corporeality and diversity more generally appear much more accepted.

Even though perspectives on Kafka through the lenses of literary disability studies and disability culture have been sparse so far, the few existing interpretations never tire of emphasising how productive his work in general, and *The Metamorphosis* in particular, are with regard to the phenomenon of disability. This is true both for perspectives on the affected individual, who has to deal with an unusual physicality, as well as on society, which all too often patronises, discriminates and excludes people as soon as they no longer fit into the grids, patterns and conventions prescribed by social institutions.[7] Central aims of Kafka projects from disability studies and culture are accordingly to »see more clearly through the mechanisms underlying this reduction« or to »reclaim the freedom« to »be oneself [...] through creative action.«[8] Kafka's literature thus offers opportunities for identification and

5 Christoph Keller: Der beste Tänzer, Frankfurt/Main 2003 [This book has not yet been translated into English; the translations are therefore my own]. Christoph Keller: Every Cripple a Superhero, London 2022.

6 Jürgen Link: Versuch über den Normalismus. Wie Normalität produziert wird, Opladen 1997.

7 The few existing short interpretations include James A. Metzger: Re-Visioning Kafka's *Metamorphosis* Through Illness and Disability, in: Journal of the Kafka Society of America 33/34:1 (2009), pp. 56–61; Uttara Ghosh: The Metamorphosis: Through the Looking Glass of a Disabled, in: The Criterion 4:4 (2013), pp. 1–7; Katherine Findley: Living as the Bug: Kafka's The Metamorphosis as Read Through Critical Disability Theory. Texas State University 2020 [Honours Thesis].

8 Renate Hofmann: Zu Kafka gemalt, in: Kölner Stadt-Anzeiger, 16.5.2002 (www.ksta.de/zu-kafka-gemalt-13836196) (6.9.2024) [first quote]; Olaf Dehler: Literatur ohne Schranken (web.archive.org/ web/20180808114839/http://literatur-ohne-schranken.de) (6.9.2024) [second quote].

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invites further critical debate. This applies not least to the interplay between proximity and distance regarding Kafka's work which is evident in the case of Keller's autobiographical and fictional writings. Keller, who lives with spinal muscular atrophy, reveals both a strong connection especially to *The Metamorphosis* and objections to individual elements of the world-renowned story, in particular to the way it ends. As such, this literary dialogue between Kafka and Keller provides some key elements of continuity and change in literary representations of disability in the transition from the early 20th to the 21st century.

2. The »monstrous vermin«: Gregor Samsa's disabilities

Not only in *The Metamorphosis*, but in his work in general, Kafka's narrative world bears clear traits of an artistically designed protonormalism in accordance with Link's theory.[9] Boundaries between normality and deviation often appear strictly drawn in Kafka's texts. Normality is generally understood as normative, while deviations from the norm are highly unwelcome and are barely accepted by the authorities and most often punished with severe sanctions. Just two of the most famous examples are the bank employee Josef K., who struggles in vain with the mechanisms of an impenetrable bureaucracy during *The Trial* [*Der Process*], or the land surveyor K. in *The Castle* [*Das Schloss*], who is similarly isolated and powerless in the face of the societal principles surrounding him. In many instances, the society depicted in Kafka's narratives asserts a high degree of sociocultural conformity and establishes only narrow zones of normality. Instead of flat hierarchies, steep ones dominate; instead of egalitarianism and democracy, forms of authoritarian or patriarchal behaviour often characterise the narrative events. This constitutive protonormalism permeates all social areas from work life to private life. Instructions from the authorities must be obeyed at all costs; men must start families and provide for them; women must subordinate themselves to their husbands and children to their parents – these are just some of the guiding imperatives of the protonormalist settings that Kafka formulated in equally highly canonical texts such as *Letter to His Father* [*Brief an den Vater*], *The Judgement* [*Das Urteil*] and *In the Penal Colony* [*In der Strafkolonie*].

9 Cf. Link: Versuch über den Normalismus, for the following in particular the tabular comparison of »protonormalistische Strategie« and »flexibel-normalistische Strategie« on pp. 79–80. The fact that Link's work on normalism is central to the disability studies approach is also emphasised by Anne Waldschmidt: Disability Studies zur Einführung, Hamburg 2020, p. 111.

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These and many other texts thus reflect – in the author's own ›Kafkaesque‹ manner – dominant social behaviour as it was widespread at the time of his writing, both in his immediate surroundings in Prague, as well as in Europe more broadly, at the time of the First World War.[10] This early 20th century protonormalism also included guiding principles of a ›healthy‹, ›non-disabled‹ physicality. Such principles should fundamentally enable people to take up employment and procreate, and, in the case of men, to perform military service. The fact that Kafka was intimately familiar with such protonormalist norms and the social problems that arose in the event of deviations from them is not only demonstrated by his literary texts, but also by his everyday legal work at the Prague Workers' Accident Insurance Institution in Prague.[11] His official writings largely consist of documenting work accidents at industrial companies, and, during the Great War, impairments acquired on the battlefield that resulted in physical disabilities. Meanwhile, in his literary works, protagonists often transform, from one moment to the next, into involuntary deviants from the prevailing protonormalist physical norms. Gerhard Neumann has described this process, which is so constitutive of Kafka's literature, as »the dropping out of every narrative, every justifying context draining away, and as the protagonist finding himself at the mercy of a shocking event […]: ›What has happened to me?‹«[12]

The Metamorphosis also proceeds along these lines. With its famous first sentence, Gregor Samsa suddenly finds himself cast out of his normal/protonormalist physicality and into deviance. Whereas he was previously a relatively inconspicuous young adult who went through life without being known to violate any norms, he is now highly alienated from his environment in his new form as a »monstrous vermin«. All the criteria for disability as developed by the sociologist Jörg Michael Kastl can be applied to Kafka's transformed protagonist.[13] Firstly, Gregor's capacities deviate from the requirements for certain general activities; for example, his altered physicality makes it impossible for him to continue his previous form of employment.

10 For a detailed account of the socio-historical background to Kafka's writing cf. the voluminous biography by Reiner Stach, especially Die Jahre der Entscheidungen, Frankfurt/M. 2002 or, for a broad historical contextualisation of *The Metamorphosis*, Hartmut Binder: Kafkas »Verwandlung«. Entstehung – Deutung – Wirkung. Frankfurt/M., Basel 2004.

11 For a short introduction to Kafka's legal work cf. Benno Wagner: Amtliche Schriften, in: Engel/Auerochs (eds.): Kafka-Handbuch, pp. 402–409.

12 Gerhard Neumann: Kafka-Lektüren, Berlin 2013, p. 234.

13 Cf. the definition of ›Behinderung‹ (›disability‹) in Jörg Michael Kastl: Einführung in die Soziologie der Behinderung, Wiesbaden 2016, p. 88.

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Secondly, they are essentially linked to his physique (and less so to his psyche). Thirdly, they reveal themselves as relics of a process of physical damage that occurred immediately before the beginning of the story. Fourthly, they prove to be permanent right up to the very end of *The Metamorphosis.* And fifthly, they are evaluated negatively throughout by Gregor's social environment, which is also typical of disability phenomena. Thus, certain everyday activities in several crucial areas of life no longer work as they used to do, contrary to the expectations of Gregor himself and his environment. The protagonist's physical mobility changes from walking upright to moving ›on all fours‹. Although he can still passively understand and reflect on the verbal communication of his fellow human beings, he can no longer take part in their conversations himself. Moreover, Gregor's senses (especially his sense of sight) and his ability to eat are increasingly impaired as the story progresses, which ultimately means he can hardly perceive or eat anything, and finally dies an agonising death of starvation, barely conscious. Whereas before his metamorphosis, Gregor pursued a seemingly unproblematic existence as a travelling salesman, seamlessly integrated into the protonormalism of his environment and living independently with his parents and sister, he now finds himself increasingly dependent on the support of his surroundings. Gregor is transformed from the breadwinner of the family into someone in need of care, from a restless traveller to someone locked in his room, from a socially integrated citizen to an ostracised victim of repression and violence.

In the narrative, »a photograph of Gregor from his time in the military, showing him as a second lieutenant whose carefree smile as he rested his hand on his dagger commanded respect for his bearing and his uniform« (14) serves as an image that directly contrasts to the protagonist's transformed existence. The difference could hardly be greater: on the one hand, there is the soldier standing upright, fitting into the hierarchies, fulfilling norms;[14] on the other hand, there is the vermin, always bent over, increasingly isolated, who cannot be integrated into any professional or private hierarchy or convention, and who therefore drops out of any social framework that would match with protonormalist norms.[15] While Gregor's body language as a lieutenant confidently commands »respect for his bearing«, which radiates strength and vitality, he now requires, because of his metamorphosis, »many, many

14 Cf. Harald Neumeyer: Ein Leutnant und drei Insekten: Franz Kafkas *Die Verwandlung,* in: Neumeyer, Harald/Steffens, Wilko (eds.): Kafkas narrative Verfahren, Würzburg 2015, pp. 91–109, here p. 95.

15 Along the same lines, cf. Ghosh: The Metamorphosis, p. 3.

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minutes [...] like an old invalid [...] to hobble across his room« (32). This comparison once again places him in the semantic sphere of the military, but now in the vicinity of phenomena resulting from war injuries and the ageing process, two of the most common causes of impairment. The contrast between the vermin form and the uniform is also striking. Whereas Gregor's outward appearance before could barely conform more to what early 20th century society expected of its male members, his transformed appearance overrides all such norms. Gregor's overnight metamorphosis is thus one that leads him from the ›compulsory able-bodiedness‹ of his previous existence to an ›embodied difference‹ with which he continually confronts and challenges his social environment throughout the course of the narrative.[16]

It is noteworthy that Kafka endows his protagonist with attributes that strictly speaking cannot apply to his vermin form.[17] Unlike Gregor, insects do not have »eyes« that open and close (3/4), and certainly not a »mouth« (13) from which an »animal's voice« (11) could sound – they have mandibles and are voiceless. Kafka's description of a physical ›above‹ and ›below‹ also does not apply to insects, as Susanne Hochreiter has pointed out: »Because everything that moves on more than two legs is not described from top to bottom, but from front to back. Insects have a three-part body, i.e. head, chest and abdomen: only humans have an upper and lower body«.[18] On the one hand, Gregor's body therefore still has unambiguously human characteristics. On the other, Kafka's narrative also exhibits a certain fabulism in the direction of the abject, in that it presents Gregor's metamorphosis precisely in the direction of a vermin and not more like another animal species. That is because, despite all the beneficial insects – butterflies, bees, ladybirds etc. – insects are often regarded as distinctively ugly, disgusting and harmful, especially as soon as they nest in human homes. Waking up in the morning to find yourself in the form of an insect, or finding your own brother, son or colleague transformed in that way is a nightmarish image that the text further develops with all kinds of details. »Waving«, »struggling«, »trembling« and »whirring« legs (3, 4, 17, 20); »peregrinations« of his body that leave behind »sticky trails

16 Cf. Robert McRuer: Compulsory Able-Bodiedness and Queer/Disabled Existence, in: Davis, Lennard J. (ed.): The Disability Studies Reader. Fourth Edition, London, New York 2013, pp. 369–378.

17 Cf. in detail Binder: Kafkas »Verwandlung«, pp. 372–390.

18 Susanne Hochreiter: Kreißende Krisen. Männlichkeiten und Körper in Kafkas Erzählung *Die Verwandlung*, in: Hindinger, Barbara/Langner, Martin-M. (eds.): »Ich bin ein Mann! Wer ist es mehr?« Männlichkeitskonzepte in der deutschen Literatur vom Mittelalter bis zur Gegenwart, Munich 2011, pp. 234–255, here pp. 243–244.

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here and there« (25); a back hard »like a carapace« (3); a »curved brown belly segmented by rigid arches« (ibid.); a »brown fluid« that runs out of Gregor's »mouth« (12); a skin rash with »a cluster of tiny white dots« (4) – all this sums into an overall impression of Gregor's embodied difference which can hardly be captured in any way other than with the word ›repulsive‹.[19] As much as Kafka's protagonist retains certain human traits, the text also works hard to not leave the guiding metaphor of the ›vermin‹ as is, but to flesh it out with more details.[20] Gregor's form thus clearly presents a physicality full of ambiguities, which, while still evoking remnants of human ›normality‹ in those around him, at the same time presents them with glaring characteristics of animalistic ›deviations‹.[21]

In his pioneering contribution to literary disability studies, James A. Metzger has provided an illuminating account of how Gregor Samsa himself deals with his transformations. In his view, Kafka's protagonist goes through various phases that correspond to what people are often directly faced with after or during the acquisition of physical impairments. Gregor

> 1) is suddenly faced with a body that he neither understands very well nor is able to control; […] 2) initially denies the reality of his new form and tries to proceed with his day as if nothing has changed […]; 3) gradually adapts and even learns to take pleasure in new sensations and abilities […]; 4) fears losing touch with his past […]; 5) longs to be reintegrated into his prior social circle while understandably experiencing moments »of rage at the way [members of his family] were neglecting him« […]; 6) accustoms himself to solitude imposed both by real bodily limitations […] and negative social response […]; 7) is sensitive to the inconvenience he is causing his family and coworkers […]; and 8) is unable to communicate his experience to others.[22]

It is worth exploring some of the points from Metzger's phase model in more depth. For example, the situational comedy at the beginning of the story, which arises from the discrepancy between Gregor's habits and his

19 Cf. on the aspect of the ›repulsive‹ in the narrative Bernhard Winkler: Der kontaminierte Käfer. Eine ausnehmend ekelhafte Annäherung an Franz Kafkas *Verwandlung*, in: Literatur für Leser 40:1 (2017), pp. 73–83, and (with a guiding reference to Julia Kristeva's theory of the abject) Edith H. Krause: Aspects of Abjection in Kafka's The Metamorphosis, in: Literature Interpretation Theory 30:4 (2019), pp. 303–322.

20 Cf. Abraham: Franz Kafka, p. 23.

21 Andrew J. Webber: Kafka, *Die Verwandlung*, in: Hutchinson, Peter (ed.): Landmarks in German Short Prose, Oxford et al. 2003, pp. 175–190, here p. 180, interprets Gregor similarly as a member of a »doubly negated non- or un-species«, which can neither be regarded entirely as human nor entirely as animal.

22 Metzger: Re-Visioning Kafka's *Metamorphosis*, p. 57.

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radically changed appearance. After Gregor wakes up, his main concern is not with elements of his vermin form. Rather, his thoughts are mainly focused on the details of his usual daily routine and professional tasks – as if his transformed physicality was merely a trivial matter that could be neglected. At the end of the story, too, it seems almost grotesque when Gregor, shortly before his death, thinks back to his family full of »tenderness and love« (43) – to the people, it should be pointed out, who have betrayed and hurt him, and who ultimately left him alone, neglected and starving. For him, protonormalist principles typical of the early 20th century, such as an unconditional commitment to a very hierarchical white-collar existence and a strong respect for his core family with its traditional roles, remain valid even when their representatives have long turned against the protagonist and excluded him from their social circles.

Despite all the physical impairments and social disabilities to which Gregor is exposed, he does not experience his embodied difference as merely weak, frail and burdensome. After he has engaged in moving on his »many little legs« (6) for the first time, it immediately fills him with »physical well-being« (15). And after he has made a »habit« of »crawling back and forth across the walls and ceiling« in his room (26), the text tells of the »almost happy absentmindedness« with which Gregor lets his body, which he now »had […] far better under control than before«, fall from the »ceiling« to the »floor« (ibid.). Over the course of the story, Gregor thus learns to come to terms with his transformed body to a certain extent, and tries out the possibilities that this new form offers him. In this sense, Gregor's metamorphosis can also be understood as a kind of ›release‹ from previously assumed roles, which at least potentially opens scope for »unconventional being and wilful experience« for the protagonist.[23] His metamorphosis certainly brings about the »great parting« (4) in his own life that Gregor had envisioned for himself – even if not in »five or six years« (ibid.),[24] but virtually overnight and in a way completely different to any he had previously imagined.

23 Cf. Waldschmidt: Disability Studies zur Einführung, p. 181.

24 Fuji Neri: Kafka und der Körper. *Die Verwandlung* und *Ein Hungerkünstler*, in: Doitsu bungaku ronkō 38 (1996), pp. 73–91, sees »Gregor's new insect body« similarly »liberated from both economic utility and the bourgeois order« (p. 90).

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3. »It must go«: the abysses of a protonormalist environment

Gregor's immediate environment, however, especially his family, recognise little more in his transformed existence than just the abject nature of his physical ambiguity, in accordance with their protonormalist socialisation. Consequently, the protagonist is confronted with a variety of reaction patterns that people with disabilities have to endure all too often, including outside of literary fiction and throughout history, not just in the 20th century. The spectrum ranges from disgust, aversion, flight, accusation, half-hearted care, and gradually mounting negligence, all the way to outbursts of violence and obvious relief when Gregor's relatives no longer need to worry about their former provider.[25] In this context, it is of little help that the very term ›vermin‹ refers to an annoying but often completely harmless creature.[26] It is not for nothing that Vladimir Nabokov pointed out in his reading of Kafka »how kind, how good« Gregor is after his metamorphosis into a »poor little monster«.[27] Gregor's new form of existence,

> while distorting and degrading his body, seems to bring out in him all his human sweetness. His utter unselfishness, his constant preoccupation with the needs of others – this, against the backdrop of his hideous plight comes out in strong relief. Kafka's art consists in accumulating on the one hand, Gregor's insect features, all the sad detail of his insect disguise, and on the other hand, in keeping vivid and limpid before the reader's eyes Gregor's sweet and subtle human nature.[28]

However, this ›humanity‹ remains completely hidden from Gregor's social environment, in line with their very narrow understanding of ›normality‹: in the end, all they see in him is a disgusting ›thing‹ that needs to be eliminated. Therefore, Gregor *is* not only disabled, but he also *becomes* disabled: due to an increasingly hostile environment that denies him his status as a human being and, as a result, increasingly rejects any responsibility in terms of caring for his existence.

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25 Cf. also Findley: Living as the Bug, p. 26f.

26 The German term used in the narrative, »Ungeziefer«, originally simply meant »an animal not suitable for sacrifice« in the religious sense, in contrast to »Geziefer« a term that has long since ceased to be used. Cf. Simon Ryan: Franz Kafka's *Die Verwandlung.* Transformation, Metaphor, and the Perils of Assimilation, in: Seminar: A Journal of Germanic Studies 43:1 (2007), pp. 1–18, esp. p. 11, for the history of the word, related terms, and the metaphorical or ideological charge the term holds for allegedly harmful people, especially in anti-Semitic writings, which gained increasing popularity in Kafka's time.

27 Vladimir Nabokov: The Metamorphosis, in: Bowers, Fredson (ed.): Lectures on Literature, San Diego 1982, pp. 250–283, here: p. 270.

28 Ibid.

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Now, there is a broad consensus in Kafka scholarship that the text not only tells of Gregor's metamorphoses, but also of the transformations of his family members, especially those of his father and sister.[29] From the perspective of literary disability studies, these can be described not as ›dis-‹, but as ›enablement‹ of the minor characters. As Oliver Jahraus has pointed out, the basis of these transformation processes is that the Samsas react less to the »break in their reality« caused by Gregor's metamorphosis itself than to the resulting »change in their social, family, professional or also sexual circumstances.«[30] Since Gregor's embodied difference means that he can no longer think about working and starting a family in accordance with the protonormalist standards of the time, the gap he leaves behind must inevitably be filled in some other way.

Gregor's younger sister becomes this new bearer of hope and responsibility. While she previously appeared to her parents »a rather useless girl« (25), she proves to be more and more ›useful‹ in the course of the story: she initially looks after Gregor, then later begins to work and develops into a young adult. While Gregor's body continues to shrink, dry out and collapse,[31] Grete's body increasingly blossoms; by the end of the story, her ever more »beautiful, voluptuous« female characteristics make her parents think that »how it would soon be time to find her a good husband« (47). In other words, while Grete steadily gains in physical strength and agency within the family, Gregor suffers corresponding losses. This is also evident in the direct relationship between the two characters, which Joachim Pfeiffer has described as a »love-hate relationship« in the »hothouse atmosphere of an isolated nuclear family«.[32] At first, Grete seems to sacrifice herself for Gregor. The further the narrative progresses, however, the more »disgust«, »pointed negligence« and »open rejection« become evident in her.[33] Finally, it is Gregor's own sister who pronounces the death sentence on her brother with the exclamation »It has to go« (42), thus further diminishing him in his creature-like form by use of

29 Cf., for example, the handbook article by Poppe: Die Verwandlung, pp. 172–174, with references to further research literature.

30 Oliver Jahraus: Kafka. Leben, Schreiben, Machtapparate, Stuttgart 2006, p. 630. Cf. also Findley, Living as the Bug, p. 16: »Gregor's change is frightening and strange to his family, but the real animosity comes from the fact that Gregor is no longer able to support them.«

31 Cf. Peter-André Alt: Franz Kafka. Der ewige Sohn. Biographie, Munich 2005, p. 334.

32 Joachim Pfeiffer: Franz Kafka: Die Verwandlung/Brief an den Vater, Munich 1998, p. 68.

33 Ibid. Metzger: Re-Visioning Kafka's *Metamorphosis*, p. 57, places Grete's behaviour close to the phenomenon of »compassion fatigue« known from the care of relatives, in which the carer's energy for the »initial and well-intentioned commitment to compassionate, attentive care« is lost as time goes on.

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the neutral pronoun.[34] In that way, Grete deliberately uses her gain in status to further weaken Gregor's position and to ultimately eliminate him from the family altogether.

A similar ›disinhibition process‹ can also be observed in the character of the father. He had also lived at Gregor's expense for about five years after the bankruptcy of his own business. During this prolonged idleness, he had retained his habitus as the patriarch of the family, but his stature had developed into that of a superficially sluggish, overweight, tired, lethargic and slow person. Things look different after Gregor's metamorphosis, which also gets his father (back) to work. The father, who previously »would trudge […] rather slowly […] always with his gingerly advancing cane«, was again looking to be »properly erect«, with his »black eyes« peering out »acutely and attentively«; »his once dishevelled white hair […] painstakingly combed and parted until it gleamed« (30/31). Whereas his father had previously often received Gregor »in an armchair in his nightshirt«, he is now dressed at home even after work in »a smart blue uniform with gold buttons of the sort worn by porters in banking establishments« (30). The more neglected his son becomes, the more the reinvigorated father pays attention to grooming his own outward appearance, which clearly approximates to the above-mentioned »photograph of Gregor from his time in the military« (14). The father's hypocrisy is doubly evident from his behaviour. Firstly, he had obviously only faked his physical weakness to continue his role as head of the family with the least amount of effort. Secondly, he uses the uniform to present a greater social status than that which he deserves even within the family circle. As a result, he is more than ever recognised as an unchallenged authority by his wife and daughter. This is reflected in how his several physical acts of violence against his son go unquestioned. While Grete's actions remain rather latent for a long time, the father resorts to manifest violence towards Gregor from the very beginning of the story. As a result, he further weakens Gregor physically, who can only succumb to these shifts in the balance of power with respect to his relatives.

From this narrative interplay between Gregor's transformations and the highly ambivalent behaviour of his family members, it follows that what is ›disgusting‹ in the text is to be found less in the ›deviation‹ of Gregor's

34 Cf. Fernando Bermejo Rubio: Die Bedeutsamkeit der Fehlleistungen. Moralische Konflikte in Kafkas *Die Verwandlung*, in: Sabaté, Dolors/Feijóo, Jaime (eds.): Apropos Avantgarde. Neue Einblicke nach einhundert Jahren, Berlin 2012, pp. 253–270 on Grete's vacillation between the personal pronouns »he« [»er«] and »it« [»es«] to describe her brother.

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embodied difference than in the ›normality‹ of the Samsas and the society surrounding them. In Kafka's case, this is the social cosmos of Prague's petty bourgeoisie in the early 20th century, for which *The Metamorphosis* attests an unflattering, narrow-minded approach to embodied difference.[35] Gregor's work colleagues and family members show little or no flexibility in the face of the fact that their employee, son and brother no longer conforms to the usual notions of physical normality. Instead, they set in motion a whole series of processes of exclusion and stigmatisation towards him, because he no longer fulfils the social expectations placed on him.[36]

In terms of plot structure and space, this is shown by the transformation of Gregor's room and the attempts of the protagonist, situated at the end of each of the three main narrative sections, to cross the threshold of his room into the living area of the ›normals‹. Exclusion here quite literally means being shut off from the domestic social environment, by means of keys turned »from the outside« (18) to the doors of Gregor's room, which are usually kept locked and are at most »opened a tiny crack and then quickly shut again« (ibid.) to prevent Gregor from gaining access to other rooms. The transformation of his room, which is cleared out in the course of the story (cf. for example 26/27) and thus increasingly resembles a »cave or den« (27), in which more and more »refuse« (37) ends up accumulating, also shows the devaluation of its inhabitant. Gregor's repeated and always futile efforts to get out of his increasingly dishevelled room thus present him as a character of liminality in the sense of Victor W. Turner's concept,[37] which has proven itself fruitful in interpreting the situation of disabled people.[38] In both a literal and a metaphorical sense, Gregor is not in a temporary, but

35 The fact that »Kafka's heroes move on the border between normal and abnormal states, transgressing them and falling out of social convention« and are »sanctioned by being expelled from the sphere of society focused on function and performance« is similarly emphasised by Andreas Dawidowicz: Die metaphorische Krankheit als Gesellschaftskritik in den Werken von Franz Kafka, Friedrich Dürrenmatt und Thomas Bernhard, Berlin 2013, pp. 19 and 296.

36 Michael Minden: Kafka's »Die Verwandlung« and the Condition of Subjectivity, in: German Life and Letters 70:3 (2017), pp. 314–320, here p. 315, also speaks of a process of »exclusion because of its complete otherness«.

37 Cf. for example Victor W. Turner: Dramas, Fields, and Metaphors. Symbolic Action in Human Society, Ithaca 2000, esp. pp. 94–105.

38 Cf. Robert F. Murphy: The Body Silent: The Different World of the Disabled, New York 1987, p. 112, which assesses people with disabilities as »neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it.« In his view, disabled people are permanently banished to a kind of »suspended state«: »They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people.«

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in a permanent liminal situation. To cope with the uncertainties associated with his metamorphosis, his social environment has no other answer than to increasingly exclude him and ultimately deny him his humanity and let him die in isolation.

Gregor's embodied difference therefore serves to open perspectives on protonormalist social norms typical of the time of Kafka's writing, along with their unresolved contradictions, breaking points and dilemmas. On closer inspection, his counterparts exactly do not behave in a ›humane‹ way but reveal a highly irritating mixture of »greed and lust for power, sycophancy, intolerance and destructive rage towards the sick, weak and alienated.«[39] While Gregor's harmless unusual physicality brings about the most severe exclusion mechanisms, this abysmal behaviour on the part of the ›normal‹ people is not penalised by society to any significant degree. Rather, it leaves a bizarre impression when, at the end, the family discusses their »quite advantageous and […] promising […] future prospects« (46), which are supposedly on the horizon for them after Gregor's death. According to Heinz Politzer, the story thus reveals the entire »brutality of trivial life«, with which the Samsas propagate the power mechanisms and mutual dependency networks they cultivated in a newly configured way, as if nothing had happened before.[40]

Further abysses open as soon as we look back for a final time at the individual character of Gregor Samsa and specifically his ›inconspicuous‹ human existence before the metamorphosis. As with so many of Kafka's protagonists, the description of a »solipsist without ipse«, coined by Adorno, also applies to Gregor.[41] Behind his collected featurelessness, which could hardly be more inconspicuous at first, hides a whole bundle of doubtful traits. Reiner Stach sums it up aptly when he characterises Kafka's protagonist as »submissive to superiors and parents, professionally unsuccessful and without prospects, with modest hobbies, of shallow emotionality and half-smothered sexual desires«, whereby the character is at most capable of arousing »pity«, but not »sympathy«.[42] Gregor may initially appear as a socially integrated citizen in accordance with the rules of the protonormalism of his time, but at no point as a developed and self-defined personality. His novel, insect-like form

39 Dagmar C. G. Lorenz: Familie und Rollenverweigerung in Grillparzers »Der arme Spielmann« und Kafkas »Die Verwandlung«, in: Jahrbuch der Grillparzer-Gesellschaft 22 (2007/08), pp. 109–128, here p. 128.

40 Heinz Politzer: Franz Kafka, der Künstler, Frankfurt/M. 1968, p. 129.

41 Theodor W. Adorno: Gesammelte Schriften. Vol. 4: Minima Moralia. Reflexionen aus dem beschädigten Leben. Ed. by Rolf Tiedemann, Frankfurt/M. 1980, p. 255.

42 Stach: Kafka. Die Jahre der Entscheidungen, p. 224.

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can therefore also be read as a means of liberation, of escaping from his own and his social milieu's demonstrably unbearable lack of personality.[43] On both the social and the individual level, Gregor's metamorphosis into embodied difference hence serves to bring to the fore conflicts that had been smouldering in the background for quite some time – stripped of the deceptive façade of ›normality‹ that had previously cloaked them. This is triggered by a transformative process which turns the protagonist into a physically impaired figure in need of support.

4. »Samsa has SMA«: Christoph Keller's reception of *The Metamorphosis*

The considerable potential for identification and critical reflection that Kafka's story holds for people with disabilities can be seen very prominently in the literary work of contemporary author Christoph Keller. Keller, like his two elder brothers, lives with progressive spinal muscular atrophy (SMA), which he was diagnosed with at a young age. While he was still able to walk longer distances until early adulthood, for some time now he has been increasingly reliant on a wheelchair to get around. Keller addresses his disability in two of his books in more detail.[44] *The Best Dancer* tells of Keller's upbringing in Switzerland in the genre of a »fictional autobiography«.[45] *Every Cripple a Superhero* also contains mostly autobiographical passages, but these are more in the form of miniatures which now centrally related to Keller's later temporary centre of life and writing in New York City. These episodes are interrupted by ongoing chapters of the »Bug Story« mentioned at the beginning. While Keller only refers to Kafka in a single passage in *The Best Dancer*, the reference to the writer from Prague in *Every Cripple a Superhero* can be found throughout the book, both in its autobiographical and his fictional elements. Keller's pronounced admiration for *The Metamorphosis* as »one of the most powerful

43 Akila Ahouli interprets the story similarly »as a strategic rejection of the precarious conditions in which Gregor has lived and worked up to now« (p. 186); see Ahouli: Zum Zusammenwirken von Prekärem, Arbeit und Identität in Franz Kafkas *Die Verwandlung*, in: Acta Germanica 47 (2019), pp. 180–190.

44 In an interview, Keller emphasises that in the first »five or six books« of his literary oeuvre, he deliberately focused on topics other than his disability: »Until then, I was still able to suppress it well. [...] But then I was no longer able to separate a large part of my personality.« Christoph Keller: Interview with Peer Teuwsen, in: Neue Zürcher Zeitung am Sonntag, 28 November 2021, p. 65.

45 See Gieri Cavelty's review, in: Neue Zürcher Zeitung, 10.1.2004, p. 47.

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disability stories ever written« runs through both books.[46] Keller very much recognises his own situation in the narrative about Gregor:

> Rereading *The Metamorphosis*, I notice the many indications that Gregor could have my disability, and I can see the headline: SAMSA HAS SMA! As Kafka precisely describes, his muscles weaken, they atrophy, every movement is an unheard-of effort that leaves Gregor on his bed for hours, exhausted […] Not even his family wants to help him anymore. Wouldn't it be best for everyone if he died of his own accord? And the Gregor beetle does them the favour. He dies of muscle loss, starves to death because no one feeds him, finally suffocates under the weight of his body because of his weakened muscles.[47]

Keller's way of identifying himself in the reading is thus initially focused on the signs of Gregor's increasing physical impairment, especially his declining muscle strength, which similarly determines his own everyday life. Moreover, this is not the only point at which he reflects on the aversion that the social environment has towards Gregor as an »emotional and financial burden« for his family.[48] Keller describes this assessment of people with disabilities as »a monster, as a dung beetle, a deformity, a disgrace«, as »an obstacle in every respect« as the »true horror« of the disability experience even before any physical infirmity: »knowing that you're disabled and knowing that the world perceives you as such.«[49] Despite all the difficulties that somatic impairments entail in everyday life, the sociocultural forms of disability are ultimately the greater burden in Keller's view.

Alongside all the appreciation for the portrayal of Gregor Samsa's fate, a second focus of Keller's examination of Kafka's story is to imagine alternative scenarios for his handling of the experiences of disability. He works hardest on the end of Kafka's story, which already leaves a disappointing impression on him in *The Best Dancer*: »It's a pity that Gregor simply loses his strength and dies. The Samsas simply got rid of him. Kafka has evaded responsibility.«[50] Keller accuses Kafka of having given no room in his story for the »thought« that »a creature no longer conforming to the norm could

46 Keller: Every Cripple, p. 7. Cf. also p. 87, where Keller speaks of the »bravest, cruellest of all tales.«

47 Keller: Der beste Tänzer, p. 150. Cf. similarly, Keller: Every Cripple, p. 7, where, however, in addition to other similarities, differences between Kafka's character and the author are also noted: »The strength of Gregor Samsa's legs and arms is weakening. […] Quickly worsening (I am very slowly worsening), he is soon unable to make his way through his room, then even out of his bed (by now I need a lot of help getting out of my bed).«

48 Ibid.

49 Ibid., p. 87.

50 Keller: Der beste Tänzer, p. 149.

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find happiness […] outside the protected world of his room« in the Samsas' household, for example with »an insect lover«, in »an experimental laboratory«, in the »zoo« or in »a travelling circus«.[51] To a certain extent, Keller's criticism corresponds to that of Kafka towards himself. After one of his own re-readings, the latter reports a great frustration with the narrative conclusion of his own story in his diaries: »Unreadable end. Imperfect almost to the core.«[52] A major formal reason for this dissatisfaction could lie in the fact that the narrative style – which shifts here from a personal or internally-focalised perspective to a more authorial or zero-focalised one after Gregor's death – perhaps does not make sufficiently clear the irony with which the narrative instance could distance itself from the illusions and the implications of an authoritarian protonormalism as represented by the Samsa family.[53]

In *Every Cripple a Superhero*, Keller takes a somewhat more conciliatory approach to the ending of *The Metamorphosis*, which he nevertheless still identifies as the »story's flaw«: »That the master of the fragment succeeds in this case is this tragedy's real tragedy.«[54] His interpretation here is that Kafka »simply isn't a writer of happy endings«,[55] or, that he, as »so often in his stories […] [is] trying to undo his own existence«:[56]

> I realize now that Kafka gave his grisly tale a happy ending, the only one he could conceive of: one without the dung beetle in it. One without *him* in it. Or me. He, Franz Kafka, is The Other, The Cripple, who has come to the conclusion that *he* is the problem. The solution is simple: Gregor must die.[57]

Keller's reinterpretation thus consists of extending his identification with the character to the author as well. Now he understands not only Gregor's, but also Kafka's perspective as that of a ›cripple‹ who sees himself as a questionable existence, as a ›problem‹ for the world of the ›normals‹ that demands a ›solution‹. His more recent reading thus resembles biographical interpretations in Kafka research, according to which *The Metamorphosis* fulfils roughly the same function in Kafka's work that *The Sorrows of Young Werther* may have had for Goethe: that of an artistic »›self-destruction‹ whose

51 Ibid.
52 Entry from 19 January 1914, see Franz Kafka: Tagebücher. Ed. by Hans-Gerd Koch, Michael Müller, and Malcolm Pasley, in: Koch, Müller, Pasley: Schriften, Tagebücher, Briefe. Kritische Ausgabe. Ed. by Jürgen Born et al. Frankfurt/M. 2002, p. 624.
53 Cf. Pfeiffer: Franz Kafka, p. 59–60.
54 Keller: Every Cripple, p. 33.
55 Ibid.
56 Ibid., p. 7.
57 Ibid., p. 33 [original emphasis].

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literary representation replaces a real self-destruction.«[58] In this sense, Keller joins a line of interpretation that evaluates the »fate of Samsa« as the »way out of misery […] which does not exist (for Kafka).«[59]

However, even this modified interpretation does not change the fact that Kafka's story can still be read in terms of the plot pattern of a »kill or cure narrative«, as is often strongly criticised in contributions from literary disability studies on artistic representations of disability.[60] This refers to narrative plots in which a temporary disruption in a certain social order is exemplified through a disabled character, who is ultimately ›smoothed over‹ again at the end, either through a miraculous ›cure‹ or through the character's death, thereby ultimately confirming the validity of the established order. As much as the end of *The Metamorphosis* can certainly be read (in contrast to Keller's and probably also Kafka's own criticism) as a subtly ironic treatment of this narrative pattern and thus as its subversion, Kafka's story continues to be based precisely on a plot framework of this kind.

Keller's disillusionment at the fact that *The Metamorphosis* presents what he sees as »the perfectly bourgeois solution« to the ›problem‹ of Gregor's embodied difference at the end is therefore entirely understandable: »With the dung beetle out of the way (shoved away with a broom!), the remaining family, The Normal Ones, are free, freed again to resume their normal lives and celebrate their normal bodies.«[61] Alongside Kafka's delight in the literary concretisation of Gregor's body as that of vermin, which is as ›abject‹ as possible with its whirring legs, dripping bodily fluids, etc., it is certainly this ending – which even the author himself described as ›imperfect‹ and ›unreadable‹ in his diaries – that is most likely to invite fruitful critical reading from the perspective of literary disability studies, despite all the significance of the story for phenomena of disability.

5. Beyond »kill or cure«: on flexible normalism in Keller's »Bug Story«

Based on this, Keller's fictional »Bug Story« can be seen as another example of an artistic project in which people with and without disabilities can both

58 Abraham: Franz Kafka, p. 24.
59 Ibid., p. 25.
60 See, for example, the standard work by David T. Mitchell/Sharon L. Snyder: Narrative Prosthesis. Disability and the Dependencies of Discourse, Ann Arbor 2000, p. 53f.
61 Keller: Every Cripple, p. 33.

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be inspired by Kafka's work and creatively rethink it themselves. Keller's text, whose eleven sections are typographically separated from the autobiographical passages in *Every Cripple a Superhero*, thus undertakes a whole series of narrative modifications. Like Kafka's Gregor Samsa, Keller's protagonist, whom he names Dane, is confronted with a physical metamorphosis into an insect-like existence, which also begins overnight.[62] Unlike in *The Metamorphosis*, however, Dane's appearance does not change abruptly, but continually, with individual parts of his skin changing colour and then ants hatching from his navel and populating more and more parts of his body.[63]

This more gradual transformation of his protagonist is accompanied by a clear shift from manifestations of a pronounced protonormalism to those of a much more powerful flexible normalism. Keller sets his narrative in the urban cosmopolitanism of New York City in our immediate present, rather than in the petty-bourgeois milieu of Prague around one hundred years ago. His protagonist and those around him do not present themselves as colourless middle-class white-collar employees, but as self-confident urban hipster figures with a strong awareness of consumption, fashion, fitness, style and hygiene trends. Instead of the loneliness of Gregor Samsa, Dane is by no means limited to the radius of action of his flat, and neither is he increasingly isolated in his social behaviour. Instead, he can move around freely in New York City and maintain his friendships and work contacts throughout the story. Moreover, unlike Gregor, he is in a stable relationship involving an active sex life. All in all, the characterisation of Dane is not that of a colourless functionary, but rather of a dazzling personality who, before and after his metamorphosis, is standing ›in the middle of life‹ instead of on the sidelines. While Kafka's depiction of the Prague petit bourgeois cosmos is thus characterised throughout by hard boundaries and strict mechanisms of exclusion between the ›normal‹ and the ›different‹, Keller's »Bug Story« is located entirely in a setting in which such demarcations appear ›softer‹ and much easier to shift.

62 Cf. ibid., p. 65.

63 As unusual as this metamorphosis seems at first, the story hints at one point that it is fundamentally concerned with the depiction of the human body as a »host« organism. See Keller: Every Cripple, p. 109: »Dane knew well that he was some kind of planet to billions of bacteria, which kept him alive. They lived through him, and he lived through them.« The external symbiosis that Keller stages here using literary fantasy and ants thus externalises processes that ultimately take place internally in every human being in the interplay of macro- and micro-organisms.

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Against the background of this generally ›more open‹ design to diversity phenomena, a different approach to the topic of Dane's disability also unfolds in »Bug Story«. True, Keller also includes aversive social reactions to Dane's somatic changes: for example, with his ex-partner Gale, who runs away from him in horror as soon as he draws her attention to the ants on his body, and with his boss Lofty, who as soon as he learns of his employee's transformations angrily calls him a »cripple« and a »freak«, before sacking him on the spot.[64] On the other hand, Dane's somatic deviations from ›normality‹ are by no means presented as isolated, because the bodies of other characters in the story also reveal similar abnormalities. Dane's boss, for example, has a »birthmark the shape of Sicily and the size of the Sichuan province«; and the dermatologist Dr Petrossian, whom he consults, is also marked »on his left cheek« by a »strange hairy dermatological irregularity«.[65] Compared to Gregor, Dane thus is to a much lesser extent depicted as ›completely different‹ in relation to the seemingly ›completely normal‹ minor characters surrounding him. Instead, everyone in Keller's story is ultimately ›somehow different‹ such that Dane's physique differs gradually, but never categorically from those of his counterparts. While in Kafka's text, in the words of Link's normalisation theory, a »maximum compression of normality zones« can be observed, in Keller's response there is instead a »maximum expansion«, with »flexible« rather than »fixed normal and limit values«.[66]

The differentiated behaviour of Dane's partner Jess also fits in this respect. Jess at times clearly leaves the well-trodden paths of a consistently negative reaction to phenomena of embodied difference, behind. It is true that the text also describes occasional feelings of »repulsion« in Jess in the face of her partner's transformations.[67] However, this is only one aspect of a whole range of feelings towards Dane's transformations, which in other places is characterised by quite contradictory emotions such as »ardour«, a touch of enthusiasm, and a certain jealousy.[68] The ›roller coaster‹ of her feelings is made more visible in the various scenes of physical intimacy, in which Jess is both repelled and attracted by Dane's altered form. Jess thus also arrives at a variety of ways of dealing with Dane's extraordinary physicality that go

64 Ibid., p. 151.
65 Ibid., p. 88 and p. 64.
66 Link: Versuch über den Normalismus, p. 81.
67 Keller: Every Cripple, p. 89.
68 Ibid., pp. 121 and 135, where Jess is »disappointed« that Dane's ants do not also take to her body: »Wouldn't it be natural for them to migrate? Colonize me as well? Why don't they?«

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far beyond an overall gesture of negation. She is determined to see Dane's transformation as »something positive«, as »a good thing«, which she alternatively interprets as »some sort of pregnancy«, as »a second skin« for Dane, and at one point even as possibly »everybody's future« in human history.[69] She interprets changes such as those in her partner's form not simply just as »hard«, but also as »bittersweet« and ultimately as inevitable.[70] In this way, she approaches very similar thoughts to those of her partner, who sees himself living in a »trial-and-error world, a world that came with unwelcome side effects« such as his own physical metamorphosis »whether one liked it or not«.[71] Both Dane and Jess understand his metamorphosis not as a shock that causes the protagonist to fall through all existential cracks, with no prospect of improving his situation, but as an unexpected and ambivalent, but ultimately integral ›fact of life‹ that must be accepted and lived with.

Furthermore, in keeping with the title of Keller's book, Dane not only appears as a ›cripple‹, but also as a ›superhero‹. He not only loses abilities due to his insect-like, extraordinary physicality, but also gains them to a far greater extent than Kafka's protagonist. Dane's superpowers consist in using his altered physical form to solve some of mankind's everyday problems, such as ensuring a sufficient supply of food and keeping his own body warm with clothing and heating, in an unorthodox but nevertheless effective way. The »Bug Story« thus insinuates that some of humanity's central environmental problems could be solved if far more people adopted Dane's ›eco-friendly‹ extraordinary physicality, i.e., were transformed from ›normals‹ to similar ›freaks‹ resp. ›vagaries of nature‹. While Kafka's use of the term alone suggests that an entire society similar to a ›monstrous vermin‹ would almost certainly be doomed to its own destruction, Keller's ›superhero story‹, by contrast, suggests that a physicality like that of Dane could be conducive to an upswing in the general quality of life and to overcoming existential global dangers such as the consequences of environmental pollution. As such, there is much more of a focus on a ›disability gain‹ in »Bug Story« than on the ›disability loss‹ that *The Metamorphosis* emphasises over long stretches of the story.

In addition, »Bug Story«, if at all, only gives some space to a ›kill or cure‹ plot pattern through two nightmares that Dane and Jess have, in both of which the symbiotic relationship between the human body and the ant

69 Ibid., pp. 71, 109 and 133/134.
70 Ibid., p. 134.
71 Ibid., p. 123.

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population breaks down violently. However, in both cases there can be no question of restoring a certain social order via these elimination processes, especially since in the characters' waking hours, everything remains consistently peaceful in the depicted hybridisation of the macro- and micro-organisms.[72]

Here, the story ends with some of Dane's ants, which he describes as the »first of his children«, founding »a new bud colony« in an idyllic New York City park.[73] Unlike in Kafka's story, it is not old life that ends here, but new life that begins. On top of that, Dane once again presents himself both as a revenant of Kafka's protagonist and as a counterpart to Gregor Samsa's sister, in that at the end he is »delightfully stretching his young body«[74] – almost word for word identically to Grete in *The Metamorphosis* – and then is simply »floating away.«[75] While Gregor dies completely exhausted, Dane lives on full of vitality; and while Gregor's embodied difference is portrayed throughout as a ›problem‹ awaiting a ›solution‹, »Bug Story« presents Dane's extraordinary form rather as the embodiment of a new, enduring, relevant ›superhero‹ phenomenon for all people,[76] for which its environment is not yet prepared, but may be so in the future.[77] It is therefore not the protagonist himself who has to change (back) and ›overcome‹ his disability either through being ›healed‹ or through his own death to help socioculturel ›normality‹ to find its proper place again. Instead, society needs to evolve towards a broader acceptance of physical diversity, much like Dane's partner Jess already exemplifies it with her entire range of possible behaviours.

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72 Cf. also ibid., p. 150, where Dane contrasts his situation in conversation with Hale with the ›ant scene‹ in Henry David Thoreau's *Walden* (1854). Here, too, he emphasizes that in comparison to the »brutal all-out ants civil war in *Walden*«, his metamorphosis is an »entirely peaceful process.«

73 Ibid., p. 166.

74 Ibid. Cf. the last sentence of *The Metamorphosis*: »And when they arrived at their destination, it seemed to them almost a confirmation of their new dreams and good intentions, when their daughter swiftly sprang to her feet and stretched her young body« (47).

75 Keller: Every Cripple, p. 166. In Keller: Interview with Teuwsen, p. 65, the author emphasizes that in this ending he also identifies with his own protagonist, in contrast to Kafka's character: »My dying goal is to avoid the fate of Gregor Samsa. I do not want to be an obstacle that has to remove itself from life, to then be swept out of the house by the cleaning lady. I will voluntarily float away when the time comes.«

76 Cf. also the reaction of Dane's boss to his statement that he lives with a disability: »I also have a condition. Who doesn't?« (Keller: Every Cripple, p. 151).

77 Cf. the following passage at the end of the text: »He felt a bit like a product that nobody wanted. The world, however, was rarely ready for a new product upon first sight; it usually took some [time] getting used to« (ibid., p. 165).

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6. From Kafka to Keller, or: from protonormalism to flexible normalism

Franz Kafka's *The Metamorphosis* offers a rich potential for readings of the phenomenon and differentiating category of disability. The basis for this is the acquired embodied difference of the protagonist Gregor Samsa and the aversive reaction of his professional and family environment to his metamorphosis. Kafka's narrative thus corresponds with the dominant protonormalism of his time according to Jürgen Link's theory of normalism, which also has an enormous impact on the treatment of people with disabilities. Kafka's story thus exposes a problematic norm system in which ›able-bodiedness‹, which goes hand in hand with the capacity to work and start a family, appears to be an imperative. This socio-cultural environment is ill-prepared for deviations from such normality; when they occur, it reacts with a combination of flight, hypocrisy, dishonesty, disregard, neglect and physical violence that does little to promote community. In the end, Kafka's protagonist has no other way out than to step aside via his death, which provides his family members the opportunity to return to their dubious ways of being ›normal‹. Samsa's fictional ›fate‹, presented in a mixture of fantasy and realism, thus offers considerable potential for identification for all those who find themselves confronted with social aversions or experiences of devaluation due to an unusual physicality that does not meet protonormal standards.

Christoph Keller's work presents a case in point to show that Kafka's story continues to resonate with people with disabilities up to our present day. *The Metamorphosis* enables them (regrettably) to see their own common everyday experiences conveyed by social environments reflected in literary form: for example, opinions of being ›useless‹ for society, of only causing trouble, of being best kept apart from the ›normals‹ and of providing most of society with something like ›relief‹ through their own demise. At the same time, as seen in the example of Keller, the text encourages further critical thinking. This takes on both the form of autobiographical writing and the form of a fictional response narrative, which confronts the story of Gregor Samsa with a changed, historically updated understanding of disability. As we have seen, this change can be summarised with Link's terminology as one towards a much more flexible normalism, which has generally been significantly more common for large parts of ›Western‹ societies, at least since the decades immediately before and after the turn of the millennium.[78]

78 This paradigm shift is crystallised in a formula in the famous statement »It is normal to be different« in the speech given by Federal President Richard von Weizsäcker at the opening

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While Gregor finds himself exposed to a sociocultural normativity in which there is no room for his embodied difference, Dane's story ends with more confidence in social change processes towards more acceptance for his ›abnormalities‹. And while Kafka's ›vermin‹ is increasingly locked away and condemned to die isolated and abandoned in his room as a ›useless existence‹, Dane remains a lively, fully-fledged, mobile member of society until the end. In both stories, dealing with one's own altered body and with the various social reaction patterns is highly ambivalent and associated with constantly changing attitudes. These range from disgust towards the respective insect-like figure to trying out and even enjoying new somatic possibilities, in Dane's case even in the context of a ›superhero‹ existence. While Gregor's physical changes remain unintegrated to the end, Dane's appear as an integral part of a new, but still human existence: as an essential element of unexpected, unwanted and unpredictable, but ultimately also unavoidable processes of change, with which it is possible to continue living.

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Contemporary Interventions and Life Writing

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Mona Baie

»A Featureless Landscape of Humiliation and Loss«: Clinical Spaces and the Politics of Disability in Hilary Mantel's *Giving Up the Ghost* (2003)[1]

1. Introduction

The considerable increase in the publication of ›illness narratives‹[2] in recent decades presents both prospects and challenges for disability studies. On the one hand, as frequently noted, the popularity of these texts provides people with disabilities with a platform to articulate and share their stories, raising awareness for issues of health, illness and disability in the broader cultural sphere. On the other hand, there is growing concern that the upsurge of self-confessional (illness) writing in a cultural moment in which »[e]veryone has a story to tell, and everyone is telling it«[3] may only mask prevailing practices of exclusion, and may simultaneously diminish disability studies' status as a field of inquiry concerned with the *nuances* of disability's meaning across cultural and historical contexts.[4] For literary disability scholars in particular, additional hurdles arise when working on illness narratives. As

1 This article was written as part of the Swiss National Science Foundation-funded project »Medical Spaces in Literary Prose of the Long 20th Century« (SNSF project number: 50070101; principal investigator: Prof. Martina King). The research results presented here contribute to the author's PhD project in comparative literature, which explores the semantics of clinical spaces in German- and English-language autopathographical prose from the mid-twentieth century to the present.

2 Broadly conceived, »any text in which illness plays a conspicuous part can count as an illness narrative«. More narrowly defined, illness narratives are (predominantly) first-person accounts that draw on the authors' lived experience of illness and disability. Neil Vickers: Illness Narratives, in: Adam Smyth (ed.): A History of English Autobiography. New York 2016, pp. 388–401, quote on p. 388. For a discussion of related terms such as ›(auto)pathography‹ and ›disability narrative‹, see also, exemplarily: G. Thomas Couser: Body Language: Illness, Disability, and Life Writing, in: Life Writing 13:1 (2016), pp. 3–10; Rebecca Garden: Telling Stories about Illness and Disability. The Limits and Lessons of Narrative, in: Perspectives in Biology and Medicine 53:1 (2010), pp. 121–135.

3 Lorraine Adams: Almost Famous. The Rise of the ›Nobody‹ Memoir, in: Washington Monthly, 1.4.2001, www.washingtonmonthly.com/2001/04/01/almost-famous (22.2.2024).

4 See e.g. Stuart Murray: The Ambiguities of Inclusion, in: Clare Barker/Stuart Murray (eds.): The Cambridge Companion to Literature and Disability, Cambridge 2017, pp. 90–103; Harriet Cooper in this volume.

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texts written by patients, whether first-time or professional writers, illness narratives tend to be read for their showcasing of ›authentic‹ individual experience rather than for their narrative complexity and aesthetic properties. This means that despite the attention these narratives receive in popular media, scholarly explorations of the manifold ways in which they adopt, functionalise and problematise the realms of health, illness and disability are in fact often missing.[5]

Hilary Mantel's memoir *Giving Up the Ghost* (2003)[6], which chronicles the author's nearly lifelong struggle with severe endometriosis, is a case in point. Notwithstanding its widespread critical acclaim, literary scholars were slow to engage with the text. To date, most analyses of *Giving Up the Ghost* have come from scholars with an interdisciplinary perspective, relating the memoir to the insights of psychoanalytic psychosomatics, notions of female pain in the context of medical humanities/disability scholarship, and crip theory.[7] These articles already hint at the immense potential of Mantel's text as a source for disability studies. Foregrounding the way in which a physical impairment, in this case a painful chronic illness, becomes a disability by way of social isolation, medical neglect and affects of shame, *Giving Up the Ghost* provides much ground for critical readings at the intersections of health, illness, culture and society.[8] However, while said studies provide important insights into the

5 Clearly, concerns about the supposedly ›lesser‹ literary value of autobiographical writing in general and illness narratives in particular converge here. For a more detailed discussion of this issue, see: Nina Schmidt: The Wounded Self: Writing Illness in Twenty-First-Century German Literature, Rochester/NY 2018, esp. pp. 1–40.

6 Hilary Mantel: Giving Up the Ghost. A Memoir, London 2013 [2003]. In the following, references from this edition are given in parentheses within the body text.

7 See e.g. Neil Vickers: Illness and Femininity in Hilary Mantel's *Giving Up the Ghost* (2003), in: Textual Practice 33:6 (2019), pp. 917–939; Stuart Murray: Medical Humanities and Disability Studies. In/Disciplines, London 2023, esp. chapter 3: Disability/Bodies/Health/Medicine, pp. 93–115; Alexander Henry: Cripping ›Unexplained‹ Chronic Illness in 21st Century British Women's Writing. PhD Diss. Leeds 2022, esp. chapter three: ›My speech turned into a symptom‹: Ignorance, Suspicion and Chronicity in Hilary Mantel's *Giving Up the Ghost*, pp. 117–153. The (recent) scholarship on *Giving Up the Ghost* from within more ›traditional‹ literary studies has focused on autobiographical form and the peculiar position the text holds within Mantel's oeuvre, thereby, in a sense, circumventing the issue of illness and its adaptation in literature. See: Victoria Bennett: Subjectivity in Process: Writing and the ›I‹ in *Giving Up the Ghost* and *Ink In The Blood*, in: Eileen Pollard/Ginette Carpenter (eds.): Hilary Mantel: Contemporary Critical Perspectives, London 2018, pp. 73–86; Eileen Pollard: Origin and Ellipsis in the Writing of Hilary Mantel, New York 2019, esp. pp. 97–119; Lucy Arnold: Reading Hilary Mantel: Haunted Decades, London 2021, esp. pp. 13–42.

8 On this nexus see esp. Murray: Medical Humanities and Disability Studies, pp. 93–115. As Murray compellingly argues, in the case of chronically painful conditions such as en-

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broader medical and cultural concerns reflected in the memoir, many aspects of how the text narratively represents issues of chronic ill health remain unexplored. One of these aspects is the rendering of clinical settings: despite the conspicuous recurrence of such spaces – the protagonist visits numerous GPs' offices, student health services, psychiatric facilities and London's St George's Hospital – no study has specifically addressed clinical settings as one of the text's central poetological features.

Against this background, this paper considers *Giving Up the Ghost* with a focus on clinical space(s). I begin with some general observations about the text's narrative structure and discuss its status as a ›memoir‹. Taking my cues from the narratology of space, I then analyse the portrayal of ›concrete spaces‹[9] – from family homes to various outpatient clinical spaces to hospital space. Throughout these sections, I argue that the text effectively conveys a sense of a life disabled by the absence of adequate care through different forms of spatial narration: from haunted houses to uncaring clinical settings and upsetting hospital space, *Giving Up the Ghost* tells an unsettling story of the role of space in creating and sustaining the protagonist's distress.

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dometriosis, the social model of disability, which views disability largely as the result of societal barriers, loses some of its explanatory force: pain, as an immediate, physical experience cannot be ›reasoned away‹ merely by way of a theory of social construction. However, as my analysis will also show, Mantel's memoir, while exploring both the physical symptoms and the affective and social dimensions of her illness, emphasises particularly the role of medicine and society at large in failing to attend to and stigmatising her bodily experience and thus creating and sustaining an experience of disability. On chronic illnesses such as endometriosis in the context of disability theory more generally, see also: Susan Wendell: Unhealthy Disabled: Treating Chronic Illnesses as Disabilities, in: Hypatia 16:4 (2001), pp. 17–33.

9 ›Concrete space‹ is a term that I adopt from narratological theory on the textual representation of space. In contrast to metaphorical concepts of space, concrete space describes the physical environment (such as buildings, cities or landscapes) in which characters move and act. See Katrin Dennerlein: Narratologie des Raumes, Berlin 2009, p. 68; Caroline Frank: Raum und Erzählen, Würzburg 2017, p. 71. For reasons of readability, I use concrete space synonymously with the more conventional ›setting‹, which also refers to the physical surroundings of characters. See Marie-Laure Ryan: Space, in: Peter Hühn/Jan Christoph Meister/John Pier/Wolf Schmid (eds.): The Handbook of Narratology, 2nd ed., Berlin/Boston 2014, p. 797. By ›clinical spaces‹ I mean spaces in which clinical encounters – contacts between a subject/patient and a healthcare practitioner – take place.

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2. *Giving Up* on genre? A novelist's ›memoir‹

Hilary Mantel is renowned for her historical novels, particularly the *Wolf Hall* trilogy.[10] That *Giving Up the Ghost* should instead be read as a text that falls into the broad category of autobiographical writing is signalled to the reader by various (para)textual elements. The subtitle ›a memoir‹ associates the text with a specific autobiographical genre often characterised by a more focused scope than classic autobiographies, concentrating on a specific period, event or theme in the author's life.[11] That the autodiegetic narrator shares Mantel's name further suggests that the narrated life story can be presumed to align with the author herself.[12] Finally, this reading is reinforced by paratextual evidence: in journalistic writings that followed the publication of *Giving Up the Ghost*, Mantel elaborates on some of the events alluded to in the memoir, particularly her experience of chronic pain and late diagnosis with endometriosis, thus corroborating that her literary account is based on real-life experience.[13] Based on these markers in and beyond the primary text, Mantel's work could indeed be understood as a memoir in the classic sense, as it recounts in her experience with chronic illness a particularly influential and complicated aspect of the author's life.

In other parts of its formal structure, however, *Giving Up the Ghost* transgresses the generic boundaries it subscribes to in its subtitle. Instead of presenting the protagonist's life story chronologically and coherently – as memoirs typically would –, the narrative unfolds in the episodic form of five loosely linked, achronologically organised chapters. Notably, the text contains extensive passages in which memories from early childhood are recounted in great detail, beginning with the age at which the protagonist

10 Mantel was awarded the Man Booker Prize twice – for *Wolf Hall* (2009) and the sequel *Bring Up the Bodies* (2012).

11 See G. Thomas Couser: Memoir: An Introduction, Oxford 2012, esp. pp. 1–32.

12 Through the ›identity‹ of author, narrator and protagonist, the reader is offered the conclusion of an ›autobiographical (or: ›referential‹) pact‹. See Philippe Lejeune: Le Pacte Autobiographique, Paris 1996 [1975]. Please note: Because of said identity of names as well as for reasons of brevity I use ›Hilary Mantel‹, ›narrator‹ and ›protagonist‹ interchangeably in this article to denote the memoir's narrating instance. This does not mean that I am unaware of the difference between the empirical author Hilary Mantel and the protagonist-narrator featured in her memoir.

13 See e.g. Hilary Mantel: Every part of my body hurt, in: The Guardian, 7.7.2004, www.theguardian.com/society/2004/jun/07/health.genderissues (22.2.2024); How much pain is too much pain?, in: International Association for the Study of Pain Insight Magazine 2:1 (2013), pp. 8–12.

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was »sitting up in my pram« (p. 27). With this detailed representation of a toddler's inner life, Mantel obviously toys with the limits of recall, moving her narrative between the boundaries of non-fiction and fiction.[14] In addition to this, *Giving Up the Ghost* includes a meta-commentary on the act of writing that not only examines the constructed nature of the memoir as a product of language but provides further clues to its fictionality. In these self-reflective passages, Mantel presents herself as highly sceptical of the autobiographical genre. »I used to think that autobiography was a form of weakness, and perhaps I still do«, she writes (p. 6), characterising the autobiographical as a substitute genre much inferior to the novel. Her main concern with the genre, however, lies not in its presumed literary ›weakness‹ but in its potential for deception. While ›purely‹ fictional texts such as novels inherently involve imagined events, autobiographical texts exist in a grey area where fiction can masquerade as fact. Early in the book, Mantel acknowledges the challenge of writing truthfully about herself and, referencing George Orwell's aim to craft prose as clear as a »window-pane«, lists »strategies« to guard against »deception« and »persiflage«. In the subsequent section, however, she abandons these ideals:

> But do I take my own advice? Not a bit. Persiflage is my ›nom de guerre‹. […] How about some nice net curtains, so I can look out but you can't see in? How about shutters, or a chaste Roman blind? Besides, window-pane prose is no guarantee of truthfulness. Some deceptive sights are seen through glass, and *the best liars tell lies in plain words*. (p. 5, emphasis added)

Considering the text's overall narrative structure, this passage extends beyond general postmodern concerns about narrative self-fashioning and the limits of ›truth‹ in representation. The doubts the narrator here fuels regarding her reliability contribute to the text offering two contrasting interpretations to the reader: one where the text is read autobiographically and one where it is read as a highly distorted, ultimately invented life story. In allowing this ambiguity that is characteristic of ›hybrid‹ or ›autofictional‹ forms of life writing,[15] it is

14 With Zipfel, the narration of events or states of consciousness that surpass the norms of our lived reality are ›indices of fictionality‹. In a text usually read as non-fiction – such as a memoir – indices of fictionality represent a crossing of generic boundaries that lends itself to interpretation. See Frank Zipfel: Fiktion, Fiktivität, Fiktionalität: Analysen zur Fiktion in der Literatur und zum Fiktionsbegriff in der Literaturwissenschaft, Berlin 2001, esp. pp. 232–247. On the interplay between autobiographical and autofictional modes of writing in *Giving Up the Ghost*, see also Bennett: Subjectivity in Process and Pollard: Origin and Ellipsis.

15 On the ›hybrid‹ combinations of fact and fiction in autofictional writing, see also Frank Zipfel: Autofiktion. Zwischen den Grenzen von Faktualität, Fiktionalität und Literarität?, in:

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significant that Mantel parallels her writing with the telling of lies. Thus, she introduces not only a notion of border crossing or transgression in a broader sense, which can be read as working in parallel with and emphasising the protagonist's struggle with a complex condition that constantly positions her outside of the parameters of medically or socially established ›normalcy‹. She also decidedly introduces a notion of the possible deceptiveness of words that runs, as will be seen, as a red thread throughout the entire text.

3. Spatial structures I: Haunted homes

Giving Up the Ghost begins and ends with a mention of houses. In its opening passage, the middle-aged protagonist is in »Reepham, Norfolk, at Owl Cottage«; and she and her husband are trying to sell the place (p. 1). The couple walks through the premises and inspects its furnishings, and Mantel thinks back to the day when they had bought the cottage almost a decade ago in high spirits, »[climbing] the stairs to a room papered the pale yellow of a weak sunshine: better people already, calmer, kinder« (p. 16). The final chapter, titled ›Afterlife‹, also commences by talking about houses. »When we came home from Saudi-Arabia, we had various houses« (p. 233), the chapter begins, going on to recount several memories associated with the buildings and specific pieces of furniture, from the »Edwardian bathtub« to the »monster boiler« (p. 234f.). That the different houses mentioned in the memoir are intricately intertwined with the narrator's identity, as they symbolise different periods and aspects of her life, is evident not only from their prominent placement at the beginning and end but also through the extensive use of spatial metaphors that link ›houses‹ to concepts of the self. For instance, contemplating the disastrous effects years of illness had on her, Mantel likens herself to a »shabby old building in an area of heavy shelling, which the inhabitants have vacated years ago« (p. 222).

But there is something peculiar about houses as homes in Mantel's memoir: they are all haunted. In keeping with Mantel's fictional works, frequently categorised as ›gothic fiction‹, homes in *Giving Up the Ghost* are populated by various kinds of spectres; from peculiar occurrences bordering on visual or auditory misperceptions to »minor poltergeists« (p. 233) and the return of the deceased. Sometimes visible to the narrator, other times only vaguely

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Fotis Jannidis/Gerhard Lauer/Simone Winko (eds.): Grenzen der Literatur. Zu Begriff und Phänomen des Literarischen, Berlin 2009, pp. 285–314.

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sensed by her, the ›presence‹ of these ghostly figures is a recurrent theme in *Giving Up the Ghost*; a theme which is of course alluded to in the colloquial humour of the book's title as well. Considering the manifold ways in which supernatural appearances seem to irritate the protagonist, stop her in an action or alter her plans and thus change the narrative unfolding of events, Lucy Arnold's dictum of ghosts as »a ›disorganizing principle‹ that suffuses the entire body of [Mantel's] work]«[16] seems particularly apt for the memoir too.

In relation to the previous discussion on genre, the notion of spectrality which Mantel here transfers from her novels to *Giving Up the Ghost* contributes to the memoir offering itself to the reader as a fictionalised life story rather than a strictly referential text. As to the significance of inhabited spaces, ghostly appearances severely interrupt notions of homeliness and safety for the protagonist: while houses are depicted as essential in shaping her identity, it is especially through their hosting of ghostly figures that they become highly ambivalent locations – places one can never feel too safe in.[17]

4. Spatial structures II: Disabling clinical spaces

These two themes – the deception of an addressee by a speaker and the ambivalent meanings of concrete buildings – come together in another type of space portrayed in the memoir: clinical space. That clinical space holds a significant role in the narrative is hinted at early on in a remarkable scene in which Mantel parallels one of her earliest childhood memories with a situation in hospital:

> This is the first thing I remember. I am sitting up in my pram. [...] I feel dizzied. The entire world is sound, movement. Many years later, when there was a suspicion about my heart, I was sent to hospital for a test called an echocardiogram. [...] I heard the same sound, the vast, pulsing, universal roar; my own blood in my veins. (27f.)

16 Lucy Arnold: Reading Hilary Mantel, p. 2.

17 As Hilary Mantel has written elsewhere (in relation to her fictional writing): »Homes are very unsafe places to linger«. Hilary Mantel: Author, author, in: The Guardian, 24.5.2008, www.theguardian.com/books/2008/may/24/1 (22.2.2024). On the significance of houses in *Giving Up the Ghost*, and in particular how these relate to questions of gender, see also Neil Vickers: Hilary Mantel and the Space of Life Writing, in: Eveline Kilian/Hope Wolf (eds.): Life Writing and Space, London 2016, pp. 57–71.

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The scene begins in present tense, bringing the reader close to the ›experiencing I‹ in the pram, then switching to past tense, re-establishing narrative distance. By connecting early childhood memories to a heart ultrasound, the scene functions as an (implicit) prolepsis: already at the beginning of her life there is a foreboding of later years shaped by illness and series of medical interventions.

Ill health is indeed a part of the protagonist's life from childhood onwards. When the often-sickly Hilary is six years old, the local GP starts calling her »Little Miss Neverwell«; a telling nickname soon adopted by other family members (p. 82). Importantly, as Neil Vickers has argued, illness and pain are depicted as experiences that are, from an early age on, deeply gendered.[18] In her stepfather, also nicknamed as »Mr Neverill« (p. 142), the protagonist finds an example of a man who never shows bodily weakness; for him, being ill is a female privilege. Notions of (bodily) suffering are deeply enmeshed with Catholic beliefs, too, as both the upbringing at home and education at the local convent school instill in her the belief that pain is a part of life and that »short of crucifixion, you shouldn't really complain« (p. 209). Another »fact« of her life (p. 157) is her family's low social status. In the working-class family that Mantel was born into, doctors were seen as belonging to an entirely foreign, higher social class. »[Y]ou cleaned the house before they arrived« (p. 226), Mantel notes.

It is a combination of these various intersectional factors that comes together in Mantel's portrayal of clinical spaces, which she depicts as hierarchically structured, often openly hostile spheres of human interaction. Consider e.g. the following passage, which tells about the six-year-old protagonist's recurring fevers:

> My arms and legs ache with a singing pain. The doctor says it is growing pains. One day I find I cannot breathe. The doctor says if I didn't think about breathing I'd be able to do it. (p. 82)

The passage provides little spatial details, recounting appointments at the GP's office or home visits. In either case, there is a stark contrast between the patient's bodily sensations (›ache‹, ›difficulty breathing‹) and the doctor's verbal actions (›says‹), establishing a clear hierarchy where the doctor's spoken words hold authoritative sway. While the patient inhabits a physical body, the doctor possesses the power of verbalising, thereby naming/categorising (and downplaying) her symptoms.

18 See Neil Vickers: Illness and Femininity; Hilary Mantel and the Space of Life Writing.

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This type of medical encounter recurs throughout the book. During her teenage and early adult years, the protagonist continues to grapple with illness, now facing more severe symptoms, including intense (menstrual) pain and fatigue – symptoms that, a decade later, come to be seen as caused by endometriosis. Mantel's literary rendering of her severe, debilitating pain, which often left her bedridden for weeks, poignantly showcases, for one, the immense physical toll of endometriosis as a chronic gynaecological condition.[19] At the same time, the text emphasizes the experience of living undiagnosed, of enduring medically ›unexplained‹ symptoms that in various clinical and other social settings are dismissed as feigned or attributed to psychiatric causes, thereby placing emphasis on the role of society in perpetuating the protagonist's disability.[20] On a spatial level, the memoir showcases how Mantel was withheld adequate care – and therefore, effectively disabled – in two linked ways. For one, it chronicles the protagonist's fruitless search for help and a diagnosis in numerous clinical spaces, including various GPs' offices, a Student Health Service, a psychiatrist's office, and a psychiatric clinic. At the same time, despite telling of the visits to these various sites, the text invokes regarding clinical spaces what the narrator herself terms »a featureless landscape of humiliation and loss« (p. 167). This is because unlike other settings portrayed in Mantel's memoir, clinical spaces lack almost any spatial characteristics – they are narrated largely without mention of architectural or interior details, or even sensory information. Instead, clinical spaces, from the doctor's office to the psychiatric clinic, are narrated as hierarchically organised communicative settings, similar to the encounter with the GP mentioned earlier. Consider e.g. the following scene at the ›Sheffield University's Student Health Service‹:

> ›Sick?‹ said the doctor, down at the Student Health Service. ›Throw up? I'm hardly surprised. You do know that taking six aspirin is no more effective than taking three?‹
> I didn't. As it was double the ordinary pain, I'd thought I could double the aspirin. […]

19 Endometriosis is a poorly understood gynaecological condition in which uterine tissue grows outside of the womb and can cause manifold symptoms. For a discussion on the medical implications of endometriosis with regard to disability theory, see: Stuart Murray: Medical Humanities and Disability Studies, pp. 93–115.

20 On the ›inexplicability‹ of Mantel's condition as depicted in the memoir, see also: Alexander Henry: Cripping ›Unexplained‹ Chronic Illness, pp. 117–153.

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> ›Well, Miss –‹ said the doctor. He glanced down at his file, and a little jolt shot through him, as if he were electrified. ›Mrs‹ he said. ›Mrs? You've got married? Pregnant, are you?‹
> I hope not, I thought. […] (p. 168)

Numerous similar encounters with medical personnel could be cited, e.g. with staff in the psychiatric clinic where the protagonist is sent for her ›mysterious‹ pains. The structure of these encounters remains the same: an unnamed, male doctor speaks to or at her; she remains unresponsive and mostly immersed in thought. The opposition between patient and doctor is signalled graphically by the quotes that mark the doctor's speech acts while missing for the patient's ›responses‹ that take place only in thought. The conversation, or monologue, is at the centre of the scene; information on the visual, haptic or auditory characteristics of the surrounding environment is largely missing – except for minor details that allude to a medical setting, such as the ›file‹ the doctor glances at. In addition, except for Dr G., Mantel's later psychiatrist, medical characters remain nameless and are referred to only by their function: doctor, nurse, psychiatrist. Thus, clinical spaces are portrayed as de-individualised, highly standardised and functionalist sites in which the medically ›difficult‹ protagonist, who falls outside of conventional diagnostic categories, is subjected to paternalistic monologues, lacks agency, and is withheld the necessary care and interventions. Seen in this way, *Giving Up the Ghost* can be read as illustrating, in a scenic mode, how disabling spaces[21] function and feel to the individual.

5. Spatial structures III: Hospital space

However, there is one clinical space that stands out and adds a different layer to the text's exploration of illness and disability: the hospital where the protagonist eventually undergoes a hysterectomy[22]. In many ways, the atmosphere of the clinical ›landscape‹ does not change: in the hospital too, until

21 With Peter Freund, I use the term ›disabling spaces‹ to designate spaces that hinder access to care rather than provide access. Peter Freund: Bodies, Disability and Spaces: The Social Model and Disabling Spatial Organisations, in: Disability & Society 16:5 (2001), pp. 689–706. Employing Rosemarie Garland-Thomson's notion of the ›normate‹, one can think of these disabling spaces as assigning the protagonist an inferior, ›non-normate‹ subject position in which she is denied authority over her own body and experience. Rosemarie Garland-Thomson: Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature, New York 1996, p. 8 and passim.

22 Hysterectomy is the surgical removal of the uterus (womb).

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the very moment of diagnosis through biopsy, the protagonist is disbelieved to be in ›real‹ pain, even when she herself suspects endometriosis (p. 189f.). In other aspects, however, the portrayal of the hospital diverges notably from previous clinical spaces; a divergence that adds depth and complexity to the significance of the hospital setting within the narrative.

To begin with, the hospital is the only clinical space whose real-world referent as well as the exact time of narrated events are clearly indicated in the text: »Christmas week 1979. I was twenty-seven years old [and] in St George's Hospital in London« (p. 185). Interestingly, Mantel's stay coincides with the move of St George's Hospital at Hyde Park Corner to its new location in Tooting – a move which in contemporary public discourse was portrayed as a hugely exciting step to a »new hospital and teaching complex, which will be the largest and most modern in Britain«[23]. Mantel's account, however, foregrounds the chaotic, somewhat absurd experience of being a patient in a medical centre that is moving house from one side of the Thames to the other:

> Two days after I was admitted I needed to have an ultrasonic scan. For this I needed to cross London. St George's Hospital at Hyde Park Corner was in its last weeks of occupation; it was gaunt, grubby and nearly empty. My ward was almost the last to be kept open, I was told, and for the hi-tech stuff I needed to go to the new St George's at Tooting. I expected them to bring my clothes up the ward, but I was told, no, you have to go in your dressing gown, that's how patients go […] (p. 195)

In contrast to the previous ›featureless‹ clinical settings, the hospital is portrayed in much more spatial detail, not dissimilar to the family homes analysed earlier; the text mentions various subspaces within the hospital, such as different wards, nurses' stations, and an ultrasound room. The hospital is also, again akin to the family homes, a diffusely ›haunted‹ space, with hospital staff with »stricken« faces in »ashy hues« roaming the ward in the »silence of the night« and carrying stretchers with the »aspects of a bier« (p. 204). One day on her way to an examination, the protagonist stops at the »liver unit« where she sees a group of other patients waiting. These patients appear and act strangely – i.e., broadly speaking, somewhat ghostly:

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23 Anonymous: Hyde Park Corner Without St George's Hospital – It's Coming!, in: Chelsea News and General Advertiser, 25.5.1973, n.p. Despite this apparent initial enthusiasm in the press, moving St George's from Hyde Park to Tooting was a year-long affair that took about a decade longer than initially planned. See e.g. Garry B. Carruthers and Lesley A. Carruthers: A History of Britain's Hospitals, and the Background to the Medical, Nursing, and Allied Professions, Sussex 2005, esp. p. 72f.

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> They were yellow, bloated people, who resembled each other, who seemed to have joined the same family. None of them spoke to me. They just looked. They were stooped, like me. They held their abdomens draped over their forearms, holding up their own swags of flesh: like debutants scooping up their trains to nip out of Buckingham palace after their presentation.[24]

There would be more to say about the polysemous nature of the hospital in *Giving Up the Ghost*, where several other events take place that allude to a ›ghostliness‹ in combination with an ›Englishness‹ that makes the protagonist uneasy.[25] For reasons of brevity, I want to highlight one scene set in hospital space that is remarkable for both its narration of hospital experience and for its loadedness with symbolic meaning in relation to the politics of disability: the telling of the hysterectomy.

The operation in the narrative is marked by two specific points in time. On p. 203, it is »the eve of my surgery«, on p. 208 it is »a day later« when »they came to tell me what they had done«. The time span in between, i.e. the event of surgery and the situation of unconsciousness under anaesthesia, is narrated in the form of a Catholic prayer known as the ›Litany for a Happy Death‹.[26] Throughout this segment, excerpts from the prayer are interspersed with the narrator's contemplations on suffering, pain and dying in the context of Catholic faith:

> […] When my face, pale and livid, shall inspire the beholders with pity and dismay; when my hair, bathed in the sweat of death, and stiffening on my head, shall forebode my approaching end, *Merciful Jesus, have mercy on me*. When my ears, soon to be for ever shut to the discourse of men, shall be open to hear the irrevocable decree, which is to fix my doom for all eternity, *Merciful Jesus, have mercy on me*. […]
> I admire particularly the phrase about the hair stiffening on the head. This road to dissolution, the good Catholic was encouraged to walk regularly, following Christ to Calvary. St Peter, we were taught, was crucified upside down; this was more

24 See also the autobiographical short story *Meeting the Devil* (later published as *Ink in the Blood: A Hospital Diary*), in which Mantel writes about another hospital stay. It features, somewhat unsurprisingly, a ghost. Hilary Mantel: Meeting the Devil, in: Alan Bennett (ed.): Meeting the Devil: A Book of Memoir from the London Review of Books, London 2013, pp. 3–16.

25 Hilary Mantel felt ambivalent about her English identity. With Irish descent, she preferred to be called a ›European‹ writer. See: Hilary Mantel: No Passes or Documents Are Needed. The Writer at Home in Europe, in: Zachary Leader (ed.): On Modern British Fiction, Oxford 2002, pp. 93–106.

26 The ›Litany for a Happy Death‹ is a Christian prayer associated with the Catholic tradition. It is also known as ›Litany of a Happy Death‹ or ›Litany for the Dying‹ and circulates in several versions. The version that Mantel quotes seems to be among the most popular ones, published, inter alia, in *The Purgatorian Manual*, a Catholic prayer book from 1946.

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> merciful for him, since he would have lost consciousness. I was told this three times during my high school education, by the same woman, and each time in my mind I rehearsed her solemn upending, as if she were a geometrical figure that I had been asked to envisage in some other position. I think she believed Peter had got off lightly.
> When the last tear, the forerunner of my dissolution, shall drop from mine eyes […] (p. 206f.)

Mantel here employs a technique of montage, weaving together religious language deeply connected to the faith and values that had accompanied her throughout her life with personal comments. In the commentary, she criticises the rigidity of Catholic teachings on the endurance of pain and suffering in a darkly humorous, mocking tone, hereby undermining the supposed authority of the litany.

What narrating the situation of unconsciousness under anaesthesia in the form of a critical engagement with a Catholic prayer means in this instance is vastly interpretable. Encountering death is undeniably one of the central themes in these passages, as the hysterectomy symbolises various literal and metaphorical deaths for the narrator: her own potential death under anaesthesia, the loss of her unborn child, and the end of her aspirations to become a mother. But the scene also carries implications related to the politics of disability. This is because the narrated prayer comprises yet another type of ›deception‹ – with religious connotations in this case. Similar to the encounters with various doctors in GPs' offices, student healthcare facilities and psychiatric clinics, here, too, it is another instance that ›does the talking‹ and dictates her relationship to her body in pain.[27] Hence, again a form of disabling takes place, which however this time is ›actively‹ confronted by the protagonist: unlike in the clinical spaces analysed before, she enters into dialogue with her ›opponent‹, responding bit by bit to the litany's sayings in a humorous and self-confident tone. In contrast to the conversations with medical personnel, there are no quotation marks that indicate a hierarchy between

27 A detailed exploration of the profound implications the cited passage encompasses, particularly concerning Catholic conceptions of suffering and their broader impact on cultural notions of (female) pain, is beyond the scope of this discussion. In both the memoir and her journalistic works on pain, Mantel points to the influence of her religious upbringing as contributing to her downplaying and concealing her endometriosis-related symptoms for years. See e.g.: Mantel: Giving Up the Ghost, pp. 132–135; Mantel: How much pain is too much pain. Moreover, it is worth noting that Catholicism for Mantel held significance beyond religious beliefs. Being raised Catholic contributed to her feeling estranged from English society, with ›Englishness‹ in her view being a »white, male, southern, Protestant, and middle class« condition. Hilary Mantel: No Passes or Documents Are Needed, p. 96.

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spoken words and inner thoughts. Moreover, it is important to note that the final words in the dialogue stem from the protagonist, not the litany. In these final comments, she once more forcefully rejects the notion of living »in the shadow« of Catholicism and its idea of a »happy«, ›uncontested‹ death (p. 207f.) before waking up from an operation that in later passages is described as having (at least temporarily) led to some significant improvements in her overall health. In all its ambivalence, hospital space in Mantel's memoir thus functions – at least in part – as a space of tentative liberation.

6. Conclusion

This paper considered Hilary Mantel's *Giving Up the Ghost* with a focus on clinical spaces. My analysis showed that clinical spaces, from GPs' offices to outpatient clinics and hospital space, hold a significant role within the narrative. It is specifically through narrating these clinical spaces as hierarchically organised social settings dominated by deceptive speech acts that the memoir effectively conveys a sense of a life profoundly disabled by societal factors, medical neglect and verdicts of religion – whilst also telling of the tentative, difficult emancipation from all these forces. In this process of the protagonist's emancipation, hospital space is of paramount importance. Hospital space not only ›contains‹, but powerfully integrates reflections on issues as diverse as self- and motherhood, medical authority, religion, and death, thus giving material form to the culmination of the memoir's central negotiations.

In addition to having added to our understanding of Mantel's memoir, I hope to have shown that spatial analysis provides a useful methodological starting point for scholarly work on narratives of illness and disability more broadly. Future work on clinical spaces in pathographies and other genres of illness writing can build on, and extend, the methods employed in this article. And perhaps there lies an additional value in *close reading* per se (whether with attention to spatial or other phenomena) that relates back to this paper's initial remarks: paying meticulous attention to individual texts – as literary scholars are well equipped to do – may helpfully nuance our current understanding of cultural negotiations surrounding health, illness and disability.

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Jenny Bergenmar

Neurodivergent Reading: Towards a Theoretical Framework

Neurodiversity as an activist and theoretical concept is no longer new, although in academia, it is still only marginally used outside of Anglo-American contexts. The concept emerged from collective discussions in autistic communities in the mid 1990s, forwarding the idea of neurological diversity.[1] Challenging a pathology perspective that views any deviation from an assumed universal norm as necessitating remedy through curing or treating, the concept of neurodiversity offers a way of valuing subjectivity that in a pathology perspective is perceived as deficient.[2] Neurodivergence, in turn, is a term describing the neurominorities that do not fit the universal norm. Defining the term »neurodivergent«, activist Kassiane Asasumasu emphasized it as a »tool of inclusion«, encompassing »Autistic people. ADHD people. People with learning disabilities. Epileptic people. People with mental illnesses. People with MS or Parkinson's or apraxia or cerebral palsy or dyspraxia or no specific diagnosis but wonky lateralization«.[3]

It is hard to estimate the extent to which these concepts have become influential in non-British European humanities contexts. However, as a Nordic scholar, I have observed a growing interest in Denmark, as evidenced by a special issue of the academic journal *Kultur og Klasse* on neurodiversity in 2025. In Sweden, the cultural journal *Kritiker* dedicated a thematic issue to neuroqueerness in 2023.[4] This issue notably featured a translated essay by UK author Joanne Limburg, who introduced the concept of »weird« as a vehicle to establish connections with historical authors and literary characters

1 Cf. Monique M. Botha/Robert Chapman/Morénike Giwa Onaiwu/Steven K. Kapp/ Abs. Stannard Ashley/Nick Walker: The Neurodiversity Concept was Developed Collectively: An Overdue Correction on the Origins of Neurodiversity Theory, in: Autism 12.3.2024, doi-org.ezproxy.ub.gu.se/10.1177/13623613241237871 (20.4.2024).

2 Cf. Nick Walker: Neuroqueer Heresies. Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities, Fort Worth 2021, pp. 31–46.

3 Kassiane Asasumasu: PSA from the actual coiner of ›neurodivergent‹, sherlocksflataffect.tumblr.com/post/121295972384/psa-from-the-actual-coiner-of-neurodivergent (20.4.2024).

4 Cf. Elisabeth Hjorth/Anna Nygren: Vi kanske kan prata i kors på egna språk? Det neuroqueera numret, in: Kritiker 67 (2023). Moreover, in 2021, the research project »Autistic Writing in a Neuromixed Space: Reclaiming, Reloading Another Mother Tongue« was launched, bringing together scholars from literary composition (Elisabeth Hjorth, Anna Nygren), philosophy (Jonna Bornemark), and sociology (Hanna Bertilsdotter Rosqvist).

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with neurodivergent resonances before diagnosis.[5] The endeavor to establish a literary history for neurodivergent individuals that transcends current classifications of subjectivity mirrors the initiatives to construct a queer (literary) history that embraces the subjective experiences of queer individuals; texts that, as Carolyn Dinshaw expresses it, »touch across time«.[6]

In this chapter, I will reflect on what a neurodivergent critical framework for the interpretation of literary texts may look like, in relation to queer and crip theory in particular.[7] I will begin by discussing the theoretical underpinnings of the concepts neurodivergence and neuroqueerness in relation to feminist, queer and crip theory. Positioned as I am as an (undiagnosed neurodivergent) Nordic scholar in the periphery of the US and UK dominated field of literary disability studies, I will also comment on the vital link between linguistic diversity and the theoretical vocabulary we use. Finally, building on queer theory, I will propose methodologies for conducting a neuroqueer textual analysis: through worldmaking, through reparative reading,[8] and through genre and temporality, at the same time also illuminating the differences between a queer and a neuroqueer reading.

Positioning neurodivergence in theory

Neurodivergence does not align with predefined sets of critical theories. The foundational premise in this discussion is that neurodivergence serves as a vantage point that exposes gaps within existing theoretical frameworks, necessitating the fusion of theories from diverse fields. In Walker's essay »Throw away the Master's Tools: Liberating Ourselves from the Pathology Paradigm«, first published in 2012 and later revised in *Neuroqueer Heresies* (2021), Audre Lorde's seminal speech »The Master's Tools Will Never Dismantle the Mas-

5 Joanne Limburg: Perspektiv: Problemets form, translated by Ann-Marie Tung Hermelin, in: Kritiker 67 (2023). The essay was originally published as Perspective: The Shape of the Problem in: The Poetry Review 107:1 (2017).

6 Carolyn Dinshaw: Getting Medieval. Sexualities and Communities, Pre- and Postmodern, Durham 1999, p. 12.

7 I will use both the concepts »neurodivergent« and »neuroqueer«, the latter for practices of neuroqueering, and for overlappings of queer and neurodivergent identities. See Walker, Neuroqueer Heresies, pp. 158–163.

8 Cf. Eve Kosofsky Sedgwick: Paranoid Reading and Reparative Reading; or, You're So Paranoid, You Probably Think This Introduction Is about You, in: Sedgwick, Eve Kosofsky (ed.): Novel Gazing: Queer Readings in Fiction, Durham 1997.

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ter's House« from 1972 was employed to define a minoritarian stance.[9] Lorde, a black, lesbian feminist, originally used this phrase to deliberate on means and methods for attaining liberation.[10]

Drawing from Lorde's text, Walker critiqued the pathology paradigm and used the concept of »neurominority« to characterize the social experiences of neurodivergent individuals. Emphasizing a minoritarian stance foregrounds issues of oppression and rights; minority groups endure discrimination, marginalization, and share common experiences. Although the forms of oppression experienced by women, racialized individuals, LGBTQ+ individuals, and neurodivergent individuals differ, there exists a collective need for a theoretical paradigm enabling scholars and activists to challenge norms that construct power structures, be they rooted in sexism, racism, homophobia, transphobia, or ableism. For Walker, this transformation is closely tied to the development of a neurodiversity vocabulary to supplant the language of pathology.

Asserting a minority position underscores ethical considerations and positionality, just as Lorde did in her speech. She centered on the subjective experience and on marginalization as a position of knowledge. When researching neurodivergence, it is imperative to consider the position that scholars adopt. This implies a shift from being a scholar merely observing neurodivergence as an object of study to engaging in a neuromixed space that acknowledges neurocognitive privilege.[11] The ethics of research in this domain must encompass these considerations and an openness to experiences different from our own, irrespective of how well we conform to neuronorms. According to Robert Chapman, the concept of neurodiversity not only aids in challenging dehumanizing medical language and practices but also fosters solidarity, resistance, and the development of shared vocabularies for comprehending our experiences within and between neurominorities.[12]

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9 Cf. Walker: Neuroqueer Heresies, pp. 16–28.

10 Cf. Audre Lorde: The Master's Tools Will Never Dismantle the Master's House [1972], in: Sister Outsider: Essays and Speeches, Berkeley 2007, pp. 110–114.

11 Cf. Hanna Bertilsdotter Rosqvist/ Monique Botha/Kristien Hens/Sarinah O'Donoghue/Amy Pearson/Anna Stenning: Cutting Our Own Keys: New Possibilities of Neurodivergent Storying in Research, in: Autism: The International Journal of Research and Practice 27:5 (2023), pp. 1235–1244.

12 Cf. Robert Chapman: Defining Neurodiversity for Research and Practice, in: Bertilsdotter-Rosqvist, Hanna/Chown, Nick/Stenning, Anna (eds.): Neurodiversity Studies. A New Critical Paradigm, London and New York 2020, pp. 218–220, here p. 220.

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Feminist thought and intersectional theory have offered critical perspectives for conceptualizing neurodivergence. An inherent challenge in discussing disability in general within an intersectional framework lies in the vast array of differences encapsulated within disability itself – ranging from visible to invisible disabilities, among others. Walker underscores that the social dynamics related to neurodiversity mirror those associated with other forms of human diversity, such as ethnicity, gender, or culture.[13] Ableism conjoins with other systems of oppression, and a central question for neurodivergent critical frameworks is how neurodivergence is intertwined with other dimensions of difference.[14]

The term »queer«, originally denotes something peculiar or unusual, something that »marks a move away from something – a deviation from an otherwise straight path«.[15] This strongly resonates with the neurodivergent experience of being perceived as »weird«, as Limburg expresses it.[16] There are significant intersections between neurodivergence and queerness, a topic explored through the lens of the concept »neuroqueer«. Remi Yergeau has unveiled overlappings between queerness and autism in various contexts. These are for example discernible in associations between cognitive disability and sexual deviance in medical history, in present gender-normalizing objectives of treatments such as applied behavioral analysis (ABA), and in previous assumptions in the theory of mind that autistics possess a male brain.[17] Yergeau claims that »[w]hat autism provides is a backdoor pathologization of queerness, one in which clinicians and lay publics alike seek out deviant behaviors and affectations, and attempt to straighten them«.[18] Experiences of being queer and neuroqueer also overlap in shared experiences of passing and masking. Passing can be defined as presenting oneself as part of a privileged group from a position of discrimination. Masking is used to describe neurodivergent people's temporary adaption to neuronorms to avoid stigma

13 Cf. Walker: Neuroqueer Heresies, pp. 19–20.

14 Cf. Alison Kafer/Eunjung Kim: Disability and the Edges of Intersectionality, in: Barker, Clare/ Murray, Stuart (eds.), The Cambridge Companion to Literature and Disability, Cambridge 2018, pp. 123–138.

15 Will Stockton: An Introduction to Queer Literary Studies. Reading queerly, London 2022, p. 3.

16 Joanne Limburg: Letters to My Weird Sisters. On Autism and Feminism, London 2021, p. 11.

17 Remi Yergeau: Authoring Autism. On Rhetoric and Neurological Queerness, Durham 2017, pp. 68–73. See also Simon Baron-Cohen: Essential Difference. Male and Female Brains and the Truth About Autism, New York 2003, p. 109.

18 Yergeau: Authoring Autism, p. 26.

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and discrimination.[19] It is akin to the concealment experienced by other marginalized communities, where individuals purposely hide aspects of their identity.[20]

Walker purposefully refrains from precisely defining the term «neuroqueer« in terms of identity. Instead, the concept is employed as a verb – *neuroqueering* – referring to actions enacted and performed by subjects rather than an identity marker.[21] Just as the practice of queering may be described as resisting hetero- and cisnormativity, neuroqueering is the act of liberating oneself from culturally established and compulsory neuronorms concerning cognition, perception, sociality, and emotionality.[22] Neuroqueering starts from the premise that there exists a neuronormativity based on medical discourse and normative social practices, and it aims to reclaim interpretive agency from this normativity. In this sense, neuroqueering aligns closely with the concept of »crip«, which also engages with pathologization while resisting it.[23] Neuroqueering implies a queer and crip response to normative and pathologizing conceptions of gender, sexuality, and ability. As in crip theory, neuroqueering entails a critical perspective on assumptions about ability and autonomy, and how these are created in intersection with other factors. Both queer and crip theoretical perspectives aim to deconstruct and question reductionist interpretations of human experience, and challenge binary distinctions between normality and divergence.[24] As Alison Kafer argues, to »claim crip critically is to recognize the ethical, epistemic, and political responsibilities behind such claims; deconstructing the binary between disabled and able-bodied/able-minded requires *more* attention to how different bodies/minds are treated differently, not less«.[25]

19 Cf. ibid., p. 123.

20 Cf. Danielle Miller/John Rees/Amy Pearson: ›Masking Is Life‹: Experiences of Masking in Autistic and Nonautistic Adults, in: Autism in adulthood: challenges and management 3–4 (2021), pp. 330–338. Research has mainly centered on autistic masking.

21 Walker: Neuroqueer Heresies, p. 160.

22 Cf. ibid.

23 Cf. Robert McRuer: Crip theory. Cultural Signs of Queerness and Disability, New York 2006.

24 Cf. Justine Egner: A Messy Trajectory. From Medical Sociology to Crip Theory, in: Green, Sarah E./Barnartt, Sharon N. (eds.): Sociology Looking at Disability: What Did We Know and When Did We Know it, Bingley 2016, pp. 159–192.

25 Alison Kafer: Feminist, Queer, Crip, Bloomington 2013, p. 13.

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Extending the vocabulary

All the concepts and theoretical contexts discussed here have their theoretical limitations or complications. Intersectional feminist scholars have explored the social implications of the intersection of gender, race, class, and sexuality, but disability perspectives have remained more limited.[26] Crip perspectives have often centered on physical disability, by focusing on able-bodiedness.[27] However, as Kafer argues, there are »possibilities for cross-movement work, both politically and intellectually«.[28] There are potentialities in bringing queer theorizing in contact with experiences of disability.[29] The Nordic concept ›skev‹ (in Swedish) or ›skeiv‹ (in Norwegian) might be valuable to describe these intersections. This concept was originally used in Denmark and Norway to signify activist dimensions of queer culture.[30] While sometimes used as a translation of queer, its literal meaning conveys something lacking in straight direction, a divergence or deviation from a norm or expectation. In research, it has been employed to denote queerness beyond sexuality, describing deviations from a broad spectrum of norms encompassing not only gender and sexuality, but also behavior, emotions, communication, and thinking. Additionally, analogous to queer as an interpretative framework in literary studies, the concept of ›skev‹ in Nordic literary scholarship has been employed to denote a narrative mode characterized by absences, silences, and anti-climactic structures, as well as a specific kind of reading.[31]

While queer theories challenge the idea of universal heterosexuality and binary gender systems, the purpose of the concept ›skev‹ is comprehending aspects of divergence that are harder to capture. »Skewed theory is not meant to replace queer theory, but rather to grasp the intangible and unnamable aspects of not fitting into norms, including but not limited to norms of gender and sexuality«, Österholm, who has developed the concept in Nordic re-

26 Cf. Rosemarie Garland-Thomson: Integrating Disability, Transforming Feminist Theory, in: Hall, Kim Q. (ed.): Feminist Disability Studies, Bloomington and Indianapolis 2008, pp. 13–47, here p. 14.

27 Cf. Carrie Sandahl: Queering the Crip or Cripping the Queer? Intersections of Queer and Crip Identities in Solo Autobiographical Performance, in: GLQ: A Journal of Lesbian and Gay Studies 9:1–2 (2003), pp. 25–56.

28 Kafer: Feminist, Queer, Crip, p. 149.

29 Cf. ibid., p. 27.

30 Maria Margareta Österholm: The Pain and the Creeping Feeling, in: European Comic Art 15:1 (2022), pp. 46–65.

31 Cf. Hilda Jakobsson: Skev, in: lambda nordica 25:1 (2020), pp. 150–154.

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search, explains.[32] While queer theories critique the system of norms relating to sexuality, gender, relationality, ›skev‹ might also designate not being seen as ›a proper person‹, or failing to accommodate expectations of normality. In this sense, the concept is similar to Limburg's ›weird‹. However, in Nordic research it has primarily been used to describe »skewed girlhood«, which operates within a gender context.[33]

›Skev‹ cannot substitute ›neuroqueer‹ since the latter is rooted in neurodivergent activism in a way that ›skev‹ is not. However, as this volume bridges European research with the anglophone-dominated field of literature and disability, I think it worthwhile to consider how concepts stemming from various languages can contribute to these dialogues. This may potentially foster greater linguistic diversity in theory development and recognize the varied reception histories that theoretical concepts may have in diverse geographical contexts. Skev/skewed has not hitherto been explicitly utilized to explore neurodivergence. However, it has the advantage of disentangling the spectrum of differences it encompasses from neuroscience. Unlike neuroqueer, which is often linked to autistic experiences specifically,[34] ›skev‹ is not modeled on a specific aspect of neurodivergence. The difference between a skev/skewed reading and a neuroqueer reading lies in the relationship to some form of pathologization. Nevertheless, similar to Limburg's ›weird‹, ›skev‹ might be a position from which it is possible to approach both historical persons and literary characters, without performing simplistic »diagnostic speculation«.[35]

Neurodivergence in literature: previous research

Despite the growing interest, there is still a lack of readings of literary texts employing neurodivergence as a critical framework, similar to queer readings of texts. Most of the research performed the last ten or fifteen years instead concerns representation of specific diagnoses, especially of autism, that are often scripted on diagnostic traits. Critical autism studies, and cultural disability studies, which can be seen as foundational for neurodivergent approaches, have been dedicated to making sense of representation in various

32 Österholm: The Pain and the Creeping Feeling, p. 49.
33 Jakobsson: Skev, p. 151.
34 Cf. e.g. Yergeau: Authoring Autism and Julia Miele Rodas: Autistic Disturbances. Theorizing Autism Poetics from the DSM to Robinson, Ann Arbor 2018.
35 Rodas, Autistic Disturbances, p. 11.

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contexts: self-representations in ›autiebiographies‹, stereotypes in popular media, and within literature for young adults, among other examples. Stuart Murray's monograph *Representing Autism. Culture, Narrative, Fascination* (2008) stands as a pivotal contribution, not only focusing on representation across diverse media, but also on affective dimensions tied to these.[36] Much effort has been put into critiquing reductive and potentially dehumanizing portrayals of autistic characters, and to suggest more inclusive and less ableist understandings.[37] Neurodivergent readers face some of the same challenges as queer readers: to be confronted with representation in literature is to face an abundance of, on the one hand, objectification, and stigmatization, and on the other, oppression and inequality.

In some research the focus has been to re-read fictional characters that are not explicitly represented as neurodivergent, and in this way allow for a positive potential of identification. Sonya Freeman Loftis' book *Imagining Autism* (2015) is one such effort, setting out to »treat autism as a presence, an identity, a source of agency […] to explore fictional depictions of the spectrum as signs of disabled presence«, while at the same time discussing problematic and sometimes violent representations of autism.[38] One important point in this critique is that literature not only reflects ideas about autism, but also shapes them: »Suddenly, it is not autistic people who are the interpretative template for the literary character – the public perception of the literary character may reshape and inform how autism is defined as a social construct«.[39]

Recent scholarship has started to shift focus towards language and rhetoric –in Rodas' *Autistic Disturbances* (2018), and Yergeau's *Authoring Autism* (2017), for instance. However, it is important to note that these works, like the work in Critical autism studies previously, concentrate on autism as an analytical lens, rather than encompassing neurodivergence more broadly. Rodas sets out to explore autistic uses of language, and more precisely, to identify an autism poetics. She does this by gathering words from »autism-centred literature« spanning the past seven decades and categorizes them into six groups: silence, ricochet, apostrophe, ejaculation, discretion, and invention. She then uses these categories to analyse the language in a selection of

36 Cf. Stuart Murray: Representing Autism. Culture, Narrative, Fascination, Liverpool 2008.

37 Cf. e.g. Mark Osteen (ed.): Autism and Representation, New York 2008; Alicia A. Broderick/Ari Ne'eman: Autism as Metaphor: Narrative and Counter-Narrative, in: International Journal of Inclusive Education 12:5–6 (2008), pp. 459–476.

38 Sonya Freeman Loftis: Imagining Autism. Fiction and Stereotypes from the Spectrum, Bloomington and Indianapolis 2015, pp. 154–155.

39 Rodas: Autistic Disturbances, pp. 24–25.

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diverse but mostly familiar texts: the *Diagnostic and Statistical Manual of Mental Disorders*, Warhol's *The Philosophy of Andy Warhol*, Charlotte Brontë's *Villette*, Mary Shelley's *Frankenstein*, and Daniel Defoe's *Robinson Crusoe*. By »autism-centred literature« Rodas refers to »work by clinicians and therapists, autism bloggers, literary scholars, biographers and memoirists, parents, activists, and cultural scholars, some identifying as autistic, others not«.[40]

The broad selection of texts Rodas uses to generate the categories might be seen as a strength, but by including work by non-autistic clinicians and therapists, there is also a risk that this work includes pathologizing views perpetuated in clinical practice. Although Rodas' mission is to move away from simplifying diagnostic readings of literary characters, and instead focus on autistic language, which manifests in creative and productive readings of a range of canonical texts, there are also problems connected to the idea of an autism poetics. As Rodas points out, the texts included are »only a tiny fragment of the possible texts that might have been addressed«.[41] There are many texts employing the poetics that Rodas discerns as autistic. »If ›catalogue poems‹ by Raymond Carver, David Antin, and George Perec are all examples of an autistic aesthetic, what form of experimental poetry (hell, what form of *list*, beginning with the ships of the *Iliad*) is not?«, asks Michel Berubé in his review of Rodas' book.[42] Efforts to identify a specific poetic style associated with autism might inadvertently result in exclusionary outcomes. Even if not intended, establishing a defined autistic poetics could establish a standard and favor certain expressions of autistic literature over others. Furthermore, this focus on autism could also overshadow the experiences and expressions of other neurodivergent individuals. This prompts the question if there is something uniquely aesthetic about autism, or if there could also be distinct poetics associated with, for example, ADHD or dyslexia.

More and more work has been devoted to studying the works of neurodivergent writers themselves, and work written by neurodivergent scholars, emphasizing lived experience as a source of knowledge. As Anna Stenning argues, narrative agency »consists of the ›ontological‹ dimension of making sense of oneself through time, and the ›political‹ dimension of drawing on

40 Ibid., p. 4.
41 Ibid., p. 24.
42 Michael Bérubé: Autism Aesthetic, in: Sydney Review of Books, in: Sydney Review of Books, 18.10. 2019, sydneyreviewofbooks.com/review/autism-aesthetics-rodas-yergeau-savarese/ (20.4.2024).

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one's self-conception to resist normative understandings of one's life«.[43] A range of different genres, such as autobiography, poetry and prose fiction may serve as vehicles for such a narrative agency. However, Abs Ashley poses an important question: »[w]hy should it be necessary, in mapping out a critical neurodiversity framework for reading literature, for the author of a given text to have explicitly claimed neurodivergence?«[44] Building on José Esteban Muñoz concept ›ephemera‹, signifying often covertly transmitted but traceable embodied queer acts, Ashley instead discusses how neurodivergent ephemera might be identified in texts, through expressions of embodied experiences. Like Yergeau, who introduces Muñoz ephemera concept in a neuroqueer context, they are interested in how it functions to claim »space in a neuronormative environment, like the literary text«.[45] Rodas, Yergeau, and Ashley search in language, rhetoric, and literary form to recognize autistic and neurotrans embodied experiences, rather than in representation. However, there are also differences: the literary ephemera Ashley traces, is not tied to a certain autistic poetic, but is instead viewed as part of a range of creative practices that undermine neuronormative and cisheteronormative textual conventions.

Building on these previous contributions, and inspired by queer theory, I will in the following suggest some ways of neuroqueering literary analysis: through the concept of neuroqueer worldmaking, through genre and neuroqueer temporality, and through reparative reading in relation to fictional characters.

Neuroqueer worldmaking

To identify as neurodivergent or neuroqueer is to experience a lack of history, something that is often addressed in autobiographical writing by neurodivergent authors. In fact, it is a central motivation for Limburg's *Letters to My Weird Sisters*: »It's genealogy, but for my neurotype«, as she writes.[46] There are of course, the medical histories of how certain diagnoses were

43 Anna Stenning: Narrating the Many Autisms. Identity, Agency, Mattering, London 2024, p. 22.

44 Abs Ashley: Neuroqueer (a)Socialities. Mapping out Neurotrans Textualities Through Literary Ephemera, in: Bergenmar, Jenny/Creechan, Louise/Stenning, Anna (eds.): Critical Neurodiversity Studies. Divergent Textualities in Literature and Culture, London 2025, p. 73.

45 Ibid. See also Yergeau: Authoring Autism, pp. 40–45.

46 Limburg: Letters to My Weird Sisters, p. 13.

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developed, but the diagnoses are new, and medical discourse is in many cases experienced as an authoritative and reductive over-writing of subjective experience. Our descriptions and understandings of neurodivergent identities are constructions that relate to current (ableist) societal conditions, biomedical frameworks, and conceptions of normality and functionality, with the purpose to undermine them. As Wolf-Mayer states, we live in a neurological age with »institutionalized expectations of individual expressions of normalcy«.[47] Like for queer people, there is a need to invent history, beyond the identity categories that are tied to the current. This impulse to reach across history to find experiences similar to one's own, and fictions where neurodivergent readers may feel at home, mirrors the simultaneous community making activities in the present. I see both these activities, turning to the past to find traces of neurodivergence, and present community-making, as worldmaking, a term originally conceptualized by Michael Warner and Laurent Berlant to signify transformative practices that generate a sense of belonging and support transformation and inventiveness.[48] Queer worldmaking invites us to envision and enact alternative, inclusive and transformative worlds where diverse identities and experiences thrive. Berlant and Warner describe the queer world as »a space of entrances, exits, unsystematized lines of acquaintance, projected horizons, typifying examples, alternate routes, blockages, incommensurate geographies«.[49] This prompts the reflection on what spaces literature creates for neurodivergent experiences, and how neurodivergent readers navigate these spaces to foster belonging, recognition, and transformation. Going forward, I aim to illuminate how neuroqueer worldmaking may be enacted in engagement with literature, by looking at a couple of autobiographical texts by autistic writers.

In Sweden, the publication of the book *Autisterna: Kvinnor på spektrat* [The Autistics: Women on the Spectrum] in 2021 sparked a debate. The book was presented as a »personal essay«, investigating autistic women in culture. It unfolds the re-evaluation of one's one experience that the author's diagnosis with autism in adult age prompted. This is presented as a re-organization of the author's own life narrative, one *»that overturns everything I thought I*

47 Matthew J. Wolf-Mayer: Unraveling. Remaking Personhood in a Neurodiverse Age, Minneapolis and London 2020, p. 6.

48 Cf. Lauren Berlant/Michael Warner: Sex in Public, in: Critical Inquiry, 24:2 (1998), pp. 547–566.

49 Ibid., p. 558.

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knew about the protagonists and the plot«.[50] To make sense of this new life narrative, the author recounts previous experiences, and explains both the autism diagnosis and her own experience of being autistic to wider audiences. She also critiques the male norm inherent in psychological testing and turns to history and to fiction to explore female autistic identity. She discusses Virginia Woolf's half-sister Laura Stephen and autistic traces in Woolf's prose. She interprets Emily Dickinson's poems about her brain as neurodivergent (though without using that precise term), and finds personal autistic resonance with Simone Weil's philosophy, and life.

The reception of the book was mixed. Some reviewers were positive, but some deeply critical to the interpretation of certain canonical authors or texts as neurodivergent, and to the validity of discussing autism spectrum diagnoses in relation to history.[51] The critics voiced opinions that such readings were unproductive, lacked historical context, and amounted to retroactively diagnosing historical individuals.[52] However, in the context of a primarily autobiographical text, this exercise can also be viewed as an attempt to construct a genealogy of neurodivergent authors and thinkers, a space where belonging is possible for a neurodivergent writer. This endeavor serves the purpose of establishing connections between the past and the present, thereby fostering a greater sense of recognition and acknowledgement for neurodivergent individuals.

As already mentioned, a similar approach can be observed in Joanne Limburg's *Letters To My Weird Sisters: On Autism and Feminism* (2021), where the personal address to historical figures is further emphasized through the use of the letter as a literary format. Limburg initially directs herself to the reader to describe how it feels to be in a minority position:

> Autistic women are a minority demographic, and when you're in a minority, it can get lonely – your people are scarce and hard to find. The internet has helped many of us to find each other, and allowed us to group together, and to begin to discover that collective voice which any group needs if it's going to be heard. [53]

50 Clara Törnvall: Autisterna. Kvinnor på spektrat, Stockholm 2021, p. 10. My translation.

51 Cf. Mikaela Blomqvist: I hennes värld kan bara den med diagnos bli fri, in: Göteborgs Posten 3.11.2021; Saga Cavallin: Clara Törnvall lägger ett neuropsykologiskt filter över döda geniers verk, in: Dagens Nyheter 26.10.2021; Ulrika Kärnborg: Det finns något religiöst över hennes syn på autism, in: Expressen, 13.10.2021.

52 Cf. ibid.

53 Limburg: Letters to My Weird Sisters, p. 12.

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Thus, underlining the need for community, and belonging, Limburg explains her search for »weird women« in history.[54] This search is not unfamiliar for queer people, similarly searching for queer genealogies. In *Foundlings*, Christopher Nealon describes »the simple but enduring lesbian and gay practice of listing famous homosexuals from history«, and in *Feeling Backward* (2007), Heather Love explores the portrayal of queer individuals in older literature, emphasizing emotions such as loneliness, loss, self-hatred, shame, and failure as affective responses to these portrayals.[55] These same emotions are often used to describe the experiences of neurodivergent individuals navigating through a neuronormative society. Transposed to the context of neurodivergence, Love's model for queer historiography not only allows for the recognition of neuroqueer experiences across time but also enables the identification of such experiences within literary texts, thereby materializing neuroqueer experiences across various temporal settings. Readings of this nature function as a mode of neuroqueer worldmaking through literature. The work that has been done in queer theory urges us to read personal engagements with history, such as Törnvall's and Limburg's, as something other than retrospective diagnosing, namely a neuroqueering of literary and intellectual history serving to establish belonging over time, supporting communities in the present. Furthermore, such worldmaking practices may reappropriate authors and works that have long since been explored from a neuronormative point of view, while their neuroqueer potentialities have been ignored, undervalued, or interpreted in solely aesthetic terms.

Reparative reading and caring for characters

As medicalized interpretations of identity can feel invasive or even aggressive, and diagnostic frameworks sometimes overshadow personal narratives, literature may function as a sanctuary where neuroqueer individuals find validation and understanding. The practice of forming personal connections with historical figures mirrors processes described in queer studies, where historical texts and figures have been recognized as queer by queer readers, forming attachments and making readers feel »pulled out of the closet and

54 Ibid., p. 13.

55 Christopher Nealon: Foundlings. Lesbian and Gay Historical Emotion Before Stonewall, Durham 2001, p. 5. Cf. Heather Love: Feeling Backward. Loss and the Politics of Queer History, Cambridge MA 2007.

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into literature«, as Laura K. Wallace expresses it in a text about Djuna Barnes' *Nightwood* as a literary work connecting queer readers.[56] The ways in which readers – queer and neuroqueer alike – use literature as part of »everyday worldmaking projects« is often through a personal response to a text.[57] Within literary history, there exists a multitude of characters who are represented as diverging from ableist norms, enduring suffering, stigma, and are subject to stereotypical depictions. This mirrors the dilemma described by Love: »A central paradox of any transformative criticism is that its dreams for the future are founded on a history of suffering, stigma, and violence«.[58]

Collecting characters that are marked by neurodivergence or have a named diagnosis is a depressing endeavor. One may encounter countless victims of violence, feared or despised outsiders, and savants, whose intellectual abilities are only matched by their social inabilities. In *Feeling Backward*, Love calls attention to »[t]exts or figures that refuse to be redeemed [and] disrupt the progress narrative of queer history«.[59] Presented with stereotypical portrayals of neurodivergent figures, with or without named representation, might trigger a need to scrutinize these critically, and to unveil the simplifying medical or deficiency models they may rely on. This mode of reading is not unlike the »paranoid reading« Eve Kosofsky Sedgwick has described, approaching the object of inquiry with suspicion and vigilance.[60] Although such critical scrutiny may be important for neurodivergent readers as a way to talk back to popular misrepresentations, it does not support worldmaking and belonging effectively. To achieve this one needs to move beyond the idea that suspicion is the only way to engage critically with texts. The alternative that Sedgwick presents, a reparative reading instead of a paranoid one, builds not on negative affect, but on allowing for pleasure, and for sustenance. As Robyn Wiegman explains, »[y]ou could say that it is about loving what hurts but instead of using that knowledge to prepare for a vigilant stand against repetition, it responds to the future with affirmative richness«.[61] Reparative reading described in Sedgwick's words is »the many ways in which selves and

56 Laura K. Wallace: ›My History, Finally Invented‹. Nightwood and Its Publics, in: QED: A Journal in GLBTQ Worldmaking 3:3 (2016), pp. 71–94, here p. 72.
57 Ibid.
58 Love: Feeling Backward, p. 1.
59 Ibid., p. 8.
60 Cf. Sedgwick: Paranoid Reading and Reparative Reading, pp. 1–37.
61 Robyn Wiegman: The Times We're in: Queer Feminist Criticism and the Reparative Turn, in: Feminist Theory 15:1 (2014), pp. 4–25, here p. 11.

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communities succeed in extracting sustenance from the objects of a culture – even of a culture whose avowed desire has often been not to sustain them«.[62]

To search for reading methods supporting belonging and care for communities is not in conflict with Love's call to not flinch from figures that cannot immediately be framed positively. A reparative reading strategy may be to revisit figures that have been condemned, or scorned, to look for pleasurable moments and affinities. Laura Seymour has for example revisited Ben Jonson's play *Epicoene* (1609), which includes the character Morose, who is mocked and ostracized, but also manages to create what Seymour names an »autistic utopia« where he is free to »explore his selfhood and embody a way of living that offers an alternative to his society's norms«.[63] While Morose is ostracized by other characters and some readers and audiences, who sees his hatred of noise as a sign that something is wrong with him, Seymour argues that his efforts to reduce noise is in fact a way of taking care of himself, and a prerequisite for him to be able to live on his own terms.[64] Morose is a comical figure, deceived by other characters, and a type recognizable for audiences in that time as a typical misanthrope. However, at the same time, present time readers and audiences may feel an affinity with Morose, through their lived experience of neurodivergence. A paranoid reading might focus on aspects in the play that frames Morose as a ludicrous figure, fooled by others, and unable to function socially, in accordance with stereotypes of autistic people. The need to imagine worlds that may sustain neurodivergent people and allow for their well-being is still urgent, and Seymour's reading has a reparative focus on these. Although not using Sedgwick's term specifically, this can be described as one way of performing a neuroqueer reparative reading.

This example shows that new dimensions of literary works may emerge when we give literary characters our attention and empathy. In *Hooked. Art and Attachment* (2020), Rita Felski explores the diverse kinds of attachments that develops between individuals and art, »an aesthetic that is premised on relation rather than separation, on attachment rather than autonomy«.[65] Felski discerns four modes of identification with literary characters, ›alignment‹, ›allegiance‹, ›recognition‹ and ›empathy‹. These categories may cer-

62 Sedgwick: Paranoid Reading and Reparative Reading, p. 35.

63 Laura Seymour: ›All Discourses But My Own Afflict Me‹. Morose's House as a Seventeenth-century Autistic Utopia (*Epicoene*, 1609), in: Bergenmar, Jenny/Creechan, Louise/Stenning, Anna (eds.): Critical Neurodiversity Studies. Divergent Textualities in Literature and Culture, London 2025, p. 110.

64 Ibid.

65 Rita Felski: Hooked. Art and Attachment, Chicago 2020, p. viii.

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tainly be helpful for the neurodivergent reader searching for experiential resonances in literary characters. However, Felski's examples also showcase the normative assumptions in literary criticism (and postcriticism): she invents yet another category, ›ironic identification‹ to describe the readers relation to characters who are estranging and not inviting identification, such as Meursault, the narrator of Camus' *The Stranger*.[66] Does this mean that a reader associating rather than dissociating with Meursault is impossible to imagine within Felski's critical framework?

In her text »Albert Camus' *L'Étranger*: Reparative Neurodivergent Reading as Provocation« Alice Hagopian argues that it is possible to recognize oneself in Meursault as an autistic reader, not in his deeds, but in his sensory experiences, and experiences of being socially condemned as a consequence of his maladaptation to social norms. Hagopian turns the attention to the social prejudices directed towards Meursault, condemning him even before his crime, and argues that »we can restore Meursault's humanity without absolving him of the responsibility for his crime«,[67] and that this reading is an »act of care« not just directed to the character, but also to other neurodivergent readers identifying with »characters most readers distance themselves from«.[68] Though readers may acknowledge the philosophical and colonial contexts of this particular work, this does not preclude a sense of recognition in Meursault's way of functioning, being tormented by or finding joy in sensory experiences, for example. Hagopian's reading is a reparative reading, and also a reading from a neurominoritarian position, in this way activating new dimensions of this particular work.

Morose is depicted as a misanthrope, while Meursault is infamous for his act of murder. Yet, beneath these surface labels lie complex dimensions to how the characters experience the world that may deeply resonate with neurodivergent readers. Unlike the more commonly cited autistic characters, who often fit into a ›supercrip‹ framework – think of figures like Sherlock Holmes and his numerous savant-like detective successors – Morose and Meursault defy such categorizations. Revisiting these often ridiculed or condemned characters from a neurodivergent perspective – neuroqueering them

66 Cf. ibid., pp. 111–113.

67 Alice Hagopian: Albert Camus's *L'Étranger*: Reparative Neurodivergent Reading as Provocation, in: Bergenmar, Jenny/Creechan, Louise/Stenning, Anna (eds.): Critical Neurodiversity Studies. Divergent Textualities in Literature and Culture, London 2025, p. 172.

68 Ibid., p. 184. Hagopian also sheds new light on the colonial and racist aspects of the text by reading Meursault as a pied-noir working-class man.

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– is to look backward, embracing their complexity without forcing them into a narrative of overcoming or linear paths of progress. It means caring for the characters and acknowledging their resonances for neurodivergent readers.

(Neuro)queering genre and temporality

Neurodivergence, like queerness, is inextricably tied to non-normative temporalities. This makes literary genres with their inherent temporal trajectories especially interesting to explore from a neurodivergent perspective. For instance, consider the *Bildungsroman* or the novel of formation. Feminist literary studies from the 1980s onward have scrutinized its male-centric origins. They have examined how education, often a central element in the *Bildungsroman*, was not equally accessible to women, and how the typical conclusion, where the individual reconciles with social norms, often took the form of a marriage to a woman. Franco Moretti has emphasized that the *Bildungsroman* inherently strives towards normality, a trajectory that does not align with all life cycles.[69]

Queer people, and I would argue neurodivergent people as well, emerge through different forms of failure in relation to expected life trajectories, and alternative forms of growth. Jack Halberstam, in *The Queer Art of Failure* (2011), and Kathryn Stockton, in *The Queer Child, Or Growing Sideways in the Twentieth Century* (2009), both employ the notions of failure, regression, and anti-development to investigate queer growth and identity formations that reject or are denied access to the normative development so central to the *Bildungsroman* and the broader novel of formation. Halberstam highlights the productivity of »opting out« from the prescribed life cycle by embracing »failing, losing, forgetting, unmaking, undoing, unbecoming«.[70] This critical perspective can be expanded to make visible how neurodivergent characters similarly challenge and navigate the conventions and expectations present in various literary genres.

Stockton's exploration of growth and development as something other than a strictly linear, upward, or forward movement, reveals alternative forms of growth that cannot be solely measured in terms of successful adap-

69 Cf. Franco Moretti: The Way of the World: The Bildungsroman in European Culture, London 1987, p. 11.

70 Jack Halberstam: The Queer Art of Failure, Durham and London 2011, pp. 2–3.

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tation to adult life or continuous progression.[71] These queer and crip (or skeva/skewed) conceptions of temporality can certainly be applied to analyze other genres beyond the *Bildungsroman*. Children's and young adult literature, for instance, frequently operate based on the same notions of growth and progressive development. These genres often carry didactic purposes, particularly concerning diagnostic characterizations of subjects, such as conveying that one can succeed in school even with disabilities.[72]

Divergent temporalities manifest in various forms across narratives. For the purpose of illustration, I will consider a Swedish example: the young adult novel *Jag är ju så jävla easy going* (2013) [I am so damn easy going] by acclaimed Swedish children's and young adult author Jenny Jägerfeld. In this narrative, the protagonist Joanna's ADHD serves as a pivotal element, driving the plot forward. The central conflict arises when Joanna finds herself without medication due to her family's financial struggles. Desperate for funds, she becomes embroiled in a drug deal, which complicates her relationship with her love interest, Audrey. Jägerfeld, who has openly shared her own experiences with ADHD, presents this story with drastic humor, yet with a clear intent to give justice to divergent experiences of attention, sensation, and cognitive functioning. Joanna emerges as a neurodivergent and queer character, navigating social vulnerability stemming from her family's inability to provide for her. Despite these challenges, the narrative foregrounds Joanna's resilience and resourcefulness.

Beyond portraying ADHD, the plot also intricately reflects Joanna's functioning, which hinges on her impulsivity and simultaneously ongoing thought processes. The narrative consistently draws attention to the disrupted timelines: Joanna's mother, trapped in past glories and futile attempts to relive her success as an author; her father, mired in depressive inertia, marked by the repetitive cycle of daily TV quiz shows he listlessly watches; and Joanna herself, likening her mind to a constant flickering between TV channels every second: »Dad, poverty, Mum, medication, Audrey, Audrey, Audrey.« [73]

It becomes evident that though the narrative presents the unfolding of events over time, the narrative chain of cause and effect is disrupted. Instead, Joanna's functioning injects a chaotic and unpredictable element, shaping it

71 Kathryn Bond Stockton: The Queer Child, Or Growing Sideways in the Twentieth Century, Durham 2009, p. 13.

72 Cf. Patricia A. Dunn: Disabling Characters. Representations of Disability in Young Adult Literature, New York 2015, p. 7.

73 Jenny Jägerfeld: Jag är ju så jävla easy going, Stockholm 2013, p. 64. My translation.

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into a narrative of dealing with chaos rather than one of conventional development. This trajectory not only diverges from the norm but also embodies a ›crip temporality‹, misaligned with Joanna's neurotypical peers and societal expectations of social behavior and achievements. On the level of representation, Joanna's mind has to adapt to chrononormative clock time, but on the level of narrative, her crip time bends the plot to represent the experience of being out of sync.[74] The result is a narrative that is humorous and messy, creating a hyperactive pace punctuated by Joanna's simultaneous and sometimes vulgar no-filter commentary. While including an ADHD character like Joanna may serve as a didactic choice to foster understanding and promote inclusion, and to some extent does so, there exists a deeper layer beyond representation – a layer that permits Joanna's ›crip time‹ to affect plot structure.

Concluding remarks

In conclusion, I argue that directing our focus towards neurodivergent readers' engagement with literature, particularly through practices such as worldmaking and reparative reading, represents a fruitful avenue for advancing neuroqueer and neurodivergent literary studies. Moreover, while representations of neurodivergence can offer valuable insights into how it has been historically conceived, our inquiries should extend beyond traditional character analysis, to include the neurodivergent resonances the characters produce, and the potential for identification in characters that from a normative perspective may be objects of disidentification. There is also a need to explore how neuronorms are both articulated and transgressed in different genres, and with the use of different temporal frameworks, here exemplified with crip time in young adult literature.

In these endeavors, drawing from queer theory's exploration of history and readers' affective responses to texts proves invaluable. While we indeed need examinations of representations of neurodivergence and neurodivergent rhetoric and poetics, establishing an intersectional and inclusive framework for critical neurodiversity in literary studies also necessitates the exploration of neurodivergent reading modes. These modes allow for affective responses and the pursuit of acknowledgment and recognition within literary texts. This approach shifts the spotlight from the texts themselves to how texts acquire neurodivergent significance, or are neuroqueered, through the act of reading.

74 Cf. Kafer: Feminist, Queer, Crip, p. 27.

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Such readings facilitate neuroqueer worldmaking and reparative reading, providing a framework for the exercise of neurodivergent agency through the utilization of diverse, and hopefully more and more multilingual vocabularies.

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Harriet Cooper

»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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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].

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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.

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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.

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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.

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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.

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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.

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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.

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›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.

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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.

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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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