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Shame as a Performative Narrative Affect in Automedial Art by Female British Authors with ‘Disabilities’ and ‘Mental Distress’[1]

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Working Paper I: Shame as a Performative Narrative Affect in Feminist Disability Autobiography and Autobiographical Performance Art, 1981-1999 (manuscript)

In this working paper, I will provide an analysis of the uses of shame and humiliation as narrative affects[2] in a selection of autobiographical texts by female (mostly feminist) ‘disabled’ authors from Great Britain and Ireland, dating from 1981 to 1999. Almost all of my investigated examples in this paper are verbal texts but I will also explore the uses of shame and humiliation in a videotaped audio-visual performance by Irish artist Mary Duffy (1995), which contains an autobiographical monologue.

In his investigation of the formative role of narrative affects and emotions, Patrick Colm Hogan suggests that compared to sacrifice, heroism, revenge, attachment or romantic love, shame plays a minor part in the constitution of narrative plots and genre traditions. He explains the subordinate role of shame by pointing out its paralyzing impact on characters and narrators and its provocation of states of heightened, painful self-consciousness. Instead of directly forming narrative events,[3] shame defines and shapes affectively intense ‘key’ moments or ‘narrative incidents’, that is, ‘focal points of emotional response’ and ‘minimal units of emotional temporality’ below the level of narrative events.[4] In the course of the plot, causes can be inferred and attributed to incidents and responses and expressive and actional outcomes can ensue after a temporary state of shame-related paralysis or ‘freezing’ (Hogan 2011: 32-41). Whereas Mark Axelrod has described shame as a highly significant affect in Leo Tolstoy’s *Anna Karenina*,[5] Hogan’s reading suggests that the structural unit of Stiva’s experience of shame has little formative impact on the main plot of the novel (41). By contrast, Timothy Bewes and Michael Richardson demonstrate that shame and disgrace impact

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[2] On shame as a narrative emotion see Patrick C. Hogan: *Affective Narratology: The Emotional Structure of Stories* (Lincoln and London: University of Nebraska Press, 2011) 32-39.

[3] ‘The term “event” refers to a change of state as one of the constitutive features of narrativity. We can distinguish between event I, a general type of event that has no special requirements, and event II, a type of event that satisfies certain additional conditions. A type I event is any change of state explicitly or implicitly represented in a text. A change of state qualifies as a type II event if it is accredited – in an interpretive, context-dependent decision – with certain features such as relevance, unexpectedness, and unusualness. The two types of event correspond to broad and narrow definitions of narrativity, respectively: narration as the relation of changes of any kind and narration as the representation of changes with certain qualities.’ Peter Hühn: ‘Event and Eventfulness’. Hühn, Peter et al. (eds.): *the living handbook of narratology*. Hamburg: Hamburg University. URL = <http://www.lhn.uni-hamburg.de/article/event-and-eventfulness>. Web. 1 June 2021.

[4] Hogan defines narrative events as ‘the next level of temporal segmentation, encompassing a cause and response to an incident’ (Hogan 2011, 33).

[5] Mark Axelrod: ‘“Blushes & Flushes”: *Anna Karenina*’s Shameful Physiology’, Mark Axelrod: *Notions of the Feminine: Literary Essays from Dostoyevsky to Lacan* (New York: Palgrave Pivot, 2015) 9-15.

on acts of writing as well as on the formation of the genres of the post-colonial novel and trauma literature.[6] For Bewes, 'shame as a form' is connected to situated, embodied selves and to psychological reflection ('shame as a psychological phenomenon' 6). As such, it is radically opposed to 'shame as an event' that is 'revolutionary' in itself because it subverts any form ('there is no form adequate to the event of shame' 7), any sense of self and any embodied subjectivity on the sides of authors and readers (4-7). Both Bewes and Richardson focus on the 'unintelligibility' of the 'event of shame', on shame connected with the act of writing (the 'shame of being able to write') and on the incommensurability between the literary work and its ethical responsibilities. They highlight the untrustworthiness of language, the ineffability of experiences of trauma and shame, the significance of negativity and of textual gaps and absences as well as the ways in which texts defy direct representations of atrocities and oppression (Bewes 2011, 1-3, 12, 15, 60; Richardson 2016, 155). According to Bewes, writing as an event of shame carries a utopian, revolutionary potential. It enables a literature that would

> escape the shame of interpellation – the individuating gaze of a subject upon an object – by escaping altogether the organizing apparatus of self and other. This literature would have no manifest or nameable readership, no 'you', only the virtual, undifferentiated community of 'them'. (Bewes 2011, 5)

This literature would be 'free of colonial relations of perception – of the structure of *looking* and *being looked at*, of subject and object' (Bewes 2011, 5). Whereas Richardson and Bewes highlight the unintelligibility and incommensurability of the event of shame, Sally Munt emphasizes the unintelligibility of the shamed self, arguing that the response of shame (described as an 'act which reduces facial communication' by Silvan Tomkins) renders the shamed self 'non-intelligible'.[7] According to Munt, shame can release the self that has turned away to from its humiliating surroundings so that it can seek new connections and form new identities:

> This now familiar figure is the one who has been shamed, who has turned away and been released, whose gaze is momentarily free to look around and make new, propitious connections. […] Being non-intelligible means more potential for new identities to form, in the moment of radical indecypherability, when the subject is turned, s/he is lost from view and undefined. Foucault saw the homosexual as peculiarly positioned to maximise this radical potential, specifically because s/he has historically been indeterminate, and thus discursively more open to resignification. (182)

Similar to Munt, Tobin Siebers emphasizes the activating aspects of shame, stating that shame conveys (erotic, sexual) agency on objectified disabled bodies that ableist society regards as passive and asexual. Hence, Siebers extends the significance of experiences of shame and humiliation to disabled persons, the social group that –

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[6] Timothy Bewes: *The Event of Postcolonial Shame* (Princeton, et al.: Princeton Univ. Press, 2011) 11-47; Michael Richardson: *Gestures of Testimony. Torture, Trauma, and Affect in Literature* (New York, London, Oxford et al.: Bloomsbury, 2016) 155.

[7] Sally Munt: *Queer Attachments. The Cultural Politics of Shame* (Aldershot: Ashgate, 2008) 182; Eve Kosofsky Sedgwick and Adam Frank (ed.): *Shame and Its Sisters. A Silvan Tomkins Reader* (Durham and London: Duke University Press, 1995) 134.

according to Martha Nussbaum – has been most severely affected by social stigma[8] but whose feelings of shame and humiliation were mostly denied or neglected instead of explored (Siebers 2009, 202-203, 208, 211). Whereas Nussbaum focuses on the legal dimensions and functions of shame,[9] Siebers explores shame as an affective disposition, that is, as a force / intensity that passes 'body to body (human, non-human, part-body, and otherwise)' and that activates *all* bodies in the encounter,[10] including the bodies of disabled persons.[11]

Taking cue from Tobin Siebers's discussion of the activating impact of disability-related shame, my analysis of automedial texts explores how disabled bodies – far from being 'shameless' / incapable of feeling shame or being passive surfaces on which ableist society projects its shame, fears and disgust (see Nussbaum 2004, 296, 306-308) – become subjects rather than objects of representation and are (erotically and) politically activated through the affective dynamic of shame as an intensity that moves between non-normative bodies, socio-political environments and cultural texts. I will examine how disabled authors use shame as a formal strategy, as a complex, ambivalent form of communication that oscillates between intro- and extroversion (Sedgwick 1993, 6). I suggest that the automedial texts discussed in this working paper can be regarded as affect generators.[12] They use shame as a narrative affect to explore and pillory humiliating encounters between disabled bodies, medical and educational institutions and social environments, to provoke political acts of affective co-witnessing[13] and to enable disabled and non-disabled readers to identify / solidarize with humiliated autobiographical subjects.

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[8] 'No group in society has been so painfully stigmatized as people with physical and mental disabilities', Martha Nussbaum: *Hiding from Humanity. Disgust, Shame and the Law* (Princeton: Princeton UP, 2004) 305.

[9] Martha Nussbaum highlights shame's oppressive, othering, objectifying dimension, its assault on equality and mutual respect among citizens and its creation of unjust social hierarchies and on this basis objects to legal approaches that affirm the uses of shame and disgust as penalties and bases for legal regulation (4, 321, 340).

[10] Gregory J Seigworth and Melissa Gregg: 'An Inventory of Shimmers', *The Affect Theory Reader*. Ed. Melissa Gregg and Gregory J. Seigworth (Durham & London: Duke University Press, 2010) 1-25, 1-2.

[11] See Siebers 2009, 202-203. Nussbaum argues that dominant social groups project their own feelings of shame onto non-normative / non-normatively embodied subjects and thereby turn them into passive objects: 'In shaming others, people often, I have argued, project onto vulnerable people and groups the demand that they conceal something about themselves that occasions shame for the shamer. […] People's insecurity about bodily vulnerability [i. e. their mortality and animality, K. R.] leads them to demand that "the disabled" hide from the public gaze' (296, 306-308, 336, 321-322, 14, 89). She describes this process as a form of 'scapegoating, in which some vulnerable minority bears the burden of the fears of the majority' and calls it 'an unacceptable form of discrimination' (296).

[12] I use this term in accordance with Reckwitz's definition, see Andreas Reckwitz: 'Practices and their Affects.' Trans. Steven Black. *The Nexus of Practices. Connections, Constellations, Practitioners*. Eds. Allison Hiu, Theodore Schatzki and Elizabeth Shove. London and New York: Routledge, 114-125, 116, 123-125.

[13] 'To witness an event means becoming responsible to it. This is an affecting experience, even if the intensity and register changes based on specific contours, textures, and positions of any given encounter'. Affective witnessing is a mediated practice that can take the form of written, visual or audio-visual texts: 'To encounter the witnessing text – the *testimonio*, the image testimony, the event of witnessing captured in media – is to be opened onto the capacity to be affected, to becoming co-witness.' Michael Richardson and Kerstin Schankweiler: 'Affective Witnessing', *Affective Societies. Key Concepts*. Ed. Jan Slaby and Christian von Scheve (New York: Routledge, 2019) 166-177, 168-169. Importantly, Richardson and Schankweiler link affective (co-)witnessing to moral action and obligation and define it as inherently political: 'witnessing is also necessarily bound up with questions of obligation, morality, and action […] witnessing is always on the brink of becoming political, of shifting from the

As a supplementation to Hogan's, Bewes's, Munt's, Richardson's and Siebers's works on shame, my analysis highlights the significance of shame and humiliation as affective narrative and communicative strategies in automedial texts about disability. It draws on Eve K. Sedgwick's concept of shame as an embodied and relational communicative strategy, that is, an affectively intense form of communication that cannot be limited to negativity, prohibition or repression (Sedgwick 2003, 36).[14] I challenge Bewes's claim that any study of shame is only informed by a 'structure of impossibility' (Bewes 2011, 3). Furthermore, I question his propositions that 'to make shame comprehensible would be to dissolve the feeling, and hence our possibility of grasping it', that shame 'resists interpretation' and that 'to speak of it boldly' is merely 'to counteract it, to produce its opposite – or itself as its own opposite (shame as absence of shame)' (3). Some of my selected autobiographical texts use narrative gaps (ellipses) and very short, fragmentary (sometimes poetic) lines to depict shame and humiliation as inhibited forms of communication that are affectively effective. Many examples contain emotion words[15] linked to shame and humiliation, detailed, audacious depictions of humiliating situations and affectively intense descriptions of painful dialogues and inner monologues precisely because they do *not* reproduce the concept of shame as a purely subjective, internal feeling that provides access to 'given', extratextual truths. They show not only that disabled bodies do indeed experience shame (a proposition that is often denied in ableist society)[16] but also demonstrate how shame and humiliation evolve as force relations between situated non-normative bodies and their environments.

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moment of the event to its proliferation through the body politic […]' (168). On the related concept of literary testimony see Richardson: 2016, 105.

[14] Eve Kosofsky Sedgwick: *Touching Feeling – Affect, Pedagogy, Performativity* (Durham and London: Duke University Press, 2003) 36. According to Tomkins, shame is 'an interruption of and impediment to communication that is itself communicated', see Eve Kosofsky Sedgwick and Adam Frank (ed.): *Shame and Its Sisters. A Silvan Tomkins Reader* (Durham and London: Duke University Press, 1995) 137.

[15] Anna L. Berg, Christian von Scheve, N. Yasemin Ural, Robert Walter-Jochum: 'Reading for affect: A methodological proposal for analyzing affective dynamics in discourse', *Analyzing Affective Societies. Methods and Methodologies. Ed. Antje Kahl* (London & New York: Routledge, 2019) 45-62, 50-52.

[16] Tobin Siebers: 'Sex, Shame, and Disability Identity. With Reference to Mark O'Brien', *Gay Shame*. Ed. David M. Halperin and Valerie Traub (Chicago & London, U of Chicago Press, 2009) 201-216, 202, 211-213. Siebers, commenting on Sedgwick's reflections on being flooded by shame when imagining a 'half-insane' man urinating in front of the lecture hall (Sedgwick 2003, 36-37), states: 'Shame confers agency, according to Sedgwick. It floods the self, its heat pervading our physical and mental existence with a burning awareness of our own individual skin. Shame creates a form of identity in which one risks being something rather than some person. Shame is painful and isolating for this reason. Nevertheless, shame is so appealing because being something is better than being nothing' (2009, 203-204). According to Siebers, non-disabled people rarely consider that disabled people are capable of feelings of shame: 'Do people to whom we ascribe no agency feel ashamed? Can one feel shame if one has no agency? Disabled people are not often allowed to have agency, sexual or otherwise. Rather, they are pictured as abject beings, close to nothing, empty husks. To be disabled in the cultural imaginary is to cease to function. Our highways are scattered with "disabled" vehicles – sad, static things of no use or importance' (Siebers 2009, 204). He asks with regard to disabled people: 'What happens if one is always in the public eye? What if one has no privacy? What if the access between the private and public spheres is obstructed or blocked? What if one is not sufficiently mobile to move between them?' (206).

The verbal and cultural texts selected by Munt[17] describe narrative structures that highlight the link between shame and pleasure or joy[18] and depict a movement from characters' experiences of queerness-, race- and class-related shame to pride or utopian, sometimes religious, ideas of a transcendence of shame. They are characterized by direct connections between shame and ideas of religious redemption that conceptualize a liberation from shame. Most of my selected texts do not rely on this narrative structure (although Kaite O'Reilly's autobiographically inspired story 'Sight' links visual impairment to divine revelation and suggests the possibility of a triumph over disability-related shame, see more below). I contend that although my selected texts often speak audaciously about shame and humiliation, their effect is neither necessarily to 'intensify shame in those who testify to it, or those who witness it'[19] nor to produce shame's 'own opposite' (e. g. pride and 'shamelessness'), let alone an 'absence of shame' (Bewes 2011, 3). Rather, they are characterized by narrative conversions of shame into other narrative affects and emotions and by a transference of shame among narrating and narrated 'I's, textual others[20] and readers. Hence, they convey the forcefulness, pervasiveness and contingency of affective connections between shame and animate and inanimate objects.[21] I will examine the ways in which the narrative affects shame and humiliation both inhibit and provoke narrators' expressive and actional responses and how they shape and inform narrative events, plot structures and turning points, often after a considerable period that is characterized by narrators' expressive and actional inhibition. Hence, I contend that the narrative affects shame and humiliation have a formative impact on the genre of disability autobiography, its plot structures and on the ways in which readers respond to them. Relying on research that demonstrates the formative impact of shame and audacity on the genres of queer and feminist autobiography (Sedgwick 1993; Mitchell 2020; Cooke 2020; Munt 2008, 213-216),[22] I will explore the ways in which feminist disability

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[17] Similarly, Michael D. Snediker emphasizes the link between optimism and shame: Michael D. Snediker: *Queer optimism: lyric personhood and other felicitous persuasions* (Minneapolis, et al.: Univ. of Minnesota Press, 2009) 15, 25, 30, 127. See Lauren Berlant: *Cruel Optimism* (Durham, London: Duke University Press, 2011) 12.

[18] Munt 2008, 4, 74, 87, 90, 92, 96.

[19] On this reading of the effect of shame see Munt 2008, 215.

[20] I will use Sidonie Smith's and Julia Watson's notions of 'narrated "I"', 'narrating "I"' and 'textual others'. The narrating 'I' 'is the "I" who tells the autobiographical narrative'. It 'calls forth only that part of the experiential history linked to the story he is telling […] the narrated "I" is the object "I", the protagonist of the narrative, the version of the self that the narrating "I" chooses to constitute through recollection for the reader'. Sidonie Smith and Julia Watson: *Reading Autobiography. A Guide for Interpreting Life Narratives* (Minneapolis and London: University of Minnesota Press, 2010) 72, 73. Underlining the relationality of the self in autobiography, Smith and Watson argue that there are 'different kinds of textual others – historical, contingent, or significant – through which an "I" narrates the formation or modification of self-consciousness. These include historical others, the identifiable figures of a collective past […] there are also contingent others who populate the text as actors in the narrator's script of meaning but are not deeply reflected on. And there are […] significant others, whose stories are deeply implicated in the narrator's and those through whom the narrator understands her or his own self-formation' (86).

[21] Ahmed argues that the 'object is not simply what causes the feeling, even if we attribute the object to its cause. The object is understood retrospectively as the cause of the feeling', Sara Ahmed: *The Promise of Happiness* (Durham and London: Duke University Press, 2010) 28. 'Object' is here understood in the phenomenological sense as a thing / being in the world and in the psychoanalytical sense, that is, as someone or something to which a subject relates. Bonnie J. Buchele and J. Scott Rutan: 'An Object Relations Theory Perspective', *International Journal of Group Psychotherapy*, 67.sup1 (2017): S36-S43, S38.

[22] Eve Kosofsky Sedgwick: 'Queer Performativity: Henry James's *The Art of the Novel*', *GLQ: A Journal of Lesbian and Gay Studies* 1.1 (1993): 1-16. Kaye Mitchell argues that shame is an affect that is closely connected to autobiography because it makes and unmakes the self / personhood. She discusses the 'shameful' aspects of 'narcissistic' self-exposure in contemporary British and American feminist

autobiography is (in)formed by narrative strategies of disability- and gender-related shame and humiliation as well as by 'unashamed',[23] audacious textual practices. In my analysis, I will examine how the texts position themselves to the notion of disability autobiography as a 'shamefully' sensationalist genre. I will focus on representations of narrative incidents, events, scenes[24] and experiences of disability- and gender-related shame and humiliation as well as on depictions of narrators' and textual others' affective reflections on them. In this context, I will analyse in how far narrators describe their non-normative bodies as shameful and in how far they represent themselves as different from non-disabled textual others and readers.

Although my selected texts do not suggest the possibility of an 'adequate' representation of experiences of disability-related shame that might enable disabled and non-disabled readers to completely share the experiences of disabled narrators, they use shame and humiliation as narrative affects to meaningfully represent and communicate shame-related experiences to their disabled and non-disabled readers and to make these represented experiences affectively accessible for them. Their use of shame and humiliation as narrative affects establishes a forceful and complex relationship with readers that challenges the notion of a fundamental incommensurability of disabled and non-disabled people's affective and emotional experiences. The texts' relational and therefore performative grammar of shame produces a potential for practices of affective (co-)witnessing, for empathy and solidarity as well as for a transference of shame to non-disabled as well as disabled readers who might harbour ableist, disablist, sexist, racist and homophobic prejudices. Hence, my analysis challenges Sally Munt's proposition that to represent, discuss and testify to shame means exclusively / primarily to activate its 'infectious propensity to inculcate further or intensify shame in those who testify to it, or those who witness it'.[25]

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autobiography, arguing that the authors' excessive sharing of autobiographical, sexual, and embodied confessions in relation to female sexuality and female sexual desire generates both fascination and revulsion: Kaye Mitchell: *Writing Shame: Contemporary Literature, Gender and Negative Affect* (Edinburgh: Edinburgh UP, 2020) 3, 14, 150-152, 157, 171, 180. According to Jennifer Cooke, contemporary feminist autobiography is characterized by audacious textual practices that describe tabooed, shame-related subjects (rape, sex work, vulnerability, betrayal, writer's block, female sexual desire, homosexual and BDSM practices, queer forms of embodiment, mental distress), Jennifer Cooke: *Contemporary Feminist Life-Writing: The New Audacity* (Cambridge: Cambridge UP) 2, 3, 96, 111, 115.

[23] My notion of 'unashamed' textual practices appropriates Jill Locke's political concept of 'unashamed citizenship' for literary analysis, Jill Locke: *Democracy and the Death of Shame: Political Equality and Social Disturbance* (Cambridge: Cambridge University Press, 2017). In practices of unashamed citizenship, 'people take to the street to demand a life free from shame, drawing attention to the gross disparities in regimes of political equality that countenance and even depend upon social relations and hierarchies that rank some citizens more worthy of regard than others.' 'Unashamed citizenship emerges from within the experience of shame, which it names and politicizes in order to activate a set of political demands and practices' (36-37). Locke takes 'seriously the ways in which the experience of shame can valuably alert one to unjust social relations that then trigger political action' (37). She is aware of shame's ambivalence, that is, its 'ability to trigger action or cause one to recoil and retreat from the world' (37). 'Unashamed' textual practices challenge shame-inducing norms but they do not necessarily suggest an overcoming / mastery of shame as a political and narrative force.

[24] I use 'scene' in accordance with Gérard Genette's definition of the term: it refers to a narrative passage in which discourse time equals story time and that is often realized as dialogue. Gérard Genette: *Narrative Discourse. An Essay in Method*. Trans. Jane E. Lewin (Ithaca, New York: Cornell UP, 1983), 94-95, 86.

[25] Munt 2008, 215.

As David M. Halperin and Valerie Traub[26] have argued in response to Eve Kosofsky Sedgwick's assertion of the transformative energy of shame, 'assuming the mantle of shame – taking shame on – might be one means of refiguring one's own experience of humiliation' (Halperin and Traub 2009, 38). According to Halperin and Traub, the trope of shame is useful not only for generating narrative but also, potentially at least, for generating community. In my selected texts, community formation through shame does not take the form of turning 'isolation into something like a membership card' (Halperin and Traub 2009, 38; Caron 2009, 130). It does not forge ingroup solidarity that is based on a solid rejection of the norm but produces a messy outcome: feminist disability autobiography straddles complex, intersecting forms of shame and has the potential to evoke responses of affective co-witnessing among readers from different social groups, especially among disabled and non-disabled feminists from different ethnic backgrounds and with different sexual orientations.

My selected texts describe practices of shame and humiliation that are part of autobiographical narrators' ordinary, everyday lives, that occur repeatedly / regularly (often on a daily basis) and that point to underlying social structures of ableism, disablism, sexism, racism and homophobia. Hence, my approach shares this focus on ordinary forms of affective attachments with Lauren Berlant's analysis of ordinary forms of 'systemic crisis'.[27] I will demonstrate that the affective attachments of disability- and gender-related shame are mundane, structural as well as contingent, unstable and unpredictable without being necessarily / directly geared towards pride or a transcendence of and redemption from shame. In addition, I will show that practices of reading disability autobiography and of reading about disability- and gender-related shame are heterogeneous, often unpredictable and characterized by ambivalence. They do not necessarily lead to the radical, revolutionary forms of self-transformation described by Munt with regard to the affective impact of texts about queer self-formation through shame.[28] However, they have the potential to enable readers to question the binary opposition between non-disabled and disabled bodies and their social spaces, to turn readers into affective co-witnesses of forms of humiliation with which they find themselves to be complicit or which they learn to challenge.

In many of my selected texts, the autobiographical representations of structural processes of disability- and gender-related humiliation (often happening in homes and medical and educational institutions) are audacious, unashamed textual practices that pillory misconduct as well as challenge the medicalization of embodied difference together with shame-inducing ableist body norms. Hence, I will explore how the texts enable readers to become affective co-witnesses of disability- and gender-related shame and how shame is transferred from narrators to textual others as well as to readers in order to make them aware of their possible complicity with shame-inducing norms and practices. Furthermore, my analysis examines formal strategies related to shame and humiliation, e. g. the use of fragmented language, ellipses, emotion words and of affectively intense dialogues and monologues. Furthermore, it probes the role

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[26] David M. Halperin and Valerie Traub: 'Beyond Gay Pride', *Gay Shame*. Ed. David M. Halperin and Valerie Traub (Chicago & London: U of Chicago Press, 2009) 3-40.

[27] Berlant 2011, 10. As Berlant has argued, traditional trauma discourse highlights exceptional forms of violence and unintelligibility but suggests a stability and transparency of ordinary life, 9-10.

[28] '[…] every time this reader engages with a "revolutionary" text or textual fragment, s/he is subtly repositioned within the specific cultural "episteme" – she is moved emotionally and imaginatively, through that consumption, to new prospects' (Munt 2008, 182).

of autobiographical narrative as a form of affective conversion (Ahmed 2010, 21, 27, 45). The following questions will guide my analysis:

- Do autobiographical narrators' acts of witnessing disability- and gender-related shame and humiliation intensify, loosen[29] or disrupt affective ties between shame and the non-normative bodies of narrators or textual others and between shame and inanimate objects (e. g. wheelchairs)?
- How do the texts depict the relationship between disability- and gender-related shame and positive affects[30] or emotions like interest, excitement, joy, pleasure and pride?
- Do representations of the pleasures and excitements of non-normative embodiment disrupt or intensify affective connections between shame and non-normative embodiment?
- Does the use of shame and humiliation as narrative affects encourage readers to question disability- and gender-related body norms?
- Do they facilitate, support and / or subvert readers' solidarity with disabled people and a potential for political action?

1. Anthologies

Jo Campling (ed.): *Images of Ourselves: Women with Disabilities Talking* (London, Boston, Henley: Routledge, 1981).

In 1981, the International Year of Disabled People (and in the middle of United Nations Decade for Women 1975-1985), Jo Campling, lecturer in Social Policy and 'one of the foremost figures in social care publishing',[31] edited *Images of Ourselves*, a collection of 25 short autobiographical texts by female, and mostly feminist, authors with physical and sensory disabilities (Campling 1981, vii-viii).[32] Exploring disability from an intersectional feminist perspective,[33] *Images of Ourselves* is a precursor of publications

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[29] As Lauren Berlant has argued, it is difficult to loosen or unlearn one's 'attachments to regimes of injustice', Berlant 2011, 184. Sara Ahmed writes: 'We can loosen the bond between the object and the affect by recognizing the form of their bond'. Ahmed 2010, 28.

[30] On the inseparable connection between shame and positive affects see Sedgwick and Frank 1995, 22-23, 137-138. On Tomkins's classification of positive, negative and neutral affects see Sedgwick and Frank 1995, 74.

[31] *Images of Ourselves*, back cover. 'Jo Campling, one of the foremost figures in social care publishing, has died of cancer [in 2006, K. R.]. Campling edited one of the first books giving service users their own voice, *Images of Ourselves: Women with Disabilities Talking*, and also edited several series of publications for Palgrave Macmillan, including its British Association of Social Workers series. Campling lectured in social policy for many years at Hillcroft College in south London. On leaving Hillcroft, she set herself up as a freelance publishing consultant.' 'Obituary: Jo Campling, lecturer and editor', *Community Care*, 7 September 2006. Web. 26 May 2021. <https://www.communitycare.co.uk/2006/09/07/obituary-jo-campling-lecturer-and-editor/>.

[32] All references to *Images of Ourselves* are to this edition: Jo Campling (ed.): *Images of Ourselves: Women with Disabilities Talking* (London, Boston, Henley: Routledge, 1981).

[33] Beckie Rutherford emphasizes the close connection between feminism and disability activism: 'The Disabled People's Movement gained momentum at the same time as the Women's Liberation Movement, hence disabled women have been involved in disability rights politics in conjunction with feminist politics for many decades. What we see is a landscape of intersecting and overlapping liberation movements and grassroots activism unfolding in Britain throughout the 1970s, 1980s and 1990s.' Beckie Rutherford: 'Disabled women organising: Feminism and disability rights activism', *Women's Rights* 19 Oct 2020, n. p. Web. 26 May 2021. <https://www.bl.uk/womens-rights/articles/feminism-and-disability-rights-activism>.

like Gohar Kordi's *An Iranian Odyssey* (1993), Jenny Morris's *Pride Against Prejudice* (1991), Lois Keith's edition *Mustn't Grumble Writing by Disabled Women* (1994) and Michele Wates's and Rowan Jade's collection *Bigger than the Sky. Disabled Women on Parenting* (1999).

As the statements on its back cover suggest, *Images of Ourselves* owes a lot to a handbook for disabled women (titled *Better Lives for Disabled Women*) that Campling (herself able-bodied but raised by a disabled mother) had edited for the feminist publisher Virago in 1979. The autobiographical texts included in *Images of Ourselves* emerged from readers' responses to and reviews of Campling's handbook. The short statements on the back cover of *Images of Ourselves* underline the anthology's connection with the feminist sociological fieldwork informing *Better Lives*: both publications explore the links between ableism, disablism[34] and sexism. In her author's note for *Better Lives*, Campling argues that many problems of disabled women 'stem from, or are an extension of, discrimination against *all* women, and that to be female and disabled in our society is a double drawback' (Campling 1979, Author's Note).[35] *Better Lives* shows that disabled women are stigmatized in specifically gendered ways: some are devalued for failing to achieve patriarchal norms of femininity, e. g. to fulfil their reproductive and supportive roles as mothers and housewives or sexually attractive lovers, others are overprotected, especially when living with their parents. Still others try to pass as non-disabled or withdraw from social interaction to avoid embarrassment. Campling demonstrates that the problems disabled women are confronted with arise not from disability or impairment but from the structural inequality and injustice defining patriarchal disablist society (e. g. inaccessible facilities, education opportunities and career paths) as well as from the limiting notions of sexuality and partnership that pervade cultural notions and representations of disability. In *Better Lives For Disabled Women*, Campling intends to counter such forms of exclusion, injustice and limitation by providing practical advice on a broad range of topics, e. g. on possibilities of formal and higher education for disabled women and on grants, commissions and associations through which disabled women can receive support. She includes information on disabled women's possibilities of employment, motherhood and parenting, on practical home care devices, incontinence, benefits, clothing and more, mentioning feminist and disability organizations to which her readers can turn. Importantly, she describes many ways in which disabled women can experience hetero- and homosexual encounters or masturbation as pleasurable.

A considerable number of autobiographical texts in *Images of Ourselves* audaciously signpost and critique forms of gender- and disability-related humiliation happening at

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[34] David Bolt defines ableism and disablism as follows: 'In essence, both terms denote the same thing […]: discriminatory or abusive conduct toward people based on physical or cognitive abilities […] ableism and disablism render radically different understandings of disability: the former is associated with the idea of ableness, the perfect or perfectible body; and the latter relates to the production of disability, in accordance with a social constructionist understanding […]. Put differently, ableism renders non-disabled people supreme and disablism is a combination of attitudes and actions against those of us who identify as disabled. […] Disablism, then, involves not only the "social imposition of restrictions of activity" but also the "socially engendered undermining" of "psycho-emotional well-being"'. David Bolt: 'Not forgetting happiness: the tripartite model of disability and its application in literary criticism.' *Disability and Society* 30.7 (2015): 1103-1117, 1105-1107.

[35] Jo Campling: *Better Lives For Disabled Women* (London: Virago, 1979). Web. 26 May 2021. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Campling-better-lives.pdf>.

the hands of doctors, nurses, teachers, carers, family members or strangers. Importantly, these forms of humiliation were hardly described before in Britain, especially not by disabled women themselves. Resultantly, the title of the collection highlights the importance of disabled women's self-presentation.[36] In her review of *Images of Ourselves*, feminist disability theorist Anne Finger underlines the long-felt absence of a comparable publication that describes the social experiences of disabled women, admitting to her own ferocious reading of the 'much-needed' work: 'I read this book at a single, hungry sitting'.[37] The boldness of writing about such critical topics cannot be overemphasized, considering that disability-related harassment was not regarded as legally liable or as a form of discrimination before the passing of the 1995 Disability Discrimination Act (which prohibited harassment against disabled people in work contexts) and the amendment of the Disability Discrimination Act from 2005, which required public authorities to eliminate harassment of disabled people that is related to their disabilities.[38] By appropriating Jill Locke's notion of unashamed citizenship, *Images of Ourselves* can be described as an unashamed textual practice as it critiques intersectional forms of injustice and inequality that target women with disabilities (Locke 2017, 36-37).[39]

In her introduction, Campling states that she asked the authors of the autobiographical texts she collected in *Images of Ourselves* to 'write whatever they wanted about their situations as women with disabilities. I rejected the idea of interviews because even the most skilled interviewer cannot help but be directive. I did not want the impromptu answer but deeply felt, considered contribution' (Campling 1981, vii). She is very clear about her approach of strictly limiting her editorial function: 'I have written the briefest of introductions to each piece, simply to give a framework in which the reader can place the writer. I have limited the editorial function to the minimum and I have not presumed to make a commentary or interpretation' (vii-viii). In her review of *Images of Ourselves*, Lesley Day points out the possible drawbacks of this approach, arguing that Campling should have included some interpretation of this qualitative material and that the authors may have wished to be involved in the editing process (Day 1982, 121). Anne Finger, by contrast, approves of Campling's minimal intervention: 'the editor […] wisely chose not to interview the women as she sensed that the structure created by her

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[36] A similar focus is set by the title of Irving Zola's *Ordinary Lives: Voices of Disability and Disease* (Cambridge [Mass.]: Apple-wood Books, 1982), which contains male and some female voices on the topic, see Thomas Coogan: 'The Disabled Body: Style, Identity and Life Writing.' (Unpublished dissertation submitted at the University of Leicester, 2008) 204-210. Web. 16 Jan. 2020. <https://www.semanticscholar.org/paper/The-Disabled-Body%3A-Style%2C-Identity-and-Life-Writing-Coogan/dac924554aa1750de094fc4103bded9605927984>.

[37] Anne Finger: 'Review *Images of Ourselves. Women with Disabilities Talking*. Ed. Jo Campling. Routledge & Kegan Paul, 1981', *Off Our Backs* 12.11 (December 1982): 13.

[38] *Hidden in plain sight. Inquiry into disability-related harassment*. Equality and Human Rights Commission (2011) 13, 188. Web. 26 May 2021. <https://www.equalityhumanrights.com/en/publication-download/hidden-plain-sight-inquiry-disability-related-harassment>. See also: Nick O'Brien: 'Disability Discrimination Law in the United Kingdom and the New Civil Rights History: The Contribution of Caroline Gooding', *Journal of Law and Society*, 43.2 (2016): 444-468.

[39] In her review of the book, Lesley Day highlights the critique of the 'double handicap' that disabled women have to face: Lesley Day: '*Images of Ourselves. Women with Disabilities Talking*. Jo Campling (ed). Routledge & Kegan Paul, 1981. Review.', *Critical Social Policy*. 2.4 (1982): 120-122, 121.

questions would limit and inevitably impose her own ideas on what the women had to say' (1982, 13).

Campling mostly uses only the first names of the authors in her collection, thereby emphasizing the collection's feminist stance, affirming authors' individuality and protecting their anonymity. This strategy provides readers with some personal information about the authors but it does not jeopardize their rights to privacy. It is in line with the ethical code of ethnographic studies in sociology. A negative effect of this strategy is, however, that it (partly) pre-empts contributors' visibility as authors in their own right. In some cases (no doubt with their permission), Campling introduces authors by giving enough information about them so that it is rather easy to trace their full names. She includes the titles of books they have written, the names of groups and organizations they have founded or journals they have contributed to. This happens in the cases of Micheline Mason, Elsa Beckett and Julie Mimmack (23, 82, 15-16).

Introduced as a more personal elaboration on the topics discussed in the 'narrow reference' of the handbook (Campling 1981, vii) and advertised as 'a moving tribute to the strength, courage and insight of the women who wrote it' (back cover), *Images of Ourselves* is also a formal innovation within the genre of feminist disability autobiography that influenced later anthologies like those by Marsha Saxton and Florence Howe (*With Wings*, 1988), Lois Keith (*Mustn't Grumble*, 1994), Michele Wates and Rowan Jade (*Bigger Than the Sky*, 1999) and Victoria A. Brownworth and Susan Raffo (*Restricted Access. Lesbians on Disability*, 1999). These collections of autobiographical texts create a polyphony of distinct voices of heterogeneous authors that enables readers to discover patterns of connections, to draw comparisons between the texts, to notice similarities, differences, tensions and contradictions. Anne Finger has drawn attention to the complexity that is generated by the polyvocality of Campling's collection: 'The result is a highly compressed and rich piece which has at times the density of poetry' (1982, 13). Furthermore, *Images of Ourselves* creates new communities of disabled, mostly feminist authors and their disabled and non-disabled readers.

Recently, Olivia Wright has used the term 'collective autobiography' for women's prison zines from the 1970s that share some features with my selected feminist anthologies of autobiographical texts by disabled authors. Wright convincingly distinguishes her notion of 'collective autobiography' from John Downton Hazlett's concept of generational autobiography developed in *My Generation: Collective Autobiography and Identity Politics* from 1998.[40] Whereas the texts analysed by Hazlett are 'individual works of literature that represent a generational community', the zines explored by Wright 'are written and produced as a collective and do not allow one voice to speak for all' (*loc. cit.*). Many of the texts investigated by Wright are written in the third person and are characterized by the use of plural pronouns. They thereby emphasize the typical, representative and communal aspect of the experiences they describe (Wright 2018, 9-10). By contrast, the autobiographical stories[41] in Campling's collection (like

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[40] Olivia Wright: '"Freedom in her Mind": Women's Prison Zines and Feminist Writing in the 1970s', *Journal of International Women's Studies* 19.1 (2018): 6-19, 6-7 note 3.

[41] A short statement on the back cover of the book (possibly by Campling) refers to the autobiographical texts in the collection as 'stories'. Lesley Day and Judith C. Gilliom refer to the texts as 'short essays':

those in Lois Keith's *Mustn't Grumble* and Wates's and Jade's *Bigger Than the Sky*) are written in first-person perspective. They provide readers with distinct accounts of gender- and disability-related experiences that offer many points of connection, similarity or contrast. For this reason, I will not refer to Campling's, Keith's and Wates's and Jade's collections as collective autobiographies.

In her introduction to *Images of Ourselves*, Campling explains that 'all the themes which I identified in *Better Lives*', that is, 'personal relationships, sexuality, motherhood, education and employment as well as the practical issues such as benefits, clothing and so on', also appear in the texts collected in *Images of Ourselves*, together with the discussion of 'attitudes towards women with disabilities, […] their position in society and, by reflection, our own dilemma as able-bodied women' (viii). Campling emphasizes the heterogeneity of the contributors:

> Some [authors] are feminists, some would question the use of the word, and some would reject it altogether. Some could only write with the physical help of other women. They are not professional writers, although some have written for publication before and two have published books. What they do have in common is that they are all women with disabilities. (viii)

The focus on the diversity of female disabled authors is emphasized by the book-cover illustration created by Michael Davidson. It shows 25 green silhouette profile depictions of women's heads on yellow ground that can be interpreted as representing the 25 female authors who contributed texts to the collection. Importantly, the illustration draws attention to the book's focus on the (self)representations of disabled women. The 25 green profiles, although appearing similar or even identical at first sight, show marked physiognomic differences at a second, closer look. In this way, the illustration problematizes and disturbs the superficial, often ableist, glace at disabled women that hastily decides that they all look or even are 'the same'. At the same time, the uniform green colour that is used for all profiles signals the common aspect that links them: the fact that they represent women with disabilities. The back cover contains statements that highlight the collection's double focus on the authors' heterogeneity (they 'span the years from adolescence to old age', 'they come from a wide variety of backgrounds', '[t]heir disabilities are various') and their collective identity: 'What they have in common is that they are all women with serious disabilities' (back cover).

The statements on the back cover contextualize the importance of the book's publication with a reference to the 'International Year of Disabled People' and describe the goal of the stories collected in Campling's anthology. They emphasize that the stories give accounts of 'what it is like to be a disabled women […] Each woman writes of her personal feelings, about how she copes physically, emotionally and mentally with her disability, and how her roles in society and relationships with others are affected by it' (back cover). The statements on the back cover mention spontaneously emerging themes of the autobiographical texts: personal relationships, sexuality, motherhood, education, employment, benefits, clothing, and access to public places. They emphasize that the texts provide insights from the perspectives of disabled women that were lacking in public discourse. The statements on the back cover also

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Day 1982, 121; Judith C. Gilliom: 'Review of Images of Ourselves: Women with Disabilities Talking'. *American Annals of the Deaf*. 127.6 (1982): 737.

contain a résumé of the book that illustrates the broad spectrum of disabled women's experiences with their environments, suggesting that some authors 'find that they can integrate fairly well into the world of the able-bodied, while others have to rely heavily on aid from close friends, relatives and welfare organizations' (back cover). Disabled women's desire to be 'as independent of others as their disability will allow' is represented as a need that unites all authors in the collection.

The front matter of the book contains the alphabet in sign language, underlining the collection's goal to teach disabled and non-disabled readers competences that allow them to communicate with and learn from disabled persons. The overall intention of the book is to enable able-bodied women to relate to disabled women, to recognize their attitudes and prejudices towards disabilities and to 'work positively on their feelings' so that they can 'begin to see how those attitudes can be changed' (Campling 1981, viii; back cover). *Images of Ourselves* is advertised on the back cover as 'an encouragement to all of us, whether women or men, able-bodied or disabled', yet the readership that Campling envisions in her introduction primarily comprises all women (both disabled and non-disabled ones). Campling quotes Micheline Mason, one of the authors in her collection, who asserts that women are strong enough to 'overcome' their disabilities (viii), a formulation that should not be misunderstood as suggesting that disabled women should overcome their impairments. Micheline's text discusses disabilities as being caused above all by a disablist and sexist society with unaccommodating environments and infrastructures, thereby following the social model's definition of disability.[42] She regards the solidarity among women across differences of ability and race – women who all experienced different forms of body-shaming – as a strategy through which intersectional forms of devaluation and oppression can be confronted and possibly changed (Campling 1981, 25-27).

The packaging of Campling's collection lacks sensationalist strategies.[43] It's front and back covers emphasize the book's status as a serious academic publication that is firmly rooted in feminism. The fact that the 25 contributions do not carry (affectively suggestive) titles links them to the tradition of case studies. However, the contributions are indeed stories and contain literary elements (narrative perspective, imaginative elements, dialogues, monologues, irony etc.).

Although the autobiographical texts in Campling's collection describe gender- and disability-related shame and humiliation as emotions that are experienced by the

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[42] The social model emphasizes that it is not the physical or mental impairments that disable people but the unaccommodating social and infrastructural environments in which they live. On the social model of disability see Jenny Morris: *Pride Against Prejudice. Transforming Attitudes to Disability* (London: The Women's Press, 1991) 10; Carol Thomas: *Female Forms. Experiencing and Understanding Disability* (Buckingham and Philadelphia: Open University Press, 1999) 14. On the origin of the notion 'social model of disability' see Colin Barnes: 'Understanding the Social Model of Disability. Past, present and future', *Routledge Handbook of Disability Studies*. 2nd Edition. Ed. Nick Watson and Simo Vehmas (2019; London: Routledge, 2020) 14-31, 20. See also Mike Oliver: 'A New Model of the Social Work Role in Relation to Disability', in J. Campling (ed.) *The Handicapped Person: A New Perspective for Social Workers* (London: RADAR, 1981) 19-32.

[43] This stands in contrast to later book-length disability autobiographies whose packaging targets the voyeuristic interest of mainstream audiences, their 'hunger' for individual, 'authentic' stories, see e. g. Louise Medus's *No Hand To Hold & No Legs To Dance On. A Thalidomide Survivor's Story* (Mid-Glamorgan: Accent Press Ltd. 2009). Here, marketing strategies emphasize lack and negativity as well as narrators' triumph over adversities related to their dysfunctions.

narrating and narrated ‘I’s as well as textual others, they do not depict them as being located in individual bodies. Instead, shame and humiliation appear as affective dispositions that are generated in forceful encounters and interactions between the non-normatively embodied narrating and narrated ‘I’s and their socio-political environments. These environments consist of representatives and staff members of institutions (e. g. special and integrated schools, homes for the disabled, hospitals, charity organizations), teachers, doctors, personnel officers in work places as well as strangers that repeat and uphold ableist, sexist norms and prejudices and discriminate against disabled women. A great number of the 25 autobiographical texts in Campling’s collection depict narrators’ affective responses to ableist and sexist body norms and institutionalized practices of humiliation and discrimination. Resultantly, the collection represents these shame-inducing norms and practices not as singular, coincidental cases but as structural manifestations of social inequality and injustice. In her review of Campling’s book, Judith C. Gilliom argues that although the female authors do ‘not speak with unified voices, […] there is something universal about what they say – universal for disabled women and perhaps universal for all women as well’ (1982, 737). Whereas Gilliom regards the universalist dimension of the texts as an advantage, Anne Finger critiques the lack of voices of developmentally and psychiatrically disabled women as well as of ‘women who speak from a Third World perspective’ (1982, 13).

The authors in Campling’s collection have very heterogeneous social backgrounds and provide situated testimony to structural inequalities and injustices as well as abuse that disabled women faced in the 1970s and at the beginning of the 1980s. Some of the contributors are, however, directly connected to each other (Edwina dictated her text to Micheline, Campling 1981, 13) or they refer to other authors in the collection (see Merry’s text, 32). In describing disabled women’s affectively intense encounters with the able-bodied world from their own perspectives – perspectives that were hardly represented before, let alone considered culturally significant[44] – the texts in Campling’s collection provide counter-truths or counter-discourses in the sense of Michel Foucault’s use of the term.[45] Hence, they are feminist appropriations of the (traditionally male) practice of *parrhesia*. Campling’s authors are partly anonymized and use writing instead of oral speech but they critique structural forms of stigmatisation that target disabled women in an ableist, patriarchal society from an ostracized, subjugated position and with the intention to promote social change.[46] In a

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[44] Thomas Couser: *Signifying Bodies. Disability in Contemporary Life Writing* (Ann Arbour: The University of Michigan Press) 9; Jenny Morris: *Pride Against Prejudice. A Personal Politics of Disability* (London: The Women’s Press 1991) 8-9, 111, 146, 187.

[45] A counter-discourse creates ‘a space in which the formerly voiceless might begin to articulate their desires to counter the domination of prevailing authoritative discourses’, see Mario Moussa and Ron Scapp: ‘The Practical Theorizing of Michel Foucault: Politics and Counter-Discourse’, *Cultural Critique* 33 (1996): 87-112, 88 and Gilles Deleuze and Michel Foucault: ‘Intellectuals and Politics’, *Language, Counter-Memory, and Practice*. Ed. Donald F. Bouchard (Ithaca: Cornell UP, 1977) 205-217, 209.

[46] Foucault writes: ‘Parrhesia is a form of criticism, either towards another or towards oneself, but always in a situation where the speaker or confessor is in a position of inferiority with respect to the interlocutor. The *parrhesiastes* is always less powerful than the One with whom he speaks. The *parrhesiastes* comes from “below,” as it were, and is directed towards “above.” This is why an ancient Greek would not say that a teacher or father who criticizes a child uses *parrhesia*. But when a philosopher criticizes a tyrant, when a citizen criticizes the majority, when a pupil criticizes his teacher, then such speakers may be

few cases, names of localities, associations and organisations are mentioned in Campling's short introductions and in the autobiographical texts themselves so that those responsible for the depicted acts of stigmatization and abuse could be traced.[47]

In addition to their depiction of non-disabled people's practices of disablist and sexist humiliation and of the effects of these practices on autobiographical narrators, the texts critique 'horizontal hostility'[48] among members of subjugated social groups and explore narrators' own complicity with ableist and sexist body norms. Hence, they are audacious, potentially empowering autobiographical practices in the sense of Jennifer Cooke's definition of the term (2020, 2-3). The autobiographical stories in *Images of Ourselves* exhibit a 'boldness in style and content' and explore difficult, disturbing experiences related to non-normative embodiment[49] and its stigma as well as non-normative desires, pleasures and intimacies (including queer intimacies). Thereby, they can disrupt ableist, heteronormative images of disabled women. However, it is important to bear in mind that daring autobiographical acts of representing experiences of oppression, stigmatization and vulnerability are not always read as practices of empowerment. As Jennifer Cooke has observed, contemporary autobiographical writing is a practice through which female / feminist disabled authors represent themselves as vulnerable, especially through descriptions of their narrators' feelings of shame in response to structural sexism. From the perspectives of reviewers and critics, this vulnerability (especially if described by female authors) is rarely linked with 'intelligence' (Cooke, 2020, 115) and can be (mis)understood as a purportedly shameful practice of self-victimization (Cooke 2020, 96, 111).

Reviewers have focused on the ways in which Campling's book critiques the structural injustice that disabled women are subjected too. For Judith C. Gilliom, the individual viewpoints expressed in the autobiographical texts enable her to connect her own experiences as a disabled US-American woman to those represented in Campling's collection:

> As a disabled woman, I found in the book many thoughts I have had frequently and some that are new to me. There are harsh statements and hopeful ones, triumphs and defeats. As I continued to read, I found myself searching more and more eagerly for confirmation of my own views, answers to problems I have not solved, and ideas that could lead me to become something I am not. The book's message is power: the power of the individual, regardless of the barriers one

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using *parrhesia*.' Michel Foucault: *Fearless Speech*. Ed. Joseph Pearson (Los Angeles: Semiotext(e), 2001) 17-18.

[47] Pat mentions the Christmas parties of the Royal Air Force Benevolent Fund whose members treated everyone in her school 'as an idiot child' or as an 'ungrateful being' in case pupils protested against their paternalizing treatment, see Campling 1981, 53.

[48] This term denotes a form of hostility among members of oppressed groups. It was coined by Florynce Kennedy who defines it as 'misdirected anger that rightly should be focused on the external causes of oppression', Florynce Kennedy: 'Institutionalized Oppression vs. the Female', Robin Morgan (ed.): *Sisterhood is Powerful* (New York: Random House and Vintage Books, 1970), see Julia Penelope: *Call Me Lesbian: Lesbian Lives, Lesbian Theory* (Freedom, CA: Crossing Press, 1992) 60.

[49] Although the audacious feminist autobiographies discussed by Cooke do not problematize experiences related to physical disabilities, they explore experiences of mental distress, see Cooke 2020, 78-92.

> confronts; the power of women to be liberated, whether they are feminists or not. (Gilliom 1982, 737)

Whereas Gilliom's and Anne Finger's readings are marked by their desire to find points of connection between their own experiences and those described by the autobiographical narrators (Finger 1982, 13),[50] Lesley Day focuses on the collection's impact on non-disabled female readers (one of the publication's most significant targeted reader groups according to Campling, Campling 1981, viii). She finds fault with what she perceives to be the collection's individualized critique levelled against specific teachers, doctors, nurses and social workers, arguing that it may only provoke members of the same professions to wash their hands of any responsibility for such misconduct:

> Teachers, doctors, social workers, to name but a few, may wish to dissociate themselves from the condemnation and criticism levied at them by some of these women contributors. It is not sufficient, however, for individuals to decide that they are not part of the problem. This is to individualise the issue, rather than recognising the institutionalised nature of female oppression and discrimination which has a double blow for the physically handicapped woman. (Day 1982, 122)

Day here overlooks the fact that many texts in the collection independently depict similar acts of bearing witness to institutionalized forms of discrimination. Thereby, they create a cumulative effect that challenges dismissive responses which place responsibility for such practices of humiliation in the hands of individuals only. In contrast to Day's reading, Anne Finger's perspective emphasizes the collection's complex affective and emotional strategies, its decidedly political stance and its feminist strategy of '"publicizing" what were previously private pains and angers' (1982, 13):

> as I flipped through this book again to write this review, I could not help but be struck by how little happiness there was in the pages of this book and in these lives. There are moments, of course, of joy […]. But every page bristles with anger, pain, longing, resentment. In a sense the unrelenting harshness of this book is a tribute to the women who wrote it: none of them flinch away from examining the situations in which they find themselves: none of them are grateful for the not-enough they do get; nor do they take refuge in che[e]riness or cheap optimism. (13)

As these excerpts show, the collection's affective impact is mainly described as empowering and liberating for disabled / feminist readers,[51] as expressing disabled women's anger, resentment and longing as political, public emotions or as condemning individual non-disabled members of medical and educational institutions. Texts from the early phases of feminist disability activism have indeed emphasized the role of anger in the struggle for social change, an aspect that becomes visible in the critical approaches to autobiographical texts from this period. Sara Ahmed locates the origin

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[50] Finger writes: 'As I read about the lives of these women […], I found in all of their voices echoes of my own' (1982, 13).

[51] Anne Fingers has described the book as 'simple' and 'powerful', see Finger 1982, 13.

of anger in pain and, in contrast to Martha Nussbaum, emphasizes the importance of anger's inseparable connection to pain and its history (2014, 174). Hence, whereas anger is a response to (past) pain, it 'is not simply defined in relationship to a past, but as opening up the future'. It 'does not necessarily become "stuck" on its object, although that object may remain sticky and compelling' (Ahmed 2014, 175). By contrast, shame makes and unmakes selves / identities and enacts a far greater stickiness on its object, preventing it from quickly moving on towards a better future or a new self. While I acknowledge the central role of anger as a narrative affect (or 'transition-anger', to use Martha Nussbaum's term) for feminist activist writing in general[52] and for Campling's collection in particular, I will demonstrate that the narrative affects shame and humiliation play a significant, at times formative, but mostly overlooked role in at least 11 out of the total 25 contributions. I suggest that the *repeated* (and therefore structural) use of disability- and gender-related shame as an affective narrative strategy within the polyvocal network of Campling's anthology subverts an individualized approach to disability- and gender-related oppression. Rather than condemning coincidental cases of misconduct, it depicts 'sticky', structural, intersubjective and highly politicized force relations between female disabled bodies and their non-disabled or disabled environments.

My analysis shows that Campling's texts critique disablist and sexist structures and practices of humiliation not despite of, but *through* autobiographical narrators' depictions of their own and of textual others' shame and vulnerability as well as through shame's decidedly relational (political and intersubjective) making and unmaking of selves, that is, through its formation of 'spoiled' identities.[53] As Eve Kosofsky Sedgwick argues in her discussion of Erving Goffman's book *Stigma: Notes on the Management of Spoiled Identity* (1963), shame and humiliation are forces that constitute, disrupt, transform and complicate identities (Sedgwick 1993, 4). Similarly, Heather Love has drawn attention to the ambivalent nature of the form of 'identity' generated through stigma, that is, to its 'dynamic of identification and disidentification' (Love 2001, 488-489).[54] She quotes Goffman as follows:

> The stigmatized individual may exhibit identity ambivalence when he obtains a close sight of his own kind behaving in a stereotyped way, flamboyantly or pitifully acting out the negative attributes imputed to them. The sight may repel him, since after all he supports the norms of the wider society, but his social and psychological identification with these offenders holds him to what repels him, transforming repulsion into shame, and then transforming ashamedness itself

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[52] See Ana María Munar: 'Dancing between anger and love: Reflections on feminist activism', *ephemera. Theory & politics in organization* 18.4 (2018): 955-970. Transition anger, Munar writes (paraphrasing Nussbaum), is an emotional response in which 'our efforts will be directed towards creating better conditions to avoid or minimize wrongdoing in the future' rather than towards retribution for past injustices and injuries or towards the humiliation of the party that caused the anger in the first place (962-963).

[53] On the decidedly relational making and unmaking of 'spoiled' selves and identities see Kosofsky Sedgwick 1993, 4 and Heather Love: '"Spoiled Identity": Stephen Gordon's Loneliness and the Difficulties of Queer History', *GLQ: A Journal of Lesbian and Gay Studies*, 7.4 (2001) 487-519, 488-489.

[54] On the source of the quotation from Goffman's book see: Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, N.J.: Prentice-Hall, 1963) 107-108.

> into something of which he is ashamed. In brief, he can neither embrace his group nor let it go (Love 2001, 488-489).

Hence, the ‘spoiled’ identities (identities formed, deformed, disrupted and unmade through shame) are not stable, monolithic, unambiguous or clearly opposed to ‘dominant’ social groups or ‘mainstream’ society. Rather, they are marked by their intensely ambivalent entanglement with dominant social norms and values, an entanglement that repeats, cites, negotiates and sometimes challenges these norms and values. A considerable number of autobiographical narrators in Campling’s anthology struggle with and even reject what they in part describe as the humiliating, stigmatizing and ostracizing label ‘disabled’ / ‘disability’ (see e. g. Elsa Beckett’s, Sue’s and Merry’s contributions). Furthermore, my selected texts show that shame’s forceful formative impact undermines a predictable, unambiguous distribution of agency or power among the parties involved in the encounters between non-normative bodies and their social environment. Shame can indeed silence subjects and provoke their withdrawal (Frank and Sedgwick 1995, 134).[55] However, as my selected verbal texts and Mary Duffy’s autobiographical performance demonstrate, authors’ experiences of disability- and gender-related shame often have an activating influence that can involve autobiographical production, exhibitionism, extroversion, self-display, theatricality, activism and practices of shaming back.[56] Hence, shame’s impact generates a messy force field that troubles and undermines binary notions of ‘agency’ and ‘victimhood’.

The representations of disability- and gender-related feelings of shame included in Campling’s collection function as indicators of disability- and gender-related social injustice and inequality as well as of autobiographical narrators’ partial complicity with these forms of injustice. In addition, they are affective communicative strategies with a transformational relational grammar (Sedgwick 1993, 4, 11). They turn readers into potential affective co-witnesses of practices of stigmatization and shame-inducing body norms and enable them to reflect on these practices and norms. My selected autobiographical texts share some aspects of the trauma literature analysed by Richardson. They make extensive use of as well as inspire affective forms of (co-)witnessing, yet in contrast to Richardson’s selected trauma texts, their affective impact is not limited to a self-reflective performance of their inability to ‘match the participant’s experience of the historical event’ (105). Instead, the affective impact of my selected texts is inextricably linked to the audacious counter-truths and speculative, at times utopian, ideas and meanings that are generated by the imaginative forms of (co-)witnessing and the scope of affective responses that the texts represent (those of narrated and narrating ‘I’s and textual others) and evoke.

As Michael Richardson and Kerstin Schankweiler have argued convincingly, witness-bearing is a decidedly embodied, relational and (therefore) affective practice: ‘to bear witness means not only giving an account of this experience and making this incident accessible to others, but also entails affecting and being affected’ (Richardson and Schankweiler 2019, 167). Hence,

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[55] See also Silvan S. Tomkins: *Affect Imagery Consciousness. The Complete Edition*. 4 vols (New York: Springer, 2008) 178, 352, 517, 568, 971, 263, 354-355, 438, 510.

[56] On this point see Siebers 2009, 211-213; Kosofsky Sedgwick 1993, 2; Kosofsky Sedgwick 2003, 38.

> affective witnessing recognizes and insists upon the intensive relationality of the witness, the witnessed and their co-witnesses. Witnesses […] always bear witness to some*thing*; they testify to some*body*. To witness an event means becoming responsible to it. This is an affecting experience, even if the intensity and register changes based on specific contours, textures, and positions of any given encounter (Richardson and Schankweiler 2019, 168).

Similarly, in the texts included in Campling's collection, the relational grammar generated in representations of shame-inducing situations and feelings of shame enables readers as possible co-witnesses to respond to these representations through a broad range of affective dispositions (solidarity, admiration, anger, outrage, shame, interest etc.) that evoke a potential for political action.

As the texts in Campling's collection problematize encounters between female disabled bodies and their socio-political environment, their notions of shame and humiliation are in line with Sara Ahmed's as well as Gregory J. Seigworth's and Melissa Gregg's definitions of political emotion or affect. Ahmed, whose notions of 'emotion' and 'feeling' are influenced by Seigworth's and Gregg's, Baruch Spinoza's and Silvan Tomkins's concepts of 'affect' and 'emotion' (Ahmed 2014, 4, 8, 10, 18),[57] emphasizes the political dimensions of the connections and associations between bodies, emotions, cultural objects and socio-political hierarchies:

> It is not difficult to see how emotions are bound up with the securing of social hierarchy: emotions become attributes of bodies as a way of transforming what is 'lower' or 'higher' into bodily traits. So emotionality as a claim about a subject or a collective is clearly dependent on relations of power, which endow 'others' with meaning and value. […] I want to reflect on the processes whereby 'being emotional' comes to be seen as a characteristic of some bodies and not others, in the first place. In order to do this, we need to consider how emotions operate to 'make' and 'shape' bodies as forms of action, which also involve orientations towards others. […] feelings do not reside in subjects or objects, but are produced as effects of circulation […]. The circulation of objects allows us to think about the 'sociality' of emotion. (2014, 4, 8)

Ahmed here describes the generalizing (and mostly derogatory) attribution of 'being emotional' to some (mostly female, non-white, queer and, I would like to add, disabled or mentally distressed) bodies rather than others as an effect of power and structural inequality. Similarly, Seigworth and Gregg, who define affect in terms of '*force or forces of encounter*' that can be vehement, subtle or unnoticed,[58] emphasize that affects do

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[57] Ahmed states in a note: 'It may be useful to compare my approach on the relation between emotions and objects to Tomkins' (1963) theory of affect. As others have commented, Tomkins' attention to affect as opposed to drive emphasises the "freedom" of emotion from specific objects […]. I am also suggesting that emotions are "free" to the extent that they do not reside within an object, nor are they caused by an object. But the language of "freedom" is not one I will use in this book. I will argue instead that the association between objects and emotions is contingent (it involves contact), but that these associations are "sticky". Emotions are shaped by contact with objects. The circulation of objects is not described as freedom, but in terms of sticking, blockages and constraints.' Sara Ahmed: *The Cultural Politics of Emotion*. 2nd edition (Edinburgh: Edinburgh University Press, 2014) 8 note 13.

[58] Gregory J Seigworth and Melissa Gregg: 'An Inventory of Shimmers', *The Affect Theory Reader*. Ed. Melissa Gregg and Gregory J. Seigworth (Durham & London: Duke University Press, 2010) 1-25, 2.

not reside in the bodies of individuals but emerge in the encounters between bodies and between bodies and their socio-political, cultural and natural environments:

> Affect arises in the midst of *in-betweenness*: in the capacities to act and be acted upon. […] affect is found in those intensities that pass body to body (human, non-human, part-body, and otherwise), in those resonances that circulate about, between, and sometimes stick to bodies and worlds […] affect is persistent proof of a body's […] ongoing immersion in and among the world's obstinacies and rhythms, its refusal as much as its invitations. […] Affect marks a body's *belonging* [or *non-belonging*, K. R.] to a world of encounters (Seigworth and Gregg 2010, 1-2).

In the case of shame as affect, this forceful encounter of bodies and their environment happens at the boundary of what dominant society defines as normal and abnormal: according to David Carob, 'Shame is located at the precise boundary defining the normal and the abnormal'.[59]

The autobiographical texts in Campling's collection describe what Sara Ahmed has defined as the graded 'stickiness' of feelings in relation to specific bodies and objects, that is, the idea that (certain) feelings [or rather affects] stick more strongly and consistently to some (stigmatized) objects or bodies rather than others, even to the point of defining their (spoiled) identities and interactions with the world:

> Feelings may stick to some objects, and slide over others. […] some objects more than others become sticky, such that other objects seem to stick to them. It is important not to neutralise the differences between objects and to recognise that some objects become stickier than others given past histories of contact. (2014, 8, 92)

Ahmed has demonstrated that the graded stickiness of affects underlies the ways in which shame forms the bodies it sticks to as well as the social spaces in which such sticking happens: 'The very physicality of shame – how it works on and through bodies – means that shame also involves the de-forming and re-forming of bodily and social spaces, as bodies "turn away" from the others who witness the shame' (2014, 104). In line with these observations, a number of stories in Campling's collection represent how shame sticks to female disabled bodies, their wheelchairs, crutches, canes etc. so that they become sources of embarrassment for their ableist environments. Lisa, one of the authors in Campling's collection, states:

> Quite often I find that there is the added problem of the wheelchair or crutches becoming a psychological barrier between the outside world and the disabled person. They are obvious and the user is quickly registered as a 'disabled person'. The barrier is often difficult to break down and it usually takes time and patience before you are accepted as a normal human being and the disability disregarded. (Campling 1981, 5)

In addition, the texts show that shame also sticks to certain spaces of social interaction like special schools, homes for the disabled and other institutions. Out of the 11

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[59] David Caron: 'Shame on Me, or the Naked Truth about Me and Marlene Dietrich', *Gay Shame*. Ed. David M. Halperin and Valerie Traub (Chicago & London, U of Chicago Press) 117-131, 126.

autobiographical texts that I selected for my analysis, 3 include audacious descriptions of shame with regard to disability-related dysfunctions and impairments (the texts by Sue, Julie and Elsa), 2 (by Julie and Elsa) discuss the shame around incontinence in the context of sexual encounters.

Campling's collection approaches gender- and disability-related shame and humiliation above all from a discursive perspective: affectively intense situations of humiliation and feelings of shame are mostly depicted through the mode of telling, often in a report-like manner. The effect evoked by the texts is neither that of direct affective contagion (a response that might be regarded as passivizing authors as well as readers)[60] nor is it characterized by sensationalism. However, the representations of situations and experiences of disability- and gender-related forms of humiliation in Campling's collection are not free from affect, on the contrary: they activate readers' critical reflection skills and enable them to be affected in a variety of ways. This narrative strategy enables readers to become affective (co-)witnesses of disability- and gender-related injustice and inequality. As Anne Finger has emphasized, some texts in Campling's collection are pervaded by anger (especially Sue's text), others are characterized by volatile affective transformations or contain shame-inducing dialogues (see the texts by Sue and Diana – 1), still others are shaped by turning points in which narrators respond to and reflect on practices of disability-related humiliation (see Micheline's text). However, in all these cases, the affective impact of the texts is not simply that of contagion.

Many of the autobiographical stories discuss narrating and narrated 'I's' experiences of disability- and gender-related humiliation and objectification – of being showcased like animals in a cage, as Pat's text formulates (Campling 1981, 52-53) – in connection with the ableist images of disabled women they are confronted with (see the texts by Sue, Pat, Maggie and Merry). Many autobiographical narrators respond with anger and irritation to such stereotypical images and ableist norms (Diana I 77), some, however, respond by trying to 'pass' as able-bodied. They relate how they adapt to ableist gender norms through acts of role-playing, the use of an 'ultra-feminine' appearance and by seeking heterosexual relationships through which they hope to prove that they are 'attractive' and function like 'normal' women. However, the texts show that such role-playing need not lead to bio-medical normativization[61] or an affirmation of ableist and sexist norms, on the contrary: narrators' awareness about the ways in which their disabled female bodies fail heteronormative notions of femininity can have queering effects on them: Julie's and Pat's texts in particular reflect on the performativity of the concept of femininity, an aspect that leads to a queering of the autobiographical narrators' perspectives. Robert McRuer has argued convincingly that heterosexual and

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[60] On the concept of a contagious transmission of affects through which people become alike or take opposite positions see Teresa Brennan: *The Transmission of Affect* (Ithaca Cornell UP, 2004) 9; Sally Munt: *Queer Attachments. The Cultural Politics of Shame* (Aldershot: Ashgate, 2007) 3, 13-14. Linabary, Corple and Cooky have emphasized the passivizing affective impact of 'misery porn', see Jasmine R Linabary, Danielle J Corple and Cheryl Cooky: 'Feminist activism in digital space: Postfeminist contradictions in #WhyIStayed', *new media & society* 22.10 (2020): 1827–1848, 1840. Sara Ahmed has critiqued the concept of affective contagion by drawing attention to the contingency of situated bodies' affective interactions, see Ahmed 2010, 39.

[61] I use the term 'bio-medical normativization' to denote processes of making / attempting to make bodies and minds conform to a bio-medical notion of physical and cognitive / mental 'normality', which is itself a normative construct, see Davis 2010a.

able-bodied identities are performatively constructed and that the concepts of queerness and disability are intertwined and imply each other.[62] From an ableist, heteronormative perspective, disabled bodies were (and are) understood as being ‘queer’ and queer bodies were (and are) understood as ‘disabled’ because both challenge concepts of normalcy:

> people with disabilities are often understood as somehow queer (as paradoxical stereotypes of the asexual or oversexual person with disabilities would suggest), while queers are often understood as somehow disabled (as ongoing medicalization of identity, similar to what people with disabilities more generally encounter, would suggest). (McRuer 2010, 387)

The narrating ‘I’s in Julie’s, Micheline’s and Pat’s texts state that they regard this (pressure of) assimilation to heteronormative gender roles as a severe problem for disabled women. Pat describes this performance of sexist gender roles as a catch-22 situation that forces many disabled women into being complicit with patriarchal and heteronormative notions of gender difference. In some texts, this awareness is shown to lead narrating ‘I’s to a challenging, disruption or loosening of their affective attachment to shame-inducing norms.

Many stories in Campling’s collection discuss ableist stereotypes that devalue disabled women as social burdens, as being passive, overly dependent, unattractive, asexual, incapable of engaging in love relationships and that suggest that the only men interested in disabled women are disabled, emasculated or closeted gays. The autobiographical texts show that ableist preconceptions picture disabled women as being inapt for higher education and only capable of doing low-qualified jobs. In the texts, the affective response of narrators to situations of gender- and disability-related humiliation is often not only withdrawal and loss of self-confidence (cf. Sarah’s response to her school mates’ taunts and Angie’s reaction after a humiliating medical review, 2, 9-10) but also a desire for higher achievement (see Pat’s story 50-57), a wish to counter ableist assumptions about disabled women, to prove them wrong or to adapt to patriarchal roles of femininity and heteronormative ideas of female beauty. Some narrating ‘I’s describe how they (their younger selves / narrated ‘I’s) strove to prove their independence or their ability to do what able-bodied persons told them they cannot do (see the texts by Angie and Pat). Furthermore, the narrators respond to shame-inducing situations by expressing their anger, by shaming back (by transferring shame to the shamer), by exploring the interaction between shame, body pleasure and sexuality / sexual desire, by questioning or rejecting shame-inducing social norms, by embracing their embodied difference and their non-normative forms of living or by solidarizing with other oppressed groups (esp. women of colour and queers). Some stories emphasize the importance of solidarity among disabled and non-disabled women (see the texts by Maggie and Micheline 25-27) and the significance of creating alliances with members of emancipation and environmental (animal rights) movements (see Sue’s and Elsa’s texts). Furthermore, a number of texts in Campling’s collection examine shame’s cultural and social conditioning and the contingency of its sources (see Lisa’s and Julie’s texts).

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[62] Robert McRuer: ‘Compulsory Able-Bodiedness and Queer/Disabled Existence’, *The Disability Studies Reader*. Ed. Lennard J. Davis (New York & London: Routledge, 2010) 383-392, 387.

Most contributions do not explicitly address their readers. In Sue's story, however, the narrating 'I' turns to readers and society at large, stating 'dismiss me if you will, as society has dismissed the feelings and protests of blacks, Jews, gays, women for centuries. Historically it has been proven that powerless groups are not given recognition until they demand and fight for it.' (50). Maggie complains to her hearing readers that she is always expected to make hearing people feel at ease with her but rarely experiences that they make situations easier for her (37). The narrator's use of the singular second person pronoun in Julie's text can be understood as a strategy through which she addresses her disabled and non-disabled readers (17-18, see below). Merry addresses her readers directly and invites them to imitate her performance as a mal-adjusted disabled person (30).

The authors in Campling's collection discuss different targets or objects of disability- and gender-related humiliation and shame. Some explicitly expose and brand the institutionalized practices of humiliation that they witnessed and were subjected to, linking them to systemic sexism and disablism (e. g. Julie, Sue, Micheline, Merry, Maggie, Elsa and Pat), others (like Sarah) describe the harmful, inhibiting and paralyzing effects of such practices on their lives. A considerable number of authors relate that they felt ashamed of their embodied difference because of the ostracization they experienced in able-bodied society: Lisa's text is a case in point. She was 18 when she contributed her text to Campling's collection. Campling's introduction explains that Lisa has bilateral myelodisplacia, walks with crutches or uses a wheelchair, studies for her 'A' levels and hopes to go on to university to do business or computer studies (4). Furthermore, Campling states that Lisa took part in the BBC TV series 'The Handicapped Family',[63] thereby enabling readers (at least in the 1980s) to trace her full name (I was not able to do so). The narrator in Lisa's text explains that she attended a 'boarding school for handicapped students' where she led a varied social life and that she finds it hard to socialize outside the protected boundaries of her boarding school: 'I am just getting over feelings of shyness, inferiority and insecurity which have, in the past, made it even harder for me to go out and meet people' (Campling 1981, 5). Here, the narrator describes her own paralysis in response to her able-bodied environment that ostracizes her because of her embodied difference. At this point, the text depicts shame as a narrative incident. The shyness that the narrator describes inhibits her actions and suspends narrative effects. However, at a later point in the narrative, the narrator describes the action (effect) that follows from her experience of shame, thereby turning it into a narrative event (see below).

Sarah, a woman born with hemiplegia (a condition caused by brain damage or spinal cord injury that leads to paralysis on one side of the body), who was 17 years old when she wrote her text (1), describes how she became 'very self-conscious' about her disability in her local integrated comprehensive school where she was bullied because of her non-normative body (e. g. her inability to walk long distances) and was treated 'as a person set apart' (2). Resultantly, the narrator recounts that she felt 'worthless and very vulnerable every time someone made a personal remark to me or about me' (2). She was mocked by her peers because she could not go to a distant disco: 'They

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[63] 'The Handicapped Family. BBC Two England, 10 March 1980', BBC Genome Beta. Radio Times 1923 – 2009. Web. 15 June 2021. <https://genome.ch.bbc.co.uk/4bc6a80f2e0744248208ebdb84b99a55>.

used to ask questions like “Why can’t you go to the disco?” (It was four miles away.) I would say that I didn’t want to go and they would whisper and giggle. Then I would remain quiet and hurt inside’ (2.) Here again, the narrator describes her experience of shame in terms of paralysis and the inability to act. As this passage illustrates, Sarah’s story emphasizes that her self-consciousness about her disability does not originate in her own individual perspective on her body (she was born with hemiplegia into a caring and supportive family, 1) but evolves in response to the taunts and ostracization she experiences at her integrated school.

Furthermore, Sarah’s text gives insight into a form of horizontal hostility between herself and a girl with a ‘bad reputation’ who is treated as an outsider because she has many boyfriends: ‘I felt we were in the same situation in different ways’ (2). This ‘friend’ exploits the narrated ‘I’, makes her do tasks for her and threatens to end the friendship if she doesn’t comply. In one instance, this ‘friend’ humiliates the narrated ‘I’ in a cruel way: ‘Once she made me kiss the toilet floor and then told everyone that I had done it voluntarily and I was very embarrassed’ (2). Her teachers failed to redress the problem of her ostracization. They were unsure about how to handle her and gave her very little academic encouragement (2). The narrator explains that she became unhappy and depressed because of her environment’s humiliating response to her disability. When she expressed her wish to attend a school for disabled children, her mates at her integrated school berate her, taunting that she will become a ‘moron’ (3).

As these passages show, Sarah’s text names and shames her mates’ and teachers’ disablist prejudices and practices of humiliation as well as the paralyzing, inhibiting impact of these prejudices and practices. At a later point in the text, the narrator describes her (belated) action in response to these forms of stigmatization (her decision to attend a boarding school for disabled children), thereby turning the narrative incident of shame into a narrative event. In addition to her experiences of humiliation at her integrated school, the narrator describes and critiques her own fears about being considered ‘not disabled enough’ by her disabled mates in her new school as well as her fears and prejudices about severely disabled people. In the night before her departure to her new boarding school for disabled children in Kent, the narrated ‘I’ had a nightmare about the horizontal hostility that might await her there: in the nightmare, she is shamed and ostracized by severely disabled people who tell her she is not one of them:

> I had a terrifying nightmare of lots of very severely disabled handicapped people (more handicapped than I had ever seen or imagined) crowding round me in a circle, telling me that I did not belong to them. Then they tried to bury me with all their strange aids and appliances. It was very frightening and I did not know what to expect (3).

By recounting this nightmare, the narrator shows that her fears about disability have a similar paralyzing impact on her as the ableist practices of humiliation and ostracization that she had to face. Furthermore, the passage demonstrates that fears and prejudices about disability are not limited to able-bodied persons or to encounters between disabled and non-disabled people. Instead, they are part of the imagination of disabled persons as well, an idea that is also emphasized in Elsa’s story (83-84, see below). Sarah’s text demonstrates that the narrated ‘I’’s fears did not come true, on the contrary: she quickly made friends at her new school and ‘didn’t feel an outsider any more. Everyone had a disability and no one was self-conscious about it’ (3). The narrator states that her best friends at the new school are more disabled than she is and that they support each other (3).

Julie’s (Julie Mimmack’s)[64] story discusses the sexuality of the female disabled body and its relation to abjection and shame. As Campling writes in her brief introduction, Julie is paralysed from her armpits downwards after a car accident, uses a wheelchair, is incontinent and severely hypothermic (16). Julie was 25 when she contributed her text to Campling’s collection. She has an Open-University degree and wrote for *Spare Rib*, the feminist journal published in Great Britain between 1972 until 1993 (16). The narrating ‘I’ describes how the act of revealing her incontinence to her sex partners can be embarrassing to both parties and even provoke disgust. However, the text points beyond the autobiographical dimension of this problem: the use of the singular second- and third-person pronouns has a self-distancing as well as generalizing effect. Through this strategy, the ethnographic dimension of the text is emphasized and disabled (and possibly also non-disabled) female readers feel included and addressed:

> In intimate relationships there is also that first moment when the mechanics of your bladder management are revealed. This is the major test. How will he react to a mature woman who wears plastic knickers, pads and requires help when going to the loo? Rejection on this count is painful and inhibiting […]. The disabled person is unable to quickly get up, dress, wash. Even when sexually aroused, the spontaneity can soon disappear when your partner has to help empty your bladder and carefully clean and position you. Over exhaustion, especially if orgasm is achieved, can make the disabled woman feel inadequate. The mind may be willing to try out new positions and experiences, but the body function is that much weaker. I suppose we all have sexual fantasies. Mine relate to spontaneous sexual behaviour - sex in a lift, in any room of the house, and in numerous positions, on the floor, up against the wall, etc. (17).

Another problem related to disabled women’s sexuality, the narrating ‘I’ states, is their housing situation, i. e. their lack of access to spaces that enable intimacy. Due to the shortage of independent living facilities and financial support (the independent living movement in the UK only gathered pace in 1979 with the formation of the Project 81 group),[65] many disabled women were forced to live with their parents: ‘If your relationship passes the bladder test’, writes Julie, ‘the next hurdle is arranging a time and a private meeting place’ (17).

Furthermore, Julie’s story explores the impact of ableist and sexist body norms on disabled women: the narrating ‘I’ argues that many women worry about the way in which their bodies look and function, again using the singular second person pronoun

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[64] Julie Mimmack’s contribution to Campling’s collection in part resembles her 1979 article for *Spare Rib*, see Julie Mimmack: ‘Physical relationships and the disabled woman’, *Spare Rib magazine* 86.1 (September 1979): 14-15. Web. 5 June 2021. <https://www.bl.uk/collection-items/spare-rib-magazine-issue-086>.

[65] John Evans: ‘The Independent Living Movement in the UK’, 2003. Independent Living Institute (ILI), independentliving.org. Web. 10 June 2021 <https://www.independentliving.org/docs6/evans2003.html#1>. Mimmack’s article appeared in the first ever *Spare Rib* feature on disability, see Rutherford 2020.

not only in order to refer to a structural social problem but possibly also to address her disabled and non-disabled readers:

> You may also worry about your body shape. Most disabilities come equipped with drooping breasts, a thin rib-cage and a lax tum, due to lack of muscle-tone. You may compare your body shape with how it was prior to disability and wonder whether your partner is comparing your body to someone else's. The inability of the disabled person to be purely physical, showing body movement, posture, wearing attractive clothes, can be a great disadvantage within the 'market place' of relationships. Seeing such physical abilities in others can result in jealousy which is hard to admit. (17-18)

The effect of ableist and sexist body norms can be so profound that disabled women develop self-hatred and are unable to believe their partners when these express admiration of and interest in their bodies: 'If you are praised, there is always a feeling of doubt. No one can really convince you of sexual prowess when half your body isn't really normal' (17). Although Julie's text is explicit about the inhibiting impact of ableist body norms, the narrating 'I' presents herself as sexually active. She informs readers about her and other disabled women's sexual desires and fantasies. Hence, she challenges ableist stereotypes about the purported passivity and asexuality of disabled women.

The shame connected to non-normative bodies can also take the form of a strong desire to become able-bodied: In her imaginative text, Micheline admits to her own dream of becoming 'normal' in the process of growing up:

> The first time the doubt that I belonged to this particular planet struck me, was a glorious, calm, blue-skied day when I was twelve years old. Lying flat on my back in the garden, staring at the sky, I was thinking about growing up. Until that moment I think I had somehow believed that when I grew up I would become 'normal', i.e. without a disability. 'Normal' then meant to me, 'like my big sister', pretty, rebellious, going out with boys, doing wonderful, naughty things with them, leaving school and getting a job, leaving home, getting married and having children. (23)

Micheline was born with osteogenesis imperfecta (brittle bones) in 1950. She went to Art College and worked in a small charity. In 1979 she published a book titled *Creating Your Own Work*. Campling states in her introduction that Micheline teaches re-evaluation co-counselling and initiated and co-leads the London Support Group for People with Disabilities (23). The day described at the beginning of Micheline's autobiographical text is a caesura in her life, a point at which the narrated 'I' realizes that her dream of becoming 'normal' (i. e. able-bodied) scatters. She finds that her non-normative body cannot be shed like old skin, an insight that leads to disappointment and a negative self-image: 'I was going to be just the same as I had always been - very small, funnily shaped, unable to walk. It seemed at that moment that the sky cracked' (24). Her desire to be 'like everyone else' is mocked by her non-disabled social environment and leads to ostracization (24-25).

Like Sarah's, Julie's and Micheline's texts, Sue's contribution discusses the ways in which non-normative female bodies are subjected to shame and humiliation. However, it is more strongly infused by the narrative affect of anger than the other authors' contributions. Sue has MS and was in her 30s when she contributed her text to Campling's collection. Campling introduces her as a student of sociology and a radical feminist (44). Similar to Micheline's text, Sue's includes a life-changing caesura. In Sue's story, however, the caesura is caused by a change in the narrated 'I's physical condition that in turn alters the way in which she is perceived by her environment. After a long period of receiving misdiagnoses, the narrated 'I' faces the fact that she has MS (multiple sclerosis). Before this event, however, she had to explain her sudden inability to walk to her doctor. Her use of fragmentary language describes shame as a reduced, disrupted form of communication: 'I went to the doctor. "Er, Doctor, I-um-don't seem to be able to walk properly" – embarrassed, conscious of sounding silly. He eyed me bleakly and handed me some tranquillisers. I went home and threw them away.' (45) She gets misdiagnosed with mental illness (agoraphobia) and is shamed for being a neurotic hypochondriac. Sue's text laconically mimics the humiliating interview with her doctor in which her physical symptoms were mentalized. The narrating 'I' sarcastically exposes the structural sexist stereotypes that pervaded her doctor's views and the opinions of the medical profession in general. She mimics a dialogue between herself and her doctor that shows how she was blamed for being a 'bad patient' when she questions the diagnosis:

> Symptoms continued and varied. I visited the medical profession again. This time he [the doctor, K. R.] was not amused - look Mrs Housewife you are depressed/isolated/neurotic/female. Are you taking the pills? No? Exasperated, take *these* pills. I take the pills, symptoms persist. I go back to the overworked doctor. Repeat my story. He tries psychological approach (after all, he's on duty at the local 'mental hospital' sometimes, he has an interest in psychology). 'Do you find walking easier when you are not with your husband?' 'No.' I am not being helpful. 'Do you find it more difficult out of doors?'. 'Yet – I keep feeling like I'm going to fall over (and there's no furniture to hang on to).' Ah hah – his face brightens up, he's got it – agoraphobia. I'm not at all convinced, I ask for an examination. Smile fades, he refuses, says it's not necessary – I am agoraphobic. I don't feel any better, but I have a label. I go home and report that I am an agoraphobic. (45, emphasis in the original)

She questions the diagnosis of mental illness and the doctor responds by labelling her a 'hypochondriac' (45). When she 'answers back', she is 'shown hastily out of the surgery' (45). On the following day, she collapses. The same doctor must order an ambulance but his 'embarrassment' about his misdiagnoses is hardly noticeable, it is 'covered up well with professional ethos' (45).

In Sue's story, descriptions of shame and humiliation are not limited to situations in which the narrated 'I' is the object of humiliation. The narrating 'I' also pillories the doctor's sexism and misdiagnosis as well as the abuse and humiliation that elderly women in hospital are subjected to. When the narrated 'I' had to stay in hospital (a place the narrating 'I' describes as 'that place of hidden pain and despair') after her diagnosis, she observed how an elderly lady was mistreated by staff members:

> the older residents […] were got out of bed and sat in a chair for the next 13 interminable hours. Woe are those who are powerless, helpless and helped. An

> older woman who had one of the most beautiful and dignified faces I have seen, sat immobile in her chair day after day, refusing to be alive to what was happening to her, except when her husband came at night and loved her, and she became human again. Porridge time came around one morning and in bustled one of those guardian angels, a nurse. ‘Come on dear,’ said the 20-year-old to the 70-year-old, ‘Eat up your nice porridge.’ The woman sat unspeaking while the nurse tried to push the spoon into the unwilling mouth. The ward was quiet, the helpless looked away while the helper forced in the porridge. The woman turned her head, wordlessly, tears streaming down her face. The nurse, momentarily defeated, angrily turned to the helpless for support, ‘She’s got to eat it, it’s good for her.’ Man’s inhumanity to man. But then when you are the helpless, dignity is a luxury you cannot afford. (46-47)

In this passage, the narrating ‘I’ transfers shame to the represented staff member. Hence, the text enables readers to become affective co-witnesses of the de-humanizing treatment elderly female patients are subjected to.

In addition to its convincing depiction of the ways in which the complex affective dynamic of disability- and gender-related shame and humiliation unfolds its impact among narrated and narrating ‘I’s, textual others and, possibly, readers, Sue’s text describes how the negative associations evoked by the label ‘disability’ / ‘disabled person’ generate shame in those persons who receive it. The narrating ‘I’ explains in retrospect that for her, disability meant

> [t]he end of freedom, spontaneity, social anonymity; the beginning of fear, pain, existential isolation; the ambiguity of social ostracism/public property. I did not know it on that June morning but I was to become THE DISABLED; the beginning of the frightening descent into the world of the ‘social minority’. (44)

What might be viewed as an affirmation of the dominant, highly individualized and de-politicized tragedy model of disability[66] is actually an illustration of the ways in which the tragic turn in the narrator’s life was caused only in part by her progressive chronic condition and more significantly by disablist social responses to it.

Like Sue’s text, the story by Merry problematizes the exclusively negative image of impairment in ableist society. Merry was born in Kenya and was 30 years old when she wrote her autobiographical text. She was born without her left hip joint and with a very short femur. Her family returned to England with the hope that she would receive sufficient medical attention there. Merry walked with the help of a special shoe, a caliper and crutches and had an operation during which her missing hip was replaced by an artificial one. She works as an educational psychologist and did doctoral research on how disabled people’s treatment by their society effects their lives. She identifies as a feminist disability activist. In her text, she describes her three phases of growing political awareness about the intersectional stigma affecting disabled women (28-31). She argues that the exclusively negative language used to refer to physical

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[66] Sally French and John Swain: ‘There but for Fortune.’ *Disability on Equal Terms*. Eds. John Swain and Sally French (Los Angeles, London, et al.: Sage, 2008) 7-20, 7-8.

impairments is a form of disability-related humiliation that she sought to escape by trying to pass as able-bodied:

> […] when, as a sixth-former, I ran a club for people who were disabled, I used to rush about efficiently, trying to appear as different as I possibly could from the club members, and as similar as possible to the able-bodied helpers! Many years later, whilst lying on my back trying to recover from the results of wearing the caliper all those years, I began to think about how much of the language used about us (who are disabled) is negative. Youngsters would look at me and ask, 'What's WRONG with that lady's leg?' and parents (if they didn't shut the child up and rush away guiltily) would reply, 'She's got a BAD leg.' Not, anyway, the most instructive answer! People talk of us as invalids - in-valid! Well no one was ever going to call me that again and get away with it!' (29)

As this passage shows, the narrator's responses to such derision and devaluation comprise outrage and anger rather than shame. There is no description of the narrated 'I''s feelings of paralysis in response to such humiliation. However, Maggie's and Elsa's texts in Campling's collection demonstrate that the negative, humiliating impact of the negative words used to denote impairments is profound and not easy to avoid, let alone to erase.

Maggie is deaf and wears a hearing-aid. She was 31 when she contributed her text to Campling's collection. The editor introduces her as a part-time drama teacher of deaf students in further education, a student of psychology at the Open University and a feminist who is 'politically active in the disability world' (33-34). The narrating 'I' in Maggie's text recounts how her self-perception changed after she became disabled: she had seen herself as an attractive drama student and future actress but after becoming deaf she felt guilty for being a 'less than perfect person': 'My first feelings were ones of enormous guilt at having "let my parents down" and I kept the news secret until the college wrote to them. But the guilt of being less than a perfect person remained and grew, as my deafness progressed' (34). In the text, guilt and shame are regarded as different but closely related feelings: the narrating 'I' describes how the usually short-term feeling of guilt (the feeling of having *done* something wrong) is transformed into a long-term response ('being less than a perfect person') that is more akin to shame (the feeling of *being* someone wrong), an affective disposition that forms, makes and unmakes selves and identities.[67]

At the beginning of her text, Elsa describes how she hated her disabled body and avoided the society of other disabled people (83). Campling's introduction informs readers that Elsa was born in Northern Rhodesia (now Zambia) in 1939 and attended Rhodes University in South Africa to read Latin and English. She broke her back in 1957 and is paralysed from below the waist. Elsa identifies as lesbian and at the time she contributed her story to *Images of Ourselves* she lived in East London with her mate. She writes fiction, short stories, novels and plays 'in which fantasy and reality are set side by side'. Furthermore, she is a member of Gay Authors Workshop, founding member of Gemma, a group of disabled and able-bodied lesbians that was formed in 1976, and works with the Campaign for Homosexual Equality as well as with

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[67] Helen B. Lewis: 'Shame and Guilt in Neurosis', *Psychoanalytic Review* 58.3 (1971): 419-438, 426-429, 435.

the East London Gay Liberation Front (82-83). It is especially Campling's reference to Gemma that enables readers to identify the author as Elsa Beckett. At the beginning of the text, the narrating 'I' describes the narrated 'I''s hatred of and disgust towards her disabled body and her inability to even look at it:

> When I was first disabled I wouldn't look at my body, especially the legs. I left off my glasses so that I couldn't see it when the nurses washed and turned me. Looking back I am surprised that rejection of my body began so soon after my injury, before the muscles atrophied. After twenty-three years of disability I don't feel wholly resigned to my body the way it is, thin unshapely legs, navvy-like shoulders and torso (just as if tomorrow it might somehow regain a more conventionally acceptable shape). […] For everyday life I need loose clothing that I can forget, easy to get on and off, and which hides my shape as much as possible. In this camouflage I suspect I imagine that my body underneath is the same as it was. (83)

As this passage shows, the narrating 'I' has not fully overcome her negative response to her own disabled body. Instead of embracing a stable, consistent attitude towards it, she acknowledges her changing, fluid self-images:

> A lot of this will seem contradictory because I feel differently about my disability at different times, in the same day I have several different reactions to it. I don't think I've accepted completely my body's state and difficulties; I get tired of the routine of looking after it even though I know that the smallest neglect might result in trouble such as a pressure sore […]. My image of myself is not clear because for so many years I avoided thinking about this. In one way I feel my wheelchair is part of me and I resent people leaning on it, fiddling with it. I accept it and I ignore it. I feel irritated when attention is drawn to it – 'What a nice wheelchair!' I suppose I should respond as sensibly as if a car or bicycle were being praised. It was quite a shock to me recently to discover my blind spot about myself; I needed a picture of a woman in a wheelchair from which I might make an illustration, and I was hunting through magazines for some time before it occurred to me I need only look in my own photo album – there I am, in a wheelchair. Why after so long don't I see myself as a wheelchair-user? It looks as if even to me 'wheel-chair people' are other people and not me. (83-84)

The following passage shows that the narrated 'I''s negative attitude towards disability used to include a shameful rejection of associating herself with other disabled people:

> Early in my disability I had a rejecting attitude towards other disabled and have only just got rid of this (though not entirely, it would seem). I didn't then want to mix with disabled people, didn't want to be associated with them, I wanted to pass for non-disabled, as it were. (86)

The reason why Elsa rejects the label 'disabled', however, is not only related to the non-normative negativisms that are associated with it but also to the normative positivisms[68] connected with the stereotype of the ‘supercrip’ who individually triumphs over adversities:

> I compare myself unfavourably with the stereotype, a disabled person who struggles against the odds to complete her education, get a job, play sport, drive a car, travel, etc., and do a good PR job with ‘the public’, explaining competently about disability. I feel myself inferior to this image and at the same time know it is ridiculous, we have the right to be the sort of people we are, disabled or not. (85)

After her divorce, she lives with her lesbian partner with whom she can be open about her ‘physical problems’ and feels fully loved and accepted:

> it was a gradual process introducing her to my physical problems. In the first years I wasn’t happy about her helping me, for instance, when toilets were inaccessible and I had to use a bowl. Now I’m not embarrassed about it but I still wonder, is this really nice for her, could year upon year of this affect our relationship? These are only half-serious doubts. I have phases of asking her for reassurance (knowing I will get it), childish direct questions: ‘Am I grotesque?’ She is half-exasperated, half-amused. I trust her completely, I know she won’t laugh at my body as one nurse did once. If we did separate I couldn’t put the same trust in someone else, I could never start all over again, I’d be too afraid of rejection/disgust, it would take too long for me to get as close to someone else again.’ (86)

When the narrating ‘I’ here laconically recounts that she was subjected to a nurse’s derisive laughter, she includes a significant piece of information that alludes to a possible external source of the disgust and embarrassment that she feels in relation to her body. As this passage demonstrates, the narrating ‘I’’s embarrassment about her non-normative body is not erased or overcome (it returns in the sad, fearful thought about a possible separation from her partner and her intense fear of rejection) but it is transformed and suspended through her partner’s love.

In addition to non-normative embodiment and the labels of disability, impairment and illness, the autobiographical stories in Campling’s collection describe many other targets and objects of disability- and gender-related humiliation and shame.

Sue’s text discusses inaccessible buildings as a major cause of her feelings of shame and embarrassment. The narrator recounts how she struggles with inaccessible facilities like cinemas to which she has to be carried piggy-back, a position she ironically describes as ‘feminism gone wild!’ (49), and points to the sexist implications and historical dimensions of excluding women from public spaces. She shows how she is made to feel out of place ‘in a place of enjoyment’, a fact that she, being a feminist, finds outrageous (49). She relates how the ‘wonderland’ of cinema has become a ‘living embarrassment’ for her, not because of her non-normative body but because of her

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[68] Non-normative negativisms are defined as ‘problematised deviations from socially accepted standards […] that are marked by disablism […]’ (Bolt 2015, 1106). Normative positivisms are understood as ‘the affirmation of socially accepted standards […] that are marked by ableism’ (Bolt 2015, 1105). David Bolt writes that ‘ableism and disablism might be critically conceptualised on a continuum that moves from normative positivisms to non-normative negativisms’ (1107).

environment's unaccommodating response to her needs and desires and its devaluation of her existence as a social burden, an 'undesirable property':

> So, I wheel through this wonderland which for me, by accident, has become a nightmare, a living embarrassment. I'm told I'm lucky, Ian [Sue's husband, K. R.] is told how wonderful he is and how lucky I am. It's great for the self-esteem (it's a well-known sociological/psychological fact that we 'disabled' have low self-esteem). Implicit implication; he's wonderful/a saint for staying with an undesirable property like you. You (disabled) are lucky not to be alone, unwanted in an institution. No one has ever said he is lucky (unthinkable), or he obviously stays with you because you give as much as you take. But then of course, that's an unthinkable proposition, isn't it? After all I'm only one of THE DISABLED.' (50)

As this passage shows, the narrating 'I' describes how for her, the embarrassment related to her non-normative body 'sticks' to her environment (to use Ahmed's useful term), to inaccessible buildings that turn her into a helpless object. From the perspective of the textual others, however, her non-normative body is the cause of shame / embarrassment, it is a social burden, an 'undesirable property', the passive, troublesome recipient of her saint-like husband's selfless care.

A similar embarrassing situation in another 'place of enjoyment', this time a theatre, is described in Lisa's text. The narrator recounts that when she goes to inaccessible public places she is often greeted by a personal assistant who insists on 'helping' her. As a result, however, everybody notices Lisa's disability and makes assumptions about her 'helplessness': 'in some theatres that I have visited, I have been provided with my own personal "companion" who has insisted on pushing me to my seat and creating such a fuss that my presence in the theatre has become too obvious and rather embarrassing' (6). Such patronizing behaviour is not helpful, the narrating 'I' states, not without transferring a fair share of shame to the non-disabled '"companion"'. She argues that help should be 'provided on asking and not automatically because you are disabled. Many disabled people handle their wheelchairs better than anybody else, so the helper can become more of a hindrance than a help' (6). Through her story, Lisa wants to create more awareness about the needs of disabled people to access buildings and means of transport, arguing on the basis of the social model of disability that people are primarily disabled by their environment. She implies that if the environment would be accommodating to their needs, there would be less occasions for them to feel embarrassed. Disabled people would not be 'othered' and their capabilities would be realised:

> All disabled people must be able to mix freely with able-bodied people if they are to become as independent as possible but there is always the added problem of transportation from place to place […] The greatest help which can be given to disabled people, like myself, is a greater public awareness of our needs in access, transport and other aspects of daily living. With this is needed the realisation not only of the disability but of the capabilities of the individual, and the acceptance that there are no disabled people. We are just people who happen to use crutches or wheelchairs but we are otherwise no different than the rest of society. (7-8)

Lisa’s text postulates the contingent nature of disability-related embarrassment, locating the source of shame not in the ‘failure’ or ‘abnormality’ of the disabled body (concepts that she clearly rejects) but in the unaccommodating social and infrastructural environment that turns people in wheelchairs and on crutches into ‘helpless’, dependent beings.

In addition to her critique of the shame-inducing impact of inaccessible buildings, Sue’s text shows that the narrated ‘I’ is herself treated as a *cause* of embarrassment for others, a ‘sticky’ object of shame (Ahmed) that ‘illicited embarrassment, avoidance, condescension, personal questions’ (48). Others respond to her by ignoring her or by invading upon her as an insensitive piece of ‘public property’ without a private sphere, reactions that the narrating ‘I’ brands as forms of disability-related humiliation. She describes the social taboo and silence surrounding chronic illness (MS in her case) as well as practices of humiliation (e. g. being ignored, being addressed in disrespectful, intrusive or paternalizing ways) that affect her after she left the hospital as a disabled person:

> I noticed people were not talking to me, only to the person who was standing on their own two feet behind, and if they did they were inexplicably embarrassed, or talking loudly. I became public property, anyone could come up to me (being friendly of course) and ask me ‘What’s happened to you dear?’ and they all seemed to know somebody or somebody who knew somebody who had MS and then proceeded to tell me in graphic detail what happened to them. (48)

In addition to such paternalizing, superficial and most often unwanted ‘attention’ she is surrounded by silence and taboo when she tries to speak about the pain and fear of her existence:

> Friends either departed or tried manfully to ignore what had happened to me. I was surrounded by a conspiracy of silence. I discovered the topic I wanted and needed to discuss was taboo. Talk about broken affairs, politics, etc., was OK, in fact socially desirable, but my fear and pain of my experience was not. (48)

When she went out, she noticed that people either stared or looked away. These responses turn her into an object that is both hypervisible (an object of stares) and invisible as an active member of society, a seeming paradox of disability explored by Petra Kuppers (see Kuppers 2003, 49).[69] As Sue’s text demonstrates, the (seemingly) paradoxical combination of being treated as invisible and hypervisible are two sides of the same coin as both responses turn her into a passive object without personality rights or agency. Her friends relate these responses to the ‘disparate images’ she presents: ‘I’m young and attractive, I don’t present the “disabled” image expected (you work out the implications of that one)’ (49).

Similar to Sue who is treated as being ‘invisible’ in her wheelchair, Maggie is ignored because of her deafness by hearing party guests and teachers. In the following

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[69] According to Kuppers, disabled people are marginalized, passivized and made invisible, being excluded from the spheres of cultural / social activity by medical discourse. On the other hand, people with physical impairments are ‘hypervisible, instantly defined by their physicality’, Petra Kuppers: ‘Deconstructing Images. Performing Disability’, Kuppers: *Disability and Contemporary Performance. Bodies on Edge* (London, New York: Routledge, 2003) 49.

passage, the narrator describes such exclusion / ostracization as causing her the 'pain of 1000 rejections' even after her coming out as Deaf (35-36). Addressing above all her hearing readers, she states:

> it is your fear of my deafness I have to help you with when we first meet. Sometimes I fail and the pain of your rejection goes down to join the pain of a thousand rejections. When I succeed, I am Maggie, lively, intelligent and lovable. As a mother of two small children I can be excluded in subtle ways even by those who otherwise understand my needs. People will speak beautifully for me and then drop the signs and turn to talk 'normally' to the children. What are they saying? Is it trivial or important? Don't I exist any more? […] Doctors and school-teachers address questions to the children which would otherwise be addressed to me. Hey, I'm their mother! What is it that isn't fit for my ears?' (37-38)

Here, the narrator describes how she is not only made responsible for her non-disabled environment's fears of deafness but also for solving problems of inaccessibility and for failing to do so. Similarly, when the narrated 'I' in Sue's text complains about being objectified, that is, being either treated as invisible or as a piece of 'public property', she is blamed for causing non-disabled people embarrassment, a disablist line of argumentation that inverts power inequalities between disabled and non-disabled people and that places the responsibility for dealing with the social problems related to disability exclusively with the disabled person, not the unaccommodating environment:

> Such attention as I received was jocularity and curiosity from the insensitive (of which I found many) and embarrassment from the more sensitive. When I did mention the bewilderment I felt at the treatment I was now experiencing I was told, 'They are embarrassed, they cannot cope.' So I had become an embarrassment! They cannot cope, but they don't have to, I felt like screaming, I have to and they are making it impossible. (48-49)

Julie's text describes how she becomes a cause of embarrassment at parties, being greeted with awkwardness, that is, either with rejection or paternalizing over-enthusiasm. The narrating 'I' explains that social interactions with non-disabled people can be difficult because they can provoke feelings of shame or embarrassment on both sides:

> Encounters at parties or other social functions vary, but tend to follow certain patterns. One is complete rejection, where even eye contact is impossible, because people are embarrassed or indifferent and you are written off. Another is over-enthusiasm, when you may be treated as a novelty and the fact that you are the only wheelchair guest can draw excess attention, not so much for yourself but your situation. Sometimes you receive too much admiration, often from older, married men, who will then pour out all their troubles. Often, promises are made at the end of what may seem a fruitful evening but will you ever see him again? Even if sincere at the time, parties can be a superficial basis for a relationship. (16)

In Campling's collection, non-disabled people's assumptions about disabled women's (low) intelligence or professional (in)capacities are further significant forms disability-and gender-related humiliation. In Lisa's story, the narrator recounts that many non-disabled people assume that because she is physically disabled, she must also be cognitively disabled. As a consequence, they treat her 'as they would someone of low intelligence or as a child', a situation that she regards as 'degrading and upsetting' as well as 'deeply embarrassing' (5). Like Lisa's text, Elsa's story shows that she was often mistaken for a person with a cognitive / mental disability. The narrating 'I' describes how she tried to escape the stigma of cognitive disability by talking more and becoming more extrovert (84). In retrospect, the narrating 'I' recognizes her own disablism towards people with cognitive disabilities:

> I don't entirely approve of the chatty personality I seem to have developed for this. Since having a friend with Down's syndrome, however, I feel less the urge to dissociate myself from mentally disabled people. So what if I am taken for one of them, they also have the right to go about the world. (85)

Like Elsa's story, Pat's contribution describes how she was systematically confronted with ableist assumptions about her intelligence. Pat had Polio at the age of 2, is paralyzed from her waist downwards and uses a wheelchair. She works as a full-time Advisory and Information Officer for the Disablement Income Group and is a committee member of a service provider of individual care for disabled people. She was in her early thirties when she contributed her story to Campling's collection (50-51).

Pat's text exposes the ways in which the intelligence of disabled girls was notoriously underestimated at her special school for 'mentally and physically handicapped girls', an experience that is shown to have shaped her life. It demonstrates that the pupils were treated like 'pathetic creatures shut away in a cupboard of society. One became valueless without shape or form' (53). The narrator describes how the girls' education was neglected and that they were treated like refuse. Disabled girls' curriculum was limited to classical Victorian occupations like sewing, sitting passively and prettily and having good manners:

> Their [i. e. teachers'] expectations or our future were either continuing in residential care or being a seamstress. At all costs it was essential that we learn to appreciate a Victorian view of being a woman, sit passively listening to classical music, if possible learn to play a musical instrument, be able to sew the most intricate things and have courteous manners. The norm was passively to obey, at all costs, one's elders (52).

As a result, the narrated 'I' felt ashamed of her lack of education when meeting her brother who did his 'A' levels and 'tutor[ed]' her:

> My brother was taking his 'A' levels and laying the foundations of a successful career. Our single reunion every school holiday showed me he spoke well, had a sense of dress and knew where he was going. I felt ashamed. He would tutor me, on his visit, through a book on how to pronounce words and spelling. The school was asked to give me particular attention in these areas but after one or two lessons, it was decided that it was unnecessary! (53)

Like Pat's text, Angie's contribution is very critical of the lack of education and academic encouragement she received at her residential school for disabled children.

Angie has cerebral palsy, uses a wheelchair and was 21 when she wrote her autobiographical story. The narrator in her text recounts that her teachers were of the opinion that disabled children do not have to be educated to 'O' or 'A' level because they will not get jobs anyway (8-9).

The neglect of disabled children's (esp. girls') education impacts on the ways in which disabled women's professional capacities are judged in job interviews, a point that is emphasized in the story by 'Diana – 1'. She was 39 when she wrote her text. Diana has mobility problems as a result of her Polio infection and uses a wheelchair most of the time. She works in 'health service in the rehabilitation side' (73-74). Her text illustrates how disabled women's intellectual capacities and professional qualifications are systematically underrated. The narrating 'I' emphasizes the pervasive impact of psychological difficulties disabled women are confronted with in their careers:

> For the disabled woman who is career minded or just wants to work, the difficulties placed in her way are not only the physical ones of coping with the disability linked to the access problems, but more often the subtle psychological ones that can have a far greater effect on confidence and her own awareness and understanding of her disability. (74)

She describes a 'very distressing', humiliating job interview that shows that despite some awareness about disabled people's rights to have jobs and even careers and to be treated as being equal to non-disabled people has been created, 'in some quarters "things ain't changed"' (76). Diana's text demonstrates how little the 'equality policy' established by the Chronically Sick and Disabled Persons Act (passed in 1970) and the Disabled Person's Employment Act from 1944[70] protected disabled persons against prevalent intersectional forms of discrimination:

> I always expect to be dealt with in the same way as other candidates at interview, but it was very obvious these three gentlemen were not at ease with me. The board consisted of a young personnel officer, the area personnel officer and the doctor in whose department the job was based. Most of the talking was done by the younger personnel officer. He could see nothing but my chair, worse still he could not even say the word wheelchair, pointing at my chair and saying, 'How will you manage in that thing?' We progressed through the mechanics of how I would arrange my office furniture to how much help the DRO [Disabled Resettlement Officer, 74] would give to make the front door of the office accessible. (77)

Her expertise is bluntly and condescendingly rejected and she is cut off:

> My information on the help that employers can be given on this subject seemed to be totally opposite to that the personnel officer had, and after gently correcting his information once (I had only recently given up a job that included running an information service which included this subject, information this gentleman had in front of him) and getting an icy stare from the rest of the interview board, I found myself closing up. I sat through his comments on the fact that I should

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[70] 'A history of disability rights in the UK', *Disability Medway Network* 19 Jan 2019. Web. 26 May 2021. <https://www.disabilitymedwaynetwork.org.uk/2019/01/19/a-history-of-disability-rights-in-the-uk/>.

> have been registered as a disabled person, 'It makes my job easier'. On questions about the actual job I received a sharp 'What do you know?' on an area where I had admitted my experience to be limited, and this was followed by, 'We have young male candidates anxious to gain experience.' I remember wondering at this point whether he had difficulty in keeping female staff in the building, or whether the fact that I was wearing trousers labelled me women's lib. (77-78)

The doctors' superficial questions betray his assumption about disabled women's low educational level and lack of professional expertise:

> The only questions the doctor asked were 'Did I like music?' 'How did I drive a car?' and 'Why did I use the back of the chair to walk on because they used walking frames in the rehabilitation department?' (78)

Diana's text demonstrates that the regulations established by existing disability law (the 1970 Chronically Sick and Disabled Persons Act and the Disabled Person's Employment Act from 1944) were ignored by her employer. It provides a sceptical perspective on the possibility of social change with regard to disabled women's career options:

> I was particularly angry at the personnel officer's lack of knowledge about the help available to him via the DRO's office; this seemed to imply that the hospital was well below its quota for employing disabled people, a situation which he gave the impression he was anxious to maintain. (78)

Diana's story illustrates how disabled women who want to get promotion in their jobs face discrimination and humiliation. Likewise, being jobless or not being in paid employment are described as significant causes of disability- and gender-related shame. Julie's text shows how lack of employment leads to ostracization and prevents disabled people from joining their friends' and partners' conversations, a situation that provokes even more intense feelings of inadequacy in the disabled person:

> If a disabled woman is unable to go out to work she is at a great disadvantage in terms of meeting other people. During weekdays when I see young women leaving for and returning from work, I feel quite apart from the outside world. Whatever activities you take up, whether it is painting or an Open University degree, nobody can convince you that it is the same as being active within a normal work situation. This can make you feel inadequate both physically and mentally, especially if you worked prior to disability. If you have boyfriends, girlfriends or a husband, it is extremely difficult to join in a discussion of their working day. (16)

Like Julie's text, Elsa's story discusses the topic of disabled women's employment. In addition, it problematizes non-disabled people's patronizing assumptions about the purported 'laziness' and 'uselessness' of disabled people:

> No wonder we're asked, 'What do you do with yourself all day? I suppose you read a lot,' or a patronising, doubtful, 'Well, you seem to keep busy.' This even if the disabled person has full use of hands, eyes and brain. Their [non-disabled people's, K. R.] inadequacies are projected onto us. (85)

In this dialogue, the narrating 'I' rejects the role of the passive target of ableist humiliation by projecting the stereotype of the 'lazy', 'useless' disabled person back onto the non-disabled interlocutor. She emphasizes that her disability brought significant advantages because it enabled her to be a writer and artist rather than having to work in an unpleasant, boring job:

> Not being expected to do a full-time paid job benefited me in one way; it meant I had time to devote to my fiction writing, art and handcrafts. Mainly for my family's sake I wish I had more material success in these fields, though I think that as soon as I was disabled their expectations of me ceased. I haven't told my family I work with the Gemma group - and I think they would regard this sort of work with a disabled group as very much second best - pretend work. I partly subscribe to this, observing how much other people dislike working and feel I have 'got away with it'. Work should be unpleasant or boring, and what I do is neither. I half believe even a tedious job would be 'better' because that would bring in money and be socially acceptable - illogically perhaps I would be proud of doing such a job, uncreative and stultifying though it might be. (85-86)

As the final sentence shows, the narrating 'I', although happy with her work as a feminist author and activist, cannot completely dismiss ableist assumptions that devalue non-profit activist work as 'pretend work' and ostracize those without 'profitable' jobs.

Another significant source of disability-related shame and humiliation that is represented in Campling's collection is the experience of being objectified, especially in schools and during medical reviews. Pat's text describes the process of being paraded before the governors of her special boarding school for mentally and physically handicapped girls:

> The burden of passive oppression was crushing. For example, a small thing that incensed me. Every time visitors, particularly the governors, came to the school, we had to remove the awful pinnies that we had to wear at all times, brush our shoes and be ready for inspection and 'answer up' to questions anyone might ask. (52)

When the narrated 'I' revolts against this humiliating procedure (more about her strategy below), she almost gets expelled from the school and must vindicate herself.

Angie describes another case of humiliating objectification, focusing on her experience of being publicly stripped and touched by doctors during a medical review. Her text pillories the humiliating procedure that the narrated 'I' was subjected to:

> I remember a humiliating experience I had when I was twelve. It was in the physiotherapy room. I was seeing the doctor who came from the local hospital on weekly visits. On this particular day he had brought five male student doctors with him, and I was made to walk naked in front of them and then lie on a mat while in turn they examined my body, opening and closing my legs, poking and prodding here and there and making comments. (9-10)

Eli Clare has convincingly linked disabled people's objectification in freak shows to their ongoing pervasive and mundane objectification in medical institutions, arguing that what happened historically is a process of transition rather than social change:

> the decline of the freak show in the early decades of the 20th century coincided with the medicalization of disability. As pity, tragedy, and medical diagnosis / treatment entered the picture, the novelty and mystery of disability dissipated. Explicit voyeurism stopped being socially acceptable except when controlled by the medical establishment. […] The end of the freak show didn't mean the end of our display or the end of voyeurism. […] Today's freakdom happens in hospitals and doctors' offices.[71]

Clare asks:

> Tell me, what is the difference between the freak show and [the medical practice] of public stripping? Which is more degrading? Which takes more control away from disabled people? Which lets a large group of nondisabled people gawk unabashedly for free? (Clare 2015, 103-104)

In the passage from Angie's autobiographical text that I quoted above, readers are put into the position of affective co-witnesses of this institutionalized form of abuse. The narrative mode of telling predominates, yet the graphic but unadorned account ('walk naked in front of them and then lie on a mat', 'opening and closing my legs, poking and prodding here and there', 9-10) makes its impact affectively intense. It is possible that readers identify with the narrated 'I' in ways described by Suzanne Keen's discussion of techniques of 'broadcast strategic empathy' and 'ambassadorial strategic empathy.[72] However, the affective impact of this representation of a shame-inducing event is not limited to strategic empathy or affective contagion. Rather, it enables readers to adopt 'the other's vulnerability to being shamed', to preserve the other's difference[73] and to develop critical positions towards this humiliating medical

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[71] On Clare's detailed descriptions of the objectifying, abusive procedures disabled persons are subjected to during medical reviews see Eli Clare: *Exile and Pride. Disability, Queerness, and Liberation* (1999; Durham & London: Duke University Press 2015) 103-104.

[72] Strategic broadcast empathy signifies 'the intentional, though not invariably efficacious, work of authors to sway the feelings of their readers in audiences closer and further from the authors of and subjects of representation. […] strategic empathizing occurs when an author employs empathy in the crafting of fictional texts, in service of "a scrupulously visible political interest".' Suzanne Keen: 'Strategic Empathizing: Techniques of Bounded, Ambassadorial, and Broadcast Narrative Empathy,' *Deutsche Vierteljahrsschrift für Literaturwissenschaft und Geistesgeschichte* 82 (2008): 477–493, 478-479. 'Ambassadorial strategic empathy addresses targeted audiences with the aim of cultivating their empathy for the needy, the disenfranchised, or the misunderstood, often with a specific appeal for recognition, assistance or justice. While matching identity and experience limits the audience for bounded strategic empathy, ambassadorial empathy is most limited by the historical moment of publication and reception.' Ambassadorial strategic empathy is not only at work in the reading of fictional texts, it is also characteristic of forms of life writing: 'Like fiction reading, encountering works of life writing exercises our skills of mental visualizing, cultivates our empathy and sympathy, and cements us into communities of fellow readers. Life writing introduces us to universals of experience in spite of every kind of human difference, which biographies, memoirs, autobiographies and testimonial works clearly represent. Allowing oneself to engage with a written life, even one radically different from ours in terms of identity and experience, links us with our kin, by which I mean all those other uniquely story-telling animals – all the rest of humankind.' Suzanne Keen: 'Life Writing and the Empathetic Circle,' *Concentric: Literary and Cultural Studies* (2016): 9-26, 20-21, 24.

[73] Douglas Crimp: 'Mario Montez, for Shame', *Gay Pride*. Ed. David M. Halperin and Valerie Traub (Chicago: University of Chicago Press, 2009) 63-77, 70.

procedure, positions that can comprise, but are not limited to, shock, outrage, anger, pity, compassion and solidarity. Douglas Crimp comments on Eve Kosofsky Sedgwick's reflections on being flooded by another person's shame by arguing that 'I put myself in the place of the other only insofar as I recognize that I too am prone to shame' (Crimp 2009, 71). This connection to the other's vulnerability can be profound and painful, but it does not lead to identification because it does not erase the other's perspective.

It is important to note here that the representation of the medical review in Angie's text is not eroticized. However, the narrating perspective challenges the objectifying gaze of the doctor and the students by presenting the narrated 'I' as a sexual subject who 'was developing from a child to a woman' (10). The narrator emphasizes that she refused the role of the passive victim (a fact emphasized by her audacious writing about this humiliating experience) but she also states that it took her a long time before she could start to respect her body again: 'I had learned how to defend myself from an early age. I had to be strong minded and strong willed and by the age of fourteen I started to respect my body again. It took a long time and even today I sometimes find it difficult' (10).

Being regarded as an asexual object also features prominently as a source of gender- and disability-related shame in a great number of other texts in Campling's collection.[74] Micheline's story recounts that she was regarded as asexual by her social environment:

> Sex was distinctly not talked about. Nor was the issue of my having children [...] I dared not ask anyone for help because I knew they could not give me the help I wanted. People said to me that I would accept, in time, my restricted life. […] I just wanted to be told that I was beautiful and that everything would be all right (24-25).

As a result of this ostracization and devaluation, she starts to hate herself and then blames herself for having the wrong attitude:

> I guess when you go about feeling like a mouldy artichoke, people tend to react to you as though you were one. I was so shy, especially with boys, that very few managed to over-come their reactions to my disability and my self-consciousness enough for any conversation to last more than five minutes, thus affirming my belief that I was unlovable. (25)

Similarly, Pat's text shows that the narrated 'I' was told at her special boarding school that she is not to have a sexuality or wear pretty clothes:

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[74] On the representation of disabled women as asexual see Rosemarie Garland-Thomson: 'Integrating Disability, Transforming Feminist Theory.' *The Disability Studies Reader*. Ed. Lennard J. Davis (New York: Taylor & Francis, 2010) 353-373, 358, 364; Margrit Shildrick: *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Basingstroke and New York: Palgrave Macmillan, 2009) 66; A. C. Santos and A. L. Santos: 'Yes, we fuck! Challenging the misfit sexual body through disabled women's narratives.' *Sexualities* 21.3 (2018): 303-318. Web. 16 Jan. 2020. <https://doi.org/10.1177/1363460716688680>. Margrit Shildrick draws attention to the ways in which disabled women are both objectified / fetishized and considered to be asexual (Shildrick 2009: 60).

> I found I was not expected to have adolescent feelings of sexuality or wish to wear pretty things. A disabled woman was a neutered sexual being and a dependent on society and always to be ‘grateful’ for what was meted out. The burden of passive oppression was crushing. […] As a young girl, I was keen to wear fashionable clothes but the two visual images of womanhood were denied me: that of bodily beauty and a sense of fashion. I was plump and as I rarely had any clothes and only those decreed to be ‘practical’ I did not develop any dress sense. In fact I can remember the two dresses, two jumpers and the three blouses I had. Society quietly decreed that I need not bother to become a ‘woman’; my disability precluded such a luxury. (52-53)

The narrating ‘I’ in Merry’s story argues that due to her disability, she was not perceived as feminine or sexy, neither by non-disabled men nor women:

> I was not seen to be a woman, so I did not really see myself as a woman […] When I listened to, or read about, other women growing up as women, I felt a numbness which said ‘What are they talking about?’ and ‘Where was I?’ It’s not that I’m saying I hadn’t tried to look ‘pretty’, for instance, and even thought that I looked pretty sometimes […] My prettiness was not about being feminine, for them [i. e. non-disabled friends]. It was a let-out; it redeemed me from being just a freak in their eyes and permitted them to normalise me in their minds. It has been rare in my life that I have feared men getting sexual with me, because most men don’t see me as a sex object in the same way as they see most women. For THAT I am profoundly grateful! ! ! [...] But if only more women had made me feel like a woman. (31-32)

Elsa’s text describes how the narrating ‘I’ felt self-conscious about meeting lesbian friends because she feared they could view her as asexual / sexually passive:

> I felt self-conscious about meeting other lesbians, I thought they’d see me as non-sexual, they’d think ‘how can she be gay like us’. When I was passing for heterosexual it didn’t occur to me to think I’d be regarded as non-sexual – I think this is because I saw heterosexual women as sexually passive anyway, whereas I see lesbians as sexual equals. (86)

Although the narrating ‘I’ in Angie’s text does not suggest that she was regarded as sexless, she recounts her teachers’ restrictive ideas about disability, sexual attractiveness and marriage:

> The school had really strange ideas on marriage and the disabled. They believed that if a disabled person got married it should be to another disabled person. I didn’t go along with this idea at all. I knew for a fact that able-bodied boys fancied me. I had proved that when I went home for weekends. (9)

As this passage shows, the narrated ‘I’ not only critiques disablist assumptions about disabled people’s love life, she directly refutes them.

In addition to the variety of targets and objects of disability- and gender-related shame and humiliation, the autobiographical texts in Campling’s collection describe a broad range of affective / emotional reactions to practices of disability- and gender-related humiliation. Narrated and narrating ‘I’s respond with anger and outrage, with intense, paralyzing feelings of shame, by shaming back and by transferring shame to humiliating textual others, with personal ambition to disprove prejudice about disabled women, with attempts to pass as able-bodied, with role-playing, feminist disability activism and consciousness-raising, complicity with and critique of shame-inducing norms and with solidarity towards other targets of disability-, gender- and race-related shame. Hence, the autobiographical narratives not only use narrative affects to point to structural inequality and injustice, they also (performatively) transform them. Thus, they operate in accordance with Sara Ahmed's description of narrative as a 'form of affective conversion' in which e. g. 'good', pleasurable, happy objects turn into 'bad' / 'unhappy' ones and vice versa (2010, 21, 27, 45). As my selected texts from Campling's collection show, such affective conversions can be observed especially with regard to the texts' engagement with shame and humiliation as particularly volatile affective dispositions (Sedgwick 1993, 12): in some of the stories, the female disabled body changes from a devalued, isolated and at times shameful object to an ambivalent or beloved, interesting and exciting one (see the texts by Micheline Mason and Elsa Beckett), but this does not mean that the texts suggest that narrators triumph over shame. My selected autobiographical narratives show how specific emotions and affects stick to specific bodies and objects but they also generate an affective aura through which connections between affects and objects can intensify, crystallize or flatten, shift and become loose or ambivalent. As Lauren Berlant has argued, it is difficult (but not impossible) to loosen or unlearn one's 'attachments to regimes of injustice' (Berlant 2011, 184). Sara Ahmed emphasizes that the recognition of the form of bonds between objects and affects can enable a loosening of purportedly stable, unalterable connections: 'We can loosen the bond between the object and the affect by recognizing the form of their bond' (2010, 28). I contend that such processes of recognition can occur in the process of narrating and of reading stories. The different ways in which narrating and narrated 'I's in Campling's book respond to shame-inducing situations generate intense and often ambiguous affective auras and dynamics that intensify, question or loosen the affective bonds between shame / humiliation, non-normative bodies and disabled people's supportive devices (wheelchairs, crutches, canes etc.).

In the text by Diana - 1, the narrated 'I' responds to her humiliating job interview with anger and self-doubt:

> I was furiously angry at the whole tone of the interview […]. I actually felt like a freak. […] I was also being talked down to and wondering how I could overcome this. No doubt had I come back at them it would have just enforced their view of disabled people as having chips on their shoulder. (78)

The narrator highlights the futility of protest and the profoundly paralyzing psychological impact of the humiliation this interview had brought for her. However, she rejects the negative thoughts and self-doubts after talking to a disabled friend:

> It took me some days to rid myself of the silly ideas that the interview had planted in my mind, did I really do a good job, was I really able to organise myself […]. I actually had to talk these points through with another wheelchair user, who was able to understand the prejudice I had sensed and helped me to put it into proportion. (78)

Sarah’s story illustrates how the feelings of humiliation she experienced in her integrated school – although interrupted by the love and solidarity she enjoys among disabled girls in her new boarding school – turn into melancholic sadness and the conviction that she will always be lonely inside and rejected by able-bodied society. She recounts that she lost all contact with her former school mates, describing a feeling of loneliness and isolation that she has not overcome: ‘I am rather sad about this as it means that I have no contact with the outside world […] I have the feeling that I shall always be lonely inside’ (4).

Julie’s text explores how her inability to join non-disabled people’s discussions of their job lives often leads to withdrawal on her side because she feels excluded as an unemployed disabled woman: ‘Sometimes I find myself switching off or disappearing into the corner of the room. The outcome can be self-destructive’ (16).

Angie’s story recounts how she started to despise her body after she was subjected to humiliating practices of public stripping during medical reviews:

> I was at the age when I was developing from a child into a woman and they made me feel so embarrassed. I used to cry on these visits. Then I started to lose respect for my body but it wasn’t so embarrassing for me. There was no one I could talk to mainly because I was too young to understand what was happening. (10)

Another response to gender- and disability-related practices that a number of texts portray is the attempt to put ableist society at ease with non-normative bodies and their needs. Lisa writes: ‘Now I am realising that if I am to go out and lead a fulfilling life I must have personal confidence, for it is only through self-confidence you can make others around you relax in your company and come to accept you as a friend’ (5). Similarly, Merry states:

> I began to see how, all my life, I had worked hard at being ‘well adjusted’ and making sure that that was how others saw me. And it started to become clear what that meant. It meant smiling when I was in pain and reassuring whoever I was with. It meant only discussing my leg if I could find something funny to tell about it. It meant accepting whatever the doctors did to me (psychologically as well as physically) with unquestioning courage. All in all it meant being very untrue to myself. (30)

In some texts, narrated and narrating ‘I’s’ experiences of humiliation stimulate (academic) achievement, they generate a desire to disprove ableist assumptions about disabled women: Angie’s story describes how she revolted against the limited educational chances for disabled children at her residential special school. The narrator recounts that she felt ashamed of her lack of education and humiliated by her teachers’ prognoses of her future professional life:

> The school was very poor on education, so much so that at the age of sixteen I was only at the level of a nine-year-old. I used to go home at weekends and talk to the able-bodied kids about what they were doing at school. I had never even heard of some of the subjects they studied. I felt so ashamed that they knew more than I did and I was a lot older. I decided to ask my teacher why I did not

> do the same things as my friends did at their school. She told me it was because I was disabled and that there wasn't much point in educating me to '0' and 'A' level as I would never get a job. (8-9)

However, Angie is rebellious and ambitious (8):

> I told her [i. e. the teacher] that I was not prepared to spend my life in a workshop making baskets. I was going to improve my education and get a job in open employment no matter how long it took. Since the age of twelve I had been very bored with school life and started to become rebellious. (9)

Similarly, Pat revolts against the very limited, severely gendered education and job opportunities for disabled girls ('continuing in residential care or being a seamstress' 52): 'The rebel in me was thus born and forged. I resolved that I was not going to become a seamstress or a 'cripple' in a home. I was going to shape my future or die in the attempt' (52). The narrated 'I's in Angie's and Pat's texts manage to achieve their individual goals through perseverance and social support. The shame and humiliation connected with disabled girls' education and the prejudice about their intellectual limitations are not erased but they are in part transferred to textual others (other disabled children who are represented as 'not very intelligent' (Angie 9) or as 'cripple[s]' in a home (Pat 52). Despite its problematic transference of shame to textual others, Pat's text avoids the conventional rhetoric and plot structure that depicts an individual's triumph over adversity[75] because it shows that her achievements are contingent upon social support by friends and educational institutions. Furthermore, it emphasizes that all disabled persons (especially women) need such support in order to lead liveable, fulfilling lives (56-57).

A very frequently represented response to disability- and gender-related humiliation is the desire to pass as able-bodied. Many texts in Campling's collection problematize how narrating and narrated 'I's use different forms of social role-playing in response to experiences of gender- and disability-related humiliation. Interestingly, whereas Tobin Siebers has described the poetic representation of a cross-dressing performance of femininity in disabled men in terms of its activating impact and its assertion of sexual agency / power in a purportedly 'asexual' body,[76] the authors in Campling's collection describe how their performance of heteronormative femininity has a limiting, disempowering effect. In both cases, the performance of femininity is marked as a way *into* shame, not out of it. Importantly, the stories by Pat, Sue, Merry, Elsa, Maggie and Julie reflect critically on this role-playing and its complicity with ableism and heteronormativity, showing how the awareness about performing normative gender roles and traditional roles of 'sickness' can lead to insights into the contingency and performativity of such norms as well as to a loosening of the conventional bonds between affects and objects (Ahmed 2010, 28).

Maggie's text recounts how the narrated 'I' played the stereotypical, sexist roles of the 'scatty dolly bird', the 'feather-brained, aspiring actress', the 'frivolous butterfly' (34) and of the silent, pretty and passive wife instead of admitting to her deafness:

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[75] On this plot structure / rhetoric see Couser 2009, 33-34.

[76] On this topic see Siebers 2009, 211-213.

> I found I could bluff my way out of awkward situations by acting the part of a rather scatty dolly bird. It wasn't that I couldn't hear you but rather that I was such a feather-brained, aspiring actress that I just didn't understand what you meant. It seemed more acceptable to be a 'normal' silly butterfly than an intelligent deaf woman. In this role I made no demands on anyone but I experienced a different kind of oppression which led me to my first awareness of sexism and the oppression of women in general. (34)

As a result of her role playing, she starts to invalidate and mistrust her own perception of the world and adopts hearing people's viewpoints as her own because she thinks they must be right. In the end, she withdraws because she wants to avoid having to face rejection:

> My ENT specialist told me not to worry. I would eventually come to terms with the change in my life. He gave me no indication as to how I was to come to terms with a world viewed largely through a plate glass window where other people live, laugh and suffer and barely know of my existence. Deprived of much positive feedback on the woman I really was, my self-esteem took an insidious dive. I began to mistrust my own perception of the world and the people around me. How could I be sure of my impressions when I couldn't hear? When the views of others differed I quickly adjusted mine. They were right because they could hear and my experience seemed invalid. I felt I had little to offer anyone and rather than face rejection, I avoided people. Grieving over the lively, gregarious woman I had once been, I felt very isolated. (35-36)

Later, she recognizes the futility of acting the role of the able-bodied woman as well as her complicity with sexist and ableist gender norms: 'My years of pretence seemed suddenly absurd. I had been making things 'normal' and easy for everyone except myself. I was a deaf woman. It was time to give up my mourning and come out deaf' (36). As these passages show, the social role playing allows the narrated 'I' to gain insight into her complicity with ableist and sexist gender norms and generates a potential to loosen the subject's attachment to shame-inducing norms.

Pat's text describes how she imitated sexist gender norms in order to be viewed as a sexual being and how she later came to see her role play from a feminist perspective, regarding it as a catch-22 situation:

> Society quietly decreed that I need not bother to become a 'woman'; my disability precluded such a luxury. But what was worse, it placed me, as I developed, into the Catch 22 syndrome. That is, I could not choose to opt out of a sexist role – if I did my choice was not recognised as a positive decision but just part of being 'disabled' and therefore my style of dress was not important. Consequently, the silent pressure by society towards my non-sexuality forced me to take a sexist role in order to demonstrate my womanhood; in fact I needed to be ultra-feminine to appear 'normal'. (53-54)

Sue's story describes how her non-disabled environment viewed her as inhabiting a stereotype after she left hospital as a disabled person:

> On leaving hospital and finding the mantle of ‘disabled’ placed firmly upon my unwilling shoulders I entered a world which was alien, absurd and ultimately defeating. My weak grasp on my identity was no real match for the massed forces of society who firmly believed themselves as ‘normal’ and myself just as firmly as ‘abnormal’. I found myself inhabiting a stereotype. I became my illness, I was of interest only because of it. (48)

The narrated ‘I’ is cast into a ‘sick role’, a stereotype that is defined by passivity and endless gratitude:

> The ‘sick role’ is society’s niche for THE DISABLED. You must behave as ‘the sick’ at all times but never complain about it. You must allow your person to have good works vented upon it, it makes THEM feel better, accept with a gracious smile the fuss, offers of ‘help’ you don’t need. It puts you in the ‘sick role’ [,] the good feel good, everyone is happy. ‘They are just trying to help’ – but whom they are actually helping is supposition in need of analysis that these good souls would never attempt. (49)

The narrating ‘I’ in Julie’s text states that in response to the pressure to be seen as a sexual being, she imitates sexist and ableist body norms, engaging in a kind of masquerade by putting on a front: ‘To compensate in some way I sometimes find myself putting on a front, pushing my personality and “sitting pretty” in order to be noticed. This can be exhausting and humiliating’ (18). As this quotation shows, putting on a front and sitting prettily in order to mimic heteronormative notions of femininity is no satisfying prospect for the narrated ‘I’. Instead, she explores the diverse ways in which societies respond to disability. She travels to Kenya and describes how the people there asked her openly why she is in a wheelchair and dealt with the situation as a fact of life:

> During a trip to Kenya I was pleasantly surprised and relieved by the black Kenyans’ attitudes. Many asked frankly and intelligently whether sitting in a wheelchair was caused by illness or an accident. Once the problems were explained, it was a case of ‘okay no problem’. They looked upon my disability realistically, no psychological hang-ups. This seems part of a fatalistic philosophy absent in the West, plus natural acceptance of daily hardships. ‘Okay, so you wear baby-type knickers but everyone has their problems,’ said a black male friend, who found me mentally and physically attractive. Our relationship involved minimal pushing on my part and I felt really relaxed. (18)

At the end of the text, the narrating ‘I’ contrasts this openness among people in Kenya to the prejudices about her disability that she confronts in Britain, describing how many strangers assume that her boyfriend must be either a nurse or homosexual (18). She pillories this response as being harmful not only for disabled women but also for men who do not fulfil heteronormative, ableist expectations of masculinity:

> ‘Is your boyfriend a nurse or homosexual?’ This question has been put to me (or implied) many times. It always annoys me since it implies a prejudice against homosexuality and also that it is unnatural for a male to take on a caring role. Essentially in a media-orientated society, caring goes against the male macho image […] Perhaps with greater sexual equality and a more flexible attitude

> towards male and female roles, as husbands, as wives, as breadwinners, as carers, this will no longer be the case. (18)

Like the stories by Pat, Sue, Merry, Elsa, Maggie and Julie, Micheline's text expounds how she imitated able-bodied notions of heteronormative femininity:

> I spent hours making my hair seem 'right', playing with make-up, fighting with my parents to wear the clothes that were fashionable, studying the 'pop' charts, talking in what I fondly imagined would be with-it language, looking in the mirror to check on my developing shape, hoping that puberty would alter my body past all recognition. It didn't. It just added a few bulges here and there and gave me period pains. (24)

Her efforts to be accepted in able-bodied society remain unsuccessful, she becomes ostracized, at times precisely because she tries so hard to be accepted by non-disabled society: 'No one seemed to understand or be interested in what I was going through. "She's trying to be like everyone else", was one comment I remember very clearly. I filled in for myself the silent, "but she isn't"' (24). After having left her intense, loving community of disabled girls at her boarding school, she faced the ableist world on her own, planning to get married to a man to prove that she is lovable. However, the text shows that this performance of ableist, sexist norms leads to a disappointing, banal relationship that neither provided her with experiences of heterosexual love nor social acceptance:

> I believed at that time that the able-bodied world was paradise, and I, an outsider, was constantly knocking on the door asking to be allowed in. Being 'let in' meant sex. When the big event happened after a great deal of manoeuvering by me, I was disappointed to discover that music and shooting stars and little pink hearts did not magically appear. Nor did the gates to heaven open. In fact, on that first occasion, the other person involved turned over, lit a cigarette and said, 'I don't really love you, you know', and I realised then that the key to ever-lasting joy was not so simple to find. (26)

Elsa's story recounts how she, despite being a lesbian (84), performed the role of the heterosexual wife. Later, she became critical of this role-play and eventually feels happy among disabled lesbians:

> I wanted desperately to be accepted as 'normal'. Having no information about gay people, I didn't even know able-bodied lesbians could have a happy purposeful life, and after my injury I rejected my sexual orientation and took on the role of being heterosexual. I saw marriage and children as the best way to prove to my family and anyone else that I was a 'real' person. (84)

In retrospect, she critiques her behaviour as a 'hurtful' and selfish campaign for survival': 'I seemed to think that if I could pass as a housewife and mother everything would be all right. Fortunately I wasted only a few years in this dangerous way' (84).

The narrating 'I' argues that although she enjoys the company of disabled lesbians she doesn't see herself as properly 'disabled' (85), an ambivalence that is understandable, given the long history of the medicalization of homosexuality (McRuer).[77] As a result of her reflections on her heterosexual role playing and her dismissal of her disabled body, the narrator recounts that her disability also brought advantages: it enables her to be an author and artist (85-86) and it transformed her into a more relational, less selfish being and an animal rights activist who feels and reflects on the material, bodily ties that connect disabled, vulnerable, objectified humans and animals:

> I feel that when I was able-bodied I was a self-centred, inactive sort of person and that I would have continued in that way. It's as if being able-bodied were my larval or pupa stage and being disabled is the real me now. Though disability has probably shortened my life it has given me a good deal by changing its direction, forcing me to communicate and sensitising me to other people's lives. It is one of the reasons I joined the animal liberation movement; seeing pictures of monkeys in restraint chairs, sows chained to the floor, makes me relive my first claustrophobic horrors when I had to lie as staff had positioned me. (87)

Interestingly, the comparison between objectified, mistreated animals and disabled women is also made in Pat's text (52-53).

Whereas passing as able-bodied and heteronormatively feminine is the goal of most forms of social role play described in Campling's collection, the narrating 'I' in Merry's text uses a parenthesis to relate how she and her friend performed the role of the maladjusted disabled woman. The role play is a joyful, liberating experience that allows her to realize and 'laugh away' the oppression she experiences:

> (By the way, if you're prepared to take the risk, you can have wonderful fun acting MAL-adjusted, especially if you're with a friend who's also disabled and who is doing the same. Once my friend and I decided to act out the stereotype about not knowing how to act in public. We were eating a meal with a lot of other people and when we saw that some 'hundreds and thousands' – those little bits of coloured sugar – had been spilt on the table, we took our opportunity. We licked our hands very noticeably, squashed them down on the hundreds and thousands and then licked them off again, laughing and nudging each other. We seemed to laugh away the strain of all those years of trying extra hard to be sure of doing everything right). (30)

This audacious, playful and pleasurable performance of being 'MAL-adjusted' not only allows the narrated 'I' to 'laugh away' the oppressive strain of having to adapt to ableist society, it can be seen as loosening the narrated 'I''s affective attachment to ableist society and its norms. Furthermore, the representation of the performance functions as a turning-point in the text: through it, she gains insight into the oppression of disabled people, that is, into the structural disablism of British society:

> Then suddenly the system's role became clear too. I saw that WE are an oppressed group, like people who are black, women and so on; that segregated and sub-standard education, a physical environment that does not take our needs into account, job discrimination, housing discrimination, lack of aids and

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[77] McRuer argues that 'homosexuality and disability clearly share a pathologized past': Robert McRuer: 'As Good as it Gets: Queer Theory and Critical Disability'. *Journal of Lesbian and Gay Studies* 9 (2003): 79-107, 79.

> services and the threat or actuality of institutionalisation keep us dependent and always ready to please. To justify this treatment, people are taught, through the media for example, to view us in certain rigid and negative ways – as stupid, unable to look after ourselves, uninterested in the world and so on, and so on. (30)

Playing the mal-adjusted disabled woman also alerts her to her former complicity with ableist norms that was meant to earn her the respect of the able-bodied world:

> This helped me to understand more about my behaviour, by seeing how I'd taken in so many of these oppressive ideas and values. I'd behaved the way I did in the club because I had learnt to look down on other people who were disabled unless they too acted 'normally'. Even more, I was scared of being categorised like them and therefore treated like them, by the able-bodied. I had this strange desire for respect! (30-31)

At the end of the text, the narrating 'I' states that she is able to bond with other disabled women and laughs about her former ambition to pass as able-bodied:

> I made firm friends with another woman who was visibly disabled, who helped run the same club. […] Anyway, now I laugh when I remember how I used to walk faster if I saw another person on crutches, trying to prove I wasn't as feeble as they were! That's the in-group competitiveness that oppression breeds, just like women trying to be more attractive than the others. (31)

In her résumé, the narrating 'I' explains that she joined a disability activism network and solidarizes with other authors who contributed to Campling's collection. Hence, her text highlights and performs feminist solidarity and gives a very emotional, upbeat description of her happy, exciting life with her female friends:

> So where am I now? Well I'm in all sorts of exciting and tingly places. For a start I'm doing what I can to change the system that relegated us to dependency. To that end I've joined the Liberation Network of People with Disabilities […] Over the last few months I've made lots of close friends with people who are disabled and know a friendship with them quite unlike my friendships with the able-bodied. Some of the other women who've written pieces for this book are people I love dearly and share with so much. We understand a great deal without need for words. We can be human with each other about things that the able-bodied are usually too impatient to wait for or too bound up in only one way of experiencing things to appreciate. We laugh helplessly together, cry together and are highly committed to each other. We know that when we are fighting to get things right for everyone in our oppressed group, we are fighting for each other, and when we are fighting for each other, we are fighting for everyone. We know we have a whole lot of treasures to offer to the world and are happy to know that we still have a lot to learn. And about myself as a woman, particularly? Recently I ventured to tell a woman friend that I felt I wanted to call her my sister (the first time ever) and wept long and loud with her. And she just loved me. (32-33)

Merry's text includes an end note in which she underlines her support of the social model of disability, her commitment to social change through her participation in disability activism and her ongoing struggle to change the negative verbal representation of disability:

> A short while ago, a member of the Union of the Physically Impaired against Segregation pointed out to me that the phrase 'people with disabilities' makes our lack of abilities sound like an inevitable result of our physical condition, whereas it is usually the result of society failing to provide us with the necessary aids, etc. Society actually does have both the necessary technology and financial resources to enable us to live independently, if it chose to allocate its resources in this way. To refer to the actual physical condition, the Union speaks of the physically-impaired, and to refer to the results of society's attitudes towards us, they refer to disablement. Thus when they say a person is disabled, they mean disabled by society. Unfortunately lots of my friends react unfavourably to the word 'impaired' and also say that it's not much good using the word disabled to mean something quite different from what everyone else means unless you say so each time. So there is a bit of a search going on for good, perhaps quite new, words. (33)

The texts in Campling's collection also depict rebellious responses to disability- and gender-related humiliation: Pat's story recounts how the narrated 'I' organized a revolt at her special school by exposing the neglect and humiliation that she and her mates were subjected to. In a performance of self-humiliation that uses shame as a protest strategy, they wear the dirty, ill-fitting 'pinnies' that teachers normally hide away when showcasing the pupils to the governors of the school. This protest action revealed the patronizing, abusive conduct that teachers adopted towards the pupils who were humiliated on a daily basis, treated like animals or infants in a cage, spoken to as if deaf and regarded as 'pathetic creatures':

> I was nearly expelled when I smuggled the pinnies back into the class and made everyone put them on just as the governors came into the classroom. The pinnies never fitted and were always marked with slops by those who had difficulty with eating, and by the general debris of the week. It was a shock-horror situation and when asked to explain my actions I tried to explain what it was like to be viewed in a cage, be talked about as if deaf and that people ought to see us how we really were – pathetic creatures shut away in a cupboard of society. One became valueless without shape or form. (52-53)

Another response to humiliation depicted in the texts is that of shaming back: Lisa's story describes how her non-disabled, patronizing companion made her feel like a pathetic, helpless being when she tried to access the inaccessible theatre. By describing her 'companion's' unhelpful behaviour, her text transfers shame to him (6). In a similar way, Sue's description of her doctor's humiliating treatment portrays him as a sexist and incompetent physician (45). Angie's text exposes the humiliating procedure of public stripping during medical interviews (9-10). Furthermore, the text shows how the narrated 'I' shames strangers (in this case a gas man coming to her house) who asks intrusive questions about her sex life:

> As he was leaving the flat he turned and asked if I was married? I told him I was, then a funny look came into his eyes and he asked if I had sex? I was shocked at his question and at first was stuck for words. Then I was angry and said the first thing that came into my head. 'Yes, do you?' He looked embarrassed and hurried away. During the rest of the day I kept thinking what a cheek he had asking me such a question. (11)

Turning away from the shame-inducing object is a response to disability- and gender-related humiliation that is represented in Micheline's text. It shows that the narrated 'I' left her devaluing social environment to join an 'intense' boarding-school community of disabled girls where she shared her insecurities and vulnerability and finds friends, love and solidarity:

> At some point during those two years, I worked out that the cosy future my family had planned for me would be so boring that I would rather die than make their gloomy prophesies come true. When the chance came for me to go to a boarding school for girls with disabilities, I jumped at it. I saw it as the beginning of my road to freedom. Our boarding school had rows of adjacent loos. One day, very soon after my arrival at the school. I was sitting in one loo whilst a new friend was sitting in the loo next door. 'Micheline,' she said, 'Do you think you will ever get married?' A flood of relief came over me then. I knew the question was coming from someone who had asked herself the same question many times already. There were other people who had gone through all that doubting too! Nice people! Other young women who had had their self-image as women so severely damaged that they too had wondered if they were entitled to anything life had to offer. My three years with nearly one hundred young women with disabilities began a slow healing process. We laughed and cried together. We experienced illness and even deaths amongst us. But we felt so strong! […] There I discovered what sharing meant, and accepting people's differences whether they be of colour, class, religion or experience of disability. I began to accept my differences, my uniqueness, as something to be proud of. When I left that intense community and went back again to join the 'real' world, I felt my battle was just beginning. (25-26)

This passage represents a narrated 'I''s (temporary) turning *away from* the shame-inducing object that 'turns its face away'[78] as well as a turning *towards* objects that provide her with love and solidarity. As the end of the quoted passage shows, however, the shift from shame to pride is not permanent but is followed by the narrated 'I''s desire to prove to be 'normal' through heterosexual marriage.

In Micheline's text, the narrated 'I''s reflections on gender- and disability-related shame alert her to the structural devaluation of all women. She begins to connect the shame-related struggles of able-bodied and black women to her own and realizes that there are other forms of communal bonds, other sources of support and love available to her beyond / in excess of the heteronormative one promised by a heterosexual marriage. In this way, the consciousness of shared female shame / body-shaming (next to the

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[78] According to Eve Kosofsky Sedgwick, shame is the 'experience of interest that a person holds toward an object after it turns its face away'. Lauren Berlant and Lee Edelman: *Sex, Or The Unbearable* (Durham: Duke University Press, 2014) 37.

love and solidarity she received from her female friends) generates a possible ‘turning point’ in her life and in her story:

> I cannot pinpoint when I first began to listen to the experiences of able-bodied women and relate them to my own. It may have been when someone said that she couldn’t go out of the house because her skin was too spotty, or when a beautiful black woman told me how all her life she had wanted to be white and blotchy like her friend at school, or it could have been when a friend of mine who had always been my envy for being followed around by drooling men, said that she was so lonely because people only reacted to her stunning body, and never to the person inside it. It may have been when my family began to talk about one of its female members who had put on weight and had, in their eyes, become not only unattractive, but somehow outrageously undutiful in her role as an ornament. It may have been none of this that made the turning point for me, but instead it could have been the way some of the women put their arms round me and called me their beautiful sister, that made me begin to see that we are not so different after all. We are all made to feel that our role is firstly to be beautiful in a highly stereotyped way, secondly to be interesting and amusing company to men, and thirdly, good servants. My experience of finding that I was not necessarily any of those things is the experience of most women sooner or later. (26-27)

As this passage shows, the turning point in the narrated ‘I’’s life and her story – whose precise date and nature are unavailable / inaccessible to the narrating ‘I’ – implies a change in perspective towards her disability and position as a disabled woman. It was generated through her growing feminist awareness about the structural experiences of shame that link *all* women across the differences of ability and race as well as through the (closely related) experience of love and solidarity among them. Micheline’s description of the impact of shame includes a growing awareness about structural shame directed against femininity at large. Thus, shame’s impact is shown to comprise identification. It has a formative dimension because it is one of the affective dispositions (next to love / solidarity) that shapes the peripety of the story. Furthermore, it generates a feeling of community and ‘loose’ solidarity[79] that implies a potential for collective political action. At the end of the text, the narrating ‘I’ states:

> I […] feel that all those dark years linked me profoundly to other women, particularly those who have not only been oppressed for being women, but also have been oppressed for being ‘different’ and have laid the foundations of a magnificent joint struggle for liberation. (27)

Here, solidarity and the (utopian) potential and desire for political action are described as being forged *through* a consciousness about shame’s relational force, not in spite of it. However, the text has no ‘redemptive’ ending and does not arrive at a state of liberation. As Anne Finger has emphasized, the texts in Campling’s collection do not ‘take refuge in che[e]riness or cheap optimism’ (13). Instead, the ending of Micheline’s story can be called utopian. It is linked in complex, contrastive ways to its imaginative beginning, to the narrated ‘I’’s daydream about her magical transformation into an able-

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[79] On the notion of ‘loose’ solidarity see Berlant 2011, 255.

bodied, ‘normal’ woman. My use of the notion ‘utopian’ does not refer to what John Storey has called ‘*blueprint utopianism*’,[80] that is, to a stable, clearly defined, thoroughly outlined blueprint of a perfect society or to a perfect model of political action and social change. Rather, I use ‘utopian’ in a speculative sense that is akin to Storey’s concepts of ‘*utopian desire*’ and ‘*utopianism*’. Utopianism is defined as ‘the depiction or enactment of something that currently does not exist, or does not yet exist in a fully developed form, in order to incite the desire for it in the here and now’. It comprises the ability to ‘imagine radically different circumstances’, an ability that ‘can produce the desire to make those circumstances a reality’ (Storey 2019, 107). Founded upon, infused with and emerging from shame as an affective disposition, arising from ‘all those dark years’ that link the narrating ‘I’ with ‘those who have not only been oppressed for being women, but also have been oppressed for being “different”’ (27), the utopianism that characterizes the ending of Micheline’s text describes a potential, a desire for solidarity and social change, an urge that is undefined and indeterminate but without which social change remains unthinkable.

Conclusion

Images of Ourselves contains no sensational or obscene representations of female disabled bodies. Campling’s brief introductions that are put in front of the individual contributions provide information about the authors’ medical conditions in a factual, scientific manner. The stories by Julie, Elsa and, to a lesser degree, Sue, expand on impairment, infirmity, incontinence and illness but they do so in a reflected, sober manner. Above all, the contributions audaciously name and shame institutionalized practices of disability- and gender-related humiliation and describe narrators’ affective, expressive and actional responses. Only few texts explicitly connect narrators’ non-normative embodiment with their feelings of shame (the texts by Julie, Sue and Elsa) but a great number of stories describe how narrators try to hide their impairments, to pass as able-bodied and to appear as heteronormatively feminine as possible. Many texts (especially those by Sarah, Elsa, Sue, Pat and Merry) demonstrate that it is not the disabled narrators that regard themselves as fundamentally different from non-disabled textual others (they don’t, as their descriptions of their desires, accomplishments, hopes and fears demonstrate). Instead, it is their society’s structural ableism and disablism, that is, inaccessible facilities, forms of education and career paths as well as the stigmatizing, humiliating responses of their social environment (which includes doctors, teachers, work colleagues, friends and strangers) that ostracize them and mark them as inherently ‘different’ from mainstream society. Furthermore, autobiographical narrators (especially those in Sue’s, Elsa’s and Merry’s texts) demonstrate that the legal and medical label ‘disabled’ is primarily defined as negative but that in order to have access to financial support, facilities, means of transport, medical care and to citizen rights (an accessible home, education, work etc.), they must get classified as such, an impasse that is only gradually resolved through the evolution of a positive category of disability based on group solidarity and disability rights activism.[81]

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[80] John Storey: ‘A Radical Unfolding: Utopianism against Complicity’, *Complicity and the Politics of Representation*. Ed. Cornelia Wächter and Robert Wirth (London and New York: Rowman and Littlefield, 2019) 107-119, 107.

[81] John Swain and Sally French: ‘Affirming Identity’, *Disability on Equal Terms*. Ed. John Swain and Sally French (Los Angeles, London, New Delhi et al.: Sage, 2008) 65-78.

The autobiographical narrators in Campling's collection turn readers into affective co-witnesses of practices of disability- and gender-related humiliation and generate a potential for political action against disablism and sexism. This narrative technique is especially noticeable in Julie's, Maggie's and Sue's texts that explicitly address disabled and non-disabled readers. The texts represent disability- and gender-related shame and humiliation as affects that paralyse narrators and inhibit their agency. However, they depict shame and humiliation as complex force relations generated in encounters between non-normative bodies and their social environments. Hence, shame and humiliation are narrative affects that subvert binary notions of 'activity' / 'agency' and 'passivity': the texts depict narrators' heterogeneous emotional, expressive and actional responses to narrative events of humiliation and shame, including anger, outrage, transferral of shame, withdrawal and compensatory strategies of passing as able-bodied, of disproving ableist stereotypes about disability[82] and of performing the patriarchal, sexist role of the heteronormative woman or wife. Further expressive and actional responses to experiences of shame and humiliation include narrators' explorations of the contingency of gender roles and of cultural approaches to disability, their affirmation of non-normative forms of living, practices of resisting injustice, of joining feminist disability activism and of establishing bonds of solidarity with other stigmatized women and social groups. The representations of shame and humiliation in the texts by Julie, Merry, Sue, Micheline, Elsa, Pat, Diana – 1, Maggie and Angie challenge shame-inducing ableist and sexist norms by loosening narrators' affective ties to these norms. They employ strategies of audacious critique, a deconstruction of ableist and sexist gender roles as well as humour and mimicry. In addition, they emphasize the contingency of body and gender norms. Sarah's, Pat's and Angie's stories describe cases of horizontal hostility and the transference of shame to textual others with cognitive and learning disabilities.

Lois Keith (ed.) *Mustn't Grumble. Writing by Disabled Women* (London: The Women's Press, 1994).

Lois Keith's anthology of writings on disability by mostly British feminist authors was published one year before the passing of the British Disability Discrimination Act. It was re-published under a different title (*'What Happened to You?' Writing by Disabled Women*) but with the same cover by New Press in 1996. The anthology stands in the tradition of feminist collections of autobiographical texts by disabled authors that was established by Jo Campling's *Images of Ourselves*. Like Campling's collection, Keith's anthology contains a polyphony of distinct voices[83] of heterogeneous authors among which readers can discover patterns of connection, draw comparisons, notice similarities, differences, tensions and contradictions. My own reading emphasizes the

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[82] See Lisa's, Elsa's, Pat's and Merry's texts.

[83] On the 'polyvocal' nature of the collection see Coogan 2008, 244. Coogan states: 'reflection and analysis may at first appear to be vitally self-conscious and self-questioning, yet can all too easily fall into the pattern of "creating" rather than "documenting" a culture. This latter risk is weighted by the implication of anthologies of disability writing by nature of their very existence in a form of identity politics, itself a product of a political intervention: the social model. Although dissenting voices are indeed contained in these collections, these contributions become defined primarily by their dissent. While it is true that certain pieces […] offer analysis and insight, […] the anthology form is ultimately too fragmentary and cursory for these insights to move beyond observation, except when they are subordinated to a strong editorial agenda: which in turn defies the apparent liberational political raison d'etre of such collections. Thus, for a more satisfying unity of content and form, and to remove the disability experience from a limiting political context, it can be seen that the more traditional autobiographical form is arguably preferable' (244).

advantages of the anthology form especially because it enables creative acts of reception through which readers can perceive the structural nature of disability-related injustice. By contrast, Thomas Coogan has disapproved of the anthology form because he regards it as a manifestation of 'identity politics' that includes contributions that are 'defined primarily by their dissent' (Coogan 2008, 244). Compared to the texts in Campling's collection, those in Keith's anthology are far more heterogeneous and belong to different genres: most are short autobiographical prose texts but the anthology also includes critical essays, short stories and poems. In contrast to the stories in Campling's collection, the texts in Keith's *Mustn't Grumble* carry affectively suggestive titles, a feature that marks them as literary texts. Furthermore, Keith's anthology includes the full names or pen names of contributors, thereby emphasizing their status as independent authors.

Lois Keith's collection aims at the formation of a community of feminist writers and readers (an activist, constructivist goal of anthologies that Thomas Coogan clearly disapproves of, 244) that allows them to share experiences about the many ways in which feminist identity interacts with categories of disability, ethnicity / race, class and sexual orientation at the end of the 20th century. The cover of the anthology draws attention to the intersectional nature of the authors' identities and the diversity of the narrating and narrated 'I's, textual others and poetic speakers in the collected texts. The playful, colourful cover illustration by Lesley Saddington depicts three women at coffee or tea in a lively conversation with each other, using their hands to gesticulate – possibly using sign language. One of the portrayed women is black and another (who is white and at the centre) is in a wheelchair (visibly disabled), with her arms lifted up and her hair and objects of everyday life (hair brush, cups, cutlery, mirror and glass) magically floating in the air at her command. In the foreground, a pen and an open booklet with written notes are visible, suggesting that the women are writers. The back cover of *Mustn't Grumble* contains short quotations from some of the texts included in the collection, a short biographic note about Lois Keith and a snippet from a review of the collection, describing it as 'wide-ranging, shattering, powerful', '[c]ontroversal, shocking, humorous', 'hard-hitting', 'honest', 'eloquent and hilarious'. The review excerpt names central topics of the collected texts like 'access', 'abuse', 'equality' and 'equanimity' and recommends the contributions as 'essential reading for every disabled and non-disabled individual'.

Keith's collection puts a strong focus on intersectional identities. In their respective short autobiographical texts that are part of Keith's collection, Gohar Kordi, a visually impaired author who migrated to the UK from Iran, and Nasa Begum, a migrant of Pakistani origin who suffered from a neurological condition that caused muscle degeneration,[84] explore how their experiences as disabled women interact with their migrant identities. Kaite O'Reilly, playwright, author and dramaturge of Irish descent, and Janice Pink, a British lesbian author who published articles and poems in *DAIL magazine* (Keith 1994, 222),[85] have emphasised their working-class backgrounds and Maria Jastrzębska (a Polish-British poet, feminist, editor, translator and playwright born

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[84] Julie Bindel (2011): 'Nasa Begum Obituary.' The Guardian 22 June 2011, n. pag. Web. <https://www.theguardian.com/society/2011/jun/22/nasa-begum-obituary>. Web. 31 May 2021.

[85] 'Contributors' Notes', Lois Keith (ed.) *Mustn't Grumble. Writing by Disabled Women* (London: The Women's Press, 1994) 215-223. All references to Keith's collection are to Lois Keith (ed.) *Mustn't Grumble. Writing by Disabled Women* (London: The Women's Press, 1994).

in Warsaw),[86] Suna Polio, Elsa Beckett, Janice Pink and Aspen, examine the ways in which their experiences as disabled feminist authors interact with their lesbian identities (Keith 1994, 215).

Lois Keith herself (born in 1950), author of *A Different Life* (a 1987 novel about a girl who becomes disabled), of *Being in a Wheelchair* (a 1998 children's book), of *Take Up Thy Bed and Walk* (2001), of *Out of Place* (a novel from 2003)[87] and of 3 contributions included in the anthology, became disabled after she was hit by a motorist. At this time, she already had a job, 2 daughters and a much-loved partner as well as a Victorian house in London, being in a rather comfortable, even privileged social position. She uses a wheelchair, underwent a number of surgeries and won a legal case for compensation. After she had moved into an accessible flat, she began what she calls a 'new way of living' (Keith 1994, 1).[88] Her experience as a disabled woman taught her that her former feminism, anti-racism and her beliefs in equality and justice were not enough to understand the complicated and hostile world in which disabled persons exist (2). In order to survive and to 'make sense' of her new life, Keith became a member of a new community of disabled persons. She argues that in the 1980s, there was little writing by disabled authors. For this reason, non-disabled persons know very little about life with a disability, about the laws and regulations that isolate disabled persons and rob them of their civil rights (access to public buildings, employment, visits to the cinema and more).

In her introduction to *Mustn't Grumble*, Keith reflects on how she was pitied, approached by strangers asking intrusive questions and recommended early retirement by her colleagues (2). In order to come to terms with these new experiences, she decided to write about them (3). At the beginning of her writing career, she focused on pain and loss, on the changes of her body and her anxiety about the loss of her independence and privacy (3). Later, she realized that her life was going to be good, she began to understand the prejudice and fear around disability as well as the dominant images of disability in books she grew up with (discussed in her own book *Take Up Thy Bed and Walk*). She argues that the disability movement needs its own literature and states that her collection is meant to fill the gap generated by the absence of writing by disabled women. In 1992, The Woman's Press accepted Keith's proposal of an anthology of writings by disabled women. She chose a '"grass roots approach"', relying on her network of female authors she knew from writing groups. In addition, she collected texts written by her own friends and acquaintances (Coogan 2008, 218). Furthermore, she included contributions from female authors who answered her announcements published in newspapers, magazines and on flyers (1, 3). Keith's collection indeed relies on as well as generates a network of influential feminist authors and editors: It includes a text by Elsa Beckett ('Taking Liberties') who had already contributed her autobiographical story to Campling's *Images of Ourselves*, a text by Jenny Morris ('The Fall'), whose book *Pride Against Prejudice* I will discuss below, and

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[86] Maria Jastrzębska: 'Maria Jastrzębska'. <https://mariajastrzebska.wordpress.com/> Web. 31 May 2021.

[87] 'Lois Keith'. Commonword. <https://www.cultureword.org.uk/commonword-writers-gallery/lois-keith/> Web. 31 May 2021; 'Lois Keith'. Thriftbooks <https://www.thriftbooks.com/a/lois-keith/409500/> Web. 31 May 2021; Lyn Gardner: 'Cured by submission. Lyn Gardner looks at the way disability tames young heroines in Lois Keith's new book *Take Up Thy Bed and Walk*', *The Guardian*. 3 Feb 2001. <https://www.theguardian.com/books/2001/feb/03/society> Web. 31 May 2021.

[88] Lois Keith: 'Introduction', Lois Keith (ed.) *Mustn't Grumble. Writing by Disabled Women* (London: The Women's Press, 1994) 1-9.

a text by Michele Wates (‘Self-Respect’), co-editor of *Bigger Than the Sky*, a collection that will also be analysed below. As yet, the significance of Keith’s collection has not been fully acknowledged: G. Thomas Couser,[89] Tom Shakespeare[90] and Susannah Mintz[91] only mention it in passing.[92] Janet Price and Margrit Shildrick have disapproved of Keith’s anthology, arguing that it represents a standpoint approach to disability and suggests that the only view on disability that counts comes from disabled people. Furthermore, they have professed that it reproduces a problematic aspect of the social model of disability by representing the disabled person as ‘distinctly other in her corporeal specificity, whilst at the same time striving to attain standards of normativity’ and neglecting the body as a site of resistance to dominant discourse.[93] By contrast, my reading demonstrates that many texts in Keith’s anthology subvert the binary opposition between ‘disability’ and ‘normality’ and value the disabled body as a ground for resistance against ableism, disablism and heteronormative concepts of gender identity. Through their use of the narrative affect shame / humiliation, many texts in Keith’s anthology undermine a binary opposition between disabled and non-disabled bodies by focusing on the affective (i. e. force) relations that are generated in encounters *between* disabled and non-disabled bodies as well as among heterogeneous disabled bodies.

As the book reviews on Goodreads show, readers comment as affective co-witnesses of the depictions of lives with a disability in Keith’s collection, not as sensationalist consumers keen on shock, horror and tragedy. However, the collection’s inclusion of texts that discuss disabled women’s sexuality is explicitly commented on: Sarah Rigg praises Mary Duffy’s and Lois Keith’s contributions, stating that she would like to become the former’s friend. She decidedly emphasizes the book’s focus on disabled women’s everyday experiences that include sexuality:

> You’d expect a lot of them to be about the shock of adjustment or the sense of loss, but a lot of them are about just the everyday life of getting around in a wheelchair or dealing with well-meaning friends who say hurtful things. As women, they have interesting things to say about sexuality and parenting as well.[94]

Cassandra Curtis calls the collection ‘inspiring, poignant, heart rending’, an expression of ‘empowerment built on the back of physical and emotional pain’. Commenting on the heterogeneous affective impact of the included contributions, Cassandra Curtis states that they are ‘strident, in turns angry and loving, reflective and impulsive’.[95] For

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[89] Couser 2009, 16.

[90] Tom Shakespeare: ‘Power and prejudice: issues of gender, sexuality and disability.’ *Disability and society. Emerging issues and insights*. Ed. Len Barton (Harlow: Longman, 1996) 191-214.

[91] Susannah Mintz: *Unruly Bodies. Life Writing by Women with Disabilities* (Chapel Hill: University of North Carolina Press. 2007) 221 n. 6.

[92] For a longer discussion of Keith’s volume see Coogan 2008, 204, 216-221, 231-242.

[93] Janet Price and Margrit Shildrick: ‘Bodies Together: Touch, Ethics, and Disability.’ *Disability/Postmodernity. Embodying Disability Theory*. Eds. Mairian Corker and Tom Shakespeare (London and New York: continuum, 2002) 62-75, 66-67.

[94] Sarah Rigg: ‘Review on Lois Keith’s What Happened to You? Goodreads. 19 November 2018. Web. 10 June 2021. <https://www.goodreads.com/book/show/654118._What_Happened_to_You_?from_search=true&from_srp=true&qid=L3avdJz8LE&rank=2 >.

[95] Cassandra Curtis: ‘Review on Lois Keith’s What Happened to You?’ Goodreads. 16 May 2012. Web. 10 June 2021.

Caitlin, Keith's collection targets the 'arrogance and ignorance [that] is embedded within our language, buildings (literally) and social interactions'.[96]

Keith's collection generates a flexible community of female authors who cherish their multiple layers of identity instead of repressing them (Keith 1994, 5).[97] Her selection of texts is not based on a homogeneous notion of what the lives of disabled women look like or how contributors are supposed to position themselves towards their disabilities. It is a collection of very heterogeneous texts, some are 'creative and original in style and form', others are more 'simple and direct' (Keith 1994, 5). Some are written in prose and others in verse, containing the voices of women from different classes, ethnic backgrounds, with different sexual orientations and with different disabilities that speak in polyphony and sound in consonance or dissonance (5). Although Keith admits that she and the editor from The Women's Press prefer texts that describe disabled women as active rather than passive, and as angry rather than compliant, the excerpts of Keith's correspondence with some of the contributors included in the appendix of the book show that she values and publishes texts containing viewpoints that differ from her own: 'I haven't felt the need to "agree" with all the contributors. As well as women who are political about being disabled, there is also writing by women who reject the pressures they feel imposed on them to take some sort of "correct" view' (6). Most contributors affirm their identities as disabled women[98] and challenge or even defy the tragic view of disability without denying or transcending the reactions of hostile social environments, the experiences of pain and suffering or the changes of their view points and senses of identity which are related to their impairments (Keith 1994, 5, 7).

The title of the first edition of Keith's anthology bears a noticeable but also ironic and playful connection to anger:

> 'Mustn't grumble' is what women say to each other when what they really want to do is have a good moan about the things which make them feel fed up. […] We tell each other stories about the ridiculous things strangers in the supermarket say, we moan about doctors, employers, inaccessible buildings, our illness or impairments, and what society and the world in general does to us. […] This book contains a lot of wonderful, poetic, powerful and funny grumbling. (8-9) [99]

As this quotation shows, anger is the predominant affect in Keith's collection but it appears in connection with many other narrative affects, emotions and literary strategies. As Keith explains, anger is a 'survival strategy' for many disabled persons and a very productive affect because it gives writers the chance to criticise the social and political conditions that cause oppression and suffering (8). Roz Rushworth's short autobiographical text 'Mustn't Grumble', whose title is taken from the name of a drama

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<https://www.goodreads.com/book/show/654118._What_Happened_to_You_?from_search=true&from_srp=true&qid=L3avdJz8LE&rank=2 >.

[96] Caitlin: 'Review on Lois Keith's What Happened to You?' Goodreads. 9 April 2010. Web. 10 June 2021. <https://www.goodreads.com/review/show/97824375?book_show_action=true&from_review_page=1 >.

[97] I disagree with Coogan who argues that Keith's collection is informed by a separatist ideological approach to disability (Coogan 2008, 219).

[98] In her poem, Jaihn Makayute expresses openly that she does not regard her disability as a condition to be proud of: Jaihn Makayute: 'Freedom Fighter.' *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 187-188. See also Coogan 2008, 237.

[99] On Keith's expression of anger about inaccessible facilities see Keith 1994, 64-65, 69-70.

group,[100] focuses on anger and on her response to this affect: '"Mustn't grumble"', readers learn, is Rushworth's retort to intrusive questions asked by strangers; it is 'what I say to people when I really mean "stop asking me stupid questions" but I'm too polite to say it!' (Rushworth 1994, 40).

In her essay 'Encounters with Strangers. The public's responses to disabled women and how this affects our sense of self', Lois Keith praises Erving Goffman's *Stigma: Notes on the Management of Spoiled Identity*, especially his analysis of what happens during interpersonal encounters that are marked by disability-related shame and humiliation. Her own approach to these affects is rather ambivalent. On the one hand, she emphasizes the structural roots of prejudice and ostracization but on the other, she reproduces a sovereign notion of the self. To feel shame, Keith states, referencing Barbara Macdonald's work on aging / ageism, is to internalize other people's negative, disablist / ageist views. It is a response that the disabled subject can and must actively and directly resist (Keith 1996, 87-88).[101] Here, Keith draws attention to the problematic impact of shame but she neglects the structural nature of stigma, its powerful, complex influence through language, media and forms of representation as well as the relationality and non-sovereignty of the subject. Rather than exploring shame, Keith relies on anger as a productive weapon against ableism and disablism, especially on the anger directed against paternalizing social responses to disability (87).

In addition to anger, many texts in Keith's anthology represent and convey feelings of sadness but also warmth, humour, pleasure and cheerfulness (Keith 1994, 7, 8). Keith emphasizes that her selection of writings does not follow a '"party line"' (5) but instead presents a great variety of intersectional perspectives on disability as well as a wide range of emotions connected with it. The collection comprises texts about illness even though many people with disabilities have been fighting against the stereotypical view that they are weak and sick, that is, against the '"medical model"' that posits the myth that disability equals illness (6). Experiences of illness and disability, Keith reminds her readers, are on a continuum. Disabled and chronically ill people are not 'either ill or healthy, weak or strong'. Some disabled persons are stable and well but others are in 'difficult', progressive and even 'frightening' conditions (6). For Keith, it is important 'to counteract the popular view' of disabled persons 'as sick, tragic figures' but she also stresses that 'we must not deny the realities of our lives, which are sometimes painful and sad' (7). She wants to avoid to swop the '"tragic but brave"' model that the ableist world imposes on disabled persons merely to create another dangerous myth about disabled women as heroic fighters (7). Keith quotes Ann Macfarlane, an author contributing to her anthology and a disability activist, who argues that in order to have a political stance and to fight for one's rights one must stay very close to the pain. Macfarlane explains that sometimes the pain is too much so that she pushes it away by putting on the '"supercrip"' role. Gradually, however, she has learnt that part of her strength in fact comes from weakness (8). A considerable number of texts in Keith's collection represent autobiographical narrators' or poetic speakers' physical and emotional pain, physical weakness, mental distress, vulnerability, fatigue, non-

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[100] Roz Rushworth, 'Mustn't Grumble', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 38-40, 40.

[101] Lois Keith: 'Encounters with Strangers. The public's responses to disabled women and how this affects our sense of self', *Encounters with Strangers. Feminism and Disability*. Ed. Jenny Morris. London: The Women's Press, 1996, 69-88, 73-75, 87.

normative bodies, body dysfunctions and deterioration connected with their disabilities in detail.[102]

Lois Keith explains that the texts in her anthology are too complex to fit any simple categorisation as narratives of ‘loss, growing, changing and moving on’. Instead, each text takes readers on its own journey (8). The collection is part of the coming-out process of female disabled authors at the end of the 20th century who break the isolation and silence imposed on them by a disablist, oppressive environment. The texts respond self-critically to the limiting stereotypes of passivity, docility, bitterness and twistedness that especially the able-bodied world fosters about disabled persons. Although Keith’s collection (and especially her introduction) emphasizes the predominance of anger as an affective response to disablism, I will show that a number of autobiographical texts in the collection (including Keith’s own poems) also discuss shame and humiliation as narrative / poetic affects. Most representations of disabled bodies and of disability-related forms of shame and humiliation in the collection do not use affective strategies of sensationalism, obscenity or voyeurism. However, O’Reilly’s, Emily Oxford’s and Duffy’s texts are characterized by aesthetic provocations, describing female disabled bodies, sexual organs and sexual desires very explicitly and in graphic detail. Hence, they play with readers’ voyeuristic expectations about depictions of female disabled bodies. Among these texts, Duffy’s is the only decidedly autobiographical one, Oxford’s and O’Reilly’s stories are autobiographically inspired. In general, most authors of the autobiographical texts in Keith’s collection depict events of gender- and disability-related humiliation and harassment that narrators and textual others experienced in their contacts with doctors, carers, nurses, physiotherapists, teachers, employers, colleagues, family members, partners or strangers, thereby discussing practices that were not prosecuted before the passing of the 1995 Disability Discrimination Act and the amendment of the Disability Discrimination Act from 2005. The texts in *Mustn’t Grumble* depict narrators that were the objects of disability-, gender-, ethnicity- and queerness-related humiliation and pathologization. They lived through experiences of illness and disability, of physical, emotional and social vulnerability, dependence and self-hatred. In addition, they describe personal ideals and goals (e. g. solidarity with disabled persons and other oppressed women) and provide reflected, critical depictions of events and incidents of humiliation and shame that turn readers into affective co-witnesses rather than voyeurs.

My selection of texts for close reading is based on project-related analytical criteria: the authors are from the UK and the texts discuss disability-related experiences, events and scenes of shame and humiliation and make use of shame- and humiliation-related textual strategies. My selected texts discuss physical and sensory disabilities, Pam Mason’s contribution about mental distress (‘Agoraphobia: Letting Go’) focuses on

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[102] See Molly Holden: ‘Pain Teaches Nothing’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 18; Pam Mason: ‘Agoraphobia: Letting Go’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 106-112; Maria Jastrzębska: ‘Friends’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 130-132; Elli O’Sullivan: ‘The Visit’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith. London: The Women’s Press, 1994) 13-17; Helen Kendall: ‘Colostomy’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith. London: The Women’s Press, 1994) 43-45; Gohar Kordi: ‘I Was Touched’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 122-128; Jeni Fulton: ‘Journey’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 84-89; Mary Duffy: ‘Making Choices’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 25-31.

anger and fear rather than shame. The textual strategies related to shame and humiliation include narrative strategies of boldly speaking out against disability- and gender-related humiliation and of challenging shame-inducing norms and practices. In addition, they comprise phenomenological depictions of the pleasures of non-normative embodiment and of non-normative ways of living. I have selected a number of short autobiographical texts from Keith's anthology that problematize – and in some cases explore – experiences of shame and humiliation related to disability, illness, gender, race, class and sexual orientation. Most of the selected texts challenge shame-inducing ableist, severely gendered, racist and heteronormative body norms but they do so in very different ways. I contend that the short autobiographies by Ellie O'Sullivan, Ruth Bailey, Gohar Kordi and Jeni Fulton represent experiences and narrative events of shame and humiliation that unfold their affective energy within the texts and beyond them. Instead of representing shame as an individual feeling that must and can be directly mastered and overcome, the texts explore its complexity (together with the non-normative positivisms that are part of shame as a complex affective disposition) and in part also transfer shame to readers. O'Sullivan's, Bailey's, Kordi's and Fulton's texts examine the role of shame as a form of intersubjective communication that constitutes affective relations between narrative 'I''s and their textual others as well as readers. Nasa Begum, Lois Keith, Suna Polio and Mary Duffy describe different ways in which the object cathexis of shame, that is, the subject's affective investment in an object that turns its face away from the subject (e. g. textual others with ableist, sexist and racist attitudes), is loosened, in which shame is displaced on textual others and converted into anger or love.

In her autobiographical vignette 'The Visit', Ellie O'Sullivan, a British film maker who died in 1999,[103] recounts her experiences of fear and shame during the visit of a female Social Service worker who grades her with regard to the amount of help she needs at home because of her arthritis. The narrated 'I' expects to be regarded as 'a fraud, a malingerer' and a burden.[104] She is worried about how the disclosure of her physical weakness will affect her daughter Charlotte who is present during the interview. In order to remain mobile, she must admit to her weakness and vulnerability and tell the Social Service worker that she needs a bath chair to get out of the bathtub by herself. This concession is at odds with her self-image as an active, resourceful and independent woman. The narrator expresses this sense of inner division when she describes her strange feelings about the fact that she is labelled an impaired person in the medical records (14). In the sheltered space of female communication, the moment in which the narrated 'I' admits to her weakness and need of support becomes a moment of affection, sympathy, solidarity, support and love:

> I finish and see the woman before me soft with sympathy. 'Don't worry,' she says kindly, 'we'll get the chair installed as quickly as possible.' I don't look at Charlotte. I want to ask her forgiveness. I want to tell her how ashamed I am, that she needn't worry, that I'm okay. But she is already moving towards me, her arms encircling my legs, reassuring me, protecting me. (17)

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[103] Marian O'Connor: 'Ellie O'Sullivan.' *The Guardian*. 25 November 1999. n. pag. Web. 31 May 2021 <https://www.theguardian.com/news/1999/nov/25/guardianobituaries3>.

[104] Elli O'Sullivan: 'The Visit', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith. London: The Women's Press, 1994) 13-17, 13-14. See also 'Appendix.' *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 199-214, 208-210.

This passage impressively describes the paralyzing impact of shame on the narrated 'I', her 'fallen face', her wish to overcome her inhibition and to be able to act and speak (Hogan 2011, 37-38). At the same time, the exchange depicts how the textual other (the narrated 'I''s daughter) disrupts the unfolding atmosphere of paralysis by her approach and embrace. In this communicative setting, the other person's contempt which activates shame is never actualised but exists as an apprehension in the narrated 'I''s mind. This event reveals not only the narrated 'I''s internalization of able-bodied persons' contempt towards non-normative bodies but also shows how much she depends on kind, supportive responses from others, that is, on their acknowledgement of her strength and abilities. Hence, the text illustrates Silvan Tomkins's observation that shame is inextricably linked to positive affects (joy, interest, excitement): in shame, 'excitement or enjoyment is only incompletely reduced. […] Because the self is not altogether willing to renounce the object, excitement may break through and displace shame at any moment […] the residual positive wish is not only to look at the other rather than look down, but to have the other look with interest or enjoyment rather than with derision (Sedgwick and Frank 1995, 137-138). A similar depiction of the anticipation of humiliation as in 'The Visit' can be found in Helen Kendall's autobiographical text 'Colostomy' in which the narrator wonders in an internal monologue (printed in italics to mark it as a form of viceral language)[105] how her environment will respond to her stoma bag: 'I walk in the street and no one knows I have a colostomy. I choose clothes with tucks at the waist to disguise it. Like the rest of you I fart but I have no control. *Will-they-turn-away-from-me? Smell, round-the-corner-in-the-playground smell, exposed smell*.'[106] In Kendall's text, this question is left unanswered. Contrary to her negative expectations, the narrated 'I' in O'Sullivan's text receives 'good things' (love, support) from others precisely because she has disclosed and shared what makes her feel ashamed. Despite this positive turn of events, O'Sullivan's text does not describe a mastery of shame but depicts its transformation into love and solidarity. Instead of ending on a triumphant note, its final passage focuses on the narrator's physical deterioration, her swollen hands and pain. A similar, albeit more playful and erotic, transformation of fear, self-hatred and shame into positive affects and emotions (affection, sympathy, excitement, interest, pleasure) is described in Emily Oxford's fictional short story 'Prue Shows Her Knickers' that is also included in Keith's anthology. Here, an adolescent disabled character with arthritis accepts a wager and undresses herself in front of her class mate Andy who has agreed to do the same. Her embarrassment and insecurity about and hatred of her non-normative body (resulting from the humiliating labels 'cripple', 'handicapped' and 'not normal' that non-disabled people use to describe it) turn into a 'pang of pity' for the non-disabled Andy who is 'terrified' and makes 'a sorrowful sight'.[107] He exposes his own insecurity about the size of his penis and expresses his admiration of Prue's private parts (177-178). Here, shame is not directly overcome or mastered but rather transformed into sexual interest and pleasure. In Oxford's story, shame is also displaced onto a different (in this case male, non-disabled) body.

The short autobiographical text 'A Tale of a Bubble' by British author Ruth Bailey critiques the management and organization of care in British homes for the disabled in

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[105] According to Coogan, the passages printed in italics represent a new language of the body as a source of knowledge, 242.

[106] Helen Kendall: 'Colostomy', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith. London: The Women's Press, 1994) 43-45, 44-45.

[107] Emily Oxford: 'Prue Shows Her Knickers', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 172-178, 172, 177.

the post-Thatcher era, that is, during the 'liberal times' of cuts in the welfare sector.[108] While it denounces the shame-inducing structures of these homes together with the bureaucrats, architects, staff members and council politicians who are responsible for them, its narrator struggles with her own shame of being forced to live in such a neglected, de-individualized, anonymous space, that is, with the shame of being associated with this place and its inhabitants. Bailey's text has the potential to make readers complicit with an objectifying ableist gaze on the disabled inmates of the home. At the same time, it generates shame about this complicity.

Readers are introduced to the narrator shortly after she spent a year in hospital. She is sick of the white and the eternal monotony of care routines around her. Her eyes crave colour, she desires to meet another person's eyes over a glass of wine (32). However, instead of returning home she must go to a home for the disabled to get rehabilitation and wait until her own house will be made accessible for her. Her social worker explains the necessity of this temporary stay in a home by hinting at the 'lack of resources' (32). Although the narrator identifies as disabled, she establishes a distance between herself – a many-faceted unique individual – and them, that is, the inmates of homes who were stripped of their souls. She describes in detail the lack of privacy in the home (where phones are shared between 5 to 7 persons) and the unavailability of staff, the long and humiliating waiting time before a staff member is able to take an inmate to the toilet (35), the crowded, ugly, anonymous and uniform flats (purpose-built containers without living space, with 'shoe box rooms' and a scarcity of bathrooms), thin walls and permanently open doors that do not allow any privacy (33, 34), permanent noise of TV sets, the stale, putrid air (35) and the stench emanating from a broken sink (36). The narrator recounts how she was marked as a home resident in the shops of the neighbourhood. She realizes that no one looked at her face, pondering that home residents who were closed off from the community behind 'thick grey walls' were a mass of stigmatized, othered, uniform beings in the eyes of strangers:

> In the local shops, no one asked where I lived. They knew I came from 'that place'. I no longer had the pleasure of being just a stranger, a pleasure as a disabled person I had fought so hard to get. […] No one looked at my face: No one looked at any of our faces. We were all the same, all that was seen to matter about us was that we sat down, down, down. We were enclosed in thick grey walls to separate us from 'the community'. Walls 'the community' cemented with their fear of our differentness, greyness they painted to make our unique selves and our unique souls indistinguishable. (33)

The experience of being ignored, of being an embarrassment, of not being considered worthy of eye contact has a profound impact on the narrated 'I'. She tried to go further and further away from the home, seeking to set herself free from her connection with the home and its inmates. She finds that whenever she tells strangers that she lives in a home, they put her 'beyond the pale'. Eventually, she lies about her place of residence, being unable to 'face the confirmation of [my] low status' (34). At the same time, she feels that when lying, she betrayed her 'fellow residents' (34). In seeking to shamefully detach herself from her fellow inmates, she is complicit with the ableist responses that she detested when she was faced with the ways in which non-disabled

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[108] Ruth Bailey: 'A Tale of a Bubble', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 32-37, 33.

strangers responded to her. She misses the luxury of private sorrow or joy in the home and notices how her sense of autonomy dwindles under the impact of others' decisions about her needs (35). She not only bears affective witness to the bad conditions and the lack of care to which the home residents are exposed but also points to the causes of these conditions, to the lack of financial resources (32), the climate of cuts (36), the uncaring 'distant politicians' (37), the ways in which staff members 'rubbed and rubbed residents' lives together and shaped us to their own designs' (35). She insists that the apathy with which the home inmates respond to such conditions is not in their 'nature' but is induced by the management bureaucracy of the home: 'We moaned, amongst ourselves. Only I, the newcomer, was outraged. Only I, the newcomer, had not learnt that apathy was the way the powerless expressed seething anger' (36). She learns to her own 'disgust' that '[i]nduced apathy' and 'reduced self-worth were insidious weapons used by the Army [Who Care, i. e. home management, carers, social workers, K. R.] to divide us, to prevent their charges attacking' (36). She is upset about the fact that the Head's devastating decisions do not meet with any resistance. After 6 months, the narrated 'I' returns to her own home. She enjoys looking at her curtains, hearing familiar sounds, being visited by friends, being in control of her life (36). The narrating 'I' emphasizes that she sought to explain 'how those deemed "different" are divided from those deemed "normal"' (36-37). In the home, she felt like being 'trapped in a bubble'. Her story ends happily but she points to the 'many tales of many more bubbles which are still wanting to be burst.' She emphasizes that her position is a privileged one because she does not have to stay in a home. Nevertheless, she solidarizes with home inmates who do not get the chance to leave or tell their stories and who suffer atrocities at the hands of underpaid and overworked carers. She feels guilty because of her past betrayal of the other residents in her home and accuses everyone who remains silent about the unbearable conditions in homes of being complicit with society's neglect of those in need of support. The guilt the narrated 'I' felt when she was too ashamed to acknowledge her place of residence in the home and her connection with the other home inmates surfaces again at the end of the text (through references to the 'no hope status' of disabled people and to disabled people being put beyond the pale: 34, 37). This time, however, the narrating 'I' switches to a 'we', signalling that this guilt and shame implicates all those who fail to expose the atrocities that happen in homes or who fail to care to learn about them, including her readers:

> My tale has a happy ending but we must not forget the many more tales of many more bubbles which are still waiting to be burst. My tale pales, pales, pales in comparison with reports of disabled children being forced to eat their vomit, of young people being abused, violated while 'in care'. In those reports I recognize the perceived 'no hope' status of residents. These are the fertile breeding grounds for atrocities […]. They thrive because we forget, if we ever knew, how to care for others […]. They thrive because all say nothing, because we think, if we think at all, there but by the grace of a god, go I. (37)

As in O'Sullivan's text, shame is neither overcome nor mastered here. However, Bailey's tale performs an impressive shift from shame and humiliation to solidarity: whereas the narrated 'I' used to distance herself from the other home inmates, the practice of recounting the neglect and abuse in the home is an act of solidarity with the other 'bubbles', the other nameless inmates of homes whose tales are unheard. Furthermore, in Bailey's text, shame is transferred to those textual others (Head of Home, the Army Who Cares) in charge of homes who create such inhumane conditions, to those who could resist and expose these conditions but choose to be complicit, potentially including her readers. Her text bears affective witness to this abuse and neglect and puts readers into the position of potential affective co-witnesses.[109] As I hope to have shown, the transference of shame to disabled and non-disabled readers in Bailey's text is not limited to a process of identification. It is an affective narrative strategy that comprises, or rather demands, consciousness-raising, solidarity and collective political action.

Gohar Kordi's autobiographical story 'I Was Touched' can be regarded as a sequel to her 1993 book-length autobiography *An Iranian Odyssey*. It describes her life as a disabled author and migrant in Britain after 1971.[110] 'I Was Touched' recounts how the (imagined or real) physical and emotional touch of bodies, national histories and cultural roots brings the narrator pleasures, how it causes her pain, guilt and shame and creates vulnerability. She starts by describing how much she enjoys her writing class in England and the warm handshake of her female tutor Yvonne who cordially welcomes her. The narrator emphasises that touches, warm handshakes and friendliness matter when one cannot see. They make her feel special, comfortable and safe (122). Kordi's text links the subject of touching and being touched – a subject connected to the dynamic of affecting and being affected – to diverse forms of shame and guilt that are related to her intersectional identity as a female visually impaired migrant. These forms of shame comprise the guilt and shame of having left Iran – especially the Iranian women put to shame and stoned to death for their (purported) breaches of patriarchal honour – in order to live in safety and comfort. Furthermore, they include the humiliation and patronization she experiences because of her blindness and because of the way she touches people to communicate with them. She shares her shame and guilt about having left Iran – a 'touchy subject' – with another female migrant from South Africa, thus creating a transient bond of solidarity through shame (122):

> We identified with each other and talked about how difficult it is to deal with the feelings and dilemmas – the relief at not being there in the middle of it all and the guilt of not being part of it, involved. We had run away from it, left the suffering and the struggle to others. We preferred to be in comfort, safe. (122)

The two migrants agree that English people without a similar migrant background cannot understand their problems: 'They don't understand, you see. They have nothing in their experience to relate it to, to compare it with.' (123) The narrator, despite her absence from Iran after 1971, identifies with the women who were publicly shamed

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[109] A similar affective impact that puts readers in the position of co-witnesses of abuse (torture) committed against disabled persons is generated by Ann Macfarlane's autobiographical poem 'Watershed' in *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 161-162. It depicts a traumatic event of physical violence and problematizes forms of witness bearing. The speaker describes how a girl was killed in her home for disabled children through water boarding: 'They lifted her effortlessly / Into the deep porcelain tub / And then, without warning / Pushed her passive pale body under the water / And held it there. / We felt the fear through our ill-clad bodies. / […] we […] understood that we must not move, / Must not show what we felt. // Mary was dead. […] her bathers had no compassion. / They stood motionless over her, / Eyes staring transfixed / Not seeing a human child, not seeing her. // Slowly their attention turned outwards to us, / Unacknowledged, unwanted onlookers. […] Then, we knew we must stay silent. / Now I speak for all the Marys / In institutions, in hospitals, in segregated schools / And for my nine-year-old self, who had no choice / But to sit and watch.'

[110] Gohar Kordi: 'I Was Touched', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 122-128.

and stoned to death, creating a solidarity through shame, both as another Iranian woman who could have gone through the same humiliating, deadly procedure of stoning and as a migrant who deserted these women, who failed to support them:

> I remembered how, during the Revolution, I had longed to be in Iran, to be involved. […] when I first heard that four women had been stoned to death in Iran for supposedly immoral activities, prostitution, that night all of my insides ached, as if I felt part of their pain. They were a part of me, we had the same roots. We were born and brought up in the same country, same culture. We breathed the same air, read the same literature, the same poetry […]. (123)

Some touches remain unfulfilled desires based on imagined forms of identification, e. g. with the paralysed man in hospital who had been shot during the Revolution:

> He was paralysed from the waist down. I felt like hugging him and saying, 'I know what you have been through. Part of it is for me too. You have taken on my struggle as well. You have paid heavily, and many others too. I ran away, didn't I? Part of your loss is mine, part of your pain is mine.' (123)

This shame is never overcome because it is a shame that is immediately connected to her writing. Referring to Alan Paton's *Cry, the Beloved Country* (1948) and to her recognition of how close the situation in South Africa was to that in Iran, she admits: 'I felt particularly touchy about this issue, I suppose because of my writing. I am touching my roots, old wounds are being opened up.' (123)

The narrator continues with descriptions of other experiences of humiliation she is subjected to, this time those that are related to her disability and her migrant identity. She describes how her little son mischievously derides her because she is unable to see and how he wants to send her back to Iran:

> Now he is three. This morning I can't find his shoes anywhere. It is getting late for nursery. 'Please, darling, will you help mummy find your shoes?' 'No, if you can't see, I can't see,' he says laughingly. It hurts. I have to bear his pain as well as mine. As he started school, he became more and more aware of my foreign origin. 'You go back to Iran where you've come from, mummy. We don't want you here,' he said when he was cross. […] 'I'm English,' he would say, with pride in his voice. He wants me to be like other mothers in his school, sighted, English. To him I am very different. This is uncomfortable, very uncomfortable at times. (124)

The narrator here admits to her emotional pain caused by her son's derision of her inability to see but also to her emotional pain connected to her visual impairment that gives rise to feelings of inadequacy. She is aware of being a source of embarrassment for him: 'He hates my white stick. "Please, mummy, when you come to fetch me from school, don't bring your stick, hide it away. Give it to me, I will break it. You embarrass me, mummy. People stare at you. I don't want to walk with you."' (124-125). The shame of being different is intensified by the shame of being unable to fight, shame back or protest, by the shame of being vulnerable:

> On one occasion he said in rage: 'You can't even see, can you?' 'Can you?' […] I felt like screaming […] 'It's not my fault, you wretched child, how can you be

> so cruel?' But the screams are squashed in my throat, which feels like splitting any second. I have to bear his pain and mine […] So I reply, simply, 'No.' My voice is unfamiliar, shaky. I am defenceless, vulnerable, like a baby. I can't protest.' (125)

She describes similar experiences of speechlessness, helplessness and victimization when she faces the humiliating, patronizing comments of strangers that she describes as repelling touches: '"I know all about the blind. My aunt was blind," the woman at the bus stop says, when I ask her to tell me when my bus arrives. Or "There's a good boy, you're mummy's eyes, aren't you? Look after her," from the man in the street […]. It makes me furious' (126). Here, as in the earlier quotation describing her inability to shout back at her son, the autobiographical text provides her with an alternative reality of angry response, with an affective potentiality that the 'real', 'original' encounter with the man in the street lacked: 'I feel like hitting him and saying, "Don't you *dare* make him feel responsible for me. I didn't have him to be my eyes!"' (126). In these imagined responses, the narrating 'I' describes an affective potential in which the attachment to shame's oppressive impact (the affective investment in the object that turns its face away) is loosened and in which anger and outrage take the place of her former lateral and actional inhibition. As Lauren Berlant remarked: 'the way you break something [e. g. normativity] isn't to just find a better object. It's to loosen up the object and transform it from within itself' (Berlant 2011, 184). Kordi's narrator admits to the difficulty of loosening up the object: 'Often I can't think of anything to say. My anger and my embarrassment in front of my son crush me and I remain speechless' (126). In addition, she is left speechless when others tell her that her son has beautiful eyes and use ocularcentric compliments to emphasize what she lacks: 'When someone tells me "Your son is beautiful. Do you know what beautiful eyes he has?" I think "No, I don't How can I?" The pain is excruciating. I envy those who can see his eyes. It makes me cross' (127).

Another form of shame is connected with the narrator's habit of touching people she communicates with. Although she describes her haptic communication as a compensation for her inability to see at the end of the text (127), she also demonstrates that it is more to her than a compensational technique that 'replaces' her loss of vision. Hence, Kordi's text in part describes what David Bolt defines as 'non-normative positivisms', that is, 'affirmed deviations from socially accepted standards' that depart from ableism and disablism (2015, 1107). '[N]ormative compensatory powers involve, say, being able to see with one's hands or ears, whereas non-normative positivisms value the senses in and on their own terms' (Bolt 2015, 1109). Kordi's narrator emphasizes that touching and being touched are common forms of communication in Iran, that is, alternative, non-ocularcentric ways of being in the world, of being connected. In the ocularcentric homophobic, heteronormative west, however, they are only regarded as a compensational means of communication, as techniques whose only function is to replace the missing vision: 'I am told that people look strangely at us when I walk arm in arm with a girlfriend, until they notice that I cannot see. My blindness legitimizes my being touched.' (126) In the following passage, the narrator describes how her spontaneous way of communicating through touch is regarded as shameful in the west, as a practise associated with homosexuality that creates uproar and social rejection:

> I used to touch people easily and freely. If I was talking about something exciting I might touch the person next to me and say, 'Do you know what happened this

> morning?’ When I first came to England I formed a friendship with Carol, a psychology student. When I touched her I noticed she drew back, and then one day she said: ‘I must tell you something, Gohar. In this country we don’t touch amongst the same sex, otherwise people might think we are homosexuals.’ That inhibited me from touching my own sex. My Eastern culture had already prohibited me from touching the opposite sex. What do I do then? Ignore people’s physical being? Some time later I made friends with a Palestinian girl. One day I was waiting for her at the bus stop. Suddenly I heard her calling my name and running towards me. She hugged and kissed me heartily. I just froze, could not respond. I had lost my ability, the spontaneity, to touch. One day in my adult education massage class, when we were practicing, I was struck by the individuality of the face of the woman I was massaging. I had forgotten how people’s faces differ, because in my day-to-day contact I seldom touch their faces. It would be nice if I could touch people’s faces, I thought. But what is it that stops me? Inhibition? This society disapproves of touching. […] I used to touch children freely, cuddle them, as I had in Iran, until some mothers told me their children didn’t like to be touched. Now I hesitate before touching a child. It maddens me because I was brought up to touch and be touched all the time. (125-127)

In her story titled ‘Sight’ that is also included in Keith’s collection, Kaite O’Reilly, a visually impaired playwright, author and dramaturge of Irish descent,[111] describes similar uproars caused by her ‘misbehaving’ visually impaired protagonist who explores her world through touches and imaginative perception. Like Kordi, O’Reilly combines the depiction of life with non-normative sight with the topics of haptic communication, relationality and religion. In Reilly’s story, however, non-normative sight is explicitly linked to transgressive sensuality, female sexual desire and divine inspiration / revelation. Whereas Kordi describes the inhibiting impact of western prohibitions to touch on her spontaneity, O’Reilly’s rendering of the humiliation caused by her protagonist’s non-normative sight, her way of viewing and touching the world – e. g. statues of saints and biblical figures – are sensual, highly imaginative and markedly comic. Visiting a chapel, Reilly’s protagonist observes how a statue of Virgin Mary

> moves and the alabaster lips smile down on her. She tingles. […] she reaches up, knowing she has been blessed with vision. The candle flickers; Our Lady breathes. Consumed with vocation her fingers glide along the moving breasts, finding them cold and inanimate beneath her touch. She is confused, her twin telling senses contradictory, making mockery. She climbs up to the statue’s ledge, clutching at the lungs beneath the stone. Do they move or not? Is this a calling or hallucination? The priest roars out and she falls on to concrete and into scandal. She is requested never to attend the church again. Her family, briefly, disown her. […] She ignores the headaches, the flashing lights, the

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[111] Kaite O’Reilly: Blog. <https://kaiteoreilly.com/blog > Web. 31 May 2021; Jo Turnbull: ‘Getting Cosy with Kaite O’Reilly’ Disability Arts Online, 3 March 2016 <https://disabilityarts.online/magazine/opinion/getting-cosy-with-kaite-oreilly/ > Web. 31 May 2021; Kaite O’Reilly: ‘Sight specific: visual impairment and hiphop theatre’, Wordpress.com, August 21, 2015. Web. 31 May 2021 <https://kaiteoreilly.wordpress.com/tag/visual-impairment/>.

> frequent migraines, and sets off alarms in Rome when fingering Michelangelo's David, discovering the famous penis is even smaller in touch than in sight.[112]

When she becomes temporarily blind and 'her fascinating eyes go out', she

> recalls her delightfully malicious sight, playing tricks on her, offering visions, mirages, hallucinations. Those moving statues, animated objects; her sight which breathed life into dead, never-living things. […] She begins to understand her outsider sensibility […]. The infusion of embarrassment, her self-loathing at never being able to do anything 'right'. (23)

The above quotations comprise descriptions of shame-related situations that are linked to sighted characters' ableist responses to the non-normative sight and transgressive behaviour of O'Reilly's protagonist. At the same time, they emphasize the non-normative pleasures that are attached to the explorations enabled by her highly imaginative, creative slant, a slant that is linked to divine inspiration. At the end of the text, O'Reilly's protagonist fully embraces her imaginative, wonderful, non-normative sight when it suddenly returns, refusing other's denigration and invalidation of it:

> She greets it [i. e. her sight, K. R.] as the prodigal daughter, embracing her flat world with a terrible tenderness. She is wiser now and contemptuous, watching her family seize the medical term. […] It's only because you're partially sighted!' She listens to them with her sphynx-like grin. She has learnt her last lesson. She knows 'only' has nothing to do with it. (24)

O'Reilly's protagonist is aware of the ableist, medicalizing belittlement and invalidation of her special vision that her family readily adopts. By contrast, she resists being defined by the medicalizing gaze[113] and refuses to feel self-loathing about her perception of the world. She responds with rage and contempt to those who disdain her non-normative form of perception and eventually embraces and values her 'outsider sensibility' (23). In this way, O'Reilly's protagonist loosens her object cathexis (her affective investment in the faces turned away or expressing derision) and directs her affective investment towards a new object: her excessively imaginative non-normative sight.

Similarly, Kordi's narrating 'I' embraces her non-ocularcentric form of communication through touching and being touched, both in a physical and emotional sense. However, in contrast to the female protagonist's embrace of her non-normative sight in O'Reilly's text, the narrator's affective attachment to her non-normative communication in Kordi's text brings deep emotional ambivalence, that is, both excruciating pain (fear of rejection and loss) and tenderness as well as love. She focuses on her fear to lose the touch of her son and her connection with him, admitting to the painful impact of her visual impairment: 'Once he started school he gradually moved away from me. Now, our physical contact has become much less. This makes me sad. For me, touch was a substitute for seeing him, and now it is diminishing. It is as though he is moving out of focus to me' (127). As this passage shows, the narrating 'I' in Kordi's text remains attached the objects that (at least in part) turn their faces and bodies away: her country

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[112] Kaite O'Reilly, 'Sight', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994), 19-24, 21-22.
[113] See also Coogan 2008, 239.

of origin, her cultural roots, the subjects she writes about, her son, strangers, friends she wants to touch. She remains attached to the ambivalent feelings connected to touching and being touched, to the danger of faces turning away, to the risk of remaining vulnerable, to the potential of objects generating both pain and pleasure and especially to her son's growing detachment and spontaneous closeness (127-128).

Jeni Fulton's autobiographical text 'Journey' depicts the narrator as being stuck in and frustrated about her disability-related shame. This shame is not only connected to her non-normative, disabled, sexually desiring female body that shows the impact of a progressive chronic illness but also linked to her inability to live up to her feminist convictions. The text opens on a placid note: the narrator sits in a car with her friend who gives her a lift home after they spent a weekend with friends. She states that they look like a couple, chatting, laughing together, exchanging smiles. Readers learn that they share a long history as friends but not a story of a wild, unbridled romance. The narrator desires both and especially and secretly the latter (85).[114] The situation of being close to her friend in the car gives rise to an extended inner monologue about body shame. Her friend, readers learn, is 'very comfortable with his body', he 'bares it to the world' without a second thought, enjoying the sun. She, by contrast, felt too uncomfortable in her body to strip off in front of him.

Since her medical condition has progressed, she has become more self-conscious about her own 'deteriorating body':

> Have I really withdrawn so far from situations of intimate contact? I've become afraid of people backing away – sensing, perhaps, the extreme discomfort I now feel about my own deteriorating body. I can only associate touch now with impersonal medical matters. (85)

The narrator explains that she used to be 'a risk-taking young woman' with casual sexual contacts (described as 'distasteful, unsatisfactory screws' 86). During these casual sexual encounters, her partners never insisted that she took off all her clothes and probably did not even notice her disability (87). She reflects that at that time, her body 'wasn't quite so bad […] – and I certainly didn't hate it so much' (86). She pretended that her body was not the way it really was and almost 'disbelieved' her 'deformities away' (86). Lately, however, she has more and more withdrawn from intimate touch. She suffers from 'an advanced state of touch deprivation' (85) and only associates touch with 'impersonal medical matters', with being regarded as an 'interesting case', an object of the medicalizing gaze (85). This admission of self-hatred shows the forceful impact of ableist body norms on the narrator. She reflects on how she met with a considerably older, unemployed social worker, an outsider like herself, who was prepared to try to understand her situation and wanted to talk about it. She, however, was never sure if she felt caresses or a fetishizing, objectifying touch – 'Caressing hands? Or hands curiously feeling for scars?' – and soon ran away (86). She observes that her 'unhappiness' about her body has grown since she has become political about being a disabled person (87). This development stands in stark contrast to her self-image as a feminist and a politically active person:

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[114] Jeni Fulton: 'Journey', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 84-89.

> In other areas of my life I have become more assertive and confident about who I am, an important part of which is me as a disabled woman. I am, after all, a woman with a happily independent life, a beautiful home, a ridiculously senior job. Yes, I can say proudly, that is me, despite the ways in which society tries to deny me the competence I have, tries to make me invisible, put me down, patronise me, exclude me, deny me my civil rights. Mostly I am strong enough to get politically angry, to challenge and continue to grow. Hard as it sometimes is, I really enjoy that part of the journey. (78)

The narrator then powerfully contrasts her political self-image as disabled woman with the physical and emotional self-image generated by her look in the mirror:

> Then I see myself naked in the bathroom mirror, and suddenly that sight redefines me. I wonder if the politics helps me avoid what I have to do in challenging my relationship with my emotional and physical self. I want to make progress in that relationship as I have done with my political self, but if I can't like my body, love it, be kind to it, how can I expect anyone else to feel differently about it? I'm so out of practice that I can't imagine what I would do now if I wanted to seduce someone. […] I would have to embark on a full discussion – what my body is like, how I'm restricted, and so on […] and so on […] and so on. Some seduction! Or I could just grab the condoms […] and risk him recoiling in horror. (87)

The narrator here suggests that her political self-image as a disabled person is above all a cognitive, rational construction that fails to take emotional, physical aspects of a disabled identity into account. This critique is in line with positions within critical disability studies that have disapproved of the neglect of the subject of the disabled body among adherents of the social model of disability (Price and Shildrick 2002, 62, 71).[115] The narrator in Fulton's text explains that she is 'frustrated' by her 'inability to act and take the emotional initiative' in the situation with her friend in the car which might 'break the deadlock' she is in. She resents her retreat 'under a shell'. Eventually, the 'Golden Opportunity' arrives, 'staring me mercilessly in the face': her friend asks her if she is okay. 'Golden Opportunity' urges her to 'tell him that you're not okay, tell him how you really feel about him' (88). The narrator hesitates and then lets this opportunity melt. She allows their friendship to carry on 'undeveloped, unchallenged – increasingly unsatisfactory', stating self-ironically that risk and vulnerability must be avoided at all cost: 'I've worked so hard to be the strong, independent, coping woman. I can't show my weakness now' (88). Despite her decision to avoid taking a risk she ponders the possibility of having acted differently: 'What would happen if I took the other route? […] It's terrifyingly unpredictable. I assume the worst, of course – rejection. He just doesn't see me as a sexual being. It would probably be the end of even what there is now' (89).

The car finally stops and the atmosphere becomes heavy. The narrator focuses on her experience of being stuck in shame, inhabits it and forces readers to do the same:

> The fog clings everywhere. Time has stopped because I can't get past the point at which the motorway divides for me. I'm frustrated by the whole situation. I

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[115] See also Petra Kuppers: 'Towards a Rhizomatic Model of Disability: Poetry, Performance, and Touch'. *Journal of Literary and Cultural Disability Studies* 3.3 (2009) 221-240.

> don’t want things to go on as they are. I’m weary of […] suppressing such an important part of myself, of behaving so inconsistently, at odds with the strong political woman I am. (89)

This passage is an impressive representation of the paralyzing impact of shame that inhibits action and suspends the formation of narrative effects (Hogan 2011, 37-38). The narrator, it becomes clear, cannot overcome or master her shame and self-hatred about her body but through inhabiting the emotional experience of being stuck in shame and the frustration of this situation she paradoxically creates a desire and, possibly, a potential for change. The text generates an affective atmosphere of discomfort, anger and impatience that makes readers feel a strong dissatisfaction with the narrator’s situation and possibly a desire for change. The narrator ends her text by emphasizing the long way she has still to go (‘There’s so much further still to go’) in developing a different – perhaps more loving and accepting – view on ‘the twisted, scarred and sagging deformity that I perceive to be me’ (89). The question arises whether Fulton’s text suggest that the task of challenging ableist body norms is left to the individual, private self. Through its critique of the cognitive, rational focus of feminist disability activism under the dominance of the social model, Fulton’s text points not only to a private, personal journey but to a journey that society as a whole – including feminist disability activism – has to take.

In her poem ‘Anger – Early Days’, Lois Keith describes her confrontation with members of the school association at her children’s school during a discussion about the installation of a safer ramp. In the poem, the speaker describes her shamefaced response to the association’s rejection of her request and the process in which she turns her embarrassment and inhibition into anger and outrage. The most obvious affects in the text are anger and outrage: emotion words related to ‘anger’ appear in the title and the first line:

> Next time I will get angry. / I will hear my own voice loud and clear / It will not tremble and fold in on itself / Never again. / Not ever will I expose myself / To your calm, white, mild-mannered complacency / To […] Your ‘I think the constitution actually says’ / Your ‘could you tell me what the Authority’s position on this issue is’ / And when my voice refused not to shake / And I let you see my half face falling to pieces as I wheeled out of the room / With the sound of my weeping echoing to you from down the corridor, / Why then, then you must have felt grey bad enough to say – ‘I think there must have been one or two misunderstandings’. (55 ll. 1-15)[116]

In addition to anger, these lines describe a situation that is marked by disability- and gender-related humiliation and a depiction of what Eve Kosofsky Sedgwick has called the ‘fallen face’ (‘my half face falling to pieces’, 55 l. 12; Sedgwick: 2003, 36). In the poem, the placid, patronizing school-association members put themselves into the position of purported rationality, objectivity, ‘Authority’ and calm superiority (traditionally the position of white heterosexual men) and expose the female disabled speaker as purportedly over-sensitive / over-emotional, unreasonable, child-like and unobjective. Hence, the poem demonstrates that ‘“being emotional” comes to be seen as a characteristic of some bodies and not others’ (Ahmed 2014, 4, 8).

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[116] Lois Keith: ‘Anger – Early Days’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 55-56.

It is important to note that Keith's depiction of the speaker's affective response is not a description of passivity. On the contrary, she uses decidedly active formulations in her representation of the speaker's shamefaced self-exposure: 'my voice refused not to shake', 'I let you see my half face falling to pieces' (55 ll. 11-12). Thereby, she emphasizes the speaker's forceful,[117] strategic employment of negative affects (shame, pain and distress) that reveals the association members' discriminatory attitudes and their failure to respond to her request with solidarity and support. In the poem, the speaker turns her shamefaced response it into an empowering speech act that amounts to a 'shame on you!', a shaming of her interlocutors who humiliated and tried to silence her:

> in the room not one of you / Could break your soft-centred, well-reasoned mould / No not one. / In discomfort you moved your chairs / Your body language removed you from the circle. / You spoke in measured terms of organisation, / Of protocol, of policy / But mostly you spoke of silence. // And not one of you, not one / was prepared to break the feeling of that meeting / And speak in clear support. / You thought it was unfair that I should embarrass you / By showing what I felt. (55-56 ll. 17-29)

The poem performs an impressive affective transformation that does not seek to directly overcome shame but that works *through* and *with* shame, even by inhabiting it. It uses shame as an affective strategy through which ableist and sexist shame-inducing prejudices are critiqued by turning readers into affective co-witnesses of an experience of disability- and gender-related humiliation. The use of shame / humiliation as affective strategies is underlined by Keith's quotation of a nursery rhyme that objectifies and derides female disabled persons. Keith's poem ends with the speaker withdrawing, thereby avoiding a new confrontation with the same members of the school association:

> Eeny meeny miney mo / Catch a cripple by her toe / If she hollers […] / Next time I still may not know how to holler / So there won't be a next time. / Not with you. / Never. / I will wait until my new shell grows / And while it does I will protect myself / From your pious, ever-so-well-meaning, calm destruction. (56 ll. 37-46)

A reading based on Eve Kosofsky Sedgwick's definition of shame as a the 'experience of interest that a person holds toward an object after it turns its face away'[118] might suggest that what Keith's poem performs is a speaking subject's turning away from the object that turns its face away, a losing of the object that induced shame in the subject (in the female disabled speaker). However, the poem and its title emphasize that the struggle has just begun, that the speaker's temporary withdrawal is a preparation to gather strength for a new fight in the future, with a 'new shell' protecting her in her confrontation with new opponents (56 ll. 44-46). Interestingly, in the last lines of the

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[117] Seigworth's and Gregg's definition of affect in terms of 'force or forces of encounter' is very productive in this context: Seigworth and Gregg 2010, 2.

[118] According to Sedgwick, shame is the 'experience of interest that a person holds toward an object after it turns its face away', see Berlant and Edelman 2014, 37. Lauren Berlant argues that one can think about the object in / of shame as 'a patterning that's loosely organized, so that it would be possible to change the object without having to lose everything', David K. Seitz: 'On Citizenship and Optimism: Lauren Berlant, interviewed by David Seitz', Society & Space. March 23, 2013. Web. 1 June 2021. <https://www.societyandspace.org/articles/on-citizenship-and-optimism>.

poem, the tempus shifts to the future (‘there won’t be a next time’ 56 ll. 41-46), linking the ending with the beginning (‘Next time I will get angry’ 55 ll. 1-10) while the middle part is in past tense (‘And when my voice refused not to shake’ 55-56 ll. 11-36).

‘Tomorrow I’m Going to Rewrite the English Language’, a poem by Lois Keith that immediately follows ‘Anger – Early Days’ in her anthology, can be understood as problematizing the female speaker’s resumed fight, her struggle against discrimination and shame as a writer. This time, the discussion of the struggle against discrimination and shaming shifts explicitly to the level of language. In the poem, the speaker envisions her creative re-formation of her ableist, patriarchal mother tongue through a gentle, indirect and non-linear form of writing that reminds readers of Hélène Cixous’s concept of *écriture féminine* but that explicitly embraces disability as a formative category:

> Tomorrow I am going to rewrite the English Language. / I will discard all those striving ambulist metaphors of power and success / And construct new ways to describe […] My new, different strength. // […] I’ll refuse to feel a failure / When I don’t stay one step ahead. […] // I will make them understand that it is a very male way to describe the world. […] // Mine will be a gentler, more womanly way / To describe my progress. / I will wheel, cover and encircle. / Somehow I will learn to say it all. (57 ll. 1-4, 7-8, 13-14, 19-22)[119]

In the lines quoted above, the speaker refuses to feel ashamed, to feel a failure when confronted with ableist and sexist categories of success, power, mobility, body posture and world view. She challenges masculine, ableist norms through a decidedly non-linear, indirect description of what she considers to be her ‘progress’. However, the speaker’s intention to refuse to ‘feel a failure’ has the ironic effect of conjuring up shame’s power, an effect that is similar to that of the invocation ‘Let me not be ashamed in grieving / for the loss of touch, / love, sexuality, personal growth / As I search and reach out / for inclusion’ in Ann Macfarlane’s poem ‘Loss’ that is part of *Mustn’t Grumble*.[120] Furthermore, although the speaker in ‘Tomorrow I’m Going to Rewrite the English Language’ states that in this new language ‘I’ll refuse to feel a failure’ (l. 7), that is, refuse to feel shame, it is important to bear in mind that it is the practice of writing in particular that holds innumerable pitfalls and possibilities of failure and shame, e. g. the shame of failing to arouse interest in readers or of failing to achieve one’s goals of writing (e. g. to de-stigmatize disability, to create a language free of prejudice), to prove equal to a work’s ethical responsibilities’.[121] Although Keith does not problematize these shame-inducing pitfalls of writing, she chooses a near but visionary future (‘tomorrow’) as the tempus of her poem whereas she uses the past and future tenses in ‘Anger – Early Days’. Thus, the poem emphasizes that the re-writing of the English language through a non-linear *écriture féminine* that embraces disability is a vision, a desire that may remain unfulfilled, rather than what Coogan calls a ‘bluster’ or bold claim that fails to deliver (2008, 219). The envisioned re-writing of the English language might look like Aspen’s creative and funny attempt that is

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[119] Lois Keith: ‘Tomorrow I’m Going to Rewrite the English Language’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 57.

[120] Ann Macfarlane: ‘Loss’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 100-101, ll. 29-33.

[121] On the shame connected with writing see Elspeth Probyn: *Blush: Faces of Shame* (Minneapolis: Minnesota University Press, 2005) xi-xii, 129-162 and Bewes 2011, 1.

included in Keith’s anthology or it might look entirely different.[122] As Sigrid Nieberle has emphasized, the practice of *écriture féminine* itself implies an awareness about this unavoidable failure to achieve a fixed goal (e. g. the creation of a new, different language that distinguishes itself from a masculine tradition of writing) and therefore should be understood as an exploratory movement rather than an art of writing with a set of fixed defining characteristics.[123] In Keith’s poem, the vision of a future rewriting / feminist cripping of the English language that comprises the idea of a refusal to feel ashamed about disability is a process that is based on a confrontation with shame, not on its direct erasure.

Nasa Begum’s short autobiographical text ‘Snow White’ describes the narrator’s confrontation with the contempt she encounters in her social environment, with its unwillingness to accept her intersectional identity as a disabled woman with a Pakistani migrant background. Begum suffered from a neurological condition that resulted in spine curvature and muscle degeneration. She was a British writer, editor and disability activist of Pakistani origin who died in 2011 (Bindel 2011). The beginning of ‘Snow White’ describes the narrated ‘I’’s semi-comic, potentially embarrassing attempts at theatrical role playing, at trying to be ‘normal’ from the viewpoints of her white and / or non-disabled peers and teachers. In her text, Begum focuses on theatrical parts that symbolize and reproduce social norms of whiteness, femininity, Christianity and able-bodiedness: Snow White, Angel Gabriel and Easter play singer / performer. The narrator recounts how her attempts to be perceived as ‘normal’, as belonging to English / Christian culture, were accompanied by her audience’s taunts and laughter:

> I always wanted to be an actress and when I was chosen to play the lead in my primary school play, I thought I had definitely started out on the road to fame and fortune in Hollywood. My teachers were rather short of irony, otherwise it might have occurred to them that there was something a little strange about putting on Snow White and the Seven Dwarfs in a school full of disabled children and casting me as the heroine. My classmates’ approach was more direct. – ‘You’re going to be painted white, Nasa Begum’ they would taunt me, along with other horrendous suggestions. Yes, Snow White was without doubt fair-skinned, and I wasn’t (not to mention the other ways I didn’t look like Walt Disney’s version of this damsel in distress). Still, I desperately wanted the part, so I spent many anxious hours trying to convince myself that I could fit the role. […] Unfortunately, I never had the chance to make dramatic history by becoming the first Pakistani Snow White because I had to go into hospital for an operation. […] For one reason or another my acting career always seemed to be fated by some disaster or another. Once again seriously miscast, but enthusiastically bringing my own Islamic experience into the role of the Angel Gabriel, I tripped up and fell straight into some poor parent’s lap. On another occasion I was so carried away with waving my palm around as we sang ‘Hosanna’ in the school Easter play (the concept of a multicultural approach to teaching hadn’t yet reached my school), that I lost my balance and fell off the stage backwards. I

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[122] Aspen: ‘What Did You Soy?’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 181.

[123] Sigrid Nieberle: *Gender Studies und Literatur. Eine Einführung* (WBG Wissenschaftliche Buchgesellschaft, Darmstadt 2013) 52.

> still have a small bald patch on the top of my head to prove what dangers I was willing to undergo in the name of drama.[124]

On a tragicomic surface level, the narrated 'I''s attempts to be perceived as 'normal', as belonging to white, able-bodied English culture, fail because of her non-normative body but on a deeper level the text shows that they miscarry because of her mates' and teacher's unwillingness to accept her intersectional identity, because they made her 'feel out of place wherever I was' (49). Her Pakistani clothes 'attracted […] derogatory remarks at school […] I ended up feeling uncomfortable in the clothes I wore at school and at home and I tried to solve this dilemma by wearing western clothes at school and changing immediately I returned' (49). Similarly, in another event referred to as 'the tragedy of the Orange Dress', the narrated 'I''s desire to emulate another Asian girl and to become her friend is frustrated, not merely because the dress is sold to someone else:

> what upset me most was that I wanted that dress and I wanted it from that shop. Most of all I wanted the girl whose family owned that dress shop to be my friend. She was the only black role model I had. Her culture was very different from mine […] but the fact that she was at my school was important for me. Until I met her, I had never seen another Asian person with a disability and I was proud to be considered to be like her. But it was still quite a shock for me to realise that the other kids at school saw us as being quite different from them. (50)

Begum's text comments on the many different ways in which the narrated 'I' is confronted with intersectional forms of humiliation:

> It took me a long time to understand why people who did not know me in my neighbourhood called me 'spastic', 'bandy legs' or 'Ironside' and why people with disabilities called me 'paki' or 'nigger'. Eventually I learned that wherever I went I would probably stand out as being different from the majority and I had to be prepared to accept being called either paki or bandy legs, and sometimes both. (50)

'Snow White' stands out among the contributions to Keith's collection because of the ways in which it evades detailed descriptions of the narrated 'I''s feelings of shame in response to acts of humiliation. Furthermore, it also seems to lack depictions of shame-related experiences of paralysis and inhibition to act. However, 'Snow White' alludes to the narrated 'I''s embarrassment in the description of her discomfort when wearing different clothes at school and at home ('I tried to solve this dilemma by wearing western clothes at school and at home'), a strategy by which she tried to straddle her cultural identities and 'manage' her desire to belong to different cultures (49). Furthermore, the references to the lapse of time before the narrated 'I' gains insight into the structural nature of the intersectional forms of stigmatization she is subjected to constitute a narrative ellipsis that may be an indicator of her shame-related paralysis, her actional and expressive inhibition (50). Hence, bearing in mind that shame is a reduced, fragmentary form of communication (Sedgwick and Frank 1995, 134-138; Hogan 2011, 32-42), the absence of descriptions of feelings of shame in Begum's text can itself be read as a formal manifestation of shame. At the end of the text, the

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[124] Nasa Begum: 'Snow White', *Mustn't Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women's Press, 1994) 46-51, 46-47.

narrating ‘I’ is proud of her multi-layered identity as a black disabled woman; she rejects the concept of normalcy altogether: ‘[…] I’ve come a long way since the days of Snow White and orange dresses. I’ve reclaimed my identity by refusing to accept a concept of ‘normality’ which tells me I must walk, have fair skin and try to blend in by wearing Western clothes’ (50). As these lines show, Begum’s text uses humour and self-irony as strategies through which the subject’s attachment to the normative object, the object that turns its face away from the non-normative body, is loosened so that a new, different form of being-in-the-world-with-others can begin to evolve.

Suna Polio, author of the short autobiographical text ‘Being Sam’s Mum’, is described as a lesbian feminist and disability activist in the ‘Contributors’ Notes’ of Keith’s anthology (Keith 1994, 222). She had polio at the age of 7, became a parent in 1990 and states that this experience opened new worlds of love, play and delight as well as new forms of oppression (222). Her text describes the normative expectations of her social environment towards women and motherhood. It demonstrates how these expectations systematically exclude the possibility of disabled lesbian mothers. At the beginning of the text, the narrator mimics straight, non-disabled people’s responses to her introduction of Sam as her son: ‘Two mummies, frankly, is a bit excessive, not natural, and hang on a minute, does that mean that you’re, you know, lesbians? And which one of you is the real mum?’ (77).[125] What is more, the narrator explicitly addresses and exposes her readers’ prejudices, provoking their immediate responses to the question whether they would identify her as Sam’s mum, judging from the initial paragraph in which Sam interacts with her and her partner Ann: ‘If you saw me and Ann and Sam together, what would you decide about us? […] Of course, one of us must be his mum, that’s obvious. Who would you choose?’ (77). The narrator emphasizes that a disabled non-biological mother in a wheelchair is not regarded as a mother in ‘the public eye’ but she insists that she is a mother. She explains that she is seen as being ‘powerless and incapable by people on the streets. Why? Their perception of the wheelchair of course’ (78). Interestingly, she connects this judgement not only to her disability but also to her gender and especially her sexual orientation, thereby emphasizing the intersectional forms of stigma that disabled lesbian women face: ‘If I’d been with a man, the picture we made may have been interpreted differently. As it was, we were two women and a baby. To the public eye I looked an unlikely candidate for motherhood. The wheelchair disqualified me’ (78). The narrator states that she met with humiliation when confronting others with the fact that she is a lesbian disabled non-biological mother: ‘My attempts to talk about my son to a few trusted people outside my immediate sphere have been laden with awkwardness and embarrassment’ (79). As a result, she states that in order to talk candidly with others about her experiences as a non-biological mother and connect with them she would have to ‘come out as a lesbian’ (79), a step that involves a number of life-threatening risks in a homophobic society:

> Lesbians get beaten up, get thrown out of their jobs, have their windows smashed. I didn’t want this to happen to us. It was safer to hide behind people’s assumption that my lover was my saintly sister giving up her chance of LIFE to dedicate herself to charity-case, than to risk their response to the truth. (80)

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[125] Suna Polio: ‘Being Sam’s Mum’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 77-83, 77.

This social context, together with the narrator’s dependence on daily care that is not always available, exposes the young parents to ‘double doses of vulnerability’ (80). As a consequence, she and her partner decided to hide the true nature of their relationship as lovers and parents of Sam before strangers: After Sam was born, the narrated ‘I’ and her partner Ann ‘carried on as before, allowing the question of our relationship to be passed over in the miasmic cloud which English people allow to obscure things they don’t want to face.’ (81) This strategy of secrecy and closeting, while it seems to have protected the young family, comes at a high price. It ostracizes the narrated ‘I’, prevents her from joining talks about motherhood with work colleagues and leaves her ‘feeling exposed, vulnerable, and like a fraud in my claim to be Sam’s mum’ (80). It results in the narrated ‘I’’s growing loneliness and despair:

> I got so desperate in my isolation and confusion about what was happening to me, that I put an ad in the personal columns of *Spare Rib*. […] I thought it was a risk worth taking. The ad went something like ‘Non-biological disabled mother seeks similar for experience-sharing and support’. Well, however much I might feel like I was the only one in the world, there must be at least one other somewhere in Britain, and who knows, maybe more. (81)

Putting an ad in the personal columns of *Spare Rib* is an act of coming out that implies a hope to overcome isolation. At the same time, it triggers feelings of self-abjection and self-hatred and puts the narrated ‘I’ at risk to encounter social rejection:

> On the one hand it seemed like a completely absurd ad to place, an absurd person to be even. Or perhaps it was just this pushing myself into the light of public day that seemed ridiculous. Perhaps it was okay to be this strange person as long as I stayed under that rock with the woodlice and other pale creepy crawlies. On the other hand the ad was like a brave little flag of hope, waving in the winds of the world, and saying ‘I’m here, I’m here, wave your flag if you’re there. (81-82)

When she receives what she believes to be an answer to her ad, her ‘heart leapt and fluttered’ and the ‘letter […] pulsated with possibilities’ (82) but when she reads it in company of a friend and her son, disappointment, embarrassment and shameful paralysis follow immediately:

> ‘… athletic outdoor woman who enjoys hill-walking, climbing and water-sports. Available for camping holiday in France any week in August.’ Was this some hideous joke? Had I revealed my need, made myself vulnerable, only to receive this punch in the guts? This woman and myself were probably the two most mismatched of *Spare Rib*’s entire readership. […] I was stunned, but it wouldn’t have been polite to burst into tears, or rage round the room, or tear the letter to shreds. It would have upset Sam […]. I registered my shock and disappointment […]. Closer examination of the letter and the latest issue of *Spare Rib* revealed what had happened. My correspondent had been replying not to me but to the athletic outdoor type whose ad had appeared above mine and who wanted a female companion for a French camping holiday. […] It was a mistake. I was bereft. (82-83)

The narrator at first thinks she is mocked, the victim of a bad joke (she stated she felt anxious because she made herself vulnerable and revealed her need) and then she is shocked. She imagines a bold answer that she never wrote: ‘Should I reply to her – “Would love to come camping but at present I’m stuck upstairs in my three bedroomed semi in suburban Chorlton. Perhaps when the lift is mended? […]”’ (82). Both the mistaken response (probably coming from an able-bodied feminist) and the fact that she did not really receive a response to her ad (the fact of rejection, of faces being indifferent or turned away) are revealed as painful sources of shame for the narrator. However, the text also critically alludes to the lack of a lesbian disabled readership of *Spare Rib*. Suna Polio’s story ends with an astonishing transformative movement that leads from shock, paralysis, disappointment, swallowed anger and bereavement towards positive affect, showing how the narrator punctuates and interrupts her attachment to the shame-inducing / indifferent object. Musing about her failed attempt to elicit a message from a lesbian disabled friend, she states:

> Perhaps she didn’t exist then, this person who was going through the same things as me. Or perhaps she was so sussed out she felt no need to reach out. Or perhaps she just didn’t read *Spare Rib* that week. Who knows? In any event, I never heard from her. I had to do without. And I did. (83)

These lines describe not only a state of failure, hopelessness and despair. They contain humour (a loosening of the object of shame), a vision of a variety of contingent reasons (chance / bad luck among them) why her desire for contact with someone similar to herself was not fulfilled as well as a determination to do without this desired object.

The ending of the text points to its beginning, to the depiction of Sam and his relationship with his ‘*two mummies*’ (77). At the end, the narrator turns toward the smiling face of her non-biological son Sam, or, rather, this object turns to her, thereby defining her as his mother:

> *He fixes me with his eyes and runs remorselessly towards me, launching himself at me at the last moment. We tumble backwards, laughing, him on top, me underneath. Looking up I see his face an inch from mine, framed by the blue sky. It is bursting with delight and triumph.* […] Sam is my son. (83)

Polio’s text performs an impressive turn towards a non-normative love object (her non-biological son), away from the embarrassment of the narrated ‘I’’s public disclosure of her loneliness and desire as well as away from the disappointment that this disclosure brings. At the same time, the embarrassment and disappointment about not being able to connect with another lesbian disabled woman remains unresolved and unmastered, together with the impact of the double doses of vulnerability that characterize the lives of lesbian disabled parents (80).

Mary Duffy’s autobiographical poem ‘Making Choices’ performs an even more radical turn away from shame-inducing social rejection and towards a non-normative object of love and pleasure. It is characterised by an audacious poetic voice that speaks in graphic detail about her female disabled body, especially its sexuality.[126] Furthermore, ‘Making Choices’ acknowledges experiences of stigmatisation and oppression as well as responds to them with an attitude of defiance. Duffy is an Irish photographer, writer,

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[126] Mary Duffy: ‘Making Choices’, *Mustn’t Grumble. Writing by Disabled Women*. Ed. Lois Keith (London: The Women’s Press, 1994) 25-31.

performer, painter and disability activist; she was born without arms because of the impact of thalidomide. Duffy uses lower case letters in the stanzas and capitals in headlines.

The poem is written in free verse, it consists of eight sections which are arranged in a chronological order. They focus on Duffy's birth, childhood and adult life, describing her relationship to her parents, her grandmother, her sisters, friends, her lover and herself. In section one ('*somebody's daughter*/CHILD'), the speaker recounts her parents' ambivalent attitude towards her. They thought they would love her 'so much / it wouldn't make any difference' but at the same time attempted to normativize her body with the help of prostheses (25 ll. 7-8). Section four, titled '*sisters*/DEPENDENCE', problematizes disability-related shame by describing how the speaker's non-disabled sister abuses her power over her to 'care, / control, / manipulate, hurt, / and humiliate' (28 ll. 6-9), a situation to which the speaker responds with 'terrible despair / and anger' (28 ll. 12-13). Duffy uses a drastic depiction of the angry and desperate speaker urinating in the school yard in protest against her sister's rejection to take her to the toilet: 'one hot summer's day I pissed in the school yard / because you would not bring me to the toilet. / I felt terrible despair / and anger, / as the steam rose from my urine / tickling towards the gutter' (28 ll. 10-15).

In sections five and six (titled 'WHOLE' and 'HOLE', respectively), the speaker describes her non-normative movement – 'falling / always headlong / and later learning to twist and fall / and hold my head up / and burst my ribs instead of my brains' (29 ll. 7-11). In addition, she challenges the taboo surrounding disabled women's sexuality by audaciously drawing attention to her body, describing how her grandmother 'scratches my crotch / when I ask', how 'someone else scratches me now' (29 ll. 14, 15, 17) and how she prepared herself for making a video about her birth at art college which 'involves being naked' (30 ll. 9-13). She expresses her worries about not being able to make the video 'wearing sanitary towels' as she 'can't insert a tampon' as well as her worst fears of 'being unlovable' and of being confronted with her friends' grotesque reactions to her body as they gather round and try to help her insert the tampon (30, ll. 15-21): 'they poke and push and prod / but they can't find the hole' (30, ll. 19-20). This section uses obscenity as an affective aesthetic strategy. It combines elements of nightmare, violence and mockery, thereby confronting readers with their own voyeuristic and grotesque reactions to female disabled bodies.

The speaker's expression of love towards her non-normative body at the beginning of the final section ('*making choices*/DIGNITY') rejects shame-inducing ableist and sexist body norms and comprises the creation of counter-normative concepts of beauty. She repudiates her lover's conditional love, his wish that she were 'more whole, complete, and beautiful', affirming instead that 'i am all these things […] / whole, complete and beautiful' (31, ll. 1-3). In the final stanza of the poem, Duffy appropriates lines from a love poem ('After a While', attributed to Veronica A. Shoffstall),[127] re-contextualizing its feminist expression of strength and love through her self-affirmation and self-love as a disabled woman (31, ll. 16-24).

Conclusion

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[127] Ruth E. Davis: '"The Strongest Women": Exploration of the Inner Resources of Abused Women', *Qualitative Health Research* 12.9 (2002): 1248-1263, 1248. On the text of the poem see Stacy Brookman: 'Real Life Resilience', Nov 11 2017. Web. 2 June 2021. <https://medium.com/@StacyBrookman/after-a-while-1675a5189c57>.

My selected texts from Keith's collection represent events of shame and humiliation in ways that enable readers to reflect upon and bear co-witness to them as well as to challenge shame-inducing practices and norms. In some cases, the texts transfer shame to their readers,[128] confronting them with their own ableist prejudice, indifference towards abuse as well as their own voyeurism. Whereas some texts primarily explore the complex affective impact of shame by using narrators that embody its ambivalence and pervasiveness,[129] others perform shame's volatility through sudden affective transformations in which narrators (desire to) loosen, punctuate or change their affective attachments to the objects that turn their faces away.[130] Compared to Campling's *Images of Ourselves*, the autobiographical texts in Keith's anthology are characterized by a stronger focus on narrators' and poetic speakers' individual non-normative bodies and forms of perception, on their physical and emotional pain, impairments, physical weakness and vulnerability that are at times described in detail and connected with feelings of shame (see esp. the texts by O'Sullivan, Fulton and Kordi). Furthermore, some texts in Keith's collection turn individual non-normative bodies and forms of perception into objects of non-normative pleasure and reject shame-inducing ableist norms (especially the texts by O'Reilly and Duffy).

Michele Wates and Rowan Jade (ed.): *Bigger Than the Sky. Disabled Women on Parenting* (London: The Women's Press Ltd. 1999).

Wates' and Jade's anthology comprises shorter autobiographical texts (mostly prose texts and some poems) that connect the topics of disability, femininity, feminism, reproductive rights and concepts of motherhood. The prose texts are referred to as 'essays' in Laura Hershey's review[131] as well as in Wates's and Jade's introduction to the anthology (1). This genre classification highlights their experimental, speculative nature and their combination of autobiographical accounts with social, political and historical reflections. A review quotation on the blurb advertises the anthology as unique, that is, as the first collection of autobiographical texts by disabled women about the topic of parenting (back cover). *Bigger Than the Sky* stands in the tradition of feminist autobiographical collections established by Campling and Keith.

Rowan Jade was born with a severe form of spinal muscular atrophy and died, aged 40, from a chest infection in 2010.[132] Jade held a first-class honours degree in English Literature and Law, worked as a disability equality trainer, was a disability rights leader and determined adviser to the government on disability matters. She came out as a lesbian aged 24.[133] Michele Wates holds a first-class honours degree in English Literature and Education. She has MS (multiple sclerosis) and experienced parenting

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[128] See the texts by Bailey, Duffy and Polio.

[129] See the texts by O'Sullivan, Fulton and Kordi.

[130] See the texts by Polio, Begum, O'Reilly, Keith, Oxford and Duffy.

[131] Laura Hershey: 'Review of *Bigger Than the Sky: Disabled Women on Parenting*, edited by Michele Wates and Rowen Jade (London: The Women's Press Ltd., 1999)'. Crip Commentary. Laura Hershey's Whenever Web Column. Web. 2 June 2021. <http://www.cripcommentary.com/review-biggerthanthesky.html>.

[132] Jane Campbell: 'Rowan Jade obituary'. *The Guardian*. 3 oct 2010. Web. 2 June 2021. <https://www.theguardian.com/society/2010/oct/03/rowen-jade-obituary>.

[133] Michele Wates and Rowan Jade: *Bigger Than the Sky*. Endpaper. All references to this book are to Michele Wates and Rowan Jade (ed.): *Bigger Than the Sky. Disabled Women on Parenting* (London: The Women's Press Ltd. 1999).

in the context of her slowly progressive condition. Wates is an active part of the disabled parenting movement in the UK. She is chronicler and researcher of the Disabled Parents Network and author of *Disabled Parents: Dispelling the Myths* (Cambridge, UK: National Childbirth Trust, 1997) and of *Supporting Disabled Adults in their Parenting Role* (London, UK: Joseph Rondtree Foundation, 2002).[134] Short autobiographical texts by Wates and Jade are included in the anthology. As the editors state in their introduction to the collection, most authors are feminists and disability activists from the UK and the US (e. g. Liz Row, Vicky D'aoust), South and North America (Mexico, Canada), South Asia (New Zealand) and Africa (Zambia). The anthology is dedicated to 'disabled women of all time and everywhere', an inscription that draws attention to the transnational, transcultural and transhistorical dimension of the publication. It is closely connected to other feminist publications on disability, especially those of The Women's Press: in their introduction, Wates and Jade mention *Encounters With Strangers*, a volume edited by Jenny Morris.[135] The editors emphasize the globalized scope of their collection and argue that its goal is to represent the ethnic and racial diversity of disabled women and their heterogeneous sexual orientations (8). Furthermore, they state that some contributors are professional authors, thereby highlighting the high quality of the contributions.

The book cover (designed by Namara) with its combination of light blue and pink colours – alluding to the binary gender colour-coding for 'boy' or 'girl' – targets readers who are a 'birth mother, an adoptive parent, a friend or a woman who has made a positive choice not to become a parent' as well as those who think about becoming parents. Despite its somewhat limiting colour-code opposition, the cover illustration also seeks to suggest the idea of boundlessness or of a transgression of boundaries. It comprises a blue sky, white clouds, pink bubbles and the title *'bigger than the sky. Disabled Women on Parenting*'. Hence, the cover draws attention to the fact that the collection seeks to encourage disabled women and mothers to explore and live their unlimited dreams and desires. The quotations from reviews appearing on the back cover emphasize that the book challenges 'rigid, limiting views of what it means to be a disabled woman' and parent, that it defends the right of disabled women to become pregnant and that it affirms the 'benefits of having a "different" mother'. In line with the quotations on the back cover, Michele Wates's and Rowan Jade's introduction explains that the collection strives to expose myths and seeks to challenge stereotypes about disability. It emphasizes the taboo-breaking, de-stigmatizing purpose of the anthology as well as its goal to encourage disabled women to believe in themselves as parents. Importantly, Wates and Jade argue that disabled women who do not parent (by choice or force of circumstances) are equally relevant for the collection (1). 'I Won't Go to Weddings' by Shallo Chand,[136] who migrated to the UK from India in 1965, depicts how her disability, while not disqualifying her for an arranged marriage in her South-Asian community, eventually proved a 'shield for her independence' (168). Although her father was angry with her for five years because she did not consent to an arranged marriage, she is allowed to live her independent life in the UK with a job and a partner

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[134] 'Mothers with Disabilities, Disabled Women on the Web'. Web. 2 June 2021. <http://www.disabilityhistory.org/dwa/library_l.html> and The Disability Archive. University of Leeds. Centre for Disability Studies. Web. 2 June 2021. <https://disability-studies.leeds.ac.uk/library/author/wates.michele/>.

[135] Michele Wates and Rowan Jade: 'Introduction', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 1-8, 3.

[136] Shallo Chand: 'I Won't Go to Weddings', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 166-169.

of her own choice. She states that in her family, a non-disabled woman would never have been allowed to remain unmarried or without children. In Chand’s text, disability becomes a ‘blessing in disguise’ from the narrating ‘I’’s perspective. Hence, her story disproves the idea that disability is inevitably linked with bad karma (168).

Wates’s and Jade’s collection deals with a topic that was and still is discussed controversially in ableist society as well as among feminists. The fact that the disabled pregnant body is still a taboo subject is demonstrated by critical responses to the unveiling of Marc Quinn’s 11.5 feet tall marble sculpture *Alison Lapper Pregnant* on the fourth plinth of Trafalgar Square in 2005, representing an idealized version of the body of artist and disability activist Alison Lapper – who was born without arms and with foreshortened legs – 7 months pregnant.[137] The sculpture was both celebrated as a heroic representation of cultural diversity and described as ‘tasteless’. According to Ann Millett-Gallant, it represents an ‘unashamed display of the pregnant disabled body and its Neoclassical form’ and is a form of public art that recycles the history of representation of disability as ‘both heroic and freakish’ (2010a, 477, 473, 474, 480). In her analysis, Millett-Gallant problematizes the heroism expressed by Quinn’s sculpture, showing that critics linked this heroism to the topic of pregnancy. She references Kim Q. Hall who argues that the sculpture suggests that Lapper ‘overcomes’ her disability through pregnancy, that is, by conforming to the patriarchal notion of women’s reproductive role in society (Millett-Gallant 2010a, 476). However, Millett-Gallant emphasizes that Lapper’s maternal situation as a single mother with a working-class background defies ideals of the nuclear family, arguing that many may view her choices ‘as amoral and her subsistence as a public burden’ (476). Lapper herself called the sculpture a ‘modern tribute to femininity, disability and motherhood’, thereby acknowledging how her body ‘becomes a monument to bodies and identities that have been socially devalued, shamed, and excluded from public life historically’ (474). Millett-Gallant explains that Quinn’s work was criticized for its purported ‘capitalizing on the shock value and taboo nature of disabled bodies in public spaces’ (475). She continues:

> for many, the work assertively provokes the fear that the disabled body will reproduce another ‘damaged’ child – from a ‘broken’ body and a ‘broken’ home. The work advocates controversial reproductive rights for disabled women and for single women more broadly. […] any attempt on Lapper’s part to fulfil her role to reproduce the next generation may produce a disabled one, which remains a horror rather than a triumph, according to mainstream values and exclusive social standards for quality of life. Lapper’s maternal ‘acts’ poignantly fail to service social ideals, as the sculpture becomes pregnant with ambivalent meanings. (476)

In their 1997 article, Virginia Kallianes and Phyllis Rubenfeld reflect on the complex discussions about women’s reproductive rights that were initiated by feminist activists, pointing to the existing double standard of a normative patriarchal ideal of motherhood in the case of non-disabled women and the quasi-eugenic[138] denial of sexuality / sexual autonomy as well as of reproductive rights in the case of disabled women:

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[137] Ann Millett-Gallant: ‘Sculpting Body Ideals: Alison Lapper Pregnant and the Public Display of Disability’, *The Disability Studies Reader*. Ed. Lennard J. Davis (New York: Taylor & Francis, 2010) 473-485, 473. This publication will be referred to as Millett-Gallant 2010a below.

[138] Marsha Saxton explains the connections between eugenics and the birth control measures to which disabled women were and often still are subjected: Marsha Saxton: ‘Disability Rights and Selective

> In most contemporary societies women are still expected to marry and have children – they are sometimes seen as rebellious or 'deviant' if they choose not to and sometimes viewed with sympathy if they are unable to bear children. […] However, a double standard exists for disabled women, who have been seen as asexual or 'defective' and undesirable as sexual partners or mothers. […] disabled women have been denied sex education and contraception, discouraged from child bearing, forced to undergo abortions or sterilization, and lost custody of their children […]. Disabled women […] view reproductive rights as more than the right to choose *not* to have a child; the concept also encompasses the right to be recognized as sexual, to bear children – even a disabled child – to be seen as 'fit' to mother and to refuse the use of genetic technologies […]. Reproductive freedom for disabled women parallels abortion rights: if all women have the right to choose not to bear a child, then all women must also have the right to choose to bear children.[139]

Marsha Saxton draws attention to the tensions between the different, at times diametrically opposed, perspectives on the execution of reproductive rights among non-disabled and disabled women, stating in a pointed manner that 'the reproductive rights movement [of non-disabled women] emphasizes the right to have an abortion; the disability rights movement, the right *not to have* an abortion' (Saxton 2010, 121, emphasis in the original). More recently, Renu Addlakha, Janet Price and Shirin Heidari have argued that although disabled people have equal rights to sexual and reproductive desires, society still largely disregards them, especially in the case of disabled women:

> While it goes without saying that people with disability have equal rights to sexual and reproductive desires and hopes as non-disabled people, society has disregarded their sexuality and reproductive concerns, aspirations and human rights. People with disabilities are infantilised and held to be asexual (or in some cases, hypersexual), incapable of reproduction and unfit sexual/marriage partners or parents. The sexual and reproductive health and rights (SRHR) of people with disabilities continue to be contested, and there are particular concerns in relation to women with disabilities. For women, disability often means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood.[140]

The analysis of the United Nation Convention on the Rights of Persons with Disabilities has shown that at the beginning of the 21st century, sexual rights were 'downgraded to focus on family life, resulting in no mentions of sexuality, sexual agency or non-hetero-patriarchal identities.' At the same time, however, disability activism has resulted in 'positive changes at regional level' (Addlakha, Price, Heidari 2017, 4).

Disabled women's struggle for access to full reproductive rights remains a highly relevant but underrepresented subject, a fact that underlines the topicality of Wates's

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Abortion', *The Disability Studies Reader*. Ed. Lennard J. Davis. New York: Taylor & Francis, 2010, 120-132, 121-122.

[139] Virginia Kallianes and Phyllis Rubenfeld: 'Disabled Women and Reproductive Rights', *Disability & Society*, 12.2 (1997): 203-221, 204-205.

[140] Renu Addlakha, Janet Price and Shirin Heidari: 'Disability and sexuality: claiming sexual and reproductive rights', *Reproductive Health Matters* 25.50 (2017): 4-9, 4.

and Jade's collection. In this context, Wates and Jade have emphasized the importance of reaching and 'inspiring' readers who can help to implement social change, that is, health care and social service professionals (to change oppressive practices), non-disabled individuals (as allies) and, most importantly, disabled women (whose ideas of parenting should be limitless: 8-9). The representations of disabled bodies and of disability-, gender- and parenting-related forms of shame and humiliation do not use affective strategies of sensationalism, obscenity or voyeurism. Most authors depict sensitive situations that are normally kept secret. They comprise instances in which the narrated and narrating 'I's were the objects of disability-, gender- and parenting-related humiliation, in which their wish to have / not have children was devalued, condemned and invalidated. Furthermore, the texts depict situations in which narrated and narrating 'I's were accused or accused themselves of being 'bad' mothers, in which they went through debilitating experiences of illness and pain during pregnancy and after childbirth, in which they experienced physical, emotional and social vulnerability, dependence and self-hatred and in which they were confronted with the threat of being deprived of their children. The texts contain reflected representations of narrators' experiences of shame and humiliation that have the potential to turn readers into affective co-witnesses.

Wates and Jade emphasize that breaking the silence surrounding the topics of disability and parenting by describing one's own experiences as a disabled parent (as well as one's reasons for not wanting to be a parent) is a powerful act, a beacon in a storm offering safety and orientation to all who see it (2). The anthology seeks to explore where disabled women are, came from and are going. For this reason, the contributions are described as stories of journeys that acknowledge the reality of living with a disability (2). Wates and Jade quote Audre Lorde who argued that sick and disabled women must not 'wait in silence for the final luxury of fearlessness' because 'the weight of silence will choke us' (3). The editors criticize the fact that a great part of the experiences of disabled women, parents and health professionals are kept silent, arguing that disabled parents don't speak about their difficulties 'for fear that someone will take their children away' (3).

Many contributions discuss the pressure of disabled parents to produce a perfect child, to prove to the able-bodied world that they are good parents (5). As Ellen Basani's text demonstrates, disabled women are not immune to fears of physical imperfection. Wates and Jades emphasize in their introduction that this is due to the stigma that disabled persons face in ableist societies. Hence, it is understandable that disabled parents fear that their children will experience the same problems as they did. The narrator in Corbett Joan O'Toole's text, however, proudly celebrates the experience of parenting a disabled child, passing her pride on through generations (5). Wates and Jade emphasize the topicality of their publication, arguing that disabled women's future is under threat. They point to ethics committees' discussions of disabled genetic inheritance and to the prevalence of pre-natal screening and abortions carried out on the grounds of the child's impairment (6). Furthermore, they state that cures and medical interventions enact pressure on disabled people to adopt them in order to conform to a non-disabled notion of normality. In this climate, Wates and Jade argue, it is particularly important to celebrate disability, to emphasize that fulfilled lives are possible provided that the needs of disabled persons are accommodated and their contributions to society are valued (6).

The editors emphasize that the individualizing, pathologizing perspective of the medical model of disability is very harmful and misleading because it masks both the commonality of experiences of disabled women and their uniqueness. The anthology explicitly rejects this model and follows the social model of disability instead which defines disability as social construction, takes a holistic approach and views disabled persons in wider contexts, liberating them from beliefs that they are the problem and responsible for the difficulties resulting from their needs (7). Many texts in the anthology demonstrate that disabled mothers' difficulties stem from inappropriate childcare equipment and the inadequate provision of support services. Some contributions describe narrators' experiences of humiliation related to female disabled embodiment and styles of parenting (especially the texts by Jade, Litwinowicz, Mason, Basani, Daly) and use shame and humiliation as significant narrative elements. They perform shifts from shame and humiliation to anger (e. g. the text by Jill Daly) or disability pride (the texts by Ellen Basani and Rowen Jade). Sue Norris's poem 'Me, I am a Mother' uses shame as a reduced form of communication and poetic strategy. Some autobiographical narrators acknowledge their failure to act like able-bodied persons, often disclosing the lack / scarcity of financial resources and social support that disabled mothers struggle with (see the texts by Sue Norris and Jill Daly). Jo Litwinowicz's, Basani's and Micheline Mason's contributions describe how narrators raise their children on the basis of different values and teach the acceptance of embodied difference, thereby seeking to transform their society. What is special about the representation of gender- and disability-related shame in *Bigger Than the Sky* is that disabled mothers who think they 'fail' as parents or have non-normative attitudes towards motherhood and children often hide these thoughts because they fear to lose custody of their children.

Wates and Jade emphasize that their selection of authors and texts is based on their networks formed during the 'first international conference on the subject of Parenting and Disability, held in California in 1997' and the use of the internet (6). My selection of texts for close reading relies on project-related analytical criteria: the authors come from the UK, the texts discuss disability-related experiences of shame and humiliation and are characterized by shame- / humiliation-related narrative strategies.

Rowen Jade's autobiographical text 'Insemination' connects two episodes that discuss the topics of lesbian parenthood and disability. The first depicts the narrating 'I' with her girlfriend in the fertility clinic, the second reflects on a past playground encounter between the narrated 'I' and a girl named Drucilla. At the beginning of the text, the narrating 'I' states that she pays with her Disability Allowance for the insemination that her girlfriend receives, thereby critically alluding to the UK government's restrictive, normative approach to disabled persons' sexuality and parenthood: 'we smile in the knowledge that my Disability Allowance was not intended for this way of living' (15).[141] As readers learn, the phrase 'this way of living' refers both to a disabled woman's decision to have a child through insemination *and* to having a child in a lesbian partnership. The Disability Living Allowance (DLA) was a state allowance available to a limited number of disabled people. From 1992 to 2013, it could be claimed by UK residents below the age of 65. From 2013 onwards, it has become available only for residents under age 16 and for all others it has been replaced by Personal

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[141] Rowen Jade: 'Insemination', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 15-17.

Independence Payment (PIP).[142] PIP was implemented in order to install regular assessments of disabled people's eligibility to receive this welfare benefit. It was introduced by the Welfare Reform Act 2012 and the Social Security Regulations in 2013.[143] As Margrit Shildrick has argued in 2009, the Disability Living Allowance signalled 'a mode of existence that is structured by personal choice and the self-administration of welfare benefits'. It 'has delivered many improvements in the way in which disabled people are able to manage their own lives, not least in the area of sexuality' (Shildrick 2009, 68). However, the self-management of funds, e. g. the spending of money for sexual services or pornography, is mostly strictly policed in the UK (Shildrick 2009, 69). Writing in 2017, Michael Richards, Lecturer in Applied Health and Social Care at Edge Hill University, stated that

> it is not illegal for a disabled person to spend their benefits on sex in the UK. Benefits such as Personal Independence Payments (PIP) and the Disability living allowance (DLA) exist to cover the extra costs of disability such as 'personal care and transport'. How it is spent is up to the recipient.[144]

However, Richards draws attention to the fact that the introduction of PIP led to severe cuts or losses of benefits and retained the taboos surrounding the subjects of disabled people's sexuality and reproductive health:

> It is well documented that people with disabilities in the UK are losing their benefits to government funding cuts and changes in assessment criteria for benefits such as PIP – payments that are crucial for offering disabled people a life that is more than merely survival. Alongside the marginalisation and discrimination that people living with a disability face every day, any discussion of sex is still a taboo subject. […] Despite the intimate rights of people with disabilities being a central part of the UN Convention of the Rights of Persons with Disabilities to 'provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons, including in the area of sexual and reproductive health', for the most part this doesn't happen. (Richards 2017)

In Jade's text, the narrating 'I' explains that she decided she will not become pregnant herself because pregnancy would endanger her health. Instead, she supports her girlfriend who receives the insemination. In this context, the narrating 'I' emphasizes the importance of having the choice to become a parent, including the possibility of

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[142] 'Appendix 6: introducing Personal Independence Payment'. 2010 to 2015 government policy: welfare reform (policy paper) (Report). Department for Work and Pensions. 8 May 2015. Retrieved 15 January 2016. Web. 2 June 2021. <https://www.gov.uk/government/publications/2010-to-2015-government-policy-welfare-reform/2010-to-2015-government-policy-welfare-reform#appendix-6-introducing-personal-independence-payment>.

[143] 'Personal Independence Payment (PIP)'. Factsheet F60. Disability Rights UK. Retrieved 4 April 2013 and 'Personal Independence Payment'. Department for Work and Pensions. Retrieved 8 April 2013. The disability rights organisation *Scope* criticized the introduction of PIP, arguing that the assessment criteria on whose basis disabled persons can claim it are flawed, cause hardships to disabled people and were only installed to 'save money', see 'Disability Living Allowance replaced by PIP scheme'. BBC News. 8 April 2013. Retrieved 8 April 2013. Web. 2 June 2021. <https://www.bbc.com/news/uk-22058059>.

[144] Michael Richards: '"Sex prescriptions" may not be the answer but we must respect disabled people's right to a sexual life', *The Conversation*. January 18, 2017, n. p. Web. 2 June 2021. <https://theconversation.com/sex-prescriptions-may-not-be-the-answer-but-we-must-respect-disabled-peoples-right-to-a-sexual-life-71244>.

insemination: ‘This is my choice and it feels right, to be in this clinic with the woman I love, creating a child who will carry my name and know me as “Mum”’ (15). The text is very explicit about the process of insemination, especially about sperms on their way to the egg:

> Together, we picture a choir of all kinds of people pushing their way to the front of the crowd. Which one will win? Which is the sperm that will enter the egg and what is it like and who will it be? I picture the tortoise being trampled by hares and hope it survives to the end of the race. (15-16)

The narrating ‘I’ here affirms the possibility of alternative processes of selection, hoping – with a possible allusion to Charles Darwin’s work on tortoises and their transatlantic migration[145] – that the sperm that is different, e. g. slower than the rest, will survive and win the race (15-16). When the narrating ‘I’ discusses possible baby names with her girlfriend, she is reminded of Drucilla, a girl with a very remarkable name whom she knew when she was a child and who bullied her by saying that she will never be a mother. The narrated ‘I’’s response is proud, angry and defiant:

> I proudly declared that I would be having a baby and that the bank was going to pay me lots of money for being a mother. She stood up, tried to perform a plié and then explained that I was stupid because no boys would love me enough to give me their babies. Had I not been a wheelchair user with a very powerful adult sized chair at this point, I might have pulled Drucilla’s hair or pushed her into the sticky ditch at the bottom of the playground where the sticky dragons lived. Instead, my instinct was to head towards her, into her, and continue moving forwards until we reached the wall. I was in fourth gear and Drucilla didn’t know how to turn my chair off. She was screaming but my voice was growing louder than hers: ‘I will be a Mummy, they will love me, they will and I’ll show you!’ (16)

The narrated ‘I’ inverts power positions, pushing the taunting girl against the wall and putting her in a powerless position. She shows that this inversion of power positions is possible not despite, but precisely because and with the help of, her wheelchair. Her forceful reaction is all the more surprising for readers who picture the narrated ‘I’ as physically fragile due to her medical condition. In her obituary for Jade, Jane Campbell describes Jade’s physical fragility that is related to her spinal muscular atrophy: ‘Indeed, anyone meeting her for the first time, as she lay like a delicate feather in her chaise-longue style wheelchair could be forgiven for thinking: “How does she survive?”’ (Campbell 2010). At the same time, Campbell emphasizes her power, strength, activism and achievements: ‘Of course, this apparent frailty was part of her power and gave her a unique ability to challenge stereotypes of disability. She could hardly eat, breath or move and never weighed more than three stone. Yet she had the physical and mental strength to achieve so much.’

In addition to its depiction of strength and forcefulness, the described playground discussion in Jade’s text also has a playful, humorous, self-consciously exaggerated dimension. Jade associates the playground-battle with the process of going through

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[145] See e. g. C. R. Darwin: *Journal of researches into the natural history and geology of the countries visited during the voyage of H.M.S. Beagle round the world, under the Command of Capt. Fitz Roy* (London: John Murray, 1845) 393–394.

the process of insemination and facing the derision and opposition of the able-bodied world. The text shows, however, that the two episodes, although thematically connected, differ strongly with regard to their depiction of the struggle against disablism and its outcome: whereas the playground conflict leads to a quick and forceful but also playful victory ('I'll show you'), the process of going through the procedure of insemination is depicted as an ongoing, repeated struggle against systemic disablism, pitiful stares and the perceived 'threat' that the disabled female body poses to ableist society:

> And now we are showing them, my girlfriend and I. Every time we come to the clinic, as we sit on the steps waiting for the ramps to be found, we show them. We pass the Harley Street waiting room where my presence is questioned by looks of pity mingled with fear, and I feel the panic rising in gold embossed women as they realise that their money might not be enough to buy their way out of conceiving someone like me. (16)

As this passage shows, paternalizing stares, humiliating pity, fear, horror, disdain and disgust persist, they are still part of the narrating 'I''s daily reality. Yet they are challenged with every choice that she makes about her life: 'And I show them all, as we are ushered into the lift ahead of the queue. My choice has been made by no one but me and whether our child is conceived this month, next, or perhaps not at all, I show them that my chances and choices are real' (16-17).

Jo Litwinowicz's autobiographical text 'In My Mind's Eye' is described as 'epic' in Wates's and Jade's introduction (4). It has four parts that are distributed in sections throughout the book, an editing strategy that enables their interaction with the texts by other authors. Litwinowicz, born with cerebral palsy, attended 'a school run by the Spastics Society', she studied shorthand, typing and English and worked in a sheltered workshop (Wates and Jade 195). '"In My Mind's Eye": I Pre-pregnancy and becoming pregnant' describes how the narrator's parents called the day 'tragic' when she informed them about her pregnancy. What is more, they humiliate her by calling her 'an irresponsible, stupid girl' (31).[146] The narrator describes the effect of this devaluation as follows: 'They might as well have kicked me in my stomach; I was so upset that I slammed the phone down. If my parents' reaction was bad, what chance did we have with complete strangers?' (31). Her doctor urges her to seriously think about the possibility of abortion but she tells him she is determined to have the child. In response, the doctor changes his mind and supports her and her husband (32-33). From then on, the doctor becomes a 'tower of strength' and 'a dear friend' (33).

'"In My Mind's Eye": II Pregnancy and birth' focuses on the narrated 'I''s stay in hospital until her child is born. Hospitalization was deemed necessary by a consultant because of her problems with blood pressure, weight loss and dizziness. When her son is born, she very much depends on the help of nurses, especially with regard to feeding her son and changing nappies. The situation is difficult, the hospital staff works under enormous time pressure and she has to wait a long time before nurses arrive to help her. In one incident, she decides not to wait any longer and tries to take her son out of

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[146] Jo Litwinowicz: '"In My Mind's Eye": I Pre-pregnancy and becoming pregnant', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 29-33.

his crib. She loses her balance but causes her son no harm. However, she is told off by the hospital staff as if she were a child, a simpleton:

> Suddenly the crib moved away and I was left outstretched over the bed still holding Peter in the crib. I was like that for ten minutes before a nurse appeared and then I was told off as if I were a child. I found quite a number of nurses on the ward treated me as if I was simple, which aggravated me, but I had to bite my tongue for my baby's sake as I needed their help and support (80).[147]

As this passage shows, the narrated 'I' felt the injustice of this humiliation but also her own powerlessness. She remains silent because she depends on the nurses' support and is at their mercy.

In '"In My Mind's Eye": III Early days of parenting', Litwinowicz describes her happiness during her first weeks at home with her son, receiving help from a midwife. She has a small independence living allowance and no washing machine. Her husband does a big share of the work with the baby, and her parents tell her to let her son live with them. She is constantly afraid that they will take Peter from her. Due to the discouraging comments that she receives from her parents, she still doesn't feel that she loves her son as a mother loves her child. She cannot speak about her feelings because she is too scared that someone could take her son away from her. Her doctor, however, acknowledges how well she takes care of Peter and transfers shame to those who undermine her self-confidence about being a good mother: 'He said that I'd put everyone to shame by showing them that I was a good mum, better than many able-bodied mums that he knew' (112).[148] One day, she tries to calm her son and takes him out of his pram. She falls but luckily lands on the sofa with her son and both he and she are fine. However, after this incident she is insecure when others watch her taking care of her son (113). She would love to have another child but realizes she would have to rely on many more people and her living allowance might not be enough. As a result, she decides to get sterilized.

'"In My Mind's Eye": IV Raising Peter' describes how well the narrated 'I' manages to take care of her son but also shows that her parents still argue that Peter would be better off if he lived with them: 'My parents […] continued to think that Peter would be better off living with them. And at every opportunity they made me cry and feel a fool in front of my son. […] I never could do anything right in their eyes and I wasted a lot of time and energy to get their blessing' (144).[149] It is difficult to bring Peter in contact with other kids but finally a couple active in the Children's Society take Peter with them on trips. The narrating 'I' states at the end of her text that she is happy that she decided to have a child. She is proud that her son rejects negative stereotypes about disabled people, never complained about having a disabled mum and is open for the possibility of falling in love with a disabled girl (146). Like the other contributions in *Bigger Than the Sky*, Litwinowicz's texts do not gloss over the difficulties of being a disabled parent. They show, however, that disabled parents are neither incompetent nor too weak to

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[147] Jo Litwinowicz: '"In My Mind's Eye": II Pregnancy and birth', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 76-81.

[148] Jo Litwinowicz: '"In My Mind's Eye": III Early days of parenting', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 110-114.

[149] Jo Litwinowicz: '"In My Mind's Eye": IV Raising Peter', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 143-146.

be good parents and that most difficulties are caused by prejudice and a lack of social and financial support. The humiliation she encounters from the sides of nurses and her parents, esp. their undermining of her confidence in her own way of caring for her son, causes the narrator to seek confirmation from able-bodied society, especially the acknowledgement that she a good mother. This desire for confirmation and validation is momentarily satisfied by her doctor but not by her parents. As the text shows, this striving for recognition comes at the price of an assimilation to the values of an able-bodied, heteronormative society and its normative ideals of motherhood. It is important to emphasize that shame and humiliation are not the only narrative affects that cause this response in Litwinowicz's text. The threat of losing her son, the fear of being considered incapable of caring for him, is a very palpable cause of the narrated 'I''s striving to prove her ability as a good mother. The same fear of being considered an incapable mother can be observed in Jill Daly's and Ellen Basani's texts in *Bigger Than the Sky*. What is a threat or fear in these texts (the fear of being a bad mother and of losing their child) is a burdening reality in Sue Norris's autobiographical poem 'Me, I am a Mother'[150] in which the speaker describes herself as being what is considered to be a 'bad' disabled mother (for a discussion of the poem see more below). Apart from describing the narrator's 'passing' as a 'good' mother, Litwinowicz's text shows that the narrator's reaction to humiliation also comprises the formation of a different ethic of children's upbringing that is based on an accommodating social response to disability, an idea that is also formulated in Ellen Basani's 'A Damned Good Job'.[151]

Basani is introduced as a trained social worker who grew up in South Australia in the 1950s. She has lived in England since 1980 (Wates and Jade 190). In her text, the narrator is informed by her doctor about complications in her pregnancy, an information that triggers many memories of anxiety and failure from her childhood during which her confidence was repeatedly undermined. She is severely visibly impaired and went through mainstream education in a Catholic school in Australia where she was repeatedly shamed and ostracized for being different and for being bottom of the class:

> By the end of primary education I was coming last in class and, added to the shame of being different, came the constant humiliation of those tell-tale school-reports, which were distributed publicly by the Head Nun. Unable to attribute this failure to its social cause, I blamed myself. To an eight-year-old the reason was obvious – I was stupid. Social isolation in an environment where everyone else had vision became so acute, that all the break times were spent unoccupied and friendless. (68)

In response to this ostracization, she turns to the church and to God as her only source of love and confidence: 'seeing myself as stupid and unworthy of friends, I would flee to the chapel where I could at least be with someone who loved me – God!' (68). The narrator explains that her disability was an ambiguous signifier: it was read as a sign of stupidity and at the same time as a sign that she is chosen by God (68). When she experiences problems in her pregnancy, she fears that she suffers God's retribution because she chose a worldly life, not the life of a nun as her teachers had recommended. When she is told that her number of platelets is too low during her pregnancy, she feels like a 'powerless rag doll' under the 'full force of the NHS',

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[150] Sue Norris: 'Me, I am a Mother', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 74-75.

[151] Ellen Basani: 'A Damned Good Job', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 67-73, 73.

receiving constant tests, transfusions and medication (69). When her son is born, she thinks he has a deformed forehead, fearing that she cannot love him, recoiling from him like her own mother had recoiled from her blind daughter (70). Eventually, she realizes that her son is not deformed and is relieved, but she does not dare to take active care of him; she remains passive and lets the nurses do the care work. When she discovers that her son suffers from spasms, her observation is invalidated by the 'sighted' doctors who apparently 'knew best' (71) but eventually they must confirm her suspicion that her son is very ill (71-72). She has great difficulties to care for her new-born son, like 'any other new mother' (72), but in her case the situation is exacerbated by the able-bodied staring 'spectators' in the hospital (an experience shared by Litwinowicz 113):

> Every eye felt riveted to my back as I trundled the cot towards the washing facilities. Like any other new mother, the first experience of bathing a squirming little boy was terrifying. Fear diminished with practice however. 'Fancy that!' spectators would whisper, as I successfully performed the simplest task. (72)

When a staff member prevents her from accompanying her son to his brain scan, the narrated 'I' gets angry about this paternalizing treatment:

> I was no longer a child to be discounted, nor a receptacle for uncomfortable feelings about disability. […] No more would I apologise for my existence. I had exercised my right, just like any other woman, to produce a child. Neither God nor society had the right to take my mothering role from me. I vowed there in my hospital room […] that I would allow nothing, no one to disempower me again. (73)

Basani's text moves from a focus on disability- and gender-related shame to self-love and the pride of being a 'good' mother. However, this pride is not tied to an affirmation of a patriarchal, gendered norm of good 'motherhood' but (similar to the joy and pride described in Litwinowicz's contribution 146) is a sign of a disruption of ableist normalcy:

> The God of old, the yearning for acceptance, has been supplanted by deep inner love. My children are strong, compassionate individuals who don't fear difference. My mothering is a cause for celebration. Despite the limited support, I'm doing a damned good job!' (73)

'Reclamation', a text by Micheline Mason[152] (introduced as Disability Equality Trainer, consultant, writer, author of *Disability Equality in the Classroom*, campaigner for Inclusive Education and single parent 196) starts with a reference to the ubiquity of prenatal screening for 'abnormal' foetuses and provides readers with a historical perspective on disability and eugenics. It explains that in Britain, doctors received the right to decide over infantile lives deemed 'worthy' or 'unworthy' of living in 1913, when the Mental Defectives Act was passed. So-called 'defective' people, 'cretins' or 'moral defectives' were incarcerated in hospitals or at home, newly born babies were separated from their parents after they had been judged to be 'deformed' by medical doctors (89).[153] Mason, who has osteogenesis imperfecta (OI) known as brittle bone

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[152] She is author of a 2011 poetry collection titled *Sorry I Don't Have the Time. Poems about Modern Life*.

[153] Micheline Mason: 'Reclamation', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 89-93.

disease (91), explicitly links her own autobiographical account with the political and medical history of disability, thereby emphasizing that her experiences of devaluation are not coincidental but systemic. The narrator reflects on the ways in which the medical profession objectified her and created humiliating and pathologizing words to describe her body (this reflection resembles Mary Duffy's monologue as Venus de Milo, see my analysis below):

> The medical profession created words to describe my body. The words they used, without a moment's reflection, as to how these words would destroy my sense of self, were 'deformed', 'abnormal', 'misshapen', 'severely handicapped', 'fragile', 'invalid'. They used them whilst standing looking at negative images of various parts of my skeleton, tutting and sighing. No one said 'pretty', 'attractive', 'unique', 'sensitive', or 'warm', although I was also all of those things. Instead they brought droves of medical students to study my sad bits, my 'thin sclerotic linings'; to have fun guessing what was 'wrong' with me. (89-90)

She remembers being 'dismembered' by a medical photographer when she was 7 years old. When he only takes close-ups of her body parts but excludes her head and face, she states that she felt objectified, shocked and deprived of her personal rights, learning that the photos were published in a medical text book without her consent:

> Once a medical photographer came to my bedside. I had combed my hair and put on my sweetest seven-year-old smile in preparation. When he put the screens around my bed and asked me to take off my nightie, I was dismayed. When he took close-ups of my arms, my legs, my back, without once including my head, I was shocked beyond measure. He said they were going into a book for medical students. If he had asked me, I would have said no. I could not bear the thought of being visually dismembered, nameless and headless in a book for all to see. They would learn nothing about me from such pictures. (90)

As this quotation shows, the narrator emphasizes that medical photography of this kind humiliates disabled persons. It turns them into passive objects, deprives them of their rights and personality and 'teach[es] nothing' about them. She describes the long-term effects of this humiliation, explaining that this objectification undermined her confidence for a very long time, including her confidence to be a mother: 'It was a long journey from being cut up by a medical photographer, to being confident enough to consider becoming a parent. Even now I am not sure that I would have made the decision from scratch' (90). When she became accidentally pregnant, she deliberately rejected any medical advice on her pregnancy because she knew from her past experience that this advice would only comprise 'fears and prejudices', considering that there was a 50 % chance that her child would inherit her condition. She decides that her child has a right to live no matter if disabled or not and that she could protect a disabled child much better against oppression than a non-disabled mother: 'I know that a disabled child's life would be of at least the same value as my own, and they therefore had every right to live it. I also thought I could protect a disabled child better than most from the oppression they would face' (90-91).

After her decision to have the child, a 'protective mechanism' kicks in: she only surrounds herself with people who support her decision (91). When confronting doctors, being accompanied with a friend as '"bodyguard"', she doesn't ask for reassurance, only for their cooperation:

> Looking back, most of my memories are of people being excited in some quite profound way. It was as though I was defying their own demons, their own fears and self-imposed limits. Perhaps it was that ‘oppressed’ person within all of us realising that we do not have to give in. (91)

She was concerned about the risks involved in giving birth but only shares her fears with a very small group of friends about whom she knew that they would encourage her (91). When she had to be monitored closely in hospital before giving birth, she met a very encouraging consultant who expressed his wonder about the way in which the baby adapts to the mother’s non-normative body:

> ‘Nature is wonderful!’ he said to his students as he showed them how the baby had taken up a sideways position instead of the expected up-and-down-one. […] it did cause another problem of how they were going to get her out, but he seemed to treat this as an interesting challenge rather than an enormous difficulty. (92)

The narrator reflects on her privileged position as a disabled mother who lives in a rich country with a functioning public health system, stating that the possibility of surviving as a disabled mother and child is contingent upon a supportive application of medical technology:

> For the first time in my life I felt as though the medical profession were using their highly developed skills to help me achieve something I truly wanted. In fact without their skills neither of us could have survived. I cannot help but feel grateful that I live in a ‘rich’ country where such help is available. (92)

The narrator remembers the happy, excited atmosphere in the Special Care Baby Unit when her daughter was born, contrasting it with the tragic response to her own birth 32 years ago:

> I remember […] an entourage of nurses, friends and domestic staff, laughing, admiring, planning little gifts and asking if they could bring their relatives to see her. I contrasted this with the sense of tragedy and sorrow that had surrounded my own early days, and wondered what had made the difference. It certainly could not be explained simply by the fact that it was 32 years later. I know that disabled infants are still greeted with shock and misery most of the time. Was it because I was able to welcome her completely, including her impairment, that allowed everyone else to follow suit? (93)

The narrator here poses the question whether the positive response can be explained by the passing of time, that is, the change of consciousness regarding disability and reproductive rights of disabled women, the social and medical progress that provides disabled persons with the conditions for a life that is worth living or whether the positive response of medical staff is the result of her individual positive, empowered approach to becoming a disabled mother of a disabled child. This question is not explicitly answered in the text but readers are allowed to ponder it and speculate. What is obvious, however, is that the narrator neither re-produces the familiar narrative structure that documents an ‘autonomous’ individual’s ‘triumph over adversity’ because they have the right (positive) attitude (on this narrative pattern in disability autobiography see Couser 2009, 33) nor contrasts a ‘backward’ past with a ‘progressive’, enlightened present. Instead, she demands an *ongoing struggle* against pervasive ableist structures and for the implementation of socio-political and medical conditions that enable all disabled people to lead liveable lives:

> In the absence of close relationships with disabled people, which is still true for the majority of the population, the dreadful legacy of the past with its eugenic undertones thoroughly distorts our view of disability, leading us endlessly back into the circle of fear, exclusion, ignorance, fear. Lucy is now 14 years old, a very strong young woman in her own right. […] But her world is still unsafe, her place in it still conditional on the judgement of medical professionals. Many of her disabled peers are not by her side in mainstream society, but are still in segregated institutions of all kinds, put there by the non-disabled world. We both still need our circle of friends to remind us that our battle is not just for us, but for all of us; for the whole of humanity. (93)

In Mason’s text, the experience of disability-related humiliation and its devastating impact on her confidence is transformed into an affirmation of her own embodied existence and of that of her disabled daughter. However, this shift is not limited to the level of the individual body. The text links personal experience to ableist and disablist social structures and their history, showing how the narrative transformation of the narrator’s body image is linked to her struggle against the ableist prejudice that informs the advice of many members of the medical profession. Hence, the narrative transformation of shame does not stop at the point of individualized self-affirmation but comprises a solidarity with all disabled persons and with all humanity.

While Litwinowicz, Basani, Mason and Sue Firth[154] describe their environment’s response to their motherhood and parenting styles in largely conciliatory, hopeful but not uncritical terms (Mason’s text is the most explicitly political among them), Jill Daly’s ‘Gonzilla the Ape Woman Gets Angry’ is characterized by a predominance of the narrative affect of anger and by a provocative, hyperbolic, partly self-ironical and semi-comic narrative style. Jill Daly is introduced as a former teacher who became an equal opportunities officer and later a ‘full-time mum to two small boys', embarking on a career as a writer (192). The text starts in the present, describing a playful interaction between the narrator and her two-year-old son. In the following passages, she describes how she lost her arm in an accident when she was 29, being overrun by a bus driver. Early in the text, she signals a change in her attitude about her disability after her son was born: ‘Strangely I had always felt sorry for the driver, as it must have been quite a shock to run someone over. I say “had” because all those benevolent feelings changed when Keir arrived on the scene’ (57).[155] During her stay in hospital after her accident she was advised by medical staff members ‘not to have children’ (57) and her later husband was encouraged to ‘leave her’ because of her disability. She finds that such prejudices about disability were ‘commonplace’ and that ‘disabled people had been subject to them for centuries’. After losing her job as a teacher because of her disability, she joined the struggle against disablism, became a member of ‘a local disability rights group’ and ‘an equal opportunities officer in local government’ (58). In 1993, when the narrated ‘I’ tried to become pregnant, she was informed by a

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[154] Sue Firth: ‘A Job for Life’, *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women’s Press Ltd. 1999) 115-117.

[155] Jill Daly: ‘Gonzilla the Ape Woman Gets Angry’, *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women’s Press Ltd. 1999) 57-63.

nurse that she was ‘polycystic’. She recounts the humiliating, disablist and misogynist attributes with which her body was described: ‘“Polycystic women,” boomed the nurse, so that everyone in the fertility clinic could hear, “are fat, spotty and have lots of superfluous hair”’ (58). The narrated ‘I’’s response to this description is ironic and semi-comic:

> My God, not only was I disabled and infertile, I was now about to turn into Gonzilla the ape woman. […] She [the nurse, K. R.] hadn’t finished. ‘Not only do you not ovulate,’ she graciously added, ‘but you kill off your husband’s sperm. You have hostile mucous.’ Blimey, now I sound like an extra from Star Wars. (58)

In response to this humiliation, the narrated ‘I’ humorously and sarcastically adopts the role of the (female) monster with a non-normative female body, a role to which she returns at a later point at the end of the text. There, however, she adopts this role in despair, unmastered anger and aggression.

After the shock about her purported infertility, she decided to adopt a disabled child with her husband in 1994. ‘Having encountered discrimination in various forms’, she is overjoyed when ‘my impairment was seen as a positive quality. Our social workers reckoned that, having had to put up with people’s prejudices on a daily basis, we would be better placed to empathise with children who were also in that position.’ (59) Eventually, she and her husband are accepted as prospective foster parents (59). However, the narrator recounts that she became pregnant and decided to have the child. In hospital, she is stared at because of her disability: ‘I had noticed a few visiting partners or husbands staring when they caught sight of my stump’ (61). When asked if she has a social worker, she freezes, thinking about reports about women whose children had been forcibly taken into care. In order to prevent this, she pretends that she has a large supportive network of family members and friends. In hindsight, the narrating ‘I’ realizes that her response was unwise: ‘I realise now that these nurses really did want to get some help for me. And I threw their offer back in their faces’ (61). At home with her child, she gets very little support from her husband and is ‘shocked into speechlessness’ when realizing that he ‘never really considered me a disabled person until he saw me struggling every day with Keir’ (62). Hence, she struggles on her own, internalizing a destructive, ableist ideal of ‘autonomy’, discovering that ‘there was no child car seat on the British market that I could use’ (62). She swallowed her pride and contacted social services to get help at home with her son for a few hours a week (62). This was impossible but she was offered 2 sessions a week with a local childminder to be able to do her household work (63). Just when she thought she was coping with the situation, ‘disaster struck’ and she developed repetitive strain injury in her remaining arm. As a consequence, she had to find a nursery for Keir, the very thing she wanted to avoid at all costs: ‘I was discovering that it was easier to be a working disabled mother than a disabled mother who stays at home. The irony of the situation hurt me intensely’ (63). She becomes angry, turning the hate against herself as a disabled woman and lashes out against the bus driver who caused her disability:

> I became angry, I began to hate myself. For the first time, I didn’t want to be disabled. I wanted my arms back. I wanted to have my baby with me all the time. […] I hated the bus driver who knocked me down and changed my life. I wanted to seek him out and shout: ‘Look! See what you have done! I love my little boy, I want to keep him at home and look after him myself, but instead I have to send

> him to strangers.' I wanted to find out his address, turn up on his doorstep and then hit him over the head with a mallet. I had flashbacks of the courses I used to run in which I strove to correct the image that disabled people are all angry, bitter people. And now here I was, Gonzilla the ape woman, gone totally and utterly berserk. (63)

As this passage shows, Daly's text is provocative but it also has a self-ironical dimension. It reflects critically on the narrated 'I''s reproduction of the 'tragedy model' of disability (French and Swain 2008, 7) when she describes the 'disaster' of her strain injury and when she adopts the stereotypical role of the embittered, angry, 'monstrous' disabled woman that she sought to disprove and make redundant through her activist work – a paradox that remains unresolved in the text. From the perspective of feminist disability studies, Daly's text contains a number of controversial positions that remain unexplored, e. g. its reproduction of the conservative concept of the 'full-time' mother (63) and – even if formulated ironically and hyperbolically – its emphasis on self-hatred and personal retribution. Given the precise description of the narrated 'I''s daily struggles as a disabled mother, readers may wonder why she almost exclusively lashes out at herself and the bus driver who turned her into a disabled woman but not against the disablist, patriarchal, unsupportive social service system that denies disabled mothers the help they need. It is important to note that the text includes a critical perspective on the failure of social service infrastructure for disabled mothers, providing the insight that a positive attitude towards one's disability is impossible without receiving the social support one needs. It shows that it is the systemic lack of social support that turns the narrated 'I' into the disablist stereotype that she had tried to correct as a disability activist. For all these reasons, Daly's text provokes an affective reader response that is not limited to an identification[156] with the shamed narrated 'I' that lashes out at herself and the bus driver. A case in point is Mindy's Goodreads review that reveals a fascination with the collection but also a desire for identification that the text frustrates: 'Since I wear a prosthetic arm, I was particularly interested in the essay written by a woman who had her arm amputated, but I found her experience was quite different from mine.'[157] Compared to the promising, provocative, affectively intense title 'Gonzilla the Ape Woman Gets Angry', the narrated 'I''s response to the injustice she is subjected to, that is, the lack of a supportive social infrastructure for disabled mothers, is rather muted or sarcastic at the most. However, she convincingly describes her exhaustion and dissatisfaction with ableism and the sexist implications of the very limited support she receives: 'I seemed to be sinking, losing control. […] I felt as though I were fighting a war on my own' (62). I suggest that although Daly's text enables readers to identify with the narrated 'I''s dilemma, its affective impact is not limited to this dimension. Even more importantly, it enables readers to become affective co-witnesses of social injustice, thereby creating a potential for political responsibility and the desire for social change.

Sue Norris's autobiographical poem 'Me, I am a Mother' in 6 stanzas, written in free verse, is a similarly unshriven, implacable response to gender-, disability- and parenting-related humiliation. Norris is introduced by Wates and Jade as a poet and

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[156] On the significance of identification as a response to humiliation and shame see Kosofsky Sedgwick 2003, 37.

[157] Mindy: 'Review on Bigger Than the Sky: Disabled Women on Parenting'. Goodreads. 24 July 2012. Web. 10 June 2021. <https://www.goodreads.com/book/show/460355.Bigger_Than_the_Sky?from_search=true&from_srp=true&qid=3YvoGzHnor&rank=1>.

'people-watcher', a lover of philosophy and architecture (196). Michael Baron introduces her as a poet who writes about her autism.[158] In her audacious, taboo-breaking poem 'Me, I am a Mother', the speaker discloses herself as what is commonly understood as a 'bad', 'abusive' mother. The title (reappearing as the headline of the second stanza) is the speaker's answer to an imagined / implicit question about her identity (who are you?). The poem is affectively intense because of its subject – a mother speaking about her love for her son, her abuse and abandonment of him, their isolation and lack of support, her being overwhelmed – and because of its form. Norris uses short (at times monosyllabic) lines that build up a growing tension, postponing the confession that it was the speaker herself who abandoned her son until the very last stanza:

> **My child** / I hit him. / Why? / I needed help; but no one noticed; nothing happened; still, / life goes on. / I hit him. / He / did not get help; / he got left, / my child. // … **My Boy** / Ah, my boy, / the one left long ago at the station, / I pass where I left you. (74-75 ll. 21-33, 55-58, emphases in the original)[159]

The short, fragmented lines give the impression of enormous pressure, speechlessness, isolation, despair and sadness. The poem employs shame and humiliation as affective textual strategies on three levels: on the level of language, that is, its use of the disrupted, reduced form of communication that is typical of shame (Sedgwick and Frank 1995 134-138; Hogan 2011, 37-38), on the level of 'content', that is, the speaker's description of her fear of derision and of her withdrawal –'If I'd asked for help, / no one would have done anything, / only laughed in my face for trying' (74 ll. 18-20) – and on the level of poetic form. The poem is an act of audacious disclosure, not only of the speaker's abuse, despair and helplessness, but also of her social environment's failure to provide her with care and support: '**I Am a Mother** […] I tried to get the right help / to give my son the best. […] I needed help; / But no one noticed; / nothing happened […] He / did not get help; he got left, my child' (74 ll. 5, 9-20, 30-33, emphasis in the original). The poem ends with the depiction of the speaker's painfully unfulfilled desire to find out something about her son: 'Now you are grown. / Who are you? / How do you look? / I do not know. / I wish I did' (75 l. 55-63). In contrast to Daly's text, Norris's poem, although expressing sadness, sorrow, guilt and remorse, does not depict how the speaker directs anger and hate against herself or another individual. Instead, the speaker turns against her social environment that neglected her and her son's needs. The phrases 'no one noticed', 'nothing happened' and 'no one would have done anything' are part of a practice of witnessing which describes the failure of a whole society, placing readers into the position of affective co-witnesses.

Conclusion

As this analysis shows, the texts in *Bigger Than the Sky* represent narrators' experiences of disability-, gender- and parenting-related shame and humiliation as well as experiences of devaluation that especially target disabled mothers. Furthermore, they describe multiple ways in which shame and humiliation impact on disabled narrators: The texts by Litwinowicz, Mason and Basani describe shame's normativizing impact, pushing narrators to prove they are 'good' mothers acting in accordance with

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[158] Michael Baron: 'Autism – a creative process? Poetry, poets, imagination', *Popular Narrative Media* 1.1 (2008), 103–114, 103.

[159] Sue Norris: 'Me, I am a Mother', *Bigger Than the Sky. Disabled Women on Parenting*. Ed. Michele Wates and Rowan Jade (London: The Women's Press Ltd. 1999) 74-75.

patriarchal ableist norms but they also describe forms of upbringing that comprise the conveyance of a positive, accommodating attitude towards disability. Furthermore, Jade's, Mason's and Basani's contributions provide insight into the necessity of ongoing disruptions of the dominance of ableism, sexism and homophobia. Daly's and Norris's texts reject conciliatory responses to ableist shaming but it is above all Norris's poem that refuses to posit personal solutions to systemic problems. 'Me, I am a Mother' does not master shame. It is a practice of unshaming[160] that works *through* the use of shame and humiliation as textual (here poetic) affective strategies. It audaciously rejects the personalized practices of guilt-tripping that shame those who fail to conform to ableist patriarchal norms of 'good' mothering.

2. Autoethnography

Jenny Morris: *Pride Against Prejudice. Transforming Attitudes to Disability* (London: The Women's Press, 1991).

Pride Against Prejudice is clearly marked by its intersectional feminist stance (10),[161] its advocation of disability activism and its formal hybridity. It combines autobiography, sociological study, biographical interviews and theoretical analysis. Like Campling's *Images of Ourselves*, *Pride Against Prejudice* draws on sociological field work. However, unlike Campling's collection, *Pride Against Prejudice* is a monograph that processes data from oral interviews covering the personal histories and statements of 8 disabled women with heterogeneous backgrounds. Using an autoethnographic approach,[162] a method that combines autobiography and ethnography and that is adopted by historians, sociologists, journalists and literary writers,[163] Morris starts the book by relating her own 'personal history' of how she became disabled, connecting it with her interviewees' histories and with theoretical reflections on broader social debates about feminism and disability. *Pride Against Prejudice* explores how disabled women experience their environment's prejudices against them and how they define a good, liveable and fulfilled life. It relates these individual perspectives to sociological studies on disabled persons' living conditions, their housing, education, career options and the representation of disability in the media. Thus, Morris's book emphasizes the socio-political dimension of disability-, gender- and race-related prejudice and humiliation. It is important to note that like *Images of Ourselves*, *Pride Against Prejudice* describes intersectional practices of humiliation carried out by doctors, carers, nurses, physiotherapists, teachers, employers, family members, partners or strangers that were very prevalent but not prosecuted before the passing of the 1995

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[160] See Locke 2017, 36-37.

[161] Jenny Morris: *Pride Against Prejudice. Transforming Attitudes to Disability* (London: The Women's Press, 1991) 10. All references to *Pride Against Prejudice* follow this edition. On Morris's intersectional stance as a disabled feminist see Lois Keith and Gillian Dalley: '*Pride against Prejudice: Transforming Attitudes to Disability*', *Disability, Handicap & Society*, 7.4 (1992): 375-381, 376.

[162] Carolyn Ellis, Tony Adams and Arthur P. Bochner: 'Autoethnography: An Overview', *Historical Social Research / Historische Sozialforschung* 36.4 (138): *Conventions and Institutions from a Historical Perspective / Konventionen und Institutionen in historischer Perspektive* (2011): 273-290, 273. The term 'autoethnography' is used to refer to a research method and the product of these approaches. Autoethnography appears in different forms, e. g. essays, different literary genres, forms of visual / performance art and music, see Carol Rambo and Carolyn Ellis: 'Autoethnography: Abstract', *The Blackwell Encyclopedia of Sociology*. Web. 2020. Access 29 March 2021. <https://onlinelibrary.wiley.com/doi/pdf/10.1002/9781405165518.wbeosa082.pub2>.

[163] See e. g. Ayesha Vernon's chapter 'A Stranger in Many Camps: The experience of disabled black and ethnic minority women', *Encounters with Strangers. Feminism and Disability*. Ed. Jenny Morris. (London: The Women's Press, 1996) 48-68 and Keith 1996.

Disability Discrimination Act and the amendment of the Disability Discrimination Act from 2005. Like *Images of Ourselves*, *Pride Against Prejudice* promotes affective consciousness-raising about intersectional forms of injustice and inequality that target women with disabilities.

Jenny Morris, born in 1950 (Morris 1991, 4), is a very influential feminist disability activist. She became paraplegic after an accident when she was in her early 30s and is author and editor of many publications on disability- and feminism-related topics, e. g. editor of the biographical collection *Able Lives: Women's Experience of Paralysis* (The Women's Press, 1989) that is based on questionnaires filled in by women with spinal cord injury. She is an Officer of the Order of the British Empire, holds a PhD in Social Policy and was a visiting professor at the University of Suffolk, teaching housing policy and sociology. Morris was a consultant and government advisor on disability policy, working with the Prime Minister's Strategy Unit on Improving the Life Chances of Disabled People, a 25-year strategy launched in 2005. She led the development of the Labour government's 2008 Independent Living Strategy and recently joined the Joint Committee on Human Rights' Inquiry into Independent Living.[164] She retired from full-time work in 2010 and is the author of a blog at jennymorrisnet.blogspot.co.uk.

Jenny Morris is part of a feminist network of disabled authors and editors that includes e. g. Lois Keith (who reviewed *Pride Against Prejudice*), Gohar Kordi, Mary Duffy and Nasa Begum: Morris's short autobiographical text 'The Fall' appears in Lois Keith's anthology *Mustn't Grumble* as do Nasa Begum's and Gohar Kordi's short autobiographies and Duffy's poem. Morris herself quotes Keith and Begum in *Pride Against Prejudice* (22, 162-164) and references Duffy's art works (114). Furthermore, Morris, Keith and Michelle Wates and Rowan Jade are connected through their choice of the same feminist publishing house, The Women's Press. *Encounters With Strangers*, a collection of critical essays edited by Morris, contains texts by Keith, Begum, Liz Crow, Sally French and Ruth Bailey. In *Pride Against Prejudice*, Morris explicitly connects her writing with that of other British and American feminists like Liz Stanley and Sue Wise (5), Bari Watkins (5), Diana Fuss, Jean Grimshaw, Caroline Ramazanoglu, Elizabeth Spelman and Susan Griffin (5, 6, 9).

Introduced in the front matter of the book as a 'disabled feminist and freelance writer / researcher', Morris argues that *Pride Against Prejudice* addresses above all female and feminist disabled readers, seeking to raise consciousness about disability, disablism and disability rights as well as to build lively and creative feminist disability communities that implement social change (especially in the directions of de-institutionalisation and independent living). The book asserts the reality of disabled people, especially of disabled women, and articulates anger about disability- and gender-related injustice as well as 'the growing strength of our pride in ourselves' (1). The cover illustration, which depicts a group of diverse disabled women holding a banner which reads 'Celebrate the Difference' highlights the book's connection to disability activism and emphasizes its celebratory approach to disability as a positive, intersectional identity category. A quotation from page 14 appearing on the cover connects the book to pride as a social emotion: 'This book is a celebration of our strength and a part of our taking pride in ourselves, a pride which incorporates our disability and values it.' The back cover contains review excerpts that do not highlight

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[164] 'Professor Jenny Morris OBE Visiting Professor of Social Policy', University of Suffolk. Website. 4 July 2016. Accessed: 9 April 2021 <https://www.uos.ac.uk/people/dr-jenny-morris-obe>.

the book's auto/biographical dimension but emphasize its manifesto-like, analytical and ethnographic character, that is, its covering of 'current and historical debates on the quality of disabled people's lives', of 'representations of disability in Western culture, of institutionalization and independence', of 'feminist research and "community care" and the politics of the disability movement'. Furthermore, the review excerpts on the back cover describe the book as being 'part of an emerging disability culture'.

In her review of *Pride Against Prejudice*, Lois Keith praises the way in which the book explains the connection between disability oppression and disability pride:

> At the national conference on 'Researching Disability' held in London in June 1992, a member of the audience asked the panel at the plenary session, 'How can something which is a source of oppression also be a source of pride?'. My own reply to this gentleman was that it is oppression when I have to deal with a disabling world each day, but it is a source of pride when I am with other disabled women, celebrating our strengths and our difference. I could have just told him to read this book. (Keith and Dalley 1992, 375)

Keith commends the book's exploration of disabled people's (and especially disabled women's) embodied experiences of pain and illness as well as its discussion of the nature of prejudice and discrimination, emphasizing that especially the topic of disabled people's personal experiences of illness, impairment and pain was hardly discussed in social-model-oriented criticism (376-377). Keith welcomes Morris's critique of the feminist neglect of disabled people's perspectives in the context of care work and reproductive rights (376-377). She describes the book as 'controversial and thought-provoking', as 'shout[ing]' loudly (377), giving a voice to disabled women (376). Gillian Dalley, one of the non-disabled feminist scholars whose neglect of disabled women's perspectives in matters of community care policies is critiqued in *Pride Against Prejudice*, finds fault with Morris's polarizing division of the world into disabled and non-disabled people, stating that this polarization makes it 'hard for non-disabled persons to enter the debate' (Keith and Dalley 1992, 378-379). Dalley correctly observes that Morris focuses on the representation of disabled person's experiences of prejudice (pity and hatred), not on physical experiences of disability (378). She defends her own critique of individualist approaches to disability living and care as well as disapproves of what she perceives to be a separatist approach in Morris's book: 'how far is it true to say that specific social issues such as ethnicity and disability can only be validly investigated by researchers who themselves are directly involved at a personal level in those issues?' (378, 380). Here, Dalley misconstrues Morris's line of argumentation that demands the inclusion of disabled persons' viewpoints in political decisions about their lives, not an exclusive right for disabled people to discuss these matters. Dalley welcomes the inclusion of disabled persons' perspectives on matters of housing, care and reproductive rights, stating that she follows the feminist tradition of not depriving other subjugated groups of their own voices by speaking 'for' them (380). She emphasizes that a dialogue between disabled and non-disabled persons is key for social change to happen, closing by stating that 'Jenny Morris's book is a revelation for nondisabled people and, as a first step in informing the non-disabled world as a prelude to that dialogue, it has to be required reading' (381).

Although *Pride Against Prejudice* does not contain extensive narrative depictions of disability-, gender- and race-related shaming, it covers many short biographical descriptions of experiences of intersectional practices of humiliation. The goal of

Morris's book is to fight disability prejudice by challenging non-disabled people's ways of interacting with and thinking about disabled people (Morris 1991, 170). Hence, Morris seeks to strengthen her readers' solidarity with disabled people as well as to encourage disabled persons to claim their diverse needs as civil rights, not as favours or charity allowances. Morris's book critiques disability- and gender-related shame, humiliation and prejudice by its audacious strategy of pillorying the ways in which non-disabled people humiliate disabled ones (especially women). It denounces the use of ostracization, abuse, neglect, staring, paternalizing behaviour and the inaccessibility of facilities. However, the book does not use sensationalist strategies that attract readers' voyeuristic attention to non-normative female bodies and the ways in which they are shamed. Instead, *Pride Against Prejudice* turns disabled and non-disabled readers into affective co-witnesses of disability- and gender-related humiliation, enabling them to critique these forms of humiliation and solidarize with disabled women without necessarily sharing all of Morris's views on reproductive or work rights. The Goodreads review by Always Pouting is a case in point. Always Pouting identifies as non-disabled but as having 'health issues', explaining that the latter cause them to feel 'uncomfortable' whenever noticing the ways in which disabled people are treated:

> Personally I've always felt uncomfortable about the way people treat disabled people to be honest. Maybe because I've had my own health issues that made people behave in paternalistic ways that deny me autonomy. I think this book does a great job of articulating the disability rights movement positions on issues and I especially appreciate the framing of these issues from a feminist lens. I honestly do not get why treating people with respect and letting them have a say in decisions related to them as well as listening to their experience has to be some contentious things. […] this is a really good book and articulated a lot of things I am predisposed to agree with but has also left me with much to think about in terms of how we can meet people's needs and my own prejudices about disability.[165]

Always Pouting's review received 64 likes and 3 comments. Sue, a commenter who defines as 'disabled', shares Always Pouting's view. Similarly, Paul's Goodreads review, which received 52 likes and 4 comments, is an example of affective co-witnessing, describing the book's representation of disabled people's institutionalized care as 'harrowing'.[166] Carly Findlay's review describes how the book changed their view on their disabled body from regarding it as a deficit to recognizing the devastating, limiting impact of ableism.[167] Beyza and Katie praise the book as 'empowering' and 'inspirational'.[168] M. commends *Pride Against Prejudice* because of its daring

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[165] Always Pouting: 'Review on Jenny Morris's Pride Against Prejudice', 17 September 2020. Goodreads. Web. 10 June 2021. <https://www.goodreads.com/review/show/3467580661?book_show_action=true&from_review_page=1 >.

[166] Paul: 'Review on Jenny Morris's Pride Against Prejudice', 9 November 2018. Goodreads. Web. 10 June 2021. <https://www.goodreads.com/book/show/857755.Pride_Against_Prejudice#other_reviews>.

[167] Carly Findlay: 'Review on Jenny Morris: Pride Against Prejudice'. Goodreads. 15 March 2020. Web. 10 June 2021. <https://www.goodreads.com/review/show/2451548127?book_show_action=true&from_review_page=1>.

[168] Beyza: 'Review on Jenny Morris: Pride Against Prejudice'. Goodreads. 14 April 2017. Web. 10 June 2021. The review received 2 likes. <https://www.goodreads.com/review/show/1867445643?book_show_action=true&from_review_page=

recognition of feminists' neglect of disabled women's perspectives and because of its powerful critique of the stereotypical representation of disability in popular culture. However, M. disapproves of the book's muted criticism of the roles of the medical profession and of religion in the context of eugenics and euthanasia.[169]

Pride Against Prejudice challenges the prevalent ableist opinion that disabled lives are not worth living and that disabled people are tragic, passive, helpless and pitiable cases. Morris emphasizes that this negative impression is often caused by the bad living conditions of disabled people (e. g. their isolation in institutions, their lack of formal education and career options) as well as by the absence of civil rights that would enable them to lead liveable, enjoyable and fulfilling lives. She argues that the pervasive problem of disability prejudice as well as the injustice and inequality connected with it can be solved through civil rights activism and legal changes that improve disabled people's living conditions, e. g. by guaranteeing them access to formal education, high-quality care, adequate housing and professional careers. The book explains that disabled persons (esp. those identifying as women) experience shame and humiliation in their social environment not because disability and impairment are inherently shameful (Morris makes it very clear that they are not) but because the social environment does not accommodate the needs and desires of disabled people. The way to fight against shame-inducing structures and practices, Morris suggests, is to campaign for disability rights, to change the environment according to disabled people's self-defined needs and desires, to guarantee them a maximum of independence and to improve disabled people's life quality through political reforms (especially reforms following the goals of the Independent Living Movement: ILM). These social and political changes alter the ways in which disability is perceived so that disabled lives are no longer viewed as being necessarily identical with tragedy, misery, passivity, pity, dependency and discrimination.

My selection of passages from *Pride Against Prejudice* for close reading is based on project-related analytical criteria: I focus on passages that describe the role of disability- and gender-related shame in the lives of disabled women, encounters with and practices of disability- and gender-related humiliation as well as bold critiques of these practices. In her introduction, Morris argues that at the moment of writing *Pride Against Prejudice*, disabled people begin to address the negative prejudice they are confronted with and to express their anger at the discrimination they face on a daily basis (1). She highlights the prevalence and structural nature of disability-related humiliation and endorses the emotional responses of anger, outrage and pride whenever disabled people are faced with disability prejudice and practices of disability-related shaming (9, 14). Her book aims at asserting the reality of disabled people, especially of disabled women, and of articulating the growing strength of disabled women and their pride in themselves (1). She emphasizes that her own identity as a disabled woman is a 'source of strength and liberation' (1). In my close reading of Morris's autobiographical narrative in the introduction to *Pride Against Prejudice*, I will use the terms narrating 'I' and narrated 'I' and in my discussion of the sociological

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1>. Katie: 'Review on Jenny Morris: Pride Against Prejudice'. Goodreads. 3 February, 2017. Web. 10 June 2021. The review received 1 like. <https://www.goodreads.com/review/show/1889468908?book_show_action=true&from_review_page=1>.

[169] M.: 'Review on Jenny Morris: Pride Against Prejudice'. Goodreads. 24 June 2019. Web. 10 June 2021. <https://www.goodreads.com/book/show/857755.Pride_Against_Prejudice#other_reviews> . The review received 3 likes.

analysis that predominates in the rest of the book (in which Morris also includes some of her own experiences) I will use the author's name to refer to the subject of utterance.

In the section titled 'Beginnings' (a part of the book's introduction) the narrator recounts how she became disabled in June 1983. Before her accident, she led an independent life as a young, politically active working mother. She broke her back as a result of falling from a wall when she tried to rescue a small girl (1). Very soon after this accident, she suspected that she had broken her back (2). Eventually, she was diagnosed with spinal cord injury and became a low-level paraplegic. In consequence of her disability, the narrated 'I' experienced ostracization and injustice. Some nurses treated her with little sympathy, assuming she had tried to commit suicide (2). Other people in her personal environment denied the reality of her pain or assumed that her life was not worth living anymore (2). Her doctor called her fate tragic, alluding to incontinence and spasms. The narrated 'I' explains that she was offended and enraged by the way in which he wrote her life for her (2). The doctor's consultant, however, had a more pragmatic attitude, predicting that she will be mobile and independent despite being paraplegic (2). The narrator defines her disability as a caesura in her highly satisfactory life, a disruption of her self-contained contentment based on her work as a teacher and her Labour Party and feminist activism (3). She decides that her newly build life structure must remain unchanged but she did not realise that she had become 'fundamentally different' (3):

> I resolved that the structure I had built would remain unchanged. All that happened was that I would now be doing things from a sitting position. I just needed to sort things out in order to be able to do this. Little did I realise that by becoming paralysed I had become fundamentally different and set apart from the non-disabled world. (3)

Compared to Sue's story in Campling's *Images of Ourselves*, it becomes clear that in Morris's autobiographical text it is not only the social environment that defines the narrated 'I' as different but the autobiographical narrator herself. She recounts that some of her friends (feminists, Labour activists, socialists) supported her and took on disability rights concerns themselves. She states that the present (1991) is an exciting time to be disabled, pointing to the feminist movement as an indispensable source of support in the struggle for disability rights. Furthermore, she emphasizes that she is angry about the pervasive impact of disablism but also hopeful about the prospect of a successful fight against disablist structures and practices (Morris 1991, 4).

As this short analysis of Morris's autobiographical narrative demonstrates, *Pride Against Prejudice* emphasizes the centrality of the affect of anger in the struggle against disablism (9). In the chapter 'Feminism and disability politics', Morris argues that disabled people's anger is not a 'personality defect' but a sign of their dissatisfaction and a 'sane response to oppression' (9). In her exploration of the impact of disablism and disablist prejudice on society, Morris carried out qualitative taped interviews with 8 disabled women who share their personal histories and experiences (11). She introduces them by using pseudonyms, mentioning their age and their disability (all have physical or sensory disabilities) as well as their sexual orientations and ethnic backgrounds (22). Morris's approach to disability is informed by a critique of the medical model that defines a disability as a defect of an individualized, decontextualized body that must be cured and bio-medically normativized. It reduces disabled people to 'the medical condition which accounts for their physical and / or intellectual characteristics' and takes no account of 'the social and economic context in which people experience such medical conditions' (9-10). Morris endorses the social model of disability that posits that 'it is environmental barriers and social attitudes which disables us' (10). On the other hand, she affirms that the embodied experiences of disabled people must be acknowledged, thereby expressing a critique of the social model's neglect of these concerns. She argues that disabled people *are* physically or cognitively different from the norm and that they have different needs, e. g. with regard to housing, help with personal care, equipment, drugs / treatments, technological help with communication, personal relationships, children or economic independence (16-18). By emphasizing that disabled people's needs differ from those of non-disabled people, Morris wants to make sure that they receive the support they need in order to lead liveable lives: 'our physical and intellectual characteristics often mean that we have additional needs which have to be met if we are to have a reasonable quality of life', e. g. in connection with 'housing, heating, help with personal care, equipment, drugs and other medical treatment, technological or human help with communication, and so on' (18). However, her line of argumentation has been critiqued for its establishment of an essentialist difference between disabled and non-disabled / 'normal' persons (Keith and Dalley 1992, 378-379):[170]

> Our bodies generally look and behave differently from most other people's […]. It is not normal to have difficulty walking or to be unable to walk; it is not normal to be unable to see, to hear; it is not normal to be incontinent, to have fits, to experience extreme tiredness, to be in constant pain; it is not normal to have a limb or limbs missing. If we have a learning disability the way we interact with others usually reveals our difference. These are types of intellectual and physical characteristics which distinguish our experience from that of the majority of the population. They are all part of the human experience but they are not the norm; that is, most people at any point in time do not experience them, although many may experience them at some point in their lives. (17)

This catalogue of 'not normal' certainly comprises a reproduction of an internalized ableist notion of normalcy and of its underlying social stigma, yet the quotation also illustrates that Morris perceives all these non-normative forms of embodiment as being part of the human experience as a whole, thereby assuming a spectrum between 'normal' and 'non-normative' forms of embodiment rather than a relationship of polar opposition. Importantly, Thomas Couser states that

> [u]nlike racial and gender minority status, disability is a minority status that anyone may assume unexpectedly at any time. Like race and gender, however, it also affects everyone in that *all* bodies are defined by the same standards and norms: just as we are all raced and we are all gendered, we are all embodied (2009, 9, emphasis in the original).

Recent statistics underline the pervasiveness of disability and mental distress in the global population. According to the 2020 report of the World Health Organisation, '[a]lmost everyone is likely to experience some form of disability – temporary or

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[170] Margrit Shildrick has criticized the concept of a binary opposition between disabled and non-disabled bodies supported by some representatives of disability activism (Shildrick 2009, 116). For a non-binary concept of disability and a related dismodernist concept of subjectivity see Lennard J. Davis: 'The End of Identity Politics', *The Disability Studies Reader*. Ed. Lennard J. Davis (New York: Taylor & Francis, 2010) 301-315.

permanent – at some point in life.' At present, about 15% of the global population live with some form of disability. The number of people with disability is dramatically increasing due to 'demographic trends and increases in chronic health conditions.'[171]

Although Morris's autobiographical text included in the introduction of *Pride Against Prejudice* contains no explicit descriptions of experiences of gender- or disability-related shame and humiliation, the book comprises other disabled women's references to experiences and practices of shame and humiliation as well as able-bodied persons' prejudices about disability-related shame: in chapter 1, titled 'Prejudice', Morris includes a list of stereotypical assumptions about disabled people and their lives that begins with the prejudice that disabled people feel ashamed, ugly and inadequate because of their disability / impairment (19). Furthermore, the list includes the prejudice that disabled people are 'ashamed' of their 'inabilities' or 'abnormalities', that they 'loathe' their 'wheelchairs, crutches or other aids' (20). A great problem connected with disability-related shame, Morris argues, is that all these ableist negative thoughts about disability become internalized by disabled people (20). Like Campling's *Images of Ourselves*, *Pride Against Prejudice* demonstrates that disability- and gender-related shame is not inherent to individual disabled bodies but is generated in their interactions with their mostly non-disabled environment, interactions that, however, undermine a clear inside / outside distinction as well as a binary opposition between passive and active entities. Through social interactions and media representations, shame and humiliation come to 'stick' to disabled bodies in profound, structural ways and mark them off against 'normality'.

Morris observes that most disabled people do not encounter overt hostility but are often confronted with patronizing, seemingly benevolent reactions to their disabilities (20). In the subchapter 'The importance of physical difference', she argues that ableist and disablist prejudices target physical difference more than physical limitations, at times driving disabled people into committing suicide (23). Referring to experiences discussed by her interviewees, Morris argues that many disabled people feel happy and 'normal' when alone and at home but uneasy when confronted with the stares, condescension, pity and hostility of mostly non-disabled persons when leaving their homes (24-25). Molly McIntosh (a pseudonym), one of the women Morris interviewed, argues that people respond with horror, staring and ostracization to physical difference (24). McIntosh is Deaf and has 'a clear physical difference' (23). Morris quotes her with the following passage:

> I have horrible scars on my face. What I mean by that is that people react to them with horror. Forty years ago, when I was in my twenties, and also when I was a child, I so hated the way that I looked. I tried not to think about it but every time I went out in the street I would be reminded about how I looked because of the way people reacted to me. As I walked down the street and someone was coming towards me, they would look and then drop their eyes or move their

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[171] Disability and Health. Key Facts. 1 December 2020. World Health Organization. Web. 21 June 2021. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>; Disability. World Health Organization. Web. 21 June 2021. <https://www.who.int/health-topics/disability#tab=tab_1>. On the increase of the number of disabled people because of long-term effects of Covid-19 infection see Chelsea Cirruzzo: 'Long COVID Sufferers Are Seeking Disability Benefits. Will They Change the System?' U.S. News Live. 15 April 2021. Web. 21 June 2021. <https://www.usnews.com/news/health-news/articles/2021-04-15/covid-long-haulers-could-change-the-disability-system>.

> head, as if the horror was too much. But then they could never, ever resist looking again. (23-24)

Here, McIntosh describes experiences of humiliation, the mixture of horror, disgust and voyeurism that is characteristic of her environment's response to her difference. Her descriptions are precise and affectively intense, detailing how the looks of disdain and horror she received were connected to the ostracization and isolation she encountered:

> I felt very lonely as a child. […] whenever I got bullied in the playground it was always in terms of insults about my face. I felt the teachers didn't want to deal with that; they never did anything about the way other children reacted towards me and anyway they themselves found it difficult to look me in the eye. (24)

She had to deal with demeaning, horrified stares whenever she left her home, feeling that her life was 'split in two' between a comfortable part lived at home and an uncomfortable, harrowing one lived in public:

> People who I saw once a week or so, in the local shops and things, tried to pretend that they had no reaction to my face […] They were friendly enough but I never felt as an equal. I was 'that poor woman down the road […] the one with the *FACE*' (the last phrase spoken in a whisper). […] you feel the way that other people think about you. And I never felt other than different. (25)

Morris also includes examples of daring responses to ableist stares. She describes the reaction of Anna Mathison (pseudonym), one of her interviewees from a Black community, as follows:

> She has the confidence to refuse to be intimidated by other people's reactions to her as someone with a very visible disability. 'If people stare, I shout "what are you staring at? You want to feel? You need glasses?" I feel I should challenge them because otherwise they think you're stupid and that they are entitled to stare.' However, Anna Mathison remains all too aware that people look at her and think her life is not worth living. 'They just see the wheelchair and they think, you'd be better off dead. And that's a problem because it hurts. But if I shout at them it makes me strong.' (26)

Morris connects the ostracization that disabled persons face on a daily basis to systemic conceptions of disabled bodies and selves as being 'incomplete' and 'lacking', stereotypes spread e. g. in advertisements for children with 'missing limbs' (27). She thereby locates the sources of disability-related shame in a disablist social environment that uses practices of humiliation to devalue and ostracize people with disabilities (25). As Morris's analysis demonstrates, the responses of disabled women to these forms of shaming differ considerably, some attempt to forget the hatred, others (like Anna Mathison) confront the starers, shout at them and stare and shame back, making their anger explicit (26). By quoting JoAnne Rome (a pseudonym) who was born with a foreshortened left arm, Morris demonstrates that disabled people's shame about their bodies is not an intrinsic, innate feeling but is generated by the structural disablism that pervades the able-bodied world (28):

> The word 'deformed' pounded in my brain […] I used to believe I owed an explanation to whomever demanded one. I felt fearful, intimidated, ashamed,

> out of control and outraged, yet ‘what happened to your arm?’ was not a question that I could choose to answer or not. I was a freak, an outsider, an ‘other’ and the world made it very clear that I owed it an explanation. I was also a little girl who was chased home from school with taunts of ‘Captain Hook!’ ringing in my ears, the object of whispers, stares and laughter. (28)[172]

Rome, who identifies as a lesbian, testifies to the systemic nature of these practices of humiliation, revealing them to be forms of harassment:

> This harassment is a fact of life. I’ve heard ‘mind if I ask you a stupid/personal question?’ from sensitive lesbian psychotherapists, suburban housewives, boys in gas stations […] and so on, ad infinitum. I feel like an object of curiosity, not a woman with a head and a heart and feelings that should matter. (28-29)

Morris argues that non-disabled people believe that they have a right to impose their feelings on disabled people because they do not consider them to be autonomous human beings (29). Non-disabled people in particular are fascinated with the ways in which disabled people ‘manage’ their lives, a curiosity that implies a considerable amount of voyeurism, objectification and devaluation (29). Morris references the American publication *No More Stares* from the 1980s, which educates readers about the ways in which gazing at disabled people (defined as seeing ‘the *most*’ of disabled people) is clearly different from staring, described as ‘a vampire bite’ that ‘sucks life out of you’ (30). In her 2009 book *Staring. How We Look*, Rosemarie Garland-Thomson also distinguishes between staring and the act of beholding but she argues that staring can underlie and be transformed into ethical practices of beholding that regard the complexity of the viewed subject (185-196).

Although it is usually not considered a form of humiliation, the condescending way in which mostly non-disabled people respond to disabled persons is often demeaning, oppressive and painful, especially in cases where non-disabled men are eager to help disabled women without being asked to do so. This patronizing behaviour (observable often, but not only, on the side of non-disabled men) puts at risk the independence that women have obtained in the course of the process of emancipation (31). Morris quotes Mary Lawson who relates how a care assistant demanded that she must say ‘please’ before they took off her shoes. Lawson describes that she felt humiliated and patronized (32).

Pride Against Prejudice includes many examples in which non-disabled people respond to disabled persons with patronizing pity mixed with distaste / disgust or outright hostility. However, it shows that disabled people and disabled women in particular experience humiliation (the interpellation ‘shame on you!’) not only because of their non-normative bodies but also whenever they step out of the role of ‘poor little cripple’ (33), a stereotypical image that fixes disabled persons in a position of passivity, endless gratitude and humility. Morris draws on her own personal history, describing how she confronted a man staring at her when she got into her car from her wheelchair. When she stares back at him, asking ‘what are you staring at’ and argues that his staring is not helpful, he explodes and humiliates her by using expletives (33).

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[172] Rome’s text is drawn from her contribution to the lesbian American journal *Sinister Wisdom* 39 (1989): 37.

Morris's book covers many topical aspects of disabled people's lives and their daily confrontation with their ableist and disablist environments. In the section titled 'Wanting to be Normal?', she discusses the topic of passing as non-disabled as a strategy adopted by disabled persons through which they seek to avoid their environment's disablism. The history of euthanasia is explored in chapter two, titled 'Lives not Worth Living' and disabled women's reproductive rights is the topic of chapter 3 ('The Chance of Life'). Morris analyses the scarce and very stereotypical representation of disability in literature and the media, critiquing the lack of disability as a significant topic in Western Culture in chapter 4 ('Disability in Western Culture', see 84). She examines the representation of disabled characters in literature, film and advertisements, arguing that for the participants in a 1986 American university research project, the most common ideas and words associated with the phrase 'disabled woman' are 'passivity, weakness or dependency […] "almost lifeless", "pity", "lonely", "crippled", "wheelchair", "grey", "old" and "sorry"', in short, 'passivity, dependency and deprivation' (97). These attributes, Morris argues, still predominate, especially in mainstream media representations of disabled women, with the exception of a few US commercials of the 1980s (112-113). Chapter 5 (titled 'Segregation, Dependence and Independence') deals with the institutionalization of disabled people. It brands their loss of liberty and autonomy, their stigmatization, depersonalisation, low material standard and physical abuse as 'a crime against humanity' (121). Morris recounts the experiences of Ruth Moore (pseudonym), one of her interviewees who has arthritis. Moore lived in an institution in England in the 1940s and 1950s and recounts the physical and emotional abuse and ostracization that disabled children were subjected to: 'Everybody was treated as if they had TB and as if they had to keep the gems away. […] I think I began to realise then how I was an object. I felt that for years […] half a day you weren't allowed to speak' (121). Ruth also witnesses the death of a disabled girl through waterboarding:

> The nurses used to play a game which they used to get groups of us to watch where they held a child under the water in the bath until she started to go blue. And they killed this child. They held her under for too long. I didn't dare to say anything. […] I never dared to tell my parents what was going on. All our letters were censored and at the visits which were allowed the staff were always around […]. (122)

Annie McDonald, who has cerebral palsy and stayed in a children's hospital in Melbourne, Australia, wrote about her experiences of neglect and abuse (also the neglect and abuse of others that she witnessed). She co-authored a book with her teacher Rosemary Crossley (*Annie's Coming Out*, 1982) who helped her to leave the institution. Crossley describes the brutal way in which the children at the hospital were fed, a practice that must be described as abuse or torture:

> […] children were being fed with their heads tilted right back, a method called, for obvious reasons, 'bird feeding'; gravity drops the food straight to the back of the throat, and there is no chance to chew. […] I have filmed a nurse feeding a child: food is piling high on his face because he is unable to swallow it at the rate the nurse spoons it in. It must have been terrifying. (123-124)[173]

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[173] On abuse in institutions for the disabled see also Tracy Odell: 'Not your average childhood: lived experience of children with physical disabilities raised in Bloorview Hospital, Home and School from 1960 to 1989', *Disability & Society* 26.1 (2011): 49-63; Jane Hubert: 'The social, individual and moral consequences of physical exclusion in long-stay institutions', *Madness, disability and social exclusion:*

Crossley shows that this practice of feeding is linked to the fact that a nurse had to feed 10 children in an hour and that ‘everything had to be sacrificed to speed’ (Morris 1991, 124), thereby laying responsibility not merely with the nurses but with hospital administrations and politicians enforcing cuts in health service. Morris specifically critiques the hospital, adding: ‘The institution continued to impose emotional and physical abuse on the children even after their practices were exposed in the newspapers and the High Court. They also continued to insist that all the children were “profoundly retarded”’ (124). Annie McDonald writes about her experiences in the hospital: ‘We cried because we felt abandoned. […] Nurses were discouraged from cuddling children. A crying child needed to be punished for its own good […]. punishment consisted of locking the crying child in a small dark store room’ (124). Annie’s response to such neglect, abuse and ostracization was not the wish to be dead but anger and revenge:

> ‘Death never appealed to me; I wanted revenge […] Time was when the strongest emotion I felt was hate, and hate makes you strong. […] Implacable hatred of the whole world which hunted handicapped children into middens like St Nicholas twisted my relationship with people for years.’ (124-125)

Institutions like St Nicholas were characterized by a devastating neglect of disabled children’s education. The children were written off as being ‘retarded’ and seen as objects of horror, disdain and disgust. Morris paraphrases Crossley’s report on Annie McDonald’s condition as follows:

> When Annie was first taken out of the hospital […] in 1975 she heard people say things like: ‘Well, if it was a puppy you’d knock it on the head, wouldn’t you?’ and ‘If it was my child I’d kill it and you couldn’t blame me’ […]. When people looked at her, her twisted and spasming body frightened them. They couldn’t conceive of a life being worth living if you looked like that. All her life people had also assumed that she was ‘profoundly retarded’, and this too was a reaction to how she looked and to the fact that she couldn’t speak – at least not a language that they could understand. Rosemary Crossley had assumed that Annie had a mental age of four or five […] within two months of establishing a way for Annie to communicate, using a board with letters and numbers, Rosemary found out that Annie not only knew how to read and spell but that her knowledge of mathematics outstripped her own’. (125)

Jenny Morris continues her chapter by advocating the Independent Living Movement that enables disabled people to be cared for in their own homes (128), adding a short history of the movement and of disability organizations in Britain (171-172, 177-178). She compares institutions for the disabled to containers where people exist in a limbo state between social and physical death (132, 133, 136). Morris re-defines independence and especially the independence of disabled people as a way of life in which they are assisted in ways that enable them to achieve their goals, not left alone without any help (137-140). She stresses that disabled and non-disabled people are all interdependent, not atomistic, individuals (137).

The archaeology and anthropology of difference, Ed. Jane Hubert (London and New York: Routledge, 2000) 196-207.

Chapter 6 deals with feminist research in the fields of disability and community care. It critiques feminists who often regard disabled people as Other and dependent. She states that the concept of collective care that is frequently advocated by feminists (e. g. by Gillian Dalley)[174] who argue that women must not be exploited in existing patriarchal structures of family care may be welcomed by many disabled people because it strengthens feminist solidarity. However, Morris objects, the feminist advocates of collective care all too often ignore the views, needs and desires of disabled people (157). Morris argues that far too little emphasis is paid in general to abuse in residential and community care (163), an abuse that is based on structural economic dependency and the inequality of power relations between carer and client (164). She emphasizes that disabled people must be able to choose between family / communal and collective / residential care, showing that although most carers (esp. full-time carers) are women, there are also many male carers (164, 167).

Chapter 7 (‘Fighting Back’) deals with the ways in which disable people must confront the ableist prejudice that disabled lives are not worth living (169). Morris quotes Pam Evans (one of her interviewees) who argues that ableist prejudice is difficult to confront head-on because much of it is not perpetuated consciously. Such prejudices are unconscious, they ‘generate from the murkier depths of humanity’ (170). Morris adds that in addition to disablism, many disabled people struggle against racism, sexism and heteronormativity (179): Anna Mathison experienced segregation as a black child and remembers the hatred and unkindness she was confronted with (179). She struggled against both disablism and racism and asserted herself as an independent woman with her own flat and personal carer. She is in paid employment which she enjoys, working with disabled people and feeling positive about herself. Morris demands that more disabled people must lead organisations of / for the disabled and she states that neither disabled people nor disability rights organizations are exempt from racism and sexism, emphasizing the necessity to fight intersectional discrimination and harassment (178). She insists that the struggle against racism, sexism and homophobia must be part of disability activism (180). The fight against disablism, Morris argues, must be based on a broad solidarity among disabled people from diverse backgrounds. Non-disabled people tend to view groups of disabled persons with pity, fascinated repulsion and fear but the only way to fight such prejudice, Morris insists, is the formation of coalitions among disabled people (170). In this context, the Independent Living Movement plays a very significant role (171-173). Together, activists must fight the dominance of the medical and tragedy models of disability (180).

Although Morris demands that activists must not forget that disability is indeed often combined with illness, old age, pain and the experience of the frailty of the body, she stresses that it is important to counter negative images of disability through positive images (181, 183). The majority of media representations show disabled people to be either pitiable, un-able and marginalized or exceptional individuals who triumph over adversities. According to Morris, the problem with stories celebrating individual disabled people as ‘wonderful exceptions’ is that they come at the price of devaluing all other disabled persons who do not achieve this norm. In order to be inspiring for disabled people, their stories must be told on their terms, that is, in ways that reveal the social conditions for their achievements (e. g. like the story by Ruth Moore 184-186). Pam Evans emphasizes the importance of naming the oppression that disabled

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[174] Dalley reviewed *Pride Against Prejudice*, see Keith and Dalley 1992, 378-381.

people face on a daily basis and of developing a new language in order to make sense of this experience (186). She states that most non-disabled people do not believe disabled ones when the latter affirm that disability has brought spiritual, philosophical and psychological benefits. Instead, they suspect that disabled people make a virtue of necessity, repress their pain and glorify suffering (187). For Pam, the experience of being 'not normal' was liberating. She warns disabled people against adapting to non-disabled people's standards, that is, against desiring ableist 'normalcy' (187). According to her, disabled people should think independently and constantly doubt outsiders who profess to embrace their condition (188). The common core of all liberation movements, Morris argues, is the right to be both different and equal (189).

The final chapter titled 'Pride' contains an autobiographical vignette from Morris's own life that describes the social progress that is being achieved through disability rights activism but it also demonstrates that experiences of prevailing paternalizing humiliation and ostracization are grounded in non-disabled people's fears of disability and their ostracization of disabled people:

> the non-disabled world mostly reacts to us with pity and revulsion […] Our disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity. It is this response which lies at the heart of the discrimination we face – in employment, in housing, in access to all the things that non-disabled people take for granted. (190, 192)

Morris recounts how she participated in a demonstration against the BBC charity event 'Children in Need', a broadcast that perpetuated the notion of disabled people as pitiable and passive. The demonstration was organized by the Campaign to Stop Patronage that opposes the charity model of disability together with the use of negative images of disability that persuade people to donate money out of pity. The organizers insist that disabled people have a right to social support and that they should not be dependent on arbitrary, patronizing charity. The protesters express their anger about the BBC Telethon event in front of the TV studio. Morris is among them, describing how celebrities and donors were astonished and embarrassed when they face the protesters (191). A donor offers Morris £ 5 but she rejects it. At first, he is shocked but when Morris explains her reaction he agrees and argues he never thought about this problem before (192). According to Eliza Chandler's reading of this vignette, the demonstration of the disability activists was a success and Morris's book ends on this upbeat note:

> this group of disabled people had shown up to trouble their normative construction as pitiful by the 'Children in Need' campaign and similar charities […]. Morris's pride is defined in opposition to, and as a rejection of, the assumption that 'we feel ugly, inadequate and ashamed of our disability' […]. As such, her pride is constituted by what it is not – shame – and therefore, it seems, dwelling in shame is an impossibility for a proud disabled person. In other words, Morris's proclamation of pride requires us to become other than the ashamed subject culture expects her/us to be. Together, through pride and

> in the abandonment of shame, Morris and her ‘crip community’ […] organize politically and advocate for necessary change.[175]

I largely agree with Chandler’s reading of Morris’s text and her critique of Morris’s construction of a notion of disability pride that demands a turning away from shame. However, at the end of Morris’s book, the depiction of the hopeful incident of educating an ableist donor about the harmful, disempowering consequences of his action for disabled people is contrasted with a less progressive development: Morris’s co-protester takes the money offered to her by another donor because she thinks it will be used to support their campaign anyway and states she was tired of explaining herself. The donor finally stooped down and patted Morris on her head (‘As he passed me, he stooped down, patted me on the head and cupped my cheek in his hand, smiling benevolently as he did so’, 192), a gesture that Morris critiques as paternalizing and humiliating because it regards disabled people as ‘icons of pity’ and allows non-disabled people to hide their fear and discomfort about disability.

Morris states that from afar, the disabled protester group looks happy. Its members enjoy each other’s company and the music and they take pride in themselves. She here describes a situation that resembles the disability pride image on the top cover of her book. On her way home in her car, Morris stops at a zebra crossing and sees a black disabled poor woman ‘struggling across the road’ in front of her. Morris argues that this woman is far more representative of the disabled population in Britain than herself and those who participated in the anti-Telethon demonstration (193). She emphasizes that the experience of disability prejudice and discrimination is what connects her and her fellow campaigners with this black, poor and old disabled woman, thereby arguing for a broad, intersectional basis of the struggle for disability rights. Morris’s position is a valuable contribution to the fight for disability rights although it risks to downplay the profound differences between the social situations, needs and desires of white and black disabled women.

Conclusion

The way to fight against structural prejudice, harassment, paternalization, humiliation and discrimination, Morris’s book suggests, is the joint activist struggle that connects disabled people across different ethnic and social backgrounds, a struggle that must also be fought in the name of those who are too weak and underprivileged to join it. *Pride Against Prejudice* locates important causes of the devaluation of disabled people’s lives (especially prevalent in institutions for the disabled) and of the humiliation and abuse of as well as discrimination against disabled people in the absence of civil disability rights. Furthermore, Morris’s book reveals ableist and disablist social norms (especially those framing disability exclusively in terms of personal tragedy, passivity and medical defect) as significant causes of disability- and gender-related shame and humiliation. She presents disability activism (especially the Independent Living Movement) and collective disability rights activism as strategies that aim at the solution of the most urgent problems that disabled people face in their daily lives, thereby tackling prejudice against disabled persons and especially against disabled women as a structural problem. However, as Pam Evans’s remark suggests, disability prejudice is not a problem that can be solved through civil rights movements

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[175] Eliza Chandler: ‘Interactions of Disability Pride and Shame.’ *The Female Face of Shame*. Ed. Erica L. Johnson and Patricia Moran (Bloomington and Indianapolis: Indiana University Press, 2013) 74-86.

and legal change alone. As an opinion or feeling, prejudice indeed generates ‘from the murkier depths of humanity’ (170), it is linked with deep-seated, subconscious and therefore affective defence responses (esp. fear, horror, disgust, shame, pity) that cannot be directly tackled / exorcised through purely rational decisions and legal changes. Morris’s own autobiographical vignette at the end of the book, describing the deeply-rooted paternalizing attitude of the donor who complacently and condescendingly pats her head, is a memorable example of these deeply-rooted devaluing attitudes towards disabled people and disabled women in particular.

3. Book-Length Autobiography

Gohar Kordi: *An Iranian Odyssey* (1991; London: Serpent's Tail, 1993).

An Iranian Odyssey is an early example of a British book-length feminist disability autobiography. Before Kordi, Jo Campling’s collection of short autobiographical texts (*Images of Ourselves: Women with Disabilities Talking*,1981) provided insight into the intersectional structural inequalities and injustices that especially disabled women have to face and it did so from the perspectives of western female, mostly feminist, disabled authors. Compared to Campling’s edition that provided authors with a rather limited scope for self-representation and that generated condensed, at times report-like sketches, Gohar Kordi’s publication of her own autobiography gave her much more space to relate her life story. At the same time, the acts of writing and publishing, like every act of becoming public (and every act of reading / reception) are also pervaded by the transformational energy of shame (Probyn 2005, 129-162; Mitchell 2020, 231). Kordi’s book is a decidedly *literary* autobiography whose title emphasizes the motif of life as a journey, which dates back to Homer’s *Odyssey*. It comprises a narrator with a fictional name, narrative scenes, suggestive, poetical descriptions of locations and atmospheres, complex, multi-faceted and embodied self-presentations as well as insights into intersectional forms of oppression that target differences in gender, ability, class, ethnicity, religion and sexual orientation.

Gohar Kordi was born in Iran, probably in the late 1940s or early 1950s. Due to the Iranian tradition of registering girls as being older than they actually are to enable their early marriage, her exact date of birth is unknown.[176] Kordi took her BA in psychology at Teheran University in 1970 and migrated to the UK in 1971 (Kordi 1993, 141; Keith 1994, 219). She grew up in Iran in the 1950s and 1960s at the time of Iran’s conflicted cold-war relationships with the USA, the USSR and the UK. This period of Iranian history was marked by processes of modernization and secularization (the ‘White Revolution’ 1963-1979) under Shah Mohammad Reza Pahlavi’s government. These processes comprised the nationalization of industries and land property, reforms of the economic, infrastructural, educational, health-care and social-security systems. Furthermore, thanks to the influence of the Shah’s sister Ashraf ol-Molouk Pahlavi, the period was characterized by the promotion of the rights of women. In the 1960s, the Shah’s form of government became increasingly corrupt and authoritarian: student revolts were violently suppressed by the secret police SAVAK.

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[176] Gohar Kordi: *An Iranian Odyssey* (1991; London: Serpent’s Tail, 1993), 12, 65. All references to *An Iranian Odyssey* follow this edition.

A review from 1992 focuses on Kordi's description of her 'heroic personal struggle' as well as on the book's 'telling indictment of a society in which being female was almost as disabling as being blind'.[177] The significance of heroism and triumph as well as of tragedy, suffering, 'miraculous' plot turns, anger and bitterness is highlighted in Abigail's review on Goodreads.[178] Furthermore, the review classifies *An Iranian Odyssey* as a trauma memoir ('traumatic memoir') that lacks the 'peculiar kind of sensationalism' typical of US-American examples of the genre. A less favourable Goodreads review by Grada (BoekenTrol) comments on the Dutch translation of Kordi's book, describing its narrative style as distanced, 'almost businesslike' and repetitive.[179]

In her critical reading of Kordi's book, Diane E. King draws attention to its packaging as 'a story of personal triumph against the odds' but she argues convincingly that it is much more than that: it is 'a methodical protest against multiple injustices' that shows how the narrator 'overcomes gendered discrimination, her family's poverty, a variety of difficult circumstances including abuse at a boarding school run by Westeners, and the loss of her sight at the age of four'.[180] Above all, King claims, *An Iranian Odyssey* challenges the subjugation and abuse of women as well as the social structures that facilitate them (458-459). She emphasizes that the text offers no final solutions to its discussion of gender-related problems of longing and abuse but she hardly touches on the significance of Kordi's disability (459).

Although critics and reviewers comment on the book's use of different narrative affects and emotions (sadness, outrage, bitterness) as well as on their own affective and emotional responses to *An Iranian Odyssey* (admiration, surprise, solidarity), the roles of shame and humiliation as narrative affects are hardly commented on: Susannah B. Mintz reads Kordi's text as 'a self-asserting narrative of a protesting voice'.[181] Although she mentions its discussion of stigma (147), she neither acknowledges the formative dimension of shame and humiliation in the text nor its impact on readers. In the following, I investigate Kordi's depictions of experiences, narrative events and scenes of disability-, gender-, ethnicity-, religion- and class-related shame and humiliation. Furthermore, I will explore Kordi's use of narrative techniques through which she transfers shame to readers and through which she turns readers into affective co-witnesses of intersectional forms of shame and humiliation.

Kordi's text is dedicated to her uncle Ezatollah Rahimifar and her husband David. A short preface explains that Kordi takes the name 'Monir' in the book and that the names

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[177] 'Review *An Iranian Odyssey by Gohar Kordi*', Kirkus Reviews. Dec. 15, 1992. Web. 8 June 2021. <https://www.kirkusreviews.com/book-reviews/gohar-kordi/an-iranian-odyssey/>.

[178] See the review by Abigail (3 likes), Nov 24, 2019. Web. 9 June 2021. <https://www.goodreads.com/book/show/510117.An_Iranian_Odyssey?ac=1&from_search=true&qid=hwvCVUzQKz&rank=1>.

[179] Goodreads review by Grada (BoekenTrol) on *Iraanse odyssee* by Gohar Kordi, Frans de Haan (translator), 1 July 2012. Web. 9 June 2021. <https://www.goodreads.com/review/show/359211726?book_show_action=true&from_review_page=1>.

[180] Diane E. King: 'Two Generations of Feminist Activism: Snapshots', *Provocations: A Transnational Reader in the History of Feminist Thought*. Ed. Susan Bordo, M. Cristina Alcalde, Ellen Rosenman (Oakland, California: University of California Press, 2015), 451-470, 458.

[181] Susannah B. Mintz: 'Dear (Embodied) Reader: Life Writing and Disability.' *Prose Studies* 26.1-2 (2003): 131-152, 148.

of her family members and of other persons she portrays are changed as well. The change of names to protect the privacy of family members, friends, peers, teachers etc. is rather common in autobiographies. Less common, however, is the change of the name of the first-person narrator. It can be read as a distancing or fictionalizing strategy that endows the writer with a considerable amount of freedom, a technique used in hybrid forms of contemporary autobiography that engage in a decolonialization of subjectivity and employ imaginative strategies of self-reinvention (Smith and Watson 2010, 12). Kordi's text shows, however, that such a practice of self-reinvention does not have to take the form of 'scriptotherapy' which results in the construction of a 'salutary paradigm'.[182] Furthermore, the change of the names of portrayed persons is also a sign that the text contains uncomfortable, politically relevant observations: *An Iranian Odyssey* describes the abuse and injustice that she and many other disabled women suffered at the hands of her family, of school and university staff members and British missionaries.

Kordi's book was translated into many languages, e. g. into German with the title 'Ich will leben wie Ihr. Ein blindes Mädchen besiegt sein Schicksal.' Ein Bericht. (Köln: Lübbe, 1991). As this title suggests, the German translation of the book is packaged as a 'triumph over adversities' narrative and highlights the 'factuality' of its story. Although *An Iranian Journey* is written in English, it is also transcultural and partly heteroglossic: Monir speaks 4 languages (English, Turkish, Kurdish and Farsi) and Kordi uses words from each of them in her book.

The cover of *An Iranian Odyssey* contains an illustration by Bekah O'Neill, a collage that combines a photograph of modern Teheran under a blue sky with white clouds (serving as vanishing point) with an illustration depicting traditional rural Iran in the foreground. It points to the enormous social changes (esp. land reform, industrialisation, educational reform, women's emancipation movement) happening during the Shah's White Revolution and its aftermath. In the upper middle of the illustration, we find 8 colourful circles surrounding a sun image, a symbol that was traditionally connected with the Persian Empire. The 8 circles contain symbols of the natural world such as a tree, a leaf, a pine cone and a goat and symbols of knowledge and globalization: a globe and a key (perhaps signifying access to a desired place, information or success). The sun symbol encloses the letters F. A. O., the abbreviation for 'Food and Agriculture Organization of the United Nations'. Furthermore, the front matter of the book contains a map of Iran with bordering countries and significant towns. The book's back cover includes a small black-and-white photograph of the author and some short biographical remarks about her, mentioning her place of birth, her blindness and her education, emphasizing that she was the 'first woman student at the university of Teheran'. Furthermore, the back cover lists review excerpts that describe the story as exerting a 'hypnotic power', as 'outstanding', 'bald', 'quiet' and 'devastating' although it does not contain 'a word of overt criticism'. *An Iranian Odyssey* is advertised as 'an autobiography that reveals its belief that adversity can be overcome' (back cover).

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[182] Suzette Henke: *Shattered Subjects: Trauma and Testimony in Women's Life Writing* (New York: Palgrave Macmillan, 2000) xv.

Kordi's book portrays and critiques many intersecting layers and modes of shame that stick to the narrator's non-normative body, that is, her blindness, gender, sexuality and class background, her Turkish origin and her Muslim confession. It covers Monir's childhood in Kurdish and Turkish villages in Iran in the 1950s, her education in a British missionary school for blind girls in Isfahan in the 1960s together with her course of studies at Teheran university, ending with her graduation in 1970 (130). Reviewers have described the memoir's impact as 'searing', 'stirring' or 'embittered' and 'grim'.[183] They have commented on its articulation of the narrator's frustration and anger provoked by her confrontation with her family's cruel, misogynistic and disablist treatment. While acknowledging the central role of the narrative affect of anger in Kordi's text, my analysis demonstrates that shame manifests as a performative narrative affect, as a motor of plot development that undermines the autobiographical tradition of the 'triumph over adversities' narrative in which a disabled narrator triumphs over social adversities.[184] Shame and humiliation are portrayed as relational and decidedly politicized affects in Kordi's autobiography, not only as internal emotional states. They manifest as forms of communication that produce affective relations with readers, above all through strategies in which the narrator's shame is externalized and transferred not only to textual others (e. g. Monir's sighted mother and her British sighted teachers) but also to readers who in many instances feel directly addressed as being part of the sighted population. In particular, readers feel directly addressed when the narrator desires her mother's praise for her achievements long after her mother has died. In these pleas for recognition, readers take the position of the absent mother.

Although the short autobiographical stories in Campling's collection and Jenny Morris's autobiographically informed monograph contain many descriptions of narrative events and experiences related to shame and humiliation, they do not start with a narrative event of disability-related shame. Kordi's book, however, begins with a narrative scene that combines humiliation with pride and triumph. The narrator recounts how an older boy called her 'blind' when she was 4 years old:

> I must have been about four years old and I was playing outside in the street, when an older boy who would have been about seven, said to me, 'You can't see. You're blind.'
>
> 'No, I'm not,' I said confident, resolute.
>
> 'Yes, you are.'
>
> 'No, I'm not,' I repeated.
>
> 'If you're not,' he said, 'then drop that coin you have in your hand and pick it up.'
>
> I dropped the coin and picked it up again straightaway. The boy walked off without a word.

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[183] 'Review *An Iranian Odyssey by Gohar Kordi*', Kirkus Reviews Dec. 15, 1992. Web. 8 June 2021. <https://www.kirkusreviews.com/book-reviews/gohar-kordi/an-iranian-odyssey/>; 'Review *An Iranian Odyssey*, Gohar Kordi', 29 June 1992. Publishers Weekly <https://www.publishersweekly.com/978-1-85242-213-4>. Web. 8 June 2021.

[184] On this tradition see Couser 2009, 33-34.

> I stood there with the coin in my hand, proud, triumphant. I had proved […]
>
> I wonder how long I went on with this illusion? (7)

The text represents the older boy’s way of addressing Monir as a form of stigmatization, as a version of the performative speech act / interpellation ‘Shame on you!’: the boy addresses Monir by using the label ‘blind’ and by focusing on what he thinks she cannot do, emphasizing incapacity, failure, lack, difference and otherness. The above-quoted passage is a scene in the sense of the literary definition of the term: it covers a dialogue, that is, it is a narrative passage in which discourse time equals story time (Genette 1983, 86). However, it is in many ways an unusual scene of humiliation as the narrator does not describe any physical signs or feelings of shame in the narrated ‘I’. Furthermore, in contrast to Patrick Colm Hogan’s example of Stiva’s moment of shame in *Anna Karenina* (Hogan 2011, 33-36), the above-quoted scene of humiliation does not show a moment of hesitation, lateral inhibition or a dead-end situation, on the contrary: Monir responds to the boy’s interpellation immediately, almost automatically, with a defiant, ‘proud’, ‘triumphant’ gesture. She denies her ‘blindness’ as a label that signifies incapacity, proving that she can do what no one thinks she can. This scene of humiliation can be viewed as an epitome, a condensed image of the course of character and plot development in Kordi’s entire text. It unfolds a transformational energy, driving the plot forward, functioning as the motor of the narrative and of Monir’s character development. The initial scene of humiliation and resistance points towards an important aspect of narrative, that is, towards its role as a ‘form of affective conversion’ in which represented objects (narrators, textual others, things, symbols, places, ideas etc.) turn from being ‘good’ / ‘happy’ into being ‘bad’ / ‘unhappy’ and vice versa (Ahmed 2010, 21, 27, 45). Whereas Patrick Colm Hogan suggests that the creative power of narrative affects is limited to the classic literary emotions (fear, anger, attachment / love, disgust, lust, Hogan 2011, 7), Kordi’s narrative shows that shame can shape a story in a book-length publication as well. It is in response to repeated acts of humiliation that Monir proves she is capable of achievements that sighted people think she is incapable of or that they fail to accomplish themselves.

Although *An Iranian Odyssey* contains passages in which the narrator responds to experiences of humiliation by turning them into a stimulus to academic achievement, it is important to realize that Monir does not simply overcome the humiliation described in the initial scene of the book. The narrator emphasizes that its impact is long-lasting and that the initial feeling of triumph was illusory. The initial scene of humiliation becomes an event that is repeated and re-configurated in the course of the plot. It stands out amongst and almost displaces all other childhood memories. It is retrospectively described as the moment at which Monir realized that she is blind, that is, different from her peers (28). In contrast to Hogan’s example of Stiva’s shame in *Anna Karenina*, the initial scene of humiliation in Kordi’s text is not limited to a narrative incident (Hogan 2011, 33-36). In *An Iranian Odyssey*, the initial scene of humiliation is shown to become a narrative event, to generate expressive and actional outcomes. It functions as a pressure point to which the narrative returns. It is repeated and re-appropriated at the beginning of chapter 4, this time told in present tense, followed by a reflection that shifts from past to present tense:

> We are in Khorbendeh, my mother's village, am about four years old. I'm playing with an older boy of about seven out in the street and I have a coin in my hand. The boy says 'You can't see.' 'Yes, I can,' I reply. 'No, you can't.' 'Yes, I can,' I insist. 'If you can, then drop that coin in your hand and pick it up,' he says. I drop the coin and pick it up straightaway. The boy walks away without a word, I stand there, triumphant.
>
> I did not accept the fact that I could not see. I performed the task set for me beautifully. On another level that was the moment when I understood that I could not see. I do not remember anything before or for long after that event. It stands out in my memory as clearly as though it were yesterday, the dusty street, the quietness, the boy's voice, his age. (28)

The use of present tense generates an impression that invests the scene with a strong sense of immediacy or flashback-quality. This time, although the scene repeats the gesture of triumph, it explicitly marks the moment when Monir realizes that she is blind / different, that the act of interpellation forms her identity as a blind girl. The initial scene of humiliation is not only repeated at the beginning of chapter 4, it can be said to proliferate and spread through the narrative, connecting and resonating with many other narrative events of humiliation that are told in later parts of the text.

Another event of humiliation that the narrator remembers is connected to her contraction of smallpox. Monir was hidden in shame, lying in the dark with her eyes bandaged for 3 months without receiving medical care or enough food:

> It was as though the world came to a standstill. I was / shut out. Doomed. Forgotten. I vegetated and yet I lived. I / was shut out from light, love, and wrapped in a curtain of / darkness which lay all around me, touching me, / squeezing me, hurting, suffocating me. / Fear fills my heart, cripples me. I lose any attempt, any effort to struggle, protest. / I feel the bandages on my eyes, on my body, on my soul. / I dare not struggle, scream, protest – too dangerous. I have lost my voice: If I make the slightest protest the bandages will be pulled tighter and that will be the end of me. / Not a sound. 'She slept the whole time,' mother said. (7-8)

Again, the narrative tense switches to present and acquires immediacy and emotional intensity. The text creates a psychological scene of 'high emotional intensity' and paralysis, depicting the narrated 'I''s state of being overwhelmed 'in proximity to a disturbance', to use Lauren Berlant's terminology (Poletti and Rak 2014: 268; Berlant 2011: 131-136, 207-209, 268). The fragmented staccato lines and images (a 'curtain of darkness' that touches, squeezes and suffocates her like a threatening human being) have a poetic quality (print also suggests the genre of poetry here). At the same time, they are typical of shame as a reduced form of communication that is characterized by disruption and 'lateral inhibition' (Hogan 2011: 37-38). The lines create the impression of pressure, fear, constraint, paralysis, limitation, petrification, intimidation and suffocation. They depict Monir's silence as the only possible means of survival. In addition, they capture a psychological scene of intersectional forms shame and exclusion: Monir suffers on two accounts: she is a girl and she is ill. Like the initial narrative scene of shame, this one is represented as an event to which the narrative returns at a later point (13).

After these two impressive depictions of humiliation, the narrative seems to take a radical turn. It switches to the present (ca. 1990) and a very vocal, angry and triumphant Monir addresses her mother and reports on her achievements,[185] counting up all elements of what is traditionally thought of as a successful life (the possession of a house, a loving husband and a son):

> I have a lot to say to you, mother, a lot! I want to show you some of my achievements. This is my son, meet him. Isn't he beautiful? And this is my husband. Isn't he handsome? And he loves me. I love him. […] And this is my house. Isn't it beautiful? Look, we've done it all by ourselves […] My son's room […] The colour scheme, everyone says how beautiful it is. I can't see it. But I want you to see it, mother. You tell me how nice it is. […] Look mother. I want you to see everything. See how well I have done? (8-9)

Despite this turn to Monir's achievements, the narrative does not leave the topic of shame and failure behind. On the contrary, by connecting the events and scenes of childhood shame so closely with the adult Monir's acquisitions, the narrative points to the connection between shame and the desire for social recognition. Rather than achieving a triumph over shame, the traces of shame remain visible in the very force, momentum and vehemence through which Monir addresses her mother: 'After all, I haven't let you down, mother […] You neglected me, didn't you, because I was a girl. […] I feel angry with you, mother. […] You negated my existence because I was female. You put a death-wish on me when I became blind […]' (9). The narrator talks about her own experiences of intersectional forms of shame and transfers shame to her mother Mahi with whom she solidarizes in other parts of the book.[186] At the same time, Monir craves Mahi's validation long after she has died. This craving for validation is typical for the affective disposition of shame in which the subject remains affectively attached to the face that turns away from the subject.[187] Shame, Silvan Tomkins explains, is inseparably connected with desire and love: '[…] the residual positive wish which informs shame is not only to look at the other rather than look down, but to have the other look with interest or enjoyment rather than with derision' (Sedgwick and Frank 1995, 138).

The angry act of addressing her mother happens belatedly and in retrospection. It is an imaginative speech act that no longer has a direct addressee in the text. As readers learn later, Monir's mother is already dead at the point when Monir has accomplished the things she wants her mother to admire (105). In addition to its act of directly addressing an absent textual other, Kordi's text points beyond itself through its specific use of *deixis*: when the narrator addresses her (dead) mother as apostrophic 'you',

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[185] On this angry address see also Mintz 2003, 143-144.

[186] In other passages of the text, however, the narrator expresses solidarity with her mother Mahi who was a rebel (she resisted her first arranged marriage) and suffered under the blatant gender inequality in Iranian society. The narrator recounts Mahi's story empathetically in chapter 3, describing her creativity and vivid imagination as well as her close connection to the other village women with whom she shares her sorrows (26-27).

[187] According to Eve Kosofsky Sedgwick, shame is the 'experience of interest that a person holds toward an object after it turns its face away'. Berlant and Edelman 2014, 37.

reproaching and shaming her as well as craving her recognition and admiration, she also addresses sighted readers, telling her and them to 'look' at and acknowledge her achievements. The use of a strongly visual language is of special significance here. As readers learn later, Monir first wrote texts (among them a play) in Braille and then read them to an audience (117). *An Iranian Odyssey*, however, was produced to reach sighted people directly in their code of visual language. As Susannah B. Mintz has argued convincingly, Kordi's use of a language that emphasizes visuality is no capitulation to the dominance of ocularcentrism but a plea for relationality and social validation (Mintz 2003, 144, 148). What is more, other parts of the text use decidedly non-ocularcentric language: many passages give detailed description of smells, sounds, noises and touch (Kordi 1993, 43).[188] The narrator emphasizes that she has only a faint memory of her time before blindness (e. g. of colours and the sky, 10) and that she cannot see the beautiful things she has achieved in her life, implicitly blaming her mother for having caused her loss of sight by denying her medical treatment: 'I said I lost my sight. No, I did not lose it. It was lost for me. Did you do it, mother? You neglected me […]' 9, see also 48). Monir's life story can be described as a response to the practices of humiliation she was subjected to. It is motivated by her desire to prove worthy in her mother's eyes, it's a way of reaching out to her mother and the reader as (co-)witnesses of her worthiness.

An Iranian Odyssey demonstrates how strongly the act of looking is connected to pride, humiliation, disgrace and condemnation: Monir is described as her mother's pride, as 'beautiful […] pretty, clever, full of life', as being able to attract attention and admiration 'straightaway' when she was sighted. This description implies (at least in part) an immoral, dishonourable transgression (a breach of female honour) on Monir's side, a form of disgrace.[189] From her mother's point of view, she unwittingly violated the gendered rules of modesty, invisibility and silence by drawing attention to herself. In this sense, Monir is (at least indirectly) blamed for her blindness. As a result, she is subjected to practices of humiliation that target her gender identity as well as her blindness. Her beauty is seen as having attracted the 'evil eye' of strangers that turned her blind and thereby 'worthless' (Kordi 1993, 13-14). Monir stands silently and motionlessly while her mother mortifies her in front of others as if she were non-existent or incapable to understand: 'That's why she lost her sight. Look at her, what is she now? The words 'look at her' – and she said them often enough – made me feel diminished, worthless' (13-14). In this passage, readers become belated affective co-witnesses[190] of an act of severe humiliation. The narrator describes herself as scared and crushed by her mother's disdain but she also appears as a survivor of injustice (10): 'And yet I said to myself, there is nothing wrong with me. I am here after all' (13).

Monir is well-accepted in her father's Turkish village and her Kurdish mother felt secure and protected in the neighbourhood. All women of the village had a strong sense of

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[188] 'The streets were quiet. We were passing the gardens. I could hear the trees, the wind rustling the leaves. […] All this space, all these gardens, no people in them […]. the emptiness I felt in the space, was it my own emptiness of human touch, concern and care?' (Kordi 1993, 48-49).

[189] Adis Duderija, Alina Isac Alak, Kristin Hissong: *Islam and Gender: Major Issues and Debates*. (Adingdon & New York: Routledge, 2020) 36-37, 3, 31, 34, 42-57.

[190] Richardson and Schankweiler 2019; Richardson 2016, 104-105; Shoshana Felman and Dori Laub: *Testimony. Crises of Witnessing in Literature, Psychoanalysis, and History* (New York, et al.: Routledge, 1992), 208.

solidarity and togetherness. They supported each other emotionally and economically (37-38). 'Loneliness was not known', the narrator observes (38). On the other hand, she states that the landlords were exploitative and cruel, raping female tenants and abusing male ones. When Monir was a child, she witnessed how a blind man was whipped because he didn't bow to his landlord as he was unable to notice him coming (30).

When Monir's family moves from the village to the modernized city of Teheran in the hope to earn money to pay their debts (a plan that fails), Monir's life changes drastically (42-43). While her parents leave the house to search for work, she is left alone, feeling sad and heartbroken (46-47). Monir is isolated and faces intersectional stigma because of her blindness and because she speaks Turkish, not Kurdish (46). Her mother is ashamed of her and Monir feels like a burden (48). When her mother cannot find work, she blames her and calls her a nuisance, an embarrassment. The narrator describes a situation in which her mother tries to depose of her by pushing her into a large hole in the ground but Monir stands steadfast (49). The passage can be read literally and metaphorically. It comprises a strong image for the way Monir felt she was treated by her mother:

> Mother was ashamed of me: She felt inadequate with me around, especially in front of her own mother. I was an embarrassment. She wished somehow I would disappear off the face of the earth. I was a disgrace. […] She kept blaming me, cursing: 'You are a headache. You are a nuisance. […] Why don't you just go and leave me free,' as she put it. […] We came to a hole in the ground on my side of the pavement near the wall. I sensed it as we approached. She pushed me towards it, pulling me, pushing me somehow, towards this hole. She wanted to throw me in it. I held on to her arm. […] I had felt her strong wish to get rid of me. I felt her willingness to get rid of me. I kept silent. It was too dangerous. I had to breathe quietly. 'What now?' I said to myself, as we stood here. […] She gave a push. I felt my heart beat. I held my breath. I felt the ground underneath my feet as though they were stuck to it. Nothing could move them. I was nailed to the ground. I stood silent. I had to be silent at danger points if I wanted to survive. (48-49)

At this point, it is clear that although *An Iranian Odyssey* includes many depictions of experiences of humiliation, the descriptions of Monir's feelings do not (primarily) include shame ('there is nothing wrong with me' describes self-acceptance) but rather defiance, anger or fear, later also bewilderment and abandonment. This changes in the course of the narrative, especially after her family moves to Teheran where the narrated 'I' struggled with intersectional forms of shame and embarrassment. The passage quoted above, however, depicts feelings of vicarious shame (her mother is ashamed of her). The narrator emphasizes that her silence is no sign of passivity, withdrawal or defeat, but an active strategy of survival (49). However, some pages later Monir is depicted as experiencing intense shame about herself. Neither she nor her parents can find jobs in Teheran, she is belittled and brushed aside. More precisely, she 'failed' (*sic*) in finding a baby-sitter job and 'failed' (*sic*) her parents in general (50). Resultantly, she feels like 'a burden' (60). Her father cannot find work either and 'has a strong sense of failure' as well (51). At a later point, Monir is made to beg for her family (55). She feels bewildered and abandoned, 'smashed' like 'a piece of glass' and is taken to the Beggar’s House (55-56, 58). Her life becomes hell when her eldest brother Ali beats hear and all other family members:

> He beat me up and threw me over a wall. […] I cried and then I said, ‘I can feel blood on my face. I’ll show mum that you hurt me.’ […] He laughed. ‘Blood. That’s not blood, that’s saliva. Stupid, she thinks that’s blood. Blood is red, stupid.’ Until then I had not realized that blood was red. I thought the wet sticky patch on my arm was blood. I was blind, could not see the colour, did not know that blood was red. I felt belittled and ignorant. I could not see. Bitter. The bitterness I felt. He used to hit me on the head and pull my hair. Handfuls of my hair would come away. (61, 71)

Ali mortifies Monir, mocking her because she is blind and calling her stupid. What is more, he manipulates her and makes her question her own sense of what is ‘real’ or ‘true’ (61, 62, 72). Here, readers get a strong sense of Monir’s embodied feelings of shame about her blindness and purported ignorance, of her loss of trust in herself. At that time, Monir repeatedly thinks of committing suicide and attempts it once (74). On the other hand, she is surrounded by and actively surrounds herself with people who respect her, who are kind and supportive, e. g. her neighbours in Teheran among whom she feels happy, like a different person (30, 72). When she is 13 years old (77), Monir gradually turns away from the sources of disdain and towards sources of kindness (her neighbours), passion and pleasure (education, knowledge, the desire to go to school). She does not attend school but educates herself by listening to the radio (73). The narrator’s focus on her own intelligence disproves the humiliating stereotypes about blind persons and especially blind girls as well as counteracts the mortification she experiences when her brother calls her ‘stupid’ (61). Monir helps her sighted neighbour with her homework although she never went to school herself (72), thereby demonstrating that she is more intelligent than sighted girls of her age. The pattern of self-definition through achievement, the desire to prove that she is more capable than many sighted people, is central to Kordi’s text. However, although Monir achieves her goals, *An Iranian Odyssey* demonstrates that she does not triumph over shame. Instead, she repeatedly becomes subject to different forms of humiliation that target her gender, disability, ethnicity, class, language and religion.

In addition to its focus on Monir’s subjection to humiliation, Kordi’s book emphasizes her boldness and self-efficacy: when she is in a state of despair, she calls a crisis line and talks about her problems at home, her desire to go to school and asks for help (75). She has a friend who writes a letter for her which is discussed during a radio problem hour (77). The people in charge of the problem hour bring her in contact with Dr Vahidi, a young female gynaecologist who knows about a British missionary school for the blind in Isfahan (80). Monir is invited to live at Dr Vahidi’s private clinic and to work for her as ‘secretary/receptionist and housekeeper’. In addition, she regards herself as Dr Vahidi’s friend (81). Before speaking to her, Dr Vahidi touches Monir on her shoulder (80). Being touched signals to her that she is not (completely) ostracized, not completely excluded (80). Dr Vahidi pays for an eye operation through which Monir’s eye sight is to be restored, an act that demonstrates Dr Vahidi’s ocularcentric stance (82). For Monir, the restoration of her eye sight is less important than the chance to live with and work for Dr Vahidi, a possibility that provides her with a new self-image and self-worth. When Dr Vahidi is disappointed because the operation fails, Monir feels guilty and embarrassed: ‘I was embarrassed when I heard her say how disappointed she was. I wished the earth would open and swallow me.’ (83) Here again, as in the case of her brother’s practices of humiliation, Monir feels deeply ashamed, she is made the cause of someone else’s disappointment. Dr Vahidi allows Monir to stay with her until she can go off to the school for the blind but she is subjected to more humiliation in the house of Dr Vahidi’s future husband. She is sexually harassed but when she complains about it, the perpetrator argues that she – being blind – is no woman but an asexual object:

> Another time their cook touched my breast, so I told Dr Vahidi this in front of her husband and her husband got angry with the cook and gave him a slap. ‘How dare you touch this girl,’ he said angrily. ‘Me touching this girl? Which girl? […] Is this a girl?’ the cook said, ‘Is this a girl?’ he repeated. (84)

In Dr Vahidi’s house, Monir speaks to a stranger on the phone and develops a romantic interest in him but when he wants to come for a visit she withdraws and stops talking to him. She becomes very self-conscious and ashamed of her embodied difference: ‘To myself I would say, “There is something wrong, something seriously wrong.” My blindness, my looks. I have no education, I am not what you’re used to. I am totally outside your experience. I was sad when I stopped talking to him’ (85). Finally, Monir leaves Dr Vahidi because of the latter’s class prejudice (85). She asks a friend to write a letter for her to the Iranian Prime Minister, asking him to organize a place in a blind school for her (86). The text here depicts Monir as desperate but also as very determined. She is accepted at the British missionary school for the blind in Isfahan and the government pays for her education. What looks at first sight like a plot structure that is characterized by a miraculous individual triumph over adversities is in fact a narrative that reveals how much Monir’s achievements depend on others’ support and on the social change happening in Iran in the 1960s, especially on reforms in the fields of education and women’s rights (140). In addition, the text explores the role of British missionary work in Iran in the context of the Cold War.

When Monir arrives with her mother at the school for blind girls, the sudden attention she receives from the sighted British staff members (especially from Mama, the person in charge) and the other visually impaired girls causes embarrassment but also pleasure, especially the pleasure and comfort of being touched, noticed and called beautiful:

> we took a taxi straight to Noorain, the blind school […]. they were expecting me. […] some of the girls came up and talked to us. ‘Are you the new girl?’ ‘What is your name?’ […] Question after question. Everybody was talking. They were laughing, they were all happy, one or two came up and touched me all over to see what I was wearing, my height, my shape. ‘She’s got long hair,’ they called out to each other. ‘Oh, it’s beautiful.’ This was strange for me, I was somewhat embarrassed. No one had touched me like this before; in fact I had not met any other blind person before. (86)

At the school, Mama, staff members and the other girls become Monir’s new family. Her own mother who takes her to the school becomes a source of shame, especially her Turkish accent that is mocked by the other girls (87). Monir feels comfortable in the blind school and happy to sleep in a bed for the first time (90). She is eager to leave her mother behind (she has no desire to visit her during holidays) but the narrator also describes her mother's profound sadness (88). Although Monir is well accepted by the other school girls and makes friends easily, the narrative includes a shadow of Monir's possible other self that is represented in the character of Mohir whose name is strikingly similar to Monir's. Mohir is ostracized and mocked because she has more than one disability: she is blind, deaf and lame (91) but the girls also stand in awe of her because she is loud and angry and because she seems to have special powers (a sixth sense, 92). There is a hierarchy among the blind girls, all avoid Mohir and resent being touched by her. Monir never actually meets Mohir but the girls are described in a similar way: like Monir, Mohir is clever and seems to have no relatives (Monir avoids contact with her family). When the girls advise Monir to stay away from Mohir (her way of walking makes her presence audible), they seem to ask her stay away from an unpopular and uncanny version of herself. Monir does exceedingly well at school, she learns Braille very quickly (94-95), completes 5 classes in only a few months (96) and transcribes books together with her fellow student Laleh (97).

Despite her great accomplishments she is always subject to different forms of humiliation. She is sexually and emotionally exploited by Miss D, a sighted British senior staff member in her late forties (99). As becomes clear in the course of the narrative, Monir was not the only victim of such abuse. She suggests that Miss D targeted those girls who were isolated from their families and thus more vulnerable than others (101). From her belated perspective, the narrator externalizes her shame and writes an angry letter to Miss D in which she exposes her and complains about the abuse. As in the case of her address directed to her dead mother, the narrator speaks (or in this case writes) from a different historical position and her act of externalizing her shame is part of the larger project of writing *An Iranian Odyssey*. The letter is an imaginative, belated act of protest and resistance that did not exist at the time when the abuse happened, i. e. in the authoritarian, repressive atmosphere of the missionary school in the 1960s. Although the narrator mentions that she once became angry, shouted, banged the doors (and thereby resembles Mohir, the unpopular girl with multiple disabilities), she did not dare to talk about Miss D's abuse, possibly also because her own needs were closely intertwined with it, because she had let it happen for a long time and felt she was complicit (103-104): 'I could not talk to anyone about Miss D. I was too ashamed, guilty, confused, I bottled it up and it burned me inside' (104). The reference to the 'burning' aspect of shame here points to shame's connection with longing, desire, love and pleasure that is emphasized by Silvan Tomkins, Eve Kosofsky Sedgwick and Elspeth Probyn.

The letter to Miss D only exists as part of *An Iranian Odyssey*. In it, the narrator transfers her sense of guilt, her self-reproaches and her shame to Miss D, whose real persona might be among the readers of *An Iranian Odyssey*. However, even in this case, the affective impact of the text does not stop here. Again, as in the narrator's address directed to her dead mother, the text points beyond itself through *deixis* and the reader steps into the position of the sighted abuser:

> Letter to Miss D:

> I am writing to tell you about your evil deeds of the past. With this letter, I want to hand over the deep sense of guilt and responsibility which I have been carrying almost a quarter of a century. It is time now to hand it back to you […] The guilt and responsibility for your deeds has crushed me, suffocated me, destroyed me all this time, crippled me. […] It is pitiful, your wretchedness. Or maybe not. You deserve it. […] You left it all to me. You loaded all the anxieties on to me. […] You put me through hell. (97, 102, 106)

The letter unfolds a poetic, intensely emotional space in the narrative. It is semi-autonomous, related to and interrupted by the main autobiographical narrative in which the narrator gives background information about this period in the narrated 'I''s life, linking her experience to the inequality that was characteristic of the hierarchical relationship between female British staff members and female blind Iranian pupils. In addition, the main autobiographical narrative adds information about Miss D's personal life and circumstances. The letter is characterized by the very complex and volatile power dynamics of shame, comprising forbidden homosexual pleasure, guilt, vulnerability, disdain, emotional neediness, anger, reproach, disillusionment and disappointment:

> You used me. You abused me. I was vulnerable, needy. You understood that […]. You had power over me. I looked up to you. I had taken refuge in there, in you, in the Blind School – my only hope. […] You made me feel that you loved me. That I was special to you. […] I trusted you. I was hungry for that. To be loved. To be accepted. I had been searching for it all my life. Searching desperately. […] In return, you asked me for sexual pleasure and I gave it. It seemed a small price to pay for my needs, love and acceptance. I gave it unquestioningly, unreservedly. (98)

The descriptions of Monir's feelings, needs and desires as well as of the sexual acts are graphic, they are capable of attracting and feeding 'voyeuristic' readers' expectations of 'shameless' exposure, thereby implicating readers in the complex affective dynamics of shame that consists of (self)contempt, disdain, hatred, anger, interest, excitement and pleasure. In the fictional letter to Miss D that is disrupted by Monir's monologue, anger, disdain, (self)disgust, hatred and humiliation seem to dominate:

> I remember the feel of your hideous face and your hideous voice, your hideous large body, your hideous laughter, your hysterical screams. […] You did try it on other girls as well. At times they would talk about your wet kisses and prolonged holding of their hands and they would laugh and giggle and mock you for it. […] What was it about me that made her choose me? Was I dirty and horrible now? How naïve I was to be tricked. How stupid I was for not having recognized her intentions. Why did I not protest? How could I have allowed all this to happen to me? What did I do to deserve it? Was I basically bad? […] The evil power and stupidity on my part must have been at the core of it. The same bad power in me that had enabled me to dream my mother's death on the very night she died and my father's death just before he died. The evil aspect of myself was responsible for these events. […] I ought to be avoided. This experience made me hate women and myself for being a woman. (99, 102-103, 105-106).

However, the narrator also describes the narrated 'I''s sexual pleasure ('you would rub my body and touch my body and caress it, the more you did so the more relaxed I would become […] you would kiss, deep kisses, rubbing yourself against me' 101-102), her potentially shameful desire to be special, loved and accepted ('I was hungry for that. To be loved. To be accepted. I had been searching for it all my life. Searching desperately' 98) and her devastation when Miss D left:

> Now I understand why I became so deeply unhappy when you left the country for a holiday in England. I felt you had deserted me, that you had forsaken me. It was like a mother leaving the baby she was deeply attached to. I would cry and cry. […] The world had stopped for me. Life had stopped. Breathing at a standstill (104).

Although the narrator's speech acts of handing the responsibility for the abuse and humiliation as well as the guilt and shame connected with it over to Miss D is very powerful ('I am handing it back to you. It is time for you to take it on. You take it back. You deal with it. You carry it. It is yours. Back to you.' 97), the specific use of *deixis* suggests that the transaction does not lead to the solution of the problem, to justice or to closure. The fact that the narrator not only addresses Miss D but all sighted readers demonstrates that the acts of externalizing and transferring guilt and shame to someone or something else is ongoing, that it does not lead to an end of or triumph over shame.

Experiences of humiliation are very characteristic of Monir's time at the blind school, a place where pupils were made to feel they are 'the wretched of the earth', abandoned by their parents and their country and 'saved' by the British missionaries whom they owe obedient gratitude and where they were treated as ungrateful outsiders, as foreigners in their own country. Their Iranian habits of eating, cleaning, going to the toilet, their music and their food were denigrated, avoided by staff members who inhabited a separate world from that of their pupils (108-109). Here, Monir experiences humiliation both because she is blind (she is abused by Miss D) and because she is Iranian and a Muslim.

However, practices of humiliation are not limited to the blind school. Although her excellent results at school qualify Monir for her attendance of lessons at the regular state school, she is, together with other blind female students, ignored, belittled and treated harshly by misogynistic teachers (107). There is only one exception, a young, lively female biology teacher who talks about politics and feminism (107). Eventually, the blind girls become jealous of Monir's learning achievements and her attendance of a sighted state school (110). She must sleep in a room of her own and is afraid of being attacked by the other girls (110). At the same time, Monir makes new friends among the sighted girls at the state school. They admire how she copes with her blindness but Monir feels embarrassed by these comments because she cannot believe that she is really smart, having internalized the pervasive experiences of humiliation in her life (111, 112). She is taught to use a type writer by Mama (112) and is able to communicate with her Teheran friends because her blind school buys a Farsi type writer (113-114). In this way, she finds new penfriends and experiences the pleasures of communicating through writing (115). She is celebrated at her school and her achievements are praised (albeit in a way that represents these achievements as the outcome of the staff's excellent training, 118). However, Monir cannot believe that she is an excellent student and feels embarrassed at her own style of letter-writing, struggling with her sense of unworthiness (115-116). She is self-conscious among sighted people, being afraid she that her manner of holding cutlery is incorrect. She feels she cannot be one of her sighted friends' family members, no matter how kindly they treat her (116).

The topics of her first stories written in Braille are related to illness and disability but also to social inequality, wealth and poverty, power and powerlessness (117). She writes about a boy who was ill and died. Thereby, she gains the bishop's attention (117). She reads her story in front of others, writes a play, directs and acts it successfully. As a reward, she is invited to the English bishop's house. Despite her achievements, the bishop treats her an inferior being because of her cultural and religious difference. As a result, Monir is embarrassed and feels like an outsider. The bishop's goal is to baptize her, his choice of words (baptism, not conversion) suggests that he, in line with the traditional view of the Anglican church, does not regard Islam as a religion in its own right but as heresy (118). When Monir contradicts the Christian doctrine of turning the other side of the face after having received a slap, her Christian teacher shames her and forces her to apologize in public (119).

The repeated experiences of humiliation cannot prevent her academic success: she achieves excellent results in the national university entrance exam and is accepted at Isfahan university and Teheran university for a course of studies in psychology (120). The national papers report about Monir's achievements: she is the first blind woman to attend university in Iran but the school staff uses Monir's success as part of an image campaign for the Anglican church (120). When she attends Teheran university, her small share of fame is of no help (123): she has difficulties to find a room because she is blind. She lacks connections and encounters discrimination and ostracization. She receives no support from the bishop because she refused to convert to Christianity (123). When she is asked to tea at the ambassador's house, she feels ashamed and out of place. She is forced into the stereotypical role of the passive, poor disabled girl ('a puppet'), a part she deeply resents:

> I counted the minutes in my head, and sat there deaf and dumb as well as blind, hearing the refined voices and accents all around me […] when the ambassador came in, I wished the ground would open up and swallow me. […] I felt like a puppet. It heightened and confirmed my experience as an outsider. […] during that time it seemed I had to perform. I had no control over my life […]. I was alone, I did not know how to cope with the sudden fame. The irony was that this suddenly famous person did not have anywhere to live, did not have the right study equipment, such as a type writer, a tape recorder […] and did not have the money to pay her fees or her living costs. (123-124)

Eventually, her school sends her a type-writer and tape recorder and she gets a teaching job through which she pay her fees (128). The conditions for her are unfair, she does less well in exams than she could have done under better circumstances (129). Monir is not the only female student who struggles: many female students don't get enough to eat and do not have enough energy to study (130). Monir finally gets a place in the hall of residence at the university through the Dean's influence (132). When the Dean learns about her difficult situation, he is ashamed that there are such grave problems at his university (132). Due to his intervention, Monir is allowed to pay the university fee after starting to work as a psychologist. In addition, the Dean offers her help through his secretary (132). She gets a single room because of her special needs. Still, she is not a ‘normal’ student, her capacities are either under- or over-estimated, she is patronized or supposed to have magical powers (133-134). She realizes that she lives among well-to-do people now and knows that most people cannot afford this lifestyle. She meets a very unhappy black nanny who is degraded and abused by her employer because of her skin colour (135-136).

In the final part of the book, the narrator recounts the growing political tensions in Iran, thereby providing the political background of her decision to migrate to the UK. She discusses Iran’s growing dependence on US-American economy and imports, arguing that this dependency destroyed Iranian self-sufficiency. As a consequence, it led to bad working conditions and the increase of child labour and prostitution in Iran (136). In addition, she recounts that more and more people were abused and disappeared during the growing autocratic tendencies of the Shah’s regime and that workers and students who protested for equality, freedom and justice were shot (137-139). The narrator emphasizes that the goals of the Shah’s White Revolution (land reform, redistribution of wealth, enfranchisement of women, literacy campaign, modernization of industry) were jeopardized and eventually betrayed. While the Shah celebrated the 10th anniversary of the Revolution in 1971, many of his subjects were starving (140).

On the final page of the book, Monir travels to Isfahan and overhears two men discussing a political show that she knows well and she wants to talk to them (141). However, she doesn’t dare to speak, fearing they could refuse, reject and ridicule her. Monir recounts her confusing feelings that oscillate between desire, interest and fear of rejection:

> I longed to talk to them about it. ‘I know it.’ ‘I’ve heard it’ ‘I love it. I understand it.’ I could not bring myself to talk to them. I was petrified they might refuse me, reject me, ridicule me, and yet I felt they were such nice people. I was in such a dilemma. My feelings were confusing. Such strong feelings, wanting to communicate with them, the feeling that they were nice people, and yet the counter-feeling that they would refuse me, ridicule me. I struggled with these feelings all the way, the whole journey, and for a long time to come. (141)

The repetitive forward and backward movement of the narrative that depicts the oscillation between fear and desire offers productive connections with other narrative events of shame that the narrator experiences. The men offer to take her to a destination with a taxi but Monir cannot trust them: she longs for their company but fears they cannot accept her as a person:

> I could not trust them, they could not have accepted me as a person. I longed for their company, and yet I could not accept their offer. It left me burning inside with conflicting, strong feelings. […] This remained with me a very long time, I could not unravel it, understand it, make sense of it. (141)

The pervasive, lasting, conflicting, burning feeling that the narrator describes but cannot make sense of might be described as shame, as a lasting sense of her own worthlessness. King calls this passage an ‘unvarnished vignette’[191] and argues it is about Monir’s inability to trust strangers in an autocratic political climate of surveillance and about abuse and longing. However, shame is not mentioned in her reading (459). King does not comment on the fact that Monir’s inability to trust is based on her fear of derision, of being rejected and ridiculed. Her mistrust is represented as part of the political atmosphere of the Shah’s autocratic regime but it also links up with the shame and humiliation that Monir experienced after becoming blind, a shame that she has internalized.

In the last sentence of the book, the narrator laconically states that she graduated from Teheran University in 1970 with a degree in psychology. It may signal a victory, a stubborn triumph, but it is not represented in this way. Instead, Kordi ends her text with a juxtaposition of accomplishment and lack of (self-)trust, with an emphasis on the persistent nature of intersectional forms of shame that are entwined with Monir’s success and fame.

Conclusion

As this analysis shows, the structure of Kordi’s text is shaped by shame as a narrative affect. On the one hand, the humiliating attributions of stupidity, helplessness, neediness and uselessness that Monir experiences in her encounters with her mother and brother function as a stimulus to prove them wrong: her ‘unlimited appetite and […] intense urge for learning’ (97) and achievement drive the plot forward and lead to academic success. On the other hand, the text shows that although Monir’s success disproves the attributions of ‘stupidity’ and worthlessness, they do not lead to a triumph over shame but to a proliferation of intersectional experiences of humiliation. They manifest as pressure points that punctuate the forward movement of the plot. Furthermore, *An Iranian Odyssey* is characterized by its emphasis on embodied relationality: ‘Writing divulges secrets, repairs hurt, garners authority, and also stimulates imagined understanding with readers who, in ‘‘looking’’ at the story of Kordi’s life, might become ‘‘friends’’’ (Mintz 2003, 149).[192] Kordi’s autobiography contains narrative strategies that enable readers to become co-witnesses of intersectional forms of humiliation and injustice and to identify with the narrator, especially through the use of affectively intense narrative scenes, events and experiences of shame in which the narrator is restrained and hidden away in shame and subjected to devaluation and abuse by her mother and brother. However, Kordi’s autobiography also challenges identificatory reading practices by using narrative strategies that transfer shame to its sighted readers, placing them into the position of the sighted humiliator (Monir’s mother

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[191] King argues that Kordi’s book is ‘fraught with nostalgia that seems guilt ridden and laden with dilemmas’ and ends with the narrator desiring very deeply to trust but ultimately chooses not to (2015, 459).

[192] According to Mintz, Kordi’s autobiography suggests ‘that readers might function for the autobiographer in the same way that a group of congenial listeners engaged in daily tasks can draw forth the intimate narratives of one another’s lives’ (2003, 148). Mintz agrees with Nancy Mairs who emphasizes the universal appeal of life writing (life writers who imagine a ‘“you” there listening’ reconnect themselves with ‘“the human community”’) but she also argues with Leigh Gilmore that readers of autobiography do not look ‘“for the universal but for the specific, the unexchangeable”’ (Mintz 2003, 148).

or Miss D). Hence, it employs shame as a forceful, ambivalent narrative strategy whose relational grammar comprises, but is not limited to, empathy, amicability and solidarity.

In addition, *An Iranian Odyssey* demonstrates shame's inseparable connection with positive affects (interest / excitement; joy / enjoyment / pleasure). It describes non-normative positivisms: the pleasures of establishing relationality / community through physical touch are not merely compensatory, e. g. when Monir is embarrassed by as well as enjoys the curious tactile contact of the other blind girls at the blind school who call her beautiful (86).[193] At the same time, Kordi's text shows that physical contact can be very uncomfortable and even life-threatening, e. g. in the depictions of Monir's experiences of being almost suffocated by the 'curtain of darkness' when tied to the bed during her illness, of being pulled towards a hole by her mother and of being beaten by her brother (8-9, 61, 71). It demonstrates that the pleasures of touching and being touched are highly ambivalent: they can involve inequality and exploitation and induce excruciating shame as in the case of Miss D's abuse of Monir's neediness and desire for love and acceptance (98). Even in this context, however, the pleasures of touching and being touched as well as the relaxation connected with them are not absent, a fact that causes considerable guilt in Monir as well as shame for 'being stupid', for not recognizing Miss D's exploitative intentions and for not protesting against the abuse when it happened (98, 101-102, 105).

Kordi's autobiography challenges shame-inducing norms related to blindness, female desire, ethnicity, confession and class (Mintz 2003, 149), an aspect that is also characteristic of Kordi's short autobiographical text 'I Was Touched' that is included in Lois Keith's 1994 anthology *Mustn't Grumble*. There, Kordi expands on the non-normative pleasures of touch, describing how her desire of touching and being touched adds a layer of (inter-)cultural shame after her migration to the UK. However, despite their critique of structural shame-inducing practices and their emphases on shame's connection to pleasure, neither 'I Was Touched' nor *An Iranian Odyssey* suggest a triumph over shame.

4. Audio-Visual Performance

Mary Duffy's Performance as Venus De Milo

Irish disability artist Mary Duffy's performance as Venus de Milo, which includes an autobiographical monologue, has met with a great amount of critical attention, yet its complex use of shame and humiliation as aesthetic performance strategies has not been discussed in depth. In this section, I demonstrate that Duffy uses shame and humiliation as volatile as well as complex aesthetic strategies with an impressive transformational energy. Rosemarie Garland-Thomson describes Duffy's work fittingly as an 'autobiographical form of feminist disability performance art'.[194] The performance was part of a disability studies conference in Michigan in 1995. A videotaped version

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[193] The positive affect that shame interrupts most frequently is love / the joy of sociality / relationality, of being connected and accepted, see Kosofsky Eve Sedgwick 1993, 5, 7-8, 11-12; Sedgwick and Frank 1995: 134-139.

[194] Rosemarie Garland Thomson: 'Dares to Stares: Disabled Women Performance Artists and the Dynamics of Staring', *Bodies in Commotion: Disability and Performance*. Ed. Carrie Sandahl and Philip Auslander (Ann Arbor: University of Michigan Press, 2005) 30-41, 39.

is included in Sharon Snyder's and David Mitchell's documentary *Vital Signs: Crip Culture Talks Back* (Duffy 1995).[195] Duffy performs with her disabled body, re-signifying it as an art object (a new version of Venus de Milo) that emphasizes its unique physicality, beauty and sexual energy.[196] As Lynda Nead has remarked, Duffy's writings, tape-slides and performances represent an intervention in the normative depictions of '[d]esirable femininity' that 'does not take the form of a disengagement of the female body from the visual economy; rather, it involves the insertion of different women's bodies that call into question prevailing norms and expectations'.[197]

Duffy's spectacular use of visuality and corporeality, her forceful practice of revealing what is hidden in ableist society and what is objectified and passivized by the male heteronormative gaze (Garland-Thomson 2005, 33-34), has been appreciated by a great number of critics. Ann Millett-Gallant writes: '[w]hereas much feminist-inspired performance and body art has objected to displays of the female body as a site of infinite desire and possession, Duffy confronts a sexual economy from which her body has been excluded, rejected, and made freakish'.[198] Lynda Nead quotes Duffy's description of her 'identity as a woman with a disability', defining it as 'strong, sensual, sexual, fluid, flexible and political'.[199] Millett-Gallant has argued convincingly that Duffy's performance daringly re-defines classical notions of female beauty and represents the disabled female body as active, vibrant and vulnerable: 'Duffy's body as the armless nude invoked the Classical Venus de Milo, while at the same time offered itself as a vulnerable human being and naked, medicalized specimen' (2010b, 25). Importantly, this representation of corporeal vulnerability questions medicalized ideas of perfectibility, cure and repair. As Lynda Nead has demonstrated, Duffy's performance as Venus de Milo challenges Peter Fuller's psychoanalytic (Kleinian) reading[200] of the damaged forms of antique Roman statues as 'condensed statements of classical principles of ideal beauty' whose fascination partly lies 'in their allowing imaginary reconstructions of the once complete figure' (Nead 1992, 78-79). In contrast to Fuller's focus on the spectator's 'need to repair and complete the form', Duffy 'rejects the conceptualization of her body as incomplete', showing in her art that it is 'whole, complete and self-bounded' (Nead 1992, 79).

I will demonstrate that Duffy's performance uses the affective power dynamic of shame and humiliation by affirming non-normative pleasures and by working with the visual economics of the voyeuristic gaze that centres on female sexuality and non-normative female beauty. The performance is defined by the 'residual positive wish' informing

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[195] The video is included in a documentary by Sharon Snyder and David Mitchell: Sharon Snyder and David Mitchell: 'Vital Signs: Crip Culture Talks Back Part 2'. Web. 28 Aug 2013. <https://www.youtube.com/watch?v=P23ov4QVHhI&t=724s>. Access 12 March 2021. On a discussion of Duffy's video see Garland-Thomson 2005, 37.

[196] Rosemarie Garland-Thomson: *Staring. How We Look* (Oxford: Oxford University Press, 2009) 135.

[197] Lynda Nead: *The Female Nude. Art, Obscenity and Sexuality* (London / New York: Routledge, 1992) 77.

[198] Ann Millett-Gallant: *The Disabled Body in Contemporary Art* (New York: Palgrave Macmillan, 2010) 39. This publication will be referred to as Millett-Gallant 2010b below.

[199] Hilary Robinson: 'The Subtle Abyss: Sexuality and Body Image in Contemporary Feminist Art' (Unpubl. MA Diss., Royal College of Art, 1987) 124; Mary Duffy: 'Cutting the Ties that Bind', *Feminist Art News*, 2.10 (1989): 6-7.

[200] Peter Fuller: 'The Venus and "Internal Objects"', Peter Fuller: *Art and Psychoanalysis* (London writers and readers, 1980) 71-129.

shame, that is, the desire ‘to look at the other rather than look down’ and ‘to have the other look with interest or enjoyment rather than with derision’ (Sedgwick and Frank 1995, 137-138). As the critical responses by Nead, Garland-Thomson and Millett-Gallant show, Duffy’s performance comprises ‘non-normative positivisms’, to use David Bolt’s term, that is, ‘affirmed deviations from socially accepted standards’ that depart from ableism and disablism (Bolt 2015, 1107). Importantly, Duffy’s use of the tradition of visual art self-consciously positions her specific female disabled body in an aesthetic sphere, thus distancing it from the creation of body norms.

Critical reception of Duffy’s performance tends to emphasize its victory over / mastery of (internalized) disability-related oppression and shame, perceiving it as an art practice that liberates the female disabled staree from her passivized position as object of the stigmatizing, medicalizing gaze. According to Rosemary Garland-Thomson, ‘performances are forums for profoundly liberating assertions and representations of the self in which the artist controls the terms of encounter’ (2005, 33). Duffy’s performance as Venus de Milo invites her ‘starers to consider armlessness as a proper form of beauty rather than insufficiency or disfigurement’, asking ‘her audience to convert the baroque stares they bring with them off the street into the reverential stares they would bring to the Louvre (Garland-Thomson 2009, 135). Garland-Thomson continues:

> By presenting herself as a work of art, Duffy repudiates the reading of her body as a pathological specimen. She instructs her starers how to stare at her, then delivers a soliloquy instructing them how to think of her. She tells them simply that she is ‘whole, complete and functional’ (2009, 135).

Garland-Thomson’s reading of Duffy’s art emphasizes the moral re-education of audiences and their staring practices, thereby capturing a highly significant aspect of her work. However, Duffy’s autobiographical monologue that is part of the performance shows that this re-definition of her body as a different, unique form of female beauty is far from simple, not least because it problematizes experiences of disability-related shame and because it uses shame and humiliation as affective performance strategies. She angrily asks herself and her audience:

> How come I always felt ashamed when answering those big staring eyes and gaping mouths? ‘Did you have an accident? Or did your mother take them dreadful tablets?’ With those big words those doctors used, they didn’t have any that fitted me properly. I felt even in the face of such opposition that my body was the way it was supposed to be, that it was right for me as well as being whole, complete, and functional. […] Today, I’m winning battles everyday against my own monster – my inner critic who has internalized all my childhood oppressions. The oppression of constantly trying to be fixed, to be changed, to be made more whole, less visible, to hide and to be hidden. (Snyder and Mitchell 12:33, 12:55)

As Ann Millett-Gallant has argued, Duffy speaks

> about her experiences as a disabled woman and artist, particularly about feeling corporeally shamed, desexualized, and dehumanized through diagnosing gazes, intrusive questions, and demeaning assumptions. […] she chose to be

> nude in these performances to explore the vast dimensions and dynamics of voyeurism (2010b, 39).

Like disability artists Cheryl Marie Wade and Lezlie Frye, Duffy flaunts her extraordinary body and strategically invites the voyeuristic, potentially stigmatizing gaze (Garland-Thomson 2009, 136; Garland-Thomson 2005, 33). She uses its affective intensity in her attempt to a de-stigmatize non-normative forms of embodiment, thereby pillorying practices of ostracizing and hiding non-normative bodies. By problematizing her feelings of shame and anger / rage[201] in response to the stigmatizing gazes and medicalizing labels she received as well as by referring to her internalized childhood oppressions, she bears witness to them, demanding her audience to do the same. However, Duffy not only gazes and talks back to starers, as Ann Millett-Gallant has argued (2010b, 27). She uses shame as a power strategy, shaming the starers she was confronted with in her past but also her (live) audience, addressing their ‘big staring eyes and gaping mouths’, calling them out on their practices of staring, holding up ‘a mirror to all those people who had stripped me bare previously […] the general public with their naked stares, and more especially, the medical profession’.[202] Considering Duffy’s use of the complex power dynamic of shame, it is questionable whether her performance can be adequately described as a direct repudiation of shame and oppression (Garland-Thomson 2009, 135) or through the notion of an aversion before disability that is itself averted (Siebers 2016, 151).

In addition to her focus on Duffy’s repudiation of readings of her body ‘as a pathological specimen’, Rosemarie Garland-Thomson emphasizes the directly liberating dimension of a full disclosure of female disabled bodies in performance:

> going for full disclosure is a liberation not from the stares themselves, but from an internal image of herself [i. e. Duffy] as deficient. By using public performance to determine the terms on which they are seen, these women [i. e. disability artists Cheryl Marie Wade and Lezlie Frye] remake their own images. At the end of their performances, they expect their audiences to be seeing them differently. […] they are not victims in these performances, but intentional meaning makers. (Garland-Thomson 2009, 139)

Ann Millett-Gallant makes a similar point: ‘[…] in Duffy’s example, performance as a freakish Venus becomes a means to intrude upon and liberate herself from histories of oppressive representations of women and disabled women specifically’ (Millett-Gallant 2010b, 37). She argues that Duffy reclaims

> her right to be seen naked while posing in the nude, as she provides a particular confusion [of] the naked/nude dyad. The nude is poignantly an idealized form

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[201] On the importance of rage as part of the performance see Tobin Siebers: ‘In/Visible: Disability on the Stage’, *Body Aesthetics*. Ed. Sherri Irvin (Oxford: OUP, 2016) 141-152, 150.

[202] Duffy writes: ‘By confronting people with my naked body, with its softness, its roundness and its threat I wanted to take control, redress the balance in which media representations of disabled woman is usually tragic, always pathetic. I wanted to hold up a mirror to all those people who had stripped me bare previously […] the general public with their naked stares, and more especially, the medical profession.’ Mary Duffy: ‘Redressing the Balance’, *Feminist Art News*, 3.8 1991, 15, qtd. in Nead 1992, 78. Interestingly, Garland-Thomson argues that Duffy’s ‘upbraid[s]’ starers. Furthermore, she argues that disability performance artists like Duffy ‘cast an evil eye upon their audiences’, see Garland Thomson 2005, 37, 40.

> and is often falsely differentiated from the state of being naked, […] which is associated with shame and with a real body or social subject exposed for the scrutiny of the gaze/stare, as well as with a medical specimen (Millett-Gallant 2010b, 39).

Millett-Gallant explicitly links Duffy's stylized body to the naked body that is free from shame, that 'may reject the very pretenses of nude versus naked' and 'suggest[s] a freedom from shame or a state of unashamed truth', thereby emphasizing a mastery of shame through performance (39).

When applied to Duffy's performance with its use of the complex power dynamic of shame, the notions of a liberation from oppression or of 'exorcizing the oppressive language' are not fully adequate (Garland-Thomson 2005, 37). Duffy's performance (a multimodal monologue discussing experiences of shame and humiliation) links visual impact – a combination of erotic pleasure, astonishment, threat, shock, uncanniness, aggression / rage, aversion[203] and shame-related discomfort – to a verbal discourse that explicitly problematizes the performer's *ongoing process* of struggling against her shame, against her internalized ableist critic. In addition, it transfers shame to viewers, involving them in the complex power dynamic of shame, that is, in its captivating, mesmerizing pleasures (the eroticism of non-normative female bodies), its contagious energy (its ability to evoke shame or vicarious shame in audiences) and its capacity to shame the starer. Hence, instead of directly mastering shame, Duffy's performance works *through* and *with* shame as an affective performance strategy.

Garland-Thomason's emphasis on intentional meaning making in disability art performances merits a critical discussion. The fact that artists like Duffy understandably emphasize their control over the ways in which their bodies are represented (especially considering the long history of visual objectification of disabled bodies) does not imply that a specific response of audiences can be fully intended or that it can be summed up as the goal to 'turn common starers into appreciative audiences' (Garland-Thomson 2009, 178). From the perspective of cultural and literary affect studies, the topics of author and performer intention and meaning making in art and media reception become highly complex because affect is not inherent in subjects (author, performer, reader / audience) or art works / media products. Rather, affect (like meaning itself) evolves *between* audiences and art works (as well as between individual audience members). As such, affects, agency and meaning are always co-created, they cannot be controlled by either of the participants in processes of artistic creation and reception.[204] Audience response to performances, especially to those that use the 'free radical'[205] shame as an aesthetic strategy, can hardly be fully intended or controlled by the performer. Admiration and appreciation of non-normative bodies are certainly interpretive ethical positions that are generated by Duffy's performance,

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[203] On the importance of rage, aversion and uncanniness as part of the performance see Siebers: 2016, 150-151.

[204] Doris Kolesch and Hubert Knoblauch: 'Audience emotions.' *Affective Societies. Key Concepts*. Ed. Jan Slaby and Christian von Scheve (London and New York: Routledge 2019) 252-263, 256, 259-260; Margret Lünenborg, et al.: 'Affekte als sozial-relationales Phänomen medialer Kommunikation. Affekttheorien für die Medienforschung nutzbar machen', SFB 1171 Affective Societies Working Paper 1 / 18 (Berlin, 2018) 11, 2, 14-17. Web. 16 Jan. 2020. <http://www.sfb-affective-societies.de/publikationen/workingpaperseries/wps_11/index.html>.

[205] Kosofsky Sedgwick 1993, 12.

especially so in the academic, activist audience at the disability conference where Duffy performed. Garland-Thomson has drawn attention to the fact that Duffy works in a theatre space which 'restricts interaction between viewer and viewed' (Garland-Thomson 2005, 38). However, admiration and appreciation are not the only possible affective audience responses. Shame, vicarious shame, anger / rage[206] and voyeuristic fascination / curiosity are affective dispositions that are not only problematized in Duffy's soliloquy but are also characteristic of the affective dynamic of the performance and its reception. My analysis of the roles of shame and humiliation as affective strategies in contemporary performances by female disabled authors on social media and of viewers' responses to them shows that this dynamic is heterogeneous, contradictory and highly ambivalent.[207] The fact that Duffy's performance was videotaped and included in Snyder's and Mitchell's documentary that is available on YouTube is significant in this context. Unfortunately, however, the videos hardly received comments and so a broader audience response is not visible. However, the few comments that are accessible already point to a very heterogeneous reception which includes both admiration and voyeurism. As I hope to have shown, Duffy's performance is powerful, audacious, sublime and exalted, enabling a new perspective on female disabled bodies precisely because it works *through* the affective power dynamic of shame / humiliation rather than by erasing or overcoming it.

General conclusion

As my close readings have shown, the texts that use shame and humiliation as narrative affects discuss primarily physical and sensorial disabilities (in the case of Sue Norris's poem a developmental disability).[208] Not all texts depict autobiographical narrators' non-normative bodies (their pain, dysfunction, infirmity and illness) as significant causes of their experiences of shame. In Campling's collection, only 4 out of 11 texts do so (the texts by Julie, Elsa, Sue, Merry and Maggie), *Pride Against Prejudice* and *Bigger Than the Sky* each contain 1 example (the excerpts from McIntosh's text and the text by Jill Daly). Most of the examples I have analysed in this paper show that narrators' experiences of shame are generated in response to external causes, that is, mundane humiliating encounters with their social environments, comprising doctors', nurses', teachers', family members', colleagues' as well as strangers' prejudices and structural practices of disability-related discrimination. The texts in Campling's collection demonstrate that it is not autobiographical narrators who separate themselves willingly from the rest of society or see themselves as fundamentally 'different' from it but that a large part of their social environment define them as such. Morris's *Pride Against Prejudice*, by contrast, posits a binary opposition between disabled and non-disabled people.

Most of the texts analysed in this working paper emphasize the contingency of connections between shame, bodies and their aids (wheelchairs, canes etc.) and social and cultural environments. Furthermore, they describe the transference of shame to textual others, the transformation of shame into anger, outrage, protest, resistance, love, solidarity and sometimes pride. Hence, they loosen and sometimes

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[206] On the importance of rage as part of the performance see Siebers 2016, 150.

[207] I will provide this analysis in a subsequent section of this research project.

[208] *Mustn't Grumble* contains a text by Pam Mason on agoraphobia that is not centred around shame and humiliation.

sever the affective connections between disability, femininity and shame. The collections, monographs as well as Mary Duffy's autobiographical performance address disabled and non-disabled readers (in Duffy's case viewers), especially feminist readers / viewers. Their use of shame as a narrative strategy (and performance strategy in Duffy's case) turns disabled and non-disabled readers (and in Duffy's case viewers) into affective co-witnesses of audacious representations of structural (often institutional) practices of disability-related shame. The texts also invite reader responses of empathetic identification with the shamed disabled narrator (see the texts by O'Sullivan, Elsa Beckett, Jenny Fulton, Gohar Kordi 1993, 1994 and Mary Duffy 1995) but their impact is not limited to emotional identification. Rather, the texts encourage readers to critically reflect on narrative events and scenes of shame, they emphasize the contingency of shame-inducing practices, prejudices and body norms and the desire, need and possibility to challenge them. In addition, the texts by Kordi (1993) and Duffy (1995) transfer shame to non-disabled readers and viewers: in *An Iranian Odyssey*, the narrators' speech acts of accusation address absent textual others as well as sighted readers that function as proxies for Monir's mother and Miss D.

Few texts show or problematize a linear or lasting transformation of embodied shame into pride. Elsa Beckett's text explicitly rejects this plot structure. If a transformation of shame into pride is described, disability pride is depicted as an abstract political category (e. g. in the text by Micheline Mason) that does not focus on embodied aspects of disability / chronic illness. Jenny Fulton's 'Journey' depicts the division of the narrator's self-image into a proud political part and an ashamed embodied one. Mary Duffy's poem 'Making Choices' describes embodied self-love rather than pride. Her performance as Venus de Milo depicts the *ongoing* struggle against internalized shame rather than the pride of having mastered it. Only Nasa Begum's and Rowen Jade's texts allude to their narrators' proud disabled identities but do not provide detailed descriptions of these states of pride. Kordi's *An Iranian Odyssey*, although starting with the young narrated 'I''s proud triumph over humiliation, shows that this triumph is an illusion (7). Both Kordi's book-length autobiography and her short text 'I Was Touched' are informed by a proliferation of narrative events depicting intersectional forms of shame. However, Kordi's texts show that their narrated and narrating 'I's explore, but are not disempowered by, the impact of repeated practices of humiliation.

In contrast to *Images of Ourselves* and *Pride Against Prejudice*, a number of texts from Lois Keith's anthology contain detailed descriptions of experiences of pain, physical weakness, infirmity and mental distress (e. g. Molly Holden's poem 'Pain Teaches Nothing', Pam Mason's text 'Agoraphobia: Letting Go' and Maria Jastrzębska's poem 'Friends'). Especially in the contributions by O'Sullivan, Fulton, Duffy and Kordi, narrators' non-normative bodies (their infirmity, impairment, 'incompleteness', fragility, physical weakness, dysfunction and deterioration) are shown to give rise to intense shame. In some cases, narrative / poetic strategies transform shame into love and solidarity (in the texts by O'Sullivan and Duffy) or make readers desire a disruption of and resistance against the paralyzing impact of shame (see the text by Fulton). However, texts that directly aim at a displacement of shame ironically conjure up its powerful spectre through their use of affective emotion words (see the contributions by

Keith and Macfarlane). ‘I Was Touched’ by Gohar Kordi critiques intercultural shame-inducing norms and practices and at the same time explores shame’s persistence and ambivalence, its generation of pain and (at times non-normative) pleasure.

The great majority of works analysed in this working paper lack sensational, spectacular representations of female disabled bodies that might attract voyeuristic readers / audiences. However, many texts contain descriptions of disabled women’s sexuality, illness, incontinence, infirmity, physical deterioration, impairment, pain or physical weakness (see the texts by Julie, Elsa Beckett, Sue, Jenny Fulton and Gohar Kordi). They are, however, less detailed and less graphic than in many of the texts analysed in work packages 3 and 4. Mary Duffy’s spectacular performance stands out as a cultural text that offensively invites, refracts and transforms the voyeuristic gaze through the use of shame and humiliation as performative narrative strategies.