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Introduction
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An ongoing project on interdisciplinary approaches to disability has grown from a brief exchange of e-mails between one of us, a professor of psychology and disability studies, and the other, a lecturer in disability studies and editor of a journal that focuses on literary and cultural studies of disability. The outcome of the exchange has thus far been twofold, both elements going under the title *Theorizing Culture and Disability: Interdisciplinary Dialogues*.

Firstly, in 2008, a conference was organized by the Research Institute of Health & Social Change and the English Research Institute at Manchester Metropolitan University, in association with the *Journal of Literary & Cultural Disability Studies (JLCDS)*. Tom Coogan and Suzanne Ibbotson chaired the international event, which hosted papers by Lucy Burke, Stuart Murray, and Irene Rose, as well as heralding five of the six articles that are included in this issue, and launching Stuart Murray's book series, *Representations: Health, Disability, Culture* (Liverpool University Press).

Secondly, in editing this special forum, we have joined forces with colleagues in the humanities and the social sciences – namely, Lucy Burke, Senior Lecturer in English at Manchester Metropolitan University, Rebecca Lawthom, Reader in Community Practice at Manchester Metropolitan University, and Rebecca Mallett, Senior Lecturer in Disability Studies at Sheffield Hallam University. The five of us have worked as a team throughout the editorial process in an endeavour to provide a multidisciplinary perspective on the topics of impairment and disability.

Hitherto, the relationship between disability studies and literary and cultural studies has, at least in the UK, been a weak one. While elsewhere scholars such as Lennard Davis, David Mitchell, Sharon Snyder, Rosemary Garland-Thomson, Rod Michalko, James Overboe, Tanya Titchkosky and Susan Wendell have forged critical links between the humanities and the development of social theories of disability, analyses in the UK and other minority world contexts such as the Nordic countries and Australasia have tended to centre around the social sciences, particularly sociology, education, and social policy. While there have been attempts to colonize other disciplines with disability studies, such as psychology (e.g., Goodley and Lawthom's (2005) edited collection *Disability and Psychology*) and literary studies (e.g., *JLCDS*, Liverpool University Press, founded in 2006), cultural and literary disability studies tend to reside on the periphery of debates outside the US. *JLCDS* and developments such as the Centre for Culture & Disability Studies, provide critical spaces to merge cultural and social scientific foci which, as demonstrated in this special forum, retain the sociocultural and political aims of a critical disability studies. An under-girding aim of all the articles presented here is that disability must be analysed as a social and cultural phenomenon, which says as much about normalizing/non-disabled society as it does about the constitution of disability. Indeed, in the current economic climate, the need for analyses of disablism in everyday cultural life is arguably more necessary than ever.

The interdisciplinarity of this issue becomes apparent in many ways, as a common interest in disability studies is combined with an array of other disciplines – most obviously,

cultural studies in Rebecca Mallett's response to contemporary British comedy, postcolonial Studies in Clare Barker's reading of Salman Rushdie's *Midnight's Children*, literary studies in Brett Smith's Bakhtinian exploration of research boundaries, media studies in Alison Wilde's investigation of attitudes toward television soap opera, queer studies in Kateřina Kolářová's discussion of pain and desire in the work of Bob Flanagan and Sheree Rose, and marketing studies in Elizabeth DePoy and Stephen Gilson's analysis of design and branding. The result is an exciting one precisely because we are reminded of the intersections of subjectivity, culture and society but also of the interconnections that disability studies must make with other transformative, trans-disciplinary and radical writings. Disability remains a complex cultural phenomenon. The articles in this special issue draw attention to the ways in which understandings of disability can never be separated from other analyses of marginalization and oppression.

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Claiming Comedic Immunity
Or, What Do You Get When You Cross Contemporary British Comedy with Disability
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Abstract: This article addresses the mechanisms by which contemporary British comedy about disability is *allowed* to be funny. It argues that the available academic literature on the phenomenon is scant and a critical public vocabulary missing.

Key Words: comedy, cultural criticism, tolerance.

“In the Cultural review we see,
Matt coughing and wheezing untruthfully.
After pushing Russell into a wheelchair
and claiming comedic immunity”
(“Blame it on the Booties,” September, 2007).

The quotation in the title of this article is taken from a poem in *The Russell Brand Show* broadcast on BBC Radio 2 on a Saturday in September 2007.¹ At the end of each two-hour show Mr Gee, the resident poet laureate, recites a poem he has written during the course of the broadcast. This particular poem relates to an anecdote told on the show about an incident the previous week when Matt Morgan (Russell’s co-host) had to wheel Russell through an airport. The anecdote was followed by a conversation about whether that situation was *allowed* to be funny, resulting in the couplet quoted above.

As an intervention in that conversation and as part of thinking through the theorisation of culture and disability, this article addresses the mechanisms by which contemporary British comedy about disability is allowed to be funny. Its primary concern is not to answer in terms of essential comedic characteristics, but rather in terms of current discursive possibilities, in both wider public discourse and in the contracted world of the academy. This article will argue that, despite the comedic use of disability appearing to be increasingly conspicuous, not only is the available academic literature on the phenomenon scant but a critical public vocabulary is also missing. It suggests further that an impact of such neglect is that comedy’s claim for immunity in relation to how it treats disability remains publically unchallenged and theoretically unproblematized (a situation not mirrored in terms of race, gender or sexuality).

In an attempt to move beyond this impasse, rather than advocate the merits of an alternative disciplinary field, the article positions the second part of its title (what do you get when you cross contemporary British comedy and disability) as a question demanding facilitation from a range of disciplinary toolboxes. Concentrating on the British versions of two television series, *The Office* and *Little Britain*, the article utilizes tools from existing work on television comedy and identity, as well as from disability-orientated work that has already begun to reap the rewards of interdisciplinary dialogues. The article illustrates the benefits of taking the cultural theorisation of disability seriously and, in doing so, demonstrates the necessity of being promiscuous and suspending established academic boundaries. In this instance, it suggests that by broadening its current scope, British disability criticism can avail itself of alternative perspectives on topics at the very heart of its project. In turn, the significance of such interdisciplinary dialogues is firmly established.

The Comedic Use of “Disability”: The Case of Contemporary British Television

Laughing at disability is anything but new. On British television, for instance, Ronnie Barker made much merriment from a stutter in *Open All Hours* and played a visually impaired character in *Clarence*, while other television sitcoms, such as *The Young Ones*, were happy to deploy words such as “spaz” and “spasy” (Barnes, 1991). Despite a long and varied history, at this cultural moment it does appear that the comedic use of disability is increasingly conspicuous. This is not to say that disability is being used more (to be supported this observation needs meticulous research), but rather that more recent comedic offerings demand attention because the disability element is unmissable and therefore its presence seems somehow different. A brief overview of a handful of British shows, all of which had their television debut within the past eight years, reveals just how prominent disability is.

The Office was a British television series, created, written and directed by Ricky Gervais and Stephen Merchant. It first aired in 2001 and ran for two six-episode series, along with two 45-minute Christmas specials. Set in the offices of a paper merchant, Gervais plays regional manager David Brent, and much of the comedy derives from his frequent attempts to win favour with employees or peers. *The Office*’s use of disability is conspicuous alongside race, gender, and sexuality in the range of subjects David Brent tries but fails to be “politically correct” about. Another example is *Little Britain*, which was a BBC radio show before it transferred to television in 2003. It is written by and stars comedians Matt Lucas and David Walliams. Two of the major characters are Lou Todd and Andy Pipkin; Andy appears to have learning disabilities [intellectual disabilities] and uses a wheelchair (of which he has no need); Lou is his kind yet oblivious caregiver. Both shows have since been bought and re-made by US networks for US television audiences: *The Office* by NBC and *Little Britain* by HBO.

A contemporary of these shows was *Phoenix Nights*, a British sitcom first broadcast in 2001. It followed the owner of The Phoenix Club, wheelchair-using Brian Potter (played by Peter Kay), as he led his dysfunctional staff (made up of an array of other misfits) in hapless pursuits of his dream to see the club become the most popular working men’s club in North West England. Other recent “disability” moments on British television include a character in *That Mitchell and Webb Look* called “The Boy With An Arse For a Face” who appears in sketches satirising the voyeurism of “reality TV” and the *Comic Relief* telethon charity single “(I’m Gonna Be) 500 Miles” where two disabled characters (Brian Potter from *Phoenix Nights* and Andy Pipkin from *Little Britain*) teamed up with the Scottish band, The Proclaimers.

As I have concentrated here on sketch or situation televised comedy, I have omitted to talk about moments, for instance, in stand-up routines, chat shows, radio broadcasts and film comedies which also rely, however incidentally, on disability references. The significance of my focus on British sketch or situation television comedy is two-fold: firstly, it enables a defined category with which to work in terms of time (within the last eight years), representational mode (television) and genre (staged ensemble comedy); secondly, it enables a concentration on the geographical dimension of the resultant cultural criticism. It is to this I now turn.

Critical Engagement: The Case of *British* Comedy and Disability

In 1991, Barnes wrote a short paper entitled, “Disabling Comedy and Anti-Discrimination Legislation” in which he asked, “[S]ince comedy with an overtly racist or sexist bias is no longer seen on television, then why is disablist humor?” Eight years later,

there was a special issue of the journal *Body and Society* that staged a transatlantic conversation about disability and humour involving four British scholars (Corker, 1999; Stronach, & Allan, 1999; Shakespeare, 1999) and two scholars from the US (Albrecht, 1999; Robillard, 1999). In 2003, an issue of *Disability Studies Quarterly* included a symposium on disability and humor. Apart from Sue Ralph (Haller and Ralph, 2003), all of the contributors were US or Australia-based. Similarly, when a paper appeared in *Disability and Society* in 2006 concerning stand up comedians, it was from a US perspective (Reid, Stoughton, & Smith, 2006). Only two out of the four solely British writings mentioned here address televised comedy, and even then the attention afforded is extremely brief.

The geography of these dialogues is significant as they demonstrate the peculiarities of *British* disability-criticism of comedy, which can be largely characterized by a reliance on a mode of *social realism* (Mallett, 2007, 2009; Mitchell & Snyder, 2001). By no means comprehensive, but significant enough to be noted, where British disability-criticism has engaged with comedy it involves presuppositions of the representational process that draw their foundations from the social model of disability as developed in Britain (Oliver, 1990: Union of Physically Impaired Against Segregation [UPIAS], 1976). In relation to critiques of comedy, when “negativity” is identified in the “joke” it is deemed to reinforce broader discriminatory attitudes. For example, Barnes (1991) argues that comedy “helps perpetuate the pre-conceived attitudes towards, assumptions about, and expectations of disabled people in the minds of non-disabled people.” The implication is that the “joke” is created by and produces these “negative” attitudes, with the “joke” consequently being condemned and its immediate retraction recommended. The posited solutions for this “problem” are also contingent upon social model discursive procedures. One solution is that comedy about disability should be made by disabled people or not at all. For instance, Barnes (1991) has discussed “the exploitation of disabled people by professional non-disabled comedians on television” and thus deploys an essentialist hint that non-disabled people have no business using “disability.”

The resulting assertions in the British literature are that mainstream disability comedy is the product, the symptom, and the cause of negative and discriminatory attitudes, with only certain sorts of comedic utterances from certain sorts of comedic authors being deemed acceptable. Via a range of diverse theoretical, methodological, and political mechanisms, these approaches produce sets of conditions for “critical correctness” (Mallett, 2009), or rather, they create what can and cannot be said about the comedic representation of disability. Not only does such a mode of criticism afford little room for other readings, other meanings, other contexts, but in doing so it also provides a criticism which has very little to offer beyond chastisements and does not offer much to support a sustained theoretical engagement.

The lack of critical engagement with British comedy’s use of disability is further demonstrated if we consider the reaction to a comedic moment, which appeared on a mainstream British sports program in 2006. During the BBC’s World Cup coverage a sketch was shown during a half-time interval on the flagship programme *Match of the Day*. The one-minute sketch was a “spoof” centred on the England football players Peter Crouch and Wayne Rooney. In the sketch, tall Peter Crouch is played by the equally tall Stephen Merchant (cowriter of *The Office*) and Ricky Gervais plays himself as a presenter/interviewer. The sketch is itself interesting as it deploys the actor Warwick Davis as Wayne Rooney and uses his small stature in juxtaposition to the tall stature of Crouch/Merchant to comedic effect. However, far more significant is the reaction (or lack of it) to Ian Wright’s rejoinder at the

end of the sketch. Ian Wright (former Arsenal and England footballer) was seated in the studio on the pundit's couch. When the sketch ended, the camera cut back to the presenter and the three pundits where upon Ian Wright laughed and said, "I don't know what it is about little people like that, I just love 'em man, I just love 'em."

Working on the premise that, "Whether or not it is acknowledged, any reading of a text will be constitutive" (Game & Metcalfe, 1996, p. 132), what we do critically with contemporary British comedy produces the text in a certain sort of way. In this example, the lack of critical engagement constitutes the text as benign. For Ian Wright what *allows* that sketch to be funny is quite clear. However, what *allows* it and his reaction to remain funny and not chastised is revealed in the lack of public outcry, official sanction or even public discussion. The only hint of disapproval was the slight awkward silence of his fellow presenters. More troublingly, a year later, the *Comic Relief* charity single, featuring the characters Andy Pipkin and Brian Potter, was met with universal acceptance. The contradiction of a charity using characters "pretending" to be impaired to raise money, in part for disabled people, was not questioned.²

I do not want to suggest that such texts should be censored or banned but rather to assert that they at least should be critically discussed. At present, as the Ian Wright moment shows, British disability-criticism is ineffectual. As the comedic use of disability is without an adequate critical vocabulary, then, cultural texts remain unchallenged, under-theorized and immune to scrutiny. On the one hand, we are left asking what we should do with a form of representation that is generally recognized as having an institutional generic requirement for indecorum and transgression: a form of representation that will not stand for chastisement. On the other we acknowledge that, to varying degrees, comedy's claim for immunity in relation to how it treats race, gender or sexuality has been publically challenged and theoretically problematized. It seems appropriate at this moment to step beyond the current boundaries of British disability-criticism.

Seeking Possibilities: The Theorization of Popular Television Comedy and Identities

Literature on popular comedy and the triad of identities (race, gender, and sexuality) is in better shape than that on disability. Havens (2000) has considered race in the *Cosby Show* and McEachern (1999) has analyzed the TV situation comedy *Home Improvement* in terms of masculinity and the men's movement. Tyler and Cohen (2008) have considered gender and heteronormativity in *The Office* whereas Medhurst (2007) and Stott (2005) have both included substantial sections of their respective books on comedy to issues around sexuality. Beyond the triad of identities Medhurst (2007) has also, and comprehensively, considered the role of popular television comedy in the construction of national identity.

All these writings display an eclecticism and refuse to be corralled into neat disciplinary boundaries. Inspired by this wilful multiplicity, for the remainder of the article I offer suggestions for a critical vocabulary around televised comedy and disability. To do this I mirror the "reckless promiscuity of paradigms" (Medhurst, 2007, p. 2) on which studies of comedy and identities rely. However, as the possibilities are many but the space remaining is small, I focus selectively on moments from the British versions of *The Office* and *Little Britain*.

The Office: Performing Political Correctness

As outlined, *The Office* was a British television series set in an administrative branch of a fictitious paper merchant and starred Ricky Gervais as “self-deluded” regional manager David Brent. During Tyler and Cohen’s (2008) reading of the series in terms of gender performativity in the workplace, they note disability alongside the usual identity triad and advocate a link between David Brent’s need for recognition and his offensive comments. When discussing a scene in which Brent makes a sexist comment, Tyler and Cohen contend that the significance of the elongated and laboured silence which follows his comment lies in how he:

“Stands uncomfortably, seemingly awaiting some degree of acknowledgement of the ‘political correctness’ or radicalism of his position, or even some degree of concurrence (providing the apparently much needed reassurance that he has adopted the ‘right’ way of thinking about dealing with sexism in the workplace)” (p. 126).

Tyler and Cohen further posit that the humor here “lies in Brent’s apparent confusion over the position he should, as ‘one of the lads’ and as a manager, be seen to be adopting in relation to gender and sexuality” (p. 126). A similar reading of the social faux pas relating to disability could be proposed: a reading which locates Brent’s apparent confusion in terms of what position he should be adopting as both “a radical humorist not afraid to be controversial” and as a good manager who is fully aware of equality and diversity issues. An example of this occurs in Episode 1 of Series 2 when he recounts an impression he did of a colleague at the Coventry conference: “Some comedians will have picked on other stuff, you know been more nasty. Like he’s got a little withered hand, like Jeremy Beadle - I didn’t mention it. No need.”

As in all written discussion of televised comedy the extra-textual is in danger of getting lost (Medhurst, 2007), and here it is particularly important as Brent accompanies this statement by making his own hand appear “withered.” Here it is apparent that he senses that talking about “withered hands” is not appropriate. His attempt to highlight his knowledge of this is consistent with Tyler and Cohen’s argument that foregrounds his desire for recognition for being a good manager. However, the manner in which he does so here reveals a misunderstanding of the appropriate behaviour and his performance of the “politically correct” manager fails.

I argue that rather than measure the show and its jokes against criteria based on social-model informed notions of un/acceptability (Mallett, 2009), being attendant to how the comedy around disability draws on a critique of “political correctness” offers an alternative reading. Here Tyler and Cohen (2008) remain helpful when they emphasize the critical potential of cultural texts such as this one alongside the role of parody as a mode of cultural critique. In its use of disability *The Office* parodies a performativity of political correctness and all that entails (such as rhetorics of inclusion, equality and diversity). David Brent reveals, by a mechanism of excess, the provisionality of the “tolerant subject position,” with the comedy coming from the failure of that positioning.

I further argue that the presence of a “tolerant subject position” in relation to disability becomes significant if we consider the policy and legislative context. In 1996, barely a year after the passing of the UK’s first anti-disability-discrimination act (DDA) (HMSO, 1995) another BBC sit-com called *The Thin Blue Line* aired an episode called “Ism Ism Ism.” Set in

a police station, the episode includes a scene where the characters are discussing racism, sexism, and homophobia in the police force. The subject is handled critically with the diverse cast of characters advocating a range of opposing views, but not once is disability mentioned alongside these oppressed identities. Since the episode was aired Britain has seen an acceleration in disability legislation, including an updating of the DDA in 2001 (HMSO, 2001) and 2005 (HMSO, 2005) as well as the amalgamation of separate equality commissions into the single *Equality and Human Rights Commission*. Since the turn of the century disability in Britain has become formally incorporated, alongside race, gender and sexuality, into diversity agendas and equality schemes making it increasingly conspicuous but less exceptional in, for example, the workplace.

Advancing the critical potential of such texts, *The Office* offers a critique of the associated rhetoric surrounding implementation of such legislative and policy developments. The ways in which David Brent's words get tangled in webs of uncomfortable contradiction and how his actions often demonstrate a disparity between the two reveals the fragility of the "tolerant subject position." In short, Brent's logic reveals the arbitrariness of the boundaries such tolerance ought not to cross.

In the next section I further this argument and explore how such a position is contingent upon wider global shifts. To do this I draw on theories derived from the theorisation of culture and another identity grouping, this time around sexuality.

David, Lou, Andy, and Neoliberal Crises

Taking neoliberal capitalism as the dominant economic and cultural system in, through and against which embodied identities have been imagined and composed, the interdisciplinary Disability Studies scholar Robert McRuer (2006) discusses how, paradoxically we are in an era "characterised by more global inequality [...] and less rigidity in terms of how oppression is reproduced" (p. 3). He argues that such a system of economic productivity demands flexible bodies, or rather able-bodies, producing a system of unacknowledged compulsory ablebodiedness. Drawing on theories from Gay and Lesbian Studies he asserts:

"Neoliberalism and the conditions of postmodernity, in fact, increasingly need able-bodied, heterosexual subjects who are visible and spectacularly tolerant of queer/disabled existences" (p. 2).

In other words, neoliberalism demands a certain sort of "tolerance." He expands on this by stating:

"The successful able-bodied subject, like the most successful heterosexual subject, has observed and internalised some of the lessons of liberation movements over the past few decades. Such movements without question throw the successful heterosexual, able-bodied subject into crisis, but he or she must perform as though they did not; the subject must demonstrate instead a dutiful (and flexible) tolerance toward the minority groups constituted through these movements" (p. 18).

Although McRuer's focus is on how gay and disabled characters are placed in subordinate positions and asked to comply flexibly so that heterosexual, nondisabled characters can

flexibly contract and expand, this is a useful idea for thinking through *The Office*. I suggest that it is from David Brent's attempts and failures to perform a visible, flexible tolerance that much of the comedy comes. Brent's utterances disrupt the "discursive climate of tolerance, which values and profits from diversity" (p. 18) precisely because, despite his better efforts, the heterosexual, able-bodied subject is shown as being in crisis.

Similarly, a reading of the BBC sketch show *Little Britain* could place the "carer" character Lou in the role of the neoliberal state (or one of its public-private partners), taking care of Andy's needs and making sure at all times that Andy has a "choice." However, Andy's pretence of a physical impairment (demonstrated by Andy leaving his wheelchair whenever Lou's back is turned) reveals a further discrepancy in this neoliberal relationship. A comparable reading of *Little Britain* could contend that the comedy produced by Andy's lack of physical impairment draws on a similar disruption to the "tolerant subject position" to that used in *The Office*. Lou (neoliberalism) is being taken as a fool with the associated subject position being revealed as fragile and inadequate. However, as the discrepancy is seen to be in the status of who is being tolerated, rather than how the tolerance is performed, such a reading seems rather less adequate. Furthermore, Lou is not shown as the heterosexual, able-bodied "tolerant" subject in crisis because he never discovers the truth about Andy.

But perhaps that is the point. By returning Lou and Andy to their rightful place alongside the other characters who populate *Little Britain*, it becomes possible that the "crisis" has just been relocated. In order to explore where the "crisis" has been moved to I now turn this theoretical lens upon a relatively minor character, Linda Flint, who first appeared in the second episode of Series 2.

"You Know the One": Linda Flint and the Other Side of the Desk/Screen

During the course of her first episode, Linda Flint appears in three sketches. In the first she is introduced as a counsellor at the University of the North West Midlands trying to help a student who has requested an extension on the deadline for one of her essays. Linda rings up Martin (whom we never see but are led to believe is "in charge") and, in putting the student's case, attempts to describe the girl in front of her eventually settling on "the big fat lesbian." The second scene involves Linda talking to a Chinese student followed by a further phone call to Martin. This time she describes the student as "straight black hair, yellowish skin, slight smell of soy sauce...that's it, the ching-chong Chinaman." In the third sketch, Linda's visitor is a student of short stature. When required to describe the student she says, "Shoulder length brown hair, wears a lot of jewelry...looks up a lot, gets his clothes from Mothercare. That's it, the Oompa-Loompa."

It can be no accident that in those first appearances Linda addresses issues of sexuality, race, and disability. In Linda we are provided with an un-reflexive David Brent and "we" (the audience) are placed into the position of Linda's reflexivity. We, on the other side of the screen, are asked whether her descriptions of those on the other side of her desk overstep the "mark." We are asked to test out the boundaries of our own "tolerant subject position" in order to discover where our "marks" lie.

This strategy obviously runs the risk of being misconstrued. The critic Johann Hari (2005) wrote in *The Independent* newspaper:

“[*Little Britain*’s] targets are almost invariably the easiest, cheapest groups to mock: the disabled, poor, elderly, gay or fat. In one fell swoop, they have demolished protections against mocking the weak that took decades to build up.”

On first reading, this appears to be a statement in support of a disability oriented critique: the jokes perpetuate prejudice and jeopardize public support. However, the positioning of “the disabled” as “weak” evokes the sort of trouble David Brent gets himself into. We are returned to considering the crisis of a “tolerant subject position,” not on screen but within ourselves. In his critique of the show, Hari is attempting to perform a subjectivity which demonstrates “a dutiful (and flexible) tolerance toward the minority groups” (McRuer, 2006, p. 18) but, in doing so, trips over himself. The fragility of the “tolerant subject position” is revealed, thanks to the publication of Hari’s comments, but I argue that audiences are similarly caught in the double-bind of *Little Britain* and a neoliberal world order.

Conclusion

“We exist at a time when we aren’t sure what to say,” asserts British Comedian David Baddiel, speaking about “categories of people” on *Ricky Gervais: New Hero of Comedy*, Channel 4, 2008. Echoing the conversation between Russell Brand and Matt Morgan about whether the wheelchair incident is *allowed* to be funny and giving voice to the awkward silence of Ian Wright’s co-presenters, David Baddiel’s comment further hints at the void created when a critical vocabulary is missing. In concluding that the current discursive capacities of British disability-criticism do not offer the bases for an effective critical engagement, this article has widened the net in an attempt to seek alternative possibilities to the cultural theorisation of disability and British comedy. By offering some emerging thoughts on a number of comedic moments from two British comedy shows, the article has demonstrated how the presentation of what could be deemed prejudicial comments or actions should not be necessarily interpreted as merely perpetuating such prejudice. Instead, I have advocated readings which pay attention to the social and political contexts of the texts and have drawn on existing considerations of comedy and identity to begin to unpack the disability-related comedy in *The Office* and how so many find *Little Britain* equally pleasurable and offensive. These readings are by no means complete and I would suggest that the use of irony, parody, and the grotesque as well as the difference made by the particular format (e.g., sitcom, sketch show) are just some areas in need of extended consideration.

However, the ultimate purpose of this article is to suggest that, like previous studies in television comedy, British disability-criticism should disregard disciplinary fences and reap the benefits of venturing further afield. Not least because a critical engagement with comedy holds the potential to explore alternative perspectives on topics at the heart of Disability Studies. In this instance, the significance of the interdisciplinary dialogues that a Cultural Disability Studies perspective can facilitate is bolstered by a demonstration of the ability of comedic texts to explore what Goodley (2007), borrowing from Azzopardi, has called the “cliché of inclusion” (p. 318), proof, if needed, that the theorization of culture has much to offer a realm that traditionally has focused on developing social policy and influencing disability practice.

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References

- Albrecht, G. L. (1999). Disability humour: What's in a joke? *Body and Society*, 5(4), 67-74.
- Barnes, C. (1991). Disabling comedy and anti-discrimination legislation. Retrieved from www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm
- "Blame it on the Booties," Mr Gee's End of Show Poem on *The Russell Brand Show*, BBC Radio 2, September, 2007 (Radio series episode).
- Comic Relief (2007). Grants approved Oct '05 to Sept '06 UK. Retrieved from <http://www.comicrelief.com/all-about-us/who-we-are/accounts/docs/uk-grant-approvals-2006.pdf>
- Corker, M. (1999). Disability--the unwelcome ghost at the banquet...and the conspiracy of normality. *Body and Society*, 5(4), 75-83.
- Game, A., & Metcalfe, A. (1996). *Passionate sociology*. London: Sage.
- Goodley, D. (2007). Towards socially just pedagogies: Deleuzoguattarian critical disability studies. *International Journal of Inclusive Education*, 11(3), 317-334.
- Haller, B., & Ralph, S. (2003). John Callahan's Pelswick Cartoon and a new phase of disability humour. *Disability Studies Quarterly*, 23(3 /4). Retrieved from http://www.dsqsds-archives.org/_articles_html/2003/summfall/dsq_2003_summfall_02.asp
- Hari, J. (2005, 22 November). Why I hate "Little Britain." *The Independent*. Retrieved from <http://www.independent.co.uk/opinion/commentators/johann-hari/johann-hari-why-i-hate-little-britain-516388.html>
- Havens, T. (2000). The biggest show in the world: Race and global popularity of "The Cosby Show". *Media Culture and Society*, 22, 371-391.
- HMSO (Her Majesty's Stationery Office) (1995). *Disability Discrimination Act 1995*. Retrieved from www.opsi.gov.uk/acts/acts1995/1995050
- HMSO (2001). *Special Educational Needs and Disability Act*. Retrieved from www.opsi.gov.uk/acts/acts2001/20010010
- HMSO (2005). *Disability Discrimination Act 2005*. Retrieved from www.opsi.gov.uk/acts/acts2005/20050013

- Mallett, R. (2007). *Critical Correctness: Exploring the Capacities of Contemporary Disability-Criticism* (Unpublished doctoral thesis). Department of Geography, University of Sheffield, UK.
- Mallett, R. (2009). Choosing stereotypes: Debating the efficacy of (British) disability-criticism. *Journal of Research in Special Educational Needs*, 9(1), 4-11.
- McEachern, C. (1999). Comic interventions: Passion and the men's movement in the situation comedy "Home Improvement." *Journal of Gender Studies*, 8(1), 5-18.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York: New York University Press.
- Medhurst, A. (2007). *A national joke: Popular comedy and English cultural identities*. Oxon, UK: Routledge.
- Mitchell, D. T., & Snyder, S. L. (2001). Representation and its discontents: The uneasy home of disability in Literature and Film. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp.195-218). Thousand Oaks, CA/London, UK: Sage.
- Oliver, M. (1990). *The politics of disablement*. London, UK: MacMillan.
- Reid, D. K., Stoughton, E. H., & Smith, R. M. (2006). The humorous construction of disability: Stand-up comedians in the United States. *Disability and Society*, 21(6), 629-643.
- Robillard, A. B. (1999). Wild phenomena and disability jokes. *Body and Society*, 5(4), 61-65.
- Shakespeare, T. (1999). Joking a part. *Body and Society*, 5(4), 47-52.
- Stott, A. (2005). *Comedy*. New York: Routledge.
- Stronach, I., & Allan, J. (1999). Joking with disability: What's the difference between the comic and the tragic in disability discourses? *Body and Society*, 5(4), 31-45.
- Tyler, M., & Cohen, L. (2008). Management in/as comic relief: Queer theory and gender performativity in "The Office." *Gender, Work and Organisation*, 15(2), 113-128.
- UPIAS (1976). *Fundamental principles of disability*. London: Union of Physically Impaired Against Segregation.

Endnotes

¹In October, 2008 Russell Brand resigned from his BBC Radio 2 show following controversy over "prank" phone calls made on air to a well-known actor. The controversy focused on whether the content of answer-phone messages left as a result of those calls were acceptable territory for comedy. While "disability" was not explicitly implicated, it is interesting to note that the mechanisms by which comedic "acceptability" is defined, assessed, and regulated were all too evident.

²St. Cuthbert Club for the Disabled and the Warwickshire and Coventry Council of Disabled People are just two

“disability” organizations to receive grants from Comic Relief according to the 05-06 UK Grant Approvals declaration (Comic Relief, 2007).

Interdisciplinary Dialogues: Disability and Postcolonial Studies
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Abstract: Disability is a constitutive material presence in many postcolonial societies but remains surprisingly absent as a subject of analysis in the field of Postcolonial Studies. Through a critical reading of disability in Salman Rushdie's novel *Midnight's Children* (1981), this article develops an interdisciplinary critical methodology that pays attention to disability both as an aesthetic textual device and as lived experience.

Key Words: postcolonial literature, disability, Rushdie

A haunting visual legacy of the Iraq war was the multiplicity of media images of Ali Abbas, a twelve-year-old Iraqi boy who lost both arms in a missile attack in March 2003. Covering the newspapers' front pages for weeks, Ali became the poster child of the conflict – the representative of innocent victimhood, of loss in the most tangible sense, and of the horrific cost of British and American intervention in Iraq. Western responses to Ali's disablement were generous and economically beneficial, yet politically troubling. The Limbless Association's fund to rehabilitate amputee casualties of the war was strategically publicized as the Ali Abbas appeal, mobilizing what has been termed the "identifiable victim effect" (Small, Loewenstein, & Slovic, 2007); maximum donation was elicited by personalizing and narrativizing the experience of trauma. Lennard Davis (1995) observes that "narrativizing an impairment ... tends to sentimentalize it" in ways that "link it to the bourgeois sensibility of individualism and the drama of an individual story" (pp. 3-4). The emergency fund capitalized effectively on a sentimental individual narrative of wounding and healing, securing the support of middle-class "conspicuous contributors" (Longmore, 1997) in raising much-needed capital. It also, however, isolated Ali's plight from its political contexts and obscured the *mass* scale of disabilities generated by the war. The appeal's representational strategies encouraged donation rather than protest, ultimately failing to stage a critical engagement with the causes and atrocities of the war.

Effective analysis of this complex cultural event requires input from various disciplinary fields. Disability studies provides the tools to examine the visual rhetoric of the poster child (Garland-Thomson, 2002; McRuer, 2006), to consider the pros and cons of sentimentality (Davis, 1995), and to critique the association of disability with helplessness, victimhood, pity, and charity (Snyder & Mitchell, 2006). Probing the intersection between disability, dependency, and *international relations*, however, demands an engagement between disability studies and postcolonial studies, an interdisciplinary field adept at interrogating western constructions of non-western Others (Said, 1995). In the proliferation of media representations of disabling global trauma, disability is made the focal point of familiar narratives of disempowerment, which render non-westerners the perennial victims of either disordered, crisis-riven environments or of western nations' militaristic and (neo)imperialist activities. The imbalance between Iraqi dependency and western paternalism that is normalized by images of Ali Abbas issues from assumptions about disabled difference and *cultural* difference, centered on a fundamental notion of "damage." At the same time, disability representations participate in the reinscription of orientalist discourses of salvation and enlightenment which feed into contemporary global development paradigms: Ali's "tragic" story ends happily in the USA with a reconstructed body. Contributing to discourses of dependency and development like this, ideas about disability are frequently co-opted to support neocolonial political agendas. In this sense the links between postcolonialism and

disability are direct, dynamic and constitutive in the contemporary world. As a critical discourse, postcolonialism can offer a crucial point of departure for the analysis of disability representations when they are manifested in, or projected onto, non-western cultural contexts.

Decolonizing Disability Studies: Literature, Criticism, and Theory

The (much contested) term *postcolonial* encompasses the historical, socioeconomic, and cultural legacies of European colonialism in previously colonized nations and cultures, engaging with the impact of global capitalism, inequalities of power, and neocolonial national and international relationships today. Postcolonial criticism can thus be defined as the “analysis of cultural forms which mediate, challenge or reflect upon the relations of domination and subordination – economic, cultural and political – between (and often within) nations, races or cultures” (Moore-Gilbert, 1997, p. 12). One effect of these relations is the fact that traumatic, violent, exclusionary or impoverished environments and histories generate high levels of disability. Approximately 80 percent of the world’s disabled population lives in developing countries (Davidson, 2008, p. 170; see also *Disability in the Majority World*), and indigenous or “Fourth World” peoples living in supposedly “First World” societies experience higher levels of disability and chronic ill health than majority populations, signaling a causal link between colonialism and disability (Durie, 2003; Smith, 1999). (Post)colonial histories are punctuated by disabling events such as war, population displacement and civil unrest, as well as ongoing poverty. In such societies, disability may consequently be “as much about national and cultural power differentials as it is a matter of medicine and bodies” (Davidson, 2008, p. 175).

This article focuses on representations of disability in postcolonial literature, a cultural form which, through its representations of disabled characters, is able to mount critiques of “relations of domination and subordination” as they apply to disability in non-western societies. Postcolonial literary criticism, in turn, offers methodologies for the analysis of marginalized subject positions, which are attentive to culturally specific constructions of identity. The dual lenses of postcolonial and disability theory can therefore draw attention to the nuances of social, cultural, political and economic histories and their impact on the representation and administration of disability. I will demonstrate this point with reference to Salman Rushdie’s *Midnight’s Children* (1981), a novel often read as a paradigmatic example of postcolonial national allegory, and whose protagonist, Saleem Sinai, could be characterized as the “poster child” of postcolonial literature. Winner of the 1981 Booker Prize, the 1993 Booker of Bookers, and the 2008 Best of the Bookers, *Midnight’s Children* arguably aestheticizes, commoditizes and packages the non-western disabled figure for global consumption.¹ Through analysis of the novel’s postcolonial politics, however, I show how literary narratives can present complex and sophisticated insights into the aesthetics and politics of disability, potentially providing an antidote to the reductive image of the non-western disabled poster child. Strategies for *reading* disability narratives must therefore be updated to account for the multiple vectors of difference and the diverse cultural contexts of disability that postcolonial writing offers.

So far, research on the interface between postcolonial studies and disability studies has tended simply to advocate, rather than develop, interdisciplinary critical methodologies. For example, Sharon Snyder and David Mitchell (2006) readily admit that their own groundbreaking work, at the forefront of cultural disability studies, lacks attention to constructions of disability outside a western framework:²

“The field needs to [...] grow more international in its critique (and less Eurocentric in its models). The future of the field depends upon its ability to take up this challenge in a way that does not replicate the global commodification of other identities. This entails a thoroughgoing recognition that Western-based methodologies have limited utility for apprehending disability in other cultural contexts” (pp. 198-199).

As Snyder and Mitchell identify, the application of disability theory to postcolonial cultural productions, and conversely the theorization of disability from the perspective of non-western cultural epistemologies, is only just beginning to be undertaken within humanities-based disability studies.³ Since most of this scholarship is emerging from western, middle-class academic contexts, there is a pressing need for disability researchers to “decolonize” their critical “methodologies” (Smith, 1999). This involves deconstructing assumptions and practices central to the analysis of mainstream western literary and cultural narratives, and reframing critical readings so they prioritize indigenous or local constructions of disability.

Metaphor, Prosthesis, and Global Disability Narratives

Literary disability theorists have persuasively shown how disability is often used within creative productions as a storytelling “crutch,” termed “narrative prosthesis” by Mitchell and Snyder (2000), which represents *other* conditions of disempowerment, lack or deviance. According to the “double bind” of disability representation, disability becomes “a master metaphor for social ills” (Mitchell, 2002, p. 24) but “firmly entrench[es]” disabled people “on the outer margins of social power and cultural value” (Mitchell & Snyder, 1997a, p. 6). Despite the existence of “disability counternarratives,” which concentrate on forms of “social awareness” generated by disability rather than aiming to “resolve” it (Mitchell & Snyder, 2000, pp. 164-165), for some literary analysts the predominance of metaphorical disability representations dooms people with disabilities to states of disenfranchisement likened to those experienced by marginalized postcolonial subjects. As Mitchell and Snyder (2005) put it, “Disabled people are left, as is often the case with other post-colonial subjects, to mull over the degree to which their social relations are mediated by constructed beliefs about variant bodies and minds.”

In theorizing disability representation in this way, Mitchell and Snyder clearly draw on postcolonial theories such as Gayatri Spivak’s (1999) seminal work on subalternism. This relationship between disabled and postcolonial subjectivity is articulated more explicitly by Mark Sherry (2007), who notes “the rhetorical connections that are commonly made between elements of postcolonialism (exile, diaspora, apartheid, slavery, and so on) and experiences of disability (deafness, psychiatric illness, blindness, etc.)” (p. 10). Similarly, Michael Davidson (2008) notes that the rhetoric of globalization “is suffused with references to physical impairment – countries suffer from *crippling* debt; national leaders who are *deaf* to the needs of their people; poverty as a *cancer* spreading throughout a region” (p. 168). In one of the most persistent postcolonial narrative tropes, employed by creative writers and critics alike, disability becomes an embodied marker of the “damage” experienced by postcolonial nations and communities. Analogies are drawn between “broken” bodies and “broken” nations; histories are described in cycles of wounding and healing; societies are characterized as fragmented and dislocated. The subaltern subject’s inability to “speak” is a major figurative theme within postcolonial theory (Spivak, 1999), as is Fanon’s pathologization of colonial subjectivity (1963; 1986). Connections can also be easily made between the supposed

physical and emotional dependency of people with disabilities and the economic or political “dependency” on international support of emerging postcolonial nations (McRuer, 2007).

Given the pervasive nature of disability as a trope, its lack of critical interrogation within postcolonial literary studies represents a considerable theoretical deficit. The *body's* figurative potential is widely recognized; Elleke Boehmer (2005), for example, identifies how, “in colonial representation, exclusion, suppression and relegation can often be seen as literally *embodied*” by “the silent and wounded body of the colonized” (p. 129; p. 131). The bodies under critical consideration here are clearly disabled bodies, and yet disability remains an unspoken and under-theorized term in postcolonial textual analysis. This is perhaps due to the instability of disability as an identity category (Davis, 2002a), which impacts upon its collective politics and, by extension, affects the theoretical constructs we use to examine literary representations of disabled identities. Because disability lacks recognition within postcolonial theory as a coherent and politicized subject position or a material component of identity, disabled figures tend to be objectified and decontextualized. Even socially engaged, culturally sensitive postcolonial reading practices, committed to establishing the agency of racial, gendered or indigenous minorities, can reproduce assumptions that disability functions in the exclusively figurative terms of narrative prosthesis. This does not always reflect inadequate modes of *representation*; however, in many cases, it indicates an underdeveloped *critical* vocabulary regarding disability. A critical perspective informed by disability studies can therefore help to fill out elisions within postcolonial theory and literary criticism. The reclamation of “wounded” postcolonial bodies as overtly *disabled* bodies helps to foreground the multifaceted material, as well as metaphorical, meanings they embody in fictional texts, and to encourage the reading of disabled characters in terms of agency and politics rather than exclusively as aesthetic devices.

Conversely, disability studies can benefit from postcolonialist reading practices, since a textual preoccupation with the materiality of postcolonial experience necessarily impacts upon disability representations. Following Robert McRuer (2006), who “would qualify the transhistorical applicability Mitchell and Snyder give to their theory” (p. 225), I contend that the *transcultural* applicability of narrative prosthesis must also be qualified. While it may be a productive point of access to disability narratives which lend themselves to allegorical interpretations, writers and texts that emerge from different cultural contexts and deal with very specific historical moments may be more or less sensitive to disability as a *social* entity, and more or less inclined to utilize disability as a sustained metaphorical device. As McRuer cogently warns, “There is no guarantee that even the most foundational disability studies theses will function in the same way when we talk about global bodies” (p. 201).

Postcolonial Endings: Sentimentality and Narrative Closure

One way in which postcolonial literary representations often differ from the canonical English and American texts discussed in current disability theory regards the function of sentimentality. Mitchell and Snyder (2000) have commented that “[s]entimental plotlines [...] offer impossible solutions by situating disability as an either/or condition forever hovering somewhere between tragic death or sudden cure” (p. 169). The “cure” trajectory, marketed as a tale of triumph over adversity, explains the continued public interest in Ali Abbas’s rehabilitation; as a form of *strategic* sentimentality, it was manipulated to galvanize an active response from the public. In contrast, according to Mitchell and Snyder’s literary model, fiction that relegates disabled characters to the status of plot resolution devices, excluding

them from participation in the projected social and political futures it depicts, produces affective responses from readers that aid narrative closure rather than intellectual engagement.

Contrary to this effect, and to the normalizing telos of conservative novels (Davis, 2002a), many postcolonial texts resist reductive or sentimental conclusions, even when they do end with the cure or death of a disabled character. This lack of sentimentality is often tied up with the materialist postcolonial preoccupations of the texts, since the cultural struggles fictionalized may remain ongoing and unresolved. Postcolonial endings often negotiate ways of *caring* for permanently marginalized communities (Barker, 2008). Further, in many disabling postcolonial spaces (landmine-ridden Angola, for example), sheer numbers of disabled citizens make it illogical to understand disability sentimentally. Some postcolonial writers necessarily deal with disability as a material presence, negotiating a complex matrix of factors operating between the individual, history, society, and its often violent machinations. As Davidson (2008) cautions, referencing Mitchell and Snyder, “There are cases in which a prosthesis is *still* a prosthesis. [...] Regarded in a more globalized environment, the social meaning of both disability and narrative may have to be expanded” (p. 176). Writers of postcolonial fiction may find it imperative to engage with disabled characters’ status as embodied subjects and *citizens* in their particular culture and nation; disability often participates in politicized discourses of community and belonging rather than sentimental narratives of pity.

Snyder and Mitchell (2006) have recently conceptualized a “cultural model of disability,” according to which “disability functions not as an identification of abnormality but rather as a tool of cultural diagnosis” (p. 12). In its current form, this model is diffuse and generic; although it usefully reinscribes the materiality of the body, addressing a weakness of the social model of disability, the “culture” it evokes is a catch-all network of experiences, ideas and practices surrounding disability, and is not articulated in any rigorous way. However, if diversified and particularized, the cultural model has a great deal of potential as a blueprint for *situated* disability theory as it emphasizes the specificity of different cultures’ approaches to the construction, politics and administration of disability. As an important part of this process of theorization, postcolonial literary texts can alert us to the multiplicity of “cultural models” that may be available, in fictional and discursive form, to enable disability studies to fill out its current absences and to address its western bias. Interdisciplinary reading practices should therefore be integral to the process of decolonizing disability studies.

Midnight’s Children and Prosthetic National Allegory

To illustrate the benefits of interdisciplinary textual analysis I turn now to *Midnight’s Children*, a text that is ideologically complex, generically ambiguous, and politically contradictory in its representations of disability. The protagonist and narrator of the novel, Saleem Sinai, is “handcuffed to history” due to his birth on the stroke of midnight, August 15, 1947, “the precise instant of India’s arrival at independence” (Rushdie, 1995, p. 9), making this a classic example of postcolonial national allegory. According to the novel’s magical realist logic, this historic moment of birth endows Saleem and a thousand others – the eponymous midnight’s children – with fantastic forms of embodied or cognitive difference, which are identified explicitly with the Indian nation’s exceptionality and potential development. Saleem is born with telepathic ability and with various impairments of function and appearance (no sense of smell, facial birthmarks and an unusually shaped face and nose). He is disabled further as the text progresses, often in tandem with “disabling” national events: he develops bandy legs; loses the hearing of one ear; loses a finger; and becomes bald as a

child. An operation to drain his inflamed sinuses leaves him with an exceptionally keen sense of smell but deprives him of his telepathic powers; he loses his memory for a number of years; and, as an adult, is castrated by State representatives during the family planning drive of the National Emergency of 1975 to 1977.⁴

Throughout the text, Saleem the adult narrator is convinced that his body is fragmenting, reflecting the breakdown of the nascent ideals of independent India and exemplifying what seems to be a straightforwardly prosthetic disability narrative. Indeed, Rushdie sets up very clear relationships between Saleem's body and the new nation: his face resembles a map of India, for example, with birthmarks in the place of Pakistan, so that the newly partitioned Islamic state is described as a stain on the face of India. The body is therefore central to Saleem's story of postcolonial national development. He writes, "[u]ncork the body, and God knows what you permit to come tumbling out" (p. 237). This "uncorking" is associated with "revolutionary" effects (p. 237), indicating the transformative potential of the unruly body in the novel. Despite the overtly prosthetic nature of the analogy between disabled body and damaged nation, the continuing bodily metamorphoses of Saleem and the children prove to be "revolutionary" textual devices, as they enable Rushdie to critique the nation-state's treatment of difference within its borders and citizenry.

The Politics of Postcolonial Freakery

The midnight's children are described variously as "miraculous" (p. 195), "fabulous beings" (p. 197), "freak kids" (p. 221) and "monsters" (p. 434). Their (dis)abilities range from supernormative skills of time travel, flight and lycanthropy to those who are "little more than circus freaks: bearded girls, a boy with the fully-operative gills of a freshwater mahaseer trout, Siamese twins with two bodies dangling off a single head and neck" (p. 198). Rushdie taps into freak discourses that have been widely theorized within disability studies. Rosemarie Garland-Thomson (1997) explains how, in the "liminal space" of the freak show, "The domesticated freak simultaneously embodied exceptionality as marvel and exceptionality as anomaly, thus posing to the spectator the implicit political question of how to interpret differences within an egalitarian social order" (p. 17). In *Midnight's Children*, the presence of the children generates the question of how to interpret difference within the newly postcolonial nation-space, and thus engages directly with Rushdie's primary concern – the exploration of postcolonial Indian identities and politics.

Garland-Thomson (1997) suggests that people with non-normative physicalities are granted a symbolic role within their cultures: "Such beings" become "magnets for the anxieties and ambitions of their times" (p. 70). In line with this, the children function as receptacles for India's unease regarding its self-definition:

"Midnight's children can be made to represent many things, according to your point of view: they can be seen as the last throw of everything antiquated and retrogressive in our myth-ridden nation, whose defeat was entirely desirable in the context of a modernizing, twentieth-century economy; or as the true hope of freedom, which is now forever extinguished" (Rushdie, 1995, p. 200).

The children are placed at the centre of debates surrounding national identity in the transitional period between colonialism and postcolonialism. In his independence day speech, quoted in the novel, India's first Prime Minister Jawaharlal Nehru promoted a vision of national inclusivity: "We have to build the noble mansion of free India, where all her children may dwell" (Rushdie, 1995, p. 118). Postcolonial criticism has been alert to *Midnight's*

Children's engagement with the Nehruvian ideal of "unity in diversity," and has identified in the children an allegorical movement towards a celebratory demographic mapping of India's diversity. In Saleem's *Midnight Children's* Conference, the nation is defined *in terms of* its exceptional inhabitants and not in opposition to them. The children therefore embody the optimism of independence by challenging reductive or monolithic views of difference, validating the exceptional, and accessing the *potential* of "unity in diversity" as a national ideology. Their liminal ontologies, however, also gesture towards the practical constraints placed on difference precisely by Nehru's idea of secular Indian modernity. As they remain unique but are subjected to surveillance, classification and hierarchization, the children simultaneously embody "possibilities and also restrictions of possibility" (Rushdie, 1995, p. 108).

A commentary on national citizenship is therefore played out through the children. Anita Ghai (2002) explains that in India (as elsewhere), "Historically, disabled people have been invisible, both physically and metaphorically" and that "disability represents horror and tragedy" (pp. 89-90). Saleem upholds this evaluation, describing India as "a country where any physical or mental peculiarity in a child is a source of deep family shame" (Rushdie, 1995, p. 169). As a disabled child, Saleem negotiates discrimination and "restrictions of possibility" in the social sphere. This means that despite its fetishization as a quintessential text of magical realism, *Midnight's Children* also provides a social realist counterpoint to celebratory national discourses of freakery. Rushdie utilizes disability metaphorically to critique the nation's incapacity to deal with difference, but also engages in material analysis of disability in its familial, social, and national contexts.

Davis (2002b) discusses how, "For the formation of the modern nation-state[,] [...] bodies and bodily practices had to be standardized, homogenized, and normalized" (p. 101). This is certainly true in the India of *Midnight's Children* where, by virtue of their exceptionality, the children's citizenship is continually placed under threat. By the end of the text, which depicts the Emergency's suspension of civil liberties and imposition of strict disciplinary regimes, a vocabulary of eugenics is mobilized to describe the children's vulnerability as disabled citizens of a conformist state. They become "[m]idnight's children: who may have been the embodiment of the hope of freedom, who may also have been freaks-who-ought-to-be-finished-off" (Rushdie, 1995, p. 304).

The novel ends ambiguously with an image of Saleem's unruly, protesting body fragmenting and being absorbed into the heterogeneous crowd of India. Rushdie therefore stakes a claim for a national identity that incorporates impairment – Saleem's disabled presence is projected past the novel's conclusion – and yet this is fragile and circumscribed as *Midnight's Children* resists closure, hovering somewhere between death and survival. The celebratory prosthetic narrative in which disability symbolizes "the true hope of freedom" is pitted against a hegemonic nationalist rhetoric of "cure"; normalcy is posited as the unrealized but frightening and rapidly crystallizing vision of a paranoid, power-hungry state.

Postcolonial Fiction: Testing the Limits of Interdisciplinary Analysis

As this strategic analysis highlights, reading *Midnight's Children* with attention to disability theory and postcolonial critical methodologies reveals how Rushdie uses disability as a productive point of access to social and cultural critique.⁵ He does not simply reduce disability to the "opportunistic metaphoric device" (Mitchell, 2002, p. 15) of narrative

prosthesis, but neither does his text comfortably fit the social model's locus of discrimination and misrepresentation. Various strands of meaning are present in Rushdie's engagements with disability – celebratory and oppressive, progressive and recidivist alike – and the metaphorical capacity of disability, when it is explored in material terms as well, only adds to the richness of its resonances. Disability is an aesthetic mechanism in this text, represented using conventions of freakery and the grotesque, and is instrumentalized to elucidate Rushdie's more carefully articulated *postcolonial* concerns. This does not mean, however, that it is definitively damaging. Indeed, texts like *Midnight's Children* grant disability the opportunity to be as multiple, as complicated, and as contradictory as any other aspect of identity. Rushdie's novel represents a test case for contemporary literary disability studies because, although offering a prosthetic narrative, its culturally and historically specific engagements with disability ultimately exceed the scope of current models and theories.

Dominant theories of literary disability tend to focus on the political shortcomings of representations at the expense of their enabling features, on their appropriation of disability's figurative capital rather than their materialist explorations of disability as an embodied social identity. Accordingly, our reading strategies need to be updated in order to reflect the variety and complexity of fictional representations, and interdisciplinary engagements can facilitate this process. In the case of *Midnight's Children*, postcolonial discourses of belonging and citizenship demonstrate the nuanced social contextualization of Rushdie's disability representations. Likewise, literary disability studies perspectives expose the omissions within postcolonial analysis, according to which Saleem and the children are rarely identified as disabled. Writing about disability politics in India, Ghai (2002) suggests that “[p]ost-colonialism can destabilize the totalizing tendencies of imported Western discourse. It brings the possibility of problematizing the norms of given cultural practices and a commitment to take responsibility for modifications that result from the situatedness of knowledge” (p. 96).

The presence of disability in postcolonial fictional texts destabilizes totalizing tendencies in two useful ways. Firstly, disabled characters challenge *western* cultural hegemony by showcasing alternative methods of constructing, understanding and managing global difference quite distinct from ubiquitous “poster child” narratives of dependency and pity. Secondly, they act as a check on the universalizing tendencies of *disability discourses* – both indigenous constructions of disability *and* imported western ones. By continually drawing attention to the “situatedness of knowledge” about disabled difference, fictional representations expose the insufficiencies of current theoretical models of disability, encourage the decolonization of reading practices, and offer alternative “cultural models” as the *basis* of politicized disability theory. In turn, critical analysis of such texts serves to illuminate the theoretical elisions within disability studies *and* postcolonial literary studies (within which “prosthetic” readings are the default position), and begins to establish a more collaborative approach towards the study of disability in postcolonial contexts.

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References

- Barker, C. (2008). *Exceptional children, disability and cultural history in contemporary postcolonial fiction* (Unpublished doctoral dissertation). University of Leeds, UK.
- Boehmer, E. (2005). *Stories of women: Gender and narrative in the postcolonial nation*. Manchester, UK: Manchester University Press.
- Davidson, M. (2008). *Concerto for the left hand: Disability and the defamiliar body*. Ann Arbor, MI: University of Michigan Press.
- Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London: Verso.
- Davis, L. J. (2002a). *Bending over backwards: Disability, dismodernism, and other difficult positions*. New York: New York University Press.
- Davis, L. J. (2002b). Bodies of difference: Politics, disability, and representation. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities*. New York: Modern Language Association of America.
- Disability in the majority world: The facts (2005, November). *New Internationalist*, 384, 12-13.
- Durie, M. H. (2003). The health of indigenous peoples. *British Medical Journal*, 326, 510-511.
- Fanon, F. (1963). *The wretched of the earth* (C. Farrington, Trans.). Harmondsworth, UK: Penguin. (Original work published 1961)
- Fanon, F. (1986). *Black skin, white masks* (C. L. Markmann, Trans.). London: Pluto Press. (Original work published 1967)
- Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Garland-Thomson, R. (2002). The politics of staring: Visual rhetorics of disability in popular photography. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities*. New York: Modern Language Association of America.
- Ghai, A. (2002). Disability in the Indian context: Post-colonial perspectives. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 88-100). London: Continuum.
- Huggan, G. (2001). *The postcolonial exotic: Marketing the margins*. London: Routledge.
- Longmore, P. K. (1997). Conspicuous contribution and American cultural dilemmas: Telethon rituals of cleansing and renewal. In D. T. Mitchell & S. L. Snyder (Eds.), *The body and physical difference: Discourses of disability*. Ann Arbor, MI: University of Michigan Press.

- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York: New York University Press.
- McRuer, R. (2007). Taking it to the bank: Independence and inclusion on the world market. *Journal of Literary Disability*, 1(2), 5-14.
- Mitchell, D. T. (2002). Narrative prosthesis and the materiality of metaphor. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities*. New York: Modern Language Association of America.
- Mitchell, D. T., & Snyder, S. L. (1997a). Introduction: Disability studies and the double bind of representation. In D. T. Mitchell & S. L. Snyder (Eds.), *The body and physical difference: Discourses of disability*. Ann Arbor: University of Michigan Press.
- Mitchell, D. T., & Snyder, S. L. (Eds.). (1997b). *The body and physical difference: Discourses of disability*. Ann Arbor: University of Michigan Press.
- Mitchell, D. T., & Snyder, S. L. (2000). *Narrative prosthesis: Disability and the dependencies of discourse*. Ann Arbor: University of Michigan Press.
- Mitchell, D. T., & Snyder, S. L. (2005). Exploitations of embodiment: *Born Freak* and the academic bally plank. *Disability Studies Quarterly*, 25(3). Retrieved from http://www.dsquds.org/articles_html/2005/summer/mitchell_snyder.asp
- Mitchell, D. T., & Snyder, S. L. (Eds.). (2010). Ablenationalism and the Geo-politics of Disability [special issue]. *Journal of Literary and Cultural Disability Studies*, 4(2).
- Moore-Gilbert, B. (1997). *Postcolonial theory: Contexts, practices, politics*. London: Verso.
- Priestley, M. (Ed.). (2001). *Disability and the life course: Global perspectives*. Cambridge: Cambridge University Press.
- Quayson, A. (2007). *Aesthetic nervousness: Disability and the crisis of representation*. New York: Columbia University Press.
- Rushdie, S. (1995 /1981). *Midnight's children*. London: Vintage.
- Said, E. W. (1995 /1978). *Orientalism: Western conceptions of the Orient*. London: Penguin.
- Sherry, M. (2007). Postcolonising disability. *Wagadu: A Journal of Transnational Women's and Gender Studies*, 4, 10-22.
- Small, D. A., Loewenstein, G., & Slovic, P. (2007). Sympathy and callousness: The impact of deliberative thought on donations to identifiable and statistical victims. *Organizational Behavior and Human Decision Processes*, 102(2), 143-153.
- Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. London: Zed Books.

- Snyder, S. L., & Mitchell, D. T. (2006). *Cultural locations of disability*. Chicago: University of Chicago Press.
- Spivak, G. C. (1999). *A critique of postcolonial reason: Toward a history of the vanishing present*. Cambridge, MA: Harvard University Press.
- Stone, E. (Ed.). (1999). *Disability and development: Learning from action and research on disability in the majority world*. Leeds: Disability Press.
- Tarlo, E. (2003). *Unsettling memories: Narratives of the emergency in Delhi*. Berkeley, CA: University of California Press.

Endnotes

¹ For the commoditization and consumption of postcolonial literary narratives, with reference to *Midnight's Children*, see Huggan (2001).

² Mitchell and Snyder's forthcoming special issue of the *Journal of Literary and Cultural Disability Studies* on The Geopolitics of Disability will be important in establishing more globalized approaches to disability.

³ Social science-based disability studies has a longer history of research in global contexts. See, for example, Priestley (2001) and Stone (1999). Essays in these collections testify to the need to decolonize western research assumptions, which are often founded on western civil rights paradigms. Within literary disability studies, Quayson (2007) notably engages with postcolonial theory in his analysis of literary texts.

⁴ For a detailed account of the events and politics of the Emergency, see Tarlo (2003).

⁵ For an extended version of this textual analysis, see Barker (2008).

Dialogism, Monologism, and Boundaries: Some Possibilities for Disability Studies and
Interdisciplinary Research

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Abstract: This article explores the possibilities of dialogism and monologism for disability studies by applying these concepts to a story in which two people orient to boundaries and express some concern over being too close or too distant from each other within a research encounter. It suggests that questions concerning “how close is too close” to research participants, and “how far is too far,” are complex and shift in time as people move between merging and unmerging, self-sufficiency and non-self-sufficiency, and finalizing and unfinalizing practices.

Key Words: dialogism, monologism, boundaries

In recent years, there has been a small but growing body of literature that has eclectically woven concepts and theories from different disciplines in an effort to better understand the lives of disabled people (e.g., Bolt, 2006; Couser, 1997; Goodley, 2007). This article is a modest attempt to add to the literature by applying the concepts of dialogism and monologism (Bakhtin, 1981, 1984, 1986) to a story in which myself, and a male (Eamonn) who became disabled through playing sport, orient to boundaries and express some concern over being too close or too distant from each other within a research encounter. Accordingly, in terms of structure, this article first describes the concepts of dialogism and monologism as outlined by Bakhtin. It then presents the story in which I and a male orient to boundaries. Following this, through the concepts of dialogism and monologism and in relation to the question, “how close is too close to research participants, and how far is too far,” analytic attention turns to my interpretations of the story. The article closes with some reflections on what dialogism and monologism might mean for interdisciplinary disability research.

Dialogism and Monologism

At the risk of riding roughshod over complex concepts, what Bakhtin (1981, 1984, 1986) calls dialogism and monologism can be elucidated and outlined as follows. In dialogism and dialogic speech a person is *non-self-sufficient*. That is, the person exists in relation to other people. Dialogic speech suggests that no matter how personally authentic anyone wants to be or wants to allow others to be, and no matter how separate from others we feel we might be, we are always connected and socially interdependent. As Bakhtin (1984) put it, “A person’s consciousness awakens wrapped in another’s consciousness” (p. 138). In contrast, monologism and monologic speech can be characterized by a person seemingly claiming to be *self-sufficient*. Here, the individual suggests that his or her existence is clearly bounded and his or her voice is simply his or her own, unaffected or effected by others. Rather than being wrapped up in another’s consciousness, the individual is separate from others and can become him or herself.

Furthermore, dialogism and monologism can be described in terms of a person *merging*, or not, with other people. For Bakhtin (1984, 1986), in dialogic speech a person makes a clear demand that he or she does not *merge* with another person. In part this is because, while recognizing that he or she is non-self-sufficient, the person also recognizes that he or she is different from other people – not apart from each other, but distinct. This

view of dialogic speech as involving not merging with another is reinforced by Clark and Holquist (1984) in the following comment:

“The way in which I create myself is by means of a quest: I go out to the other in order to come back with a self. I live into another’s consciousness; I see the world through the other’s eyes. But I must never completely meld with that version of things, for the more successfully I do, the more I will fall pray to the limits of the other’s horizon. A complete fusion...even if it were possible, would preclude the difference required for dialogue” (p. 78).

Monologic speech, on the other hand, can be characterized as a voice and narrative seeking, explicitly or implicitly, to *merge* with another person. Here, an individual seeks to enter the other’s life and fuse his or her own self with the other or assimilate the other to his or her own self. As a result, they seemingly abridge difference and the distance between each other.

In addition to the ideas of (non)-self-sufficiency and merging, dialogic speech and monologic speech can be described in terms of *finalizability* and *unfinalizability*. According to Bakhtin (1984), dialogic speech also begins with the recognition of the other’s *unfinalizability*. For him, this is partly because in dialogism the world is not only recognized as a messy place, but also as an open place in which one can never know with certainty who the other is or can become. Thus, in dialogism and dialogic speech there is a sense of unfinalizability as a person avoids giving the final word about the other. In contrast, monologism creates *finalizability*. That is, through monologic speech a person claims the last, the definitive, final word, about who the other is and what he or she can become. As Bakhtin describes it, monologic speech is:

“Finalized and deaf to the other’s response...Monologue manages without the other, and therefore to some degree materialises all reality. Monologue pretends to be the ultimate word. It closes down the represented world and represented persons” (p. 293).

Having briefly offered a description of dialogism and monologism by drawing attention to some of their key features, it would be remiss of me not to stress that like most binary distinctions, the difference between dialogic and monologic speech is not pure. Indeed, ultimately all speech is dialogical inasmuch as all speech contains remembered voices of others and orients to other people.¹ Yet, as Frank (2005a) argues, “The difference between monological and dialogical speech has practical value for thinking about what kind of people we want to be” (p. 293). Seen in this light, monologic and dialogical speech are less an opposition than a continuum, but the differences between the extremes of this continuum remain useful and significant.

Becoming Disabled Through Playing Sport: Overstepping a Boundary

With all this in mind, I now turn to a story and my interpretations of it. The story can be described as small story (Bamberg, 2006; Phoenix & Sparkes, 2009) as it was told during interaction outside the narrative environment (Gubrium & Holstein, 2008) of the formal interview. It is re-presented, and taped with consent, and is taken from a conversation over coffee during a break from an interview with one man (Eamonn) who sustained a spinal cord injury through playing sport and is now disabled.

The conversation took place at Eamonn's house and was part of a confidential, life history interview conducted by myself [Brett Smith]. It was the second interview of a series of three that formed part of a wider research project that focused on men's experiences of suffering a spinal cord injury through playing rugby football union. All interviews were tape-recorded, transcribed, and subjected to multiple forms of analysis, including a performative analysis.

Eamonn [pseudonym]: I don't know how you manage to do this research listening to me all day. It must be really depressing for you. Is it?

Brett: Sometimes it can be. But often it's not. Like I said, it's something I really believe in. And anyhow you do make me laugh sometimes.

Eamonn: Yeah, yeah. For the last hour I've been talking about how depressed I've been recently. Hardly a fun afternoon [both laugh].

Brett: For some maybe, but I do know too just how you feel. I've lived with depression, been there, at rock bottom, like you. So I know how you feel. I can identify I suppose is what I'm trying to say. I know what it feels like to be depressed, and when you talk about how you feel, I feel I enter into your world. Anyhow, you'll, I'm sure you'll get better. I know the future looks bad, but you will get better. You'll ride this out. You will be fine. By yourself you'll get out the other side.

Eamonn: But maybe I won't. Maybe I won't get out of this. It's not easy when you're disabled, alone, and down in the dumps. It's not. Nobody knows what the future holds.

Brett: You're right Eamonn. You're right; you just don't know what will happen. And I have no idea what it's like being you. I really have no idea how you feel and am out of order telling you things will be fine. They may not be. I don't know what the future has in store for you or me. I suppose I wanted to close the gap between us, know you better, empathise, but I've overstepped the boundary. I can't ever know what its like to live in your body.

Eamonn: And I can't ever know what its like to live in yours. At least we're talking though, and I've enjoyed it. It's been good today; it's been good being with you. And you never know, someone might learn from what I've said today and over the past year. They don't have to be disabled either. We're all dependent on each other.

Clearly, there are multiple ways in which the story can be interpreted.² As read through the concepts of dialogism and monologism, here I interpret it as follows. In the first part, Eamonn and I are speaking *with* each other rather than *about* each other. In so doing, we are developing dialogic speech. As the story develops, however, there is a shift in the story from a dialogical voice toward a monological voice. Here, in claiming to know, identify with, and enter into Eamonn's depressed body, I hint at a shared lived-body experience and begin to seemingly merge with him, thereby infringing on the mutual difference that sustains the boundary between persons: "But I do know too just how you feel. I've lived with depression, been there, at rock bottom, like you. So I know how you feel. I can identify I suppose is what I'm trying to say. I know what it feels like to be depressed, and when you talk about how you feel, I feel I enter into your world."

This monologic speech, in my interpretation, expands further as the story unfolds. Here I do not suggest to Eamonn that he *might* get better, thereby leaving his future open. Instead, I tell him he *will* “get better.” In doing so, I begin to finalize him. Finalization continues when I add, “You’ll ride this out. You will be fine.” This monologic voice is then strengthened when I suggest that he alone can get himself out of depression: “By yourself you’ll get out the other side.” Thus, in my words not only do I finalize Eamonn and persist in maintaining the comforting illusion that any of us can, often out of sheer desire to *empathize*, merge with another. But I also continue infringing on the mutual otherness that sustains the boundary between us by treating him as self-sufficient. In doing so, I perpetuate monologic speech as well as (at least) two preferred narratives within Western cultures. First is the narrative of a bounded individual who has the freedom to become him or herself, *by* him or herself. Second, I perpetuate the restitution narrative which tells us that when we are ill we will recover and get better (Frank, 1995).

But as the story continues, this monologic speech ends as abruptly as it began. “But,” Eamonn interrupts, “Maybe I won’t. Maybe I won’t get out of this. It’s not easy when you’re disabled, alone, and down in the dumps. It’s not. Nobody knows what the future holds.” In these words, as I understand them through Bakhtin, Eamonn disrupts monologism. This is done, in part, by problematizing one’s ability to merge with, and offer the final word on, another person. He thus signals that I’ve gotten too close and overstepped the boundary between us. As a result, Eamonn not only disrupts monologic speech but also sets in motion the potential for dialogic speech.

Midway through the story, with Eamonn’s words entering my consciousness, the research encounter as a performance is transformed. The performance shifts from being primarily monological to being dialogical. Initially this shift occurs as I receive words from Eamonn and my consciousness becomes wrapped in his consciousness. That is, my voice becomes imbued with the voice of Eamonn, but still remains distinguishable. In this voice that is both mine and Eamonn’s, I say: “You’re right Eamonn. You’re right; you just don’t know what will happen.” Thus in these words, I signal our non-self-sufficiency and move toward an unfinalizing voice and speech. My voice and speech never merges with Eamonn, but neither is my voice and speech self-sufficient. This dialogical relation is then sustained when I say: “And I have no idea what it’s like being you. I really have no idea how you feel and am out of order telling you things will be fine. They may not be. I don’t know what the future has in store for you or me. I suppose I wanted to close the gap between us, know you better, empathise, but I’ve overstepped the boundary.” Early in the sentence, Eamonn and I become unmerged as my concern with getting too close to Eamonn is expressed. As the talk unfolds, this dialogical relation continues. In my speech I suggest I was caught in a dilemma between getting too close to Eamonn and remaining too distant. I felt that I’d overstepped our boundaries rather than getting into the boundary space *between* us that sustains dialogism. This embodied knowledge is reinforced as I utter unfinalizing words: “I can’t ever know what it’s like to live in your body.”

The dialogical quality of this talk, and the performance of it, is maintained as the story unfolds further. This is done by Eamonn, however, as he responds to me: “And I can’t ever know what it’s like to live in yours. At least we’re talking though, and I’ve enjoyed it. It’s been good today; it’s been good being with you.” Here, again, Eamonn’s voice is non-self-sufficient and utters unfinalized words: the openness and “unknowability” of the future. It is too an embodied voice that speaks *with* me rather than *about* me, and which comes from a space *between* us rather than *above*. As the story continues, Eamonn becomes a *witness*

(Frank, 1995) inasmuch as he assumes a responsibility for telling me what happened: “And you never know, someone might learn from what I’ve said today and over the past year. They don’t have to be disabled either. We’re all dependent on each other.” This witnessing, therefore, is not a self-sufficient act. It implicates another in what Eamonn witnesses, and thus implies a relationship. This is reinforced toward the end of the sentence in my reading, as Eamonn questions the monological freedom of the individual. In such ways, therefore, we practice a balance between being neither self-sufficient nor merged, which sustains the boundary between us, and the boundary sustains dialogism/dialogic speech.

In sum, the story presented, and my interpretations of it, highlight the shifting dynamics of sustaining and crossing boundaries and how this is an on-going process shaped, framed, and enabled by dialogical and monological relations. We might therefore consider questions concerning “how close is too close” to research participants, and “how far is too far” from them, as neither simple nor straightforward. They are complex and shift in time and space as people move between merging and unmerging, self-sufficiency and non-self-sufficiency, and finalizing and unfinalizing practices. Accordingly, within disability research people may artfully engage in a process of boundary crossing and re-crossing that are, in part, social achievements and performances done through dialogical and monological speech (Frank, 2004).

Some Possible Implications for Disability Studies

With the above points in mind, and given the topic of this special forum, what kinds of interdisciplinary links does this article make between various fields? In what ways might the article further develop an interdisciplinary stance? How might the article develop considerations within and across disability studies and the various participatory/oppressive forms of research that have proliferated? What possibilities do the concepts of dialogism and monologism offer disability studies?

In terms of the kinds of interdisciplinary links between disability studies and various other fields, this article has eclectically woven together data generated from a project focusing on men’s experiences of becoming disabled through playing sport with theories and concepts from such fields as medical sociology, qualitative research, the sociology of the body, and narrative psychology. For example, from medical sociology it has shown the reproduction of the restitution narrative and, in relation to the sociology of the body, drawn attention to the idea that our bodies matter and our experiences of depression are embodied. The article further shows recent ideas from narrative psychology, including the extent to which our conversations are mediated by powerful cultural narratives (e.g., restitution narrative) that prompt us to say things we don’t always believe. It moreover shows in action the idea that researchers in the field of narrative should consider using not only big stories from formal interviews, but also those stories from outside the formal context of interviewing – that is, the small ones. In addition, the article has made disciplinary links between disability studies and the field of qualitative research methods inasmuch as both often advocate that to understand others, obtain significant knowledge, and do ethically admirable research we should empathize with our participants. The article has also signalled this aspiration to empathize in action through a small story. In such ways, therefore, the paper moves toward further developing an interdisciplinary stance.

Empathy

In making interdisciplinary links between disability studies and various other fields, however, the question needs to be raised, “How does this article develop considerations within and across disability studies and the various participatory/oppressive forms of research that have proliferated? What possibilities do the concepts of dialogism and monologism offer disability studies?” One response is that the article develops critical considerations on the practice of empathy and brings to the fore the possibilities dialogism and monologism might have for better understanding empathetic relations (see also Mackenzie & Scully, 2007). Within and across disability studies and the various participatory/oppressive forms of research in different fields that have proliferated, there have been calls for researchers to engage with participants in an empathetic manner. A reason given for this is that by empathically imagining the life of the other person, a researcher may increase his or her ability to better understand another person’s life, engender rapport, reduce emotional harm, and thereby develop research that moves toward working *with* rather than *on* disabled people. That is to say, the research becomes less oppressive and more ethically admirable.

Yet, while empathy can be an important consideration within disability studies and may be vital to working with disabled people as part of participatory forms of research, we should not forget its limits. The concepts of dialogism and monologism offer us some possibilities on understanding these limits. For example, the monologism and dialogism and the story presented alert us to the risk that empathy can turn into a form of symbolic violence. One form of violence is empathetic projection (Frank, 2004, 2005a). This relates to believing that one can empathically imagine being in the others’ shoes and treating him or her as feeling what I feel. But in this scenario, as in the story re-presented earlier, empathy can easily turn into projection, or sometimes introjection, which is an illusion that one can truly put oneself in the place of, and unify or merge with, another person. This symbolic violence of empathetic projection claims that you are as I am, and I *know* how you feel. In projecting oneself onto the other through empathy the difference between two people is denied. In denying that difference, one denies the other person and empathy tends toward unification, thereby becoming monological. Accordingly, without denying that empathy can be useful, the concepts of monologism and dialogism help call attention to the *limits* of empathy so that we might be cognizant of the complexities involved and are self-reflexive of how we do empathy within and across disability studies and participatory/oppressive forms of research. As Frank (2005a) points out, “Dialogue begins with empathy, but sustaining dialogue requires recognition of the limits of empathy” (p. 298).

Finalizing and Unfinalizing Research

Another way the concepts of monologism and dialogism make interdisciplinary links and develop considerations within and across disability studies, and offer possibilities for disability studies, is by drawing attention to a core ethical demand – that is, not finalizing another person. This is a particularly pertinent demand, and can have profound implications, for developing various forms of participatory research and avoiding oppressive forms of research. Finalization can occur when a researcher claims to have the last word about who another person is and what they can become. That is to say, the researcher engages in monological speech. Yet to finalize the other person through monological speech is, for Bakhtin (1984), oppressive since it can leave that person “hopelessly determined and finished off, as if he [or she] were already quite dead” (p. 58). For Bakhtin, all that is unethical begins and ends when one human being claims to determine all that another is and can be. The authorial word of the researcher becomes the person’s fate.

Therefore, as brought to the fore by the concept of monologism and dialogism, it would seem important that researchers from across the disciplines aspire to try and avoid monological speech, which utters the last word about the person(s). But, of course, that is often easier said than done. This is particularly so, given the disturbing observation made by Frank (2004, 2005b). As he points out, the claim of groups within and across disciplines to *professional* status often depends crucially on their socially sanctioned capacity to utter monological finalizations:

“Young professionals are taught that in order to be recognised as a professional, and to sustain the prestige of the profession in society, they must utter words that claim to be the *last* word, the definitive, finalising word, about those who fall within their purview, whether these are patients, students, defendants, clients, or research participants whose participation has definite limits. The worst implication of monologue is that those who are thus finalised come to expect to be spoken of in this way and...forget to notice the falseness of the approach” (Frank, 2005b, p. 967).

Given all this, how might actual interdisciplinary research practice strive to be dialogical rather than monological? According to Frank (2004, 2005b) dialogic speech begins with the recognition of the other’s unfinalizability. One way that this may be practiced is tied to a key question for qualitative research, medical sociology, disability studies, narrative psychology, and many other disciplines: “*What can one person say about another?*” As various researchers from different disciplines all propose (Couser, 1997; Denzin & Lincoln, 2005; Gubrium & Holstein, 2008; Frank, 2005b; Sparkes, 2002) research is, in the simplest terms, one person’s representation of another. In Bakhtin’s dialogical ideal, for researchers working within and across disciplines the research report that one represents another’s life must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may yet be. The researcher needs to recognize that the participant’s future is *open* and *uncertain*, and thereby consider representing him or her as such (Frank, 2005b).

Furthermore, for Frank (2004, 2005b), given that dialogic speech begins with recognition of the other’s unfinalizability within a dialogical relation, one person can never say of another, “This is who such a person *is*.” One can say, at most, “This how I see this person now, but I cannot know what she or he will *become*.” Dialogue depends on perpetual openness to the other’s capacity to *become someone other* than whoever she or he already is. Likewise in a dialogical relation, any person takes responsibility for the other’s becoming, as well as recognising that the other’s voice has entered one’s own, and that as researchers participating with disabled people there is the desire and possibility that research instigates change. As Frank (2005b) says:

“The dialogical alternative emphasises research participants’ engagement in their own struggles of becoming; its focus is stories of struggle, not static themes or lists of characteristics that fix participants in identities that fit typologies. Moreover, dialogical research requires hearing participants’ stories not as surrogate observations of their lives outside the interview but as acts of engagement with researchers. In these acts of engagement, the researcher does not passively record where the respondent is in his or her life. Any research act is necessarily reactive in its effects: The researcher, by specific questions, and even by her or his observing presence, instigates self-reflections that will lead the respondent not merely to report his or her life but to

change that life.... Research does not merely report; it *instigates*. The ethics are that instigation rest on the premise that has been endemic at least to Western thinking since Socrates: The examined life is a good thing, not always an immediately happy thing but an unavoidably important thing” (p. 968).

Closing Thoughts

Having outlined explicitly how this paper modestly develops an interdisciplinary stance, and highlighted some possibilities of dialogism and monologism for disability studies, some caveats and limitations need to be acknowledged. Firstly, the story presented here along with the points and possibilities raised above are not offered as any model or template of procedures. This is because, as Frank (2005b) cautions, it would be monological; such a model or template would finalize the researcher and their participants. As such, the story along with the points and possibilities raised are offered as guides, providing threads that others may follow and develop if they choose.

Secondly, the story presented is a transcribed exchange based wholly on tape-recorded interview data. No contextual and interactional factors, like bodily orientation, gesture, space, smell, were recorded during the research encounter. As a result, my interpretations of it focus wholly on the meaning of the words exchanged, but at the expense of a whole range of contextual and interactional factors. As Gubrium and Holstein (2008) put it, “The accent on the transcribed texts of stories tends to strip narratives of their social organisation and interactional dynamics” (p. xv). Accordingly, it is important that--when possible in future research--we aspire to document and take the range of contextual and interactional factors into account. This is especially so given that, as Bakhtin (1984) stressed, the particularity of utterance and the significance of both linguistic and extralinguistic elements in the production of meaning are vital.

Clearly, then, there is much work to be done in relation to dialogism, monologism, narrative, boundaries, extralinguistic elements, disability, and interdisciplinary research. I hope this article, as a potential resource, invites others to critically reflect on their relations with others within research encounters, how they orientate to boundaries, and the consequences this may have on them and others. Whilst not the only or the best way, theories of dialogism and monologism can be useful in this process, and may help in our efforts to engage in interdisciplinary work.

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References

- Bakhtin, M. (1981). *The dialogic imagination: Four essays*. C. Emerson & M. Holquist (Eds. & Trans.). Austin, TX: University of Texas Press.
- Bakhtin, M. (1984). *Problems of Dostoevsky's Poetics*. C. Emerson (Ed. & Trans.). Minneapolis, MN: University of Minnesota Press.
- Bakhtin, M. (1986). *Speech genres and other late essays* (V. McGee, Trans.). C. Emerson & M. Holquist (Eds.). Austin, TX: University of Texas Press.
- Bamberg, M. (2006). Stories: Big or small—Why do we care? *Narrative Inquiry*, 16, 139-147.
- Bolt, D. (2006). Beneficial blindness: Literary representation and the so-called positive stereotyping of people with impaired vision. *New Zealand Journal of Disability Studies*, 12, 80-100.
- Clark, K., & Holquist, M. (1984). *Mikhail Bakhtin*. Cambridge, MA: Harvard University Press.
- Couser, T. (1997). *Recovering bodies*. Wisconsin: University of Wisconsin Press.
- Denzin, N., & Lincoln, Y. (Eds.). (2005). *Handbook of qualitative research* (3rd ed.). London: Sage.
- Frank, A. (1995). *The wounded storyteller*. Chicago: The University of Chicago Press.
- Frank, A. (2004). *The renewal of generosity*. Chicago: The University of Chicago Press.
- Frank, A. (2005a). Generosity, care, and a narrative interest in pain. In D. Carr, J. Loeser, & D. Morris (Eds.), *Narrative, pain, and suffering*, Vol. 34, (pp. 289-300). Seattle, WA: IASP Press.
- Frank, A. (2005b). What is dialogical research, and why should we do it? *Qualitative Health Research*, 15, 964-974.
- Goodley, D. (2007). Towards socially just pedagogies: Deleuzoguattarian critical Disa9bility studies. *International Journal of Inclusive Education*, 11, 317-334.
- Gubrium, J., & Holstein, J. (2008). *Analysing narrative reality*. London: Sage.
- Mackenzie, C., & Scully, J. (2007). Moral imagination, disability and embodiment. *Journal of Applied Philosophy*, 24, 335-351.
- Phoenix, C., & Sparkes, A. (2009). Being Fred: Big stories, small stories and the accomplishment of a positive ageing identity. *Qualitative Research*, 9, 83-99.

Sparkes, A. (2002). *Telling tales in sport and physical activity: A qualitative journey*.
Champaign, IL: Human Kinetics Press.

Endnotes

¹A special thanks to Lucy Burke for kindly bringing this to the fore of my attention.

²Bakhtin died on the morning of March 7, 1975, from complications of emphysema and was attended only by a night nurse, who noted his final words as being, "I go to thee" (Clark & Holquist, 1984, p. 343). At a memorial service later that year in Moscow, a number of intellectuals gathered to read his works and discuss the impact of his career. Among those speaking was Shakespeare scholar L.E. Pinsky, who warned against any single, authoritative interpretation of Bakhtin's works (Clark & Holquist, 1984, p. 344).

Spectacle, Performance, and the Re-Presentation of Disability and Impairment
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Abstract: This article proposes the value of investigating audience interpretations as viewing performances to interrogate disabling discourses on popular television. In synthesising media and disability studies approaches, performances of identities are investigated, contextualizing the media as a crucial factor in forms of cultural identification, contributing to patterns of exclusion and inclusion.

Key Words: audience, performance, television narratives, exclusion

This paper arises out of three primary concerns. First, I have a long-standing interest in people's attitudes toward disability and the relationships between cultural representations and attitudes. Secondly, my work in media studies has stimulated my interests in ideas of the "active audience" and the dynamics of meaning-making. Finally my work in cultural studies led me to become dissatisfied with readings of disability within cultural studies texts, and their limited nature. These cultural and media studies readings are invariably based on individualistic or medical models of disability (Oliver, 1990; Barnes, Mercer, & Shakespeare 1999) where individual deviations from ascribed bodily norms are framed as "abnormal" against non-disabled forms of "normality." The individualistic, non-disabled centred assumptions, which pervade conventional media studies work on disability, limited as they are, tend to have insidious effects outside disability studies arenas, leaving individualist or deficit models of disability unchallenged.¹

The import of these concerns into my work on disability and audience led to a re-examination of Disability Studies interpretations of media in relation to questions of audience identity. Disability Studies literature has demonstrated how frequently disabled people are misrepresented in mainstream media, teaching us much about how stereotypes are used to convey messages about disabled people's difference (Barnes, 1992; Biklen & Bogdan, 1977; Klobas, 1988; Kriegel, 1987; Longmore, 1987; Norden, 1994; Shakespeare, 1994). This work provides a crucial corrective to conventional criticisms of art and media, but it also tends to be quite partial or reductive, based on fixed meanings. Reflecting social models of disability, the emphasis is placed on exploitative images and the lack of disabled people's participation in the creation of images of impairments (Barnes, 1992). In doing so, a number of assumptions are made about how depictions of media and disability are read.

Broadly, Disability Studies scholars seem to agree that there is "a problem of disability representation," that there is little cultural recognition of disabled lives and that disabled people need inclusion, both quantitatively and qualitatively in cultural industries as producers and as audiences. These points have been forcefully made by people involved in Disability Arts for many years.

Although there is much dissatisfaction about cultural imagery, there is little agreement on what the major problems of representation are, and what comprises a "good" portrayal. Despite shared political goals and cultural tastes, there is a wide range of views held by both activists and academics about what representations of disability *should* be despite our shared visions (Shakespeare, 1999).

Cursory examination of people's interpretations of the same images reveals significant differences in interpretation, even where people's views toward disability are informed by similar political viewpoints. Critics of cultural representations of disability, for example Leonard Kriegel (1987), praises the depiction of Laura Wingfield in Tennessee Williams's *Glass Menagerie* (1965) as an example of the Realistic Cripple, where traits of ordinariness are privileged and disability often relegated to secondary status. This assessment reveals the gendered properties of such stereotypes *and* the gendered positioning of observers when contrasted with Deborah Kent's (1987) reading. Whereas the depiction of Laura seems "normal" or "realistic" to Kriegel (1987), Kent (1987) has argued that her lameness is fundamental to her painfully passive personality and self-deprecating attitudes to men. This Cinderella type of identity is commonly attributed to disabled women, with a range of impairments, across a range of media (Norden, 1994; Kent, 1987). Conflicts such as this underline a more significant issue of meaning-making; *how* different people engage with images in a variety of ways. It seems that gendered reading positions may have had much to do with differing interpretations, despite shared representational concerns. Indeed, I propose that gender is a major contributory factor to reading or viewing positions adopted by readers of cultural texts. Gendered reading positions were pivotal to the experiences of audience members in a research project (see below) on the reception of images of disability in TV and soap opera viewing. This data will be discussed in the remainder of the paper.

It is this issue of meaning-making that is fundamental to debates on portrayals of disability. Accordingly, this article focuses upon how different people engage with images in a variety of ways. Although there have been a number of investigations of disabling imagery that focus on people's responses to and opinions of specific media (Cumberbatch & Negrine, 1992; Sancho, 2003) they have a tendency to focus on the limitations of the audience, but had little or nothing to say about the form, structure, and discourses of the media texts and how we interact with them.

Premised on individualistic methodologies toward disability (Oliver, 1990), these surveys tend to shift away from the limited character of portrayals toward snapshots of audience taste. This is in contrast to understanding positions towards the media as intersubjective, situated, and relational phenomena, shaping and being shaped by media, social context, capital, and access to cultural resources. Analyzing audience data from my own research project, it became increasingly evident that reception of media discourses varied over time and according to social context. Far from presenting a coherent picture of audience types and decoding practices (Hall, 1980), there were many ambivalent and contradictory understandings. The marked differences between individual and collective responses led me to focus on the uses of media in negotiations and performances of self and group identity, upon which the remainder of this paper is based.

The Research Project

The Audience

A multi-layered methodology was designed to capture the complexity of media interactions. This involved three main methods: textual analysis, focus groups, and diary keeping with a wide range of people. Participants included non-disabled and disabled men and women aged from 13 to 65, from a variety of social backgrounds.² There were seven discussion groups, most meeting a number of times over several months. All the groups were comprised of people sharing similar "significant" social groups and social categories,

reflected in age, sex, class, and impairment status in particular. These were based in “everyday life” locations, at familiar places of work, study or leisure, so the meetings were accessible, convenient and conducive to comfortable forms of discussion. Both discussion groups and diarists were asked to consider interrelationships of gender, impairment and disability. The groups were comprised of: (1) young women from an independent school (The Powerpuff Girls); (2) young people from a segregated school, all disabled, male and female (The Monday Group); (3) a youth club group of mixed sex and impairment/non-impairment status (The Tuesday Group); (4) a group of non-disabled young men (The Lads), (5) a mixed-sex disabled group from a day center (The Friday Group); and (6) two groups of single-sex, nondisabled, social groups (The Men and The Women). Diarists were recruited from these groups, from Disability Now magazine (<http://www.disabilitynow.org.uk/>) and from snowballing.

Assuming that audience reception will reflect the ideological dominance of powerful groups, but is not *directly* determined by them, I set out to understand how media products and potential outcomes are located in complex patterns of media interaction. Neither abandoning materialist perspectives nor insights on the discursively constructed character of impairment, disability and normality, I used strategies based on Abercrombie and Longhurst’s (1998) Spectacle/Performance paradigm of media circulation. The following pages will demonstrate the value of this paradigm in understanding the impact of disabling discourses on cultural processes and social practices and vice-versa.

Text, Audience, Context, and Performance

In order to gain a fuller understanding of how people interact with images of disability and impairment in media, participants’ interpretations were linked to expectations of the reader inscribed within media texts. Analysis was based on how images of disability and normality made people *feel*, what they do with particular images, exploring how people’s interpretations vary, taking account of text and social context. Examples of the roles that media images play in forms of cultural identifications are illustrated in the pages that follow, demonstrating some of the ways that media discourses contribute to patterns of exclusion and inclusion.

Taking a constructionist, relational view, both media texts and viewers’ discussions were treated as “shifting constellations” (Grossberg, as cited in Alasuutari, 1999, p. 6) and as never being “completely outside of media discourse” (p. 6). Fundamentally, a recognition of the participants’ ideas of themselves as the audience, *as performers*, was a foremost principle. Here, positioned as people who consume, interact with, and create culture, they demonstrate the significant ways that people locate themselves as performers within institutional regimes in their everyday practices.

Media analysis was synthesized with disability studies in order to place a social model of disability, impairment, and gender at the centre of analysis of audience engagements (as a politicized piece of work). Maintaining this interdisciplinary focus, I used two forms of media analysis: textual analysis and audience analysis. I began textual analysis with Hall’s (1980) Encoding/ Decoding Model. However, the classification of readings as preferred, negotiated, or resistant was inadequate in grasping the complexity of audience interpretations, obscuring researcher assumptions, and oversimplifying the range of subjectivities that are brought into interpretative contexts. The encoding/decoding model did not account for the complex processes of agency in relation to a range of intersecting discourses in different social

contexts. It was also somewhat limited in comprehending the complexity of disability and impairment images and other factors influencing interpretation from an increasingly media saturated society.

It was particularly difficult to draw clear lines between the positions of incorporation and resistance to “dominant ideology,” an issue complicated further by the lack of consensus on what should be considered as “dominant” disabling ideology. Even when clearer distinctions were drawn between incorporated and resistant positions in often “disordered” or differentiated audience responses (Abercrombie & Longhurst, 1998), such distinctions would do little to answer other questions that emanated from the data. One fundamental question arose: how and why do disabled people and non-disabled people invest their identities differently, often enthusiastically, but sometimes in (ostensibly) contradictory ways, in what seems to be a “normality genre” (Darke, 1998).

I used Abercrombie and Longhurst’s (1998) Spectacle/Performance paradigm in order to seek answers to increasingly important questions of media identity I emphasized the need to consider issues of performativity, in contextualized, relational ways. Focusing on the investments sought and made with media, spectator identities, cultural representations, and outlooks can be investigated in a dialogical manner. Focusing on audience engagements, viewers or readers are located in a view of media and everyday life as interwoven, where spectacle and performances are seen as virtually inseparable within increasingly media-saturated society and diffused audiences. Abercrombie and Longhurst propose that this novel form of performativity, facilitated by mass communications, results in the virtual elimination of cultural distance between performers and audience, whereby two simultaneous processes have occurred: the world has been constructed as “spectacle” and individuals have become constructed as narcissistic performers.³

Abercrombie and Longhurst (1998) assert that “narcissism is the treatment of the self as spectacle,” where people perceive themselves as “performing for an imagined audience” (p. 95) in all aspects of everyday life, seen as a vital facet of the ongoing construction of self-identities. Simultaneously, other social practices or “spectacles,” including those from the media, are continuously informing these reflexive “self trajectories” (Giddens, 1991 as cited in Abercrombie & Longhurst, 1998, p. 95). It is argued that this spectacle/performance dyad fuels a desire for increased “knowledge/visibility as a basis for performance” and the consequent “media drenching” creates greater interaction and discussion of media events. In turn, emotional attachments are sustained or increased, informing individual or “secondary performances” (Abercrombie & Longhurst, 1998, p. 178). It is argued that viewing performances are fundamentally related to emotional attachment and constructive of individual identities, which increases the desire for new knowledge via media resources, perpetuating the spectacle/performance cycle.

The exploration of emotional questions is fundamental to the enterprise of understanding disability in terms of socially constructed “difference” and immediate or wider relational contexts. It is proposed that depictions of impairment and disability should be explored as “narcissistic performances.” This acknowledges ambivalence and contradictory forms of spectatorship, varying over time and context, shedding light on the social conditions shaping individual interpretations.

Broadly speaking, data in this study was separated into two types of discussion; critical, ostensibly more objective discussion of soap operas, and referential talk that was

linked more obviously to the participants' personal experiences (Leibes & Katz, 1993). Excerpts from diaries and focus groups will now be examined as a means of exploring the articulation, negotiation, and re-constitutions of collective and more personal selves, focusing primarily on referential talk, where "people bounce effortlessly backward and forwards between their own world and the world of the soap opera" (Abercrombie & Longhurst, 1998, p. 111). These performances of viewing selves reveal significant attitudes towards concepts of social care, dependency, and cultural competency.

Viewing Performances

Viewing, Group, and Self Identity

One of the most significant dimensions of the data was the difference found between performances of self in group contexts and ostensibly contradictory self-expressions in diary entries (by the same people). For example, the non-disabled women's' group discussions on disability and impairment were rarely referential, focussing mainly on critical comments, demonstrating a very caring approach to depictions, questioning images of disability:

Diane: Every single baddy's got some impairment problem. Like Mini-Me from Austin Powers.

Nicole/Olive: Yeah.

Sally: You know, you go and you get, you're supposed to be scared aren't you? That's the whole thing.

Implicitly assuming the morally educative and identificatory resources of soap operas, The Women seemed to find few depictions which addressed preferred dimensions of their collective self directly, other than the character Kerry Weaver:

Sally: Oh, I've just thought of a woman. Now she is sexy. The woman in E.R.

Laughter/agreement

Olive: And she's disabled and she's a main character...now that's the way forward. You get a strong main character who has a disability there before the issue and you just play their character against the rest of the characters.

Diane: And she was a bitch for ages wasn't she?

The attachments that were expressed with Kerry were on the basis of her personality and attitudes and her Return (Nochimson, 1997) from bitchiness, rather than other ontological similarities, such as impairment or sexual identities. Their collective engagements were made primarily on the basis of group reassurances of normality. Significantly, Kerry was a disabled character⁴ from a medical drama rather than soap opera. Renowned for her independence, she was an active, if ostensibly uncaring, mediator of social care, rather than a recipient. Unusually, she was depicted as someone with an excess of cultural competency and social capital.

Conversely, participants' diary entries usually focused on depictions that were framed as abnormal. Caroline (nondisabled) wrote:

"If there is a sickness/death/dying storyline then I will turn it off because it makes me anxious. I watch T.V. sometimes for the normality of it, just to laugh for five minutes."

Normality, Disability, and Impairment

The search for normality was also true for other groups. The Powerpuff Girls, for example, had widely differing collective and personal views of concurrent teenage pregnancy narratives with Sarah Lou of *Coronation Street*, and Sonia of *Eastenders* (Wilde, 2004). Sarah Lou, as the more conventionally attractive figure was the preferred focus for group discussions of teenage pregnancy whereas the comparatively “ordinary” figure of Sonia was a primary point of identification and reassurance, particularly in articulating their own, ostensibly more private, carnal concerns. One disabled male diarist, Peter, also felt able to disclose more personal feelings of abnormality in his diary. He wrote:

“Images of disabled people in soaps invariably make me feel worse about myself because they accentuate a negative sense of difference: the disabled person/character exists by virtue of their disability or impairment, and seems to exist for that reason alone.”

These negative feelings of difference were inextricably linked to discourses of dependency and cultural competency and were, for him, a prime concern in watching portrayals of disability and impairment soap opera.

In sharp contrast, the disabled adults (Friday) group acquiesced to stereotyped impairment portrayals more readily than any other group, often seeing them as natural rather than constructed. Here they are discussing Chris Tate of *Emmerdale*:

Andrew: I suppose if you are in a wheelchair permanently you can't upset people can you? Because you need their help.

Sonny: No, you easily get very frustrated.

Andrew: I think it's a fairly realistic approach, though, I think. Er, you see him sometimes having difficulties with the chair, and getting frustrated. Er...

Jack: Mmmm. I think it's a hard world.

Here, the specific positioning of the character's narrative as an individualized problem is received transparently by men within the group. Although this group often referred to themselves as a homogenous group, defined primarily as owners, if not victims, of acquired impairments, the structural or cultural sources of their shared experiences and their negotiations of disability were rarely confronted directly, being taken on as personal attributes of their impairment experience.

The biographical disruptions (Bury, 1982) they were articulating were elaborated almost exclusively in terms of diminished physical functions. These performances of self were located in a “common-sense” body hierarchy, where the construction and performance of a good impairment identity appeared to be their major responsibility and their primary point of identification with the group and myself. Dependency, here, was taken as a given. Cultural competencies were seen as diminished, usually indexed to their previous (nondisabled) lifestyles. They expressed low expectations of social care, as their naturalized opinions towards their own positions of inferiority or subordination indicate. Depictions of disability provided no basis for performances of group identity, most engagements being performed in counter-identification to non-disabled characters that challenged heteronormativity.

Conversely, The Monday Group's approach to impairment and disability was politicized and collective. "Resistance" to dominant images was very direct for these disabled young people and often addressed in terms of absences, rather than accuracy. They discussed how they would depict impairment and disability concerns in a more playful fashion:

Alice: Just good looking disabled people. (*Group agreement and laughter*)

Oliver: Disabled pensioners over the edge. (*Group Laughter*) Although I think we'd have to have some arguments and stuff. (*Group laughter*) I don't know why there's, I don't know why there is like, they don't put up with disabled people's differences. It's a shame really because people just like, it's like shutting the mouth, sort of, isn't it?

Ruth: They're not getting close enough. They want to show them doing more things. They're always struggling.

Alison:⁵ What don't they show then?

Ruth: They never show them going down the shop for a pint of milk which is everything. We can do that. They're always showing people who are in a wheelchair and so forth, not somebody who's like, got cerebral palsy.

A strong sense of disabled pride pervades their performances of collective self. In the presence of their (non-disabled) teacher, their viewing performances proceeded in a "real," rather than "ludic" form (Liebes & Katz, 1993) with brief, guarded, reactive answers to questions. In the sessions when the teacher was absent, their ideas for alternative soap opera narratives were enthusiastic, loud, more radical (and playful) than any other group, usually through their reversals of the normality/disability dualism. They challenged conventional depictions of incompetency and dependency repeatedly, each time they met.

The "resistant," counter-identificatory, readings of this group were made more comfortable through processes of mutual aid, by the exclusive group membership of disabled people. Sharing similar life histories of disability, they had a variety of things in common. Spending considerable time in a "special school," is likely to have contributed to the feeling of being an outsider, a theme that dominated their discussions of collective self.

Stereotyping, Narrative Placement, and Processes of Group Identification

It is noteworthy that none of the young disabled group members made any sustained references to particular characters of soap operas, making no particular identifications or disidentifications (McNay, 2000) with any soap opera characters, apart from brief counter-identifications with older characters such as Dot Cotton (*Eastenders*), as a figure of fun. This contrasted sharply with the viewing performances of other groups of young people. The Lads tended to make strong counter-identifications with a range of female characters, disidentifying with disabled characters and the soap opera genre as a whole. As previously suggested, the "sense of self as a performer under the constant scrutiny of friends and strangers" (Lasch, 1980, p. 9) seemed to contribute to collective performances of identification with figures who were closer approximations to cultural ideals of body and gender performance. So, rather than express or highlight fears of personal inadequacy, the group discussions demonstrated a preference for using hegemonically normative characters. These were discussed as relatively unproblematic, symbolic resources, to negotiate moral and ethical issues and related identities, simultaneously strengthening homophilic ties.

The figures which formed the basis for discussions of moral discourses and performances of group identity were all non-disabled, with the exception of Kerry Weaver.⁶ Further, textual analysis revealed that these preferences were linked to the existence of significant narrative inequalities. That is to say, core non-disabled characters are found everywhere whereas disabled characters are rarely found outside the topical narrative level (O'Donnell, 1999). Thus, characters with impairments were almost always discussed in terms of political messages rather than in terms of personal pleasure or reassurance. This was particularly clear in the Tuesday Group. As a mixed gender and disabled/non-disabled group who had very varied experiences and perceptions, Mark Fowler, a character with HIV, from *Eastenders*, was the focus for many conflicts on disabled people's rights to lead "normal lives," including heated debates on sexuality and parenting. These discussions of disability issues strengthened the divisions within the group that were based primarily on performances of disabled or non-disabled selves, providing no clear points of contact for the group as a whole.

Re-Framing Questions of Media, Disability, and Audience

I have proposed the need to consider issues of performativity, in contextualized, relational ways. Using examples from the audience data, issues of cultural capital, cultural resources, and people's capacities for "cultural conversion" seem scant and few disabled people found any form of cultural capital in mainstream depictions of impairment and disability, other than personal reassurances and information gleaned from medical dramas. This genre seemed to afford disabled women more opportunities to perform competent impairment identities, occasionally providing material for critical reflection on the relationship between their own impairments and disabling processes (Wilde, 2004).

Examination of people's viewing performances has revealed crucial aspects of engagement and viewer identity. It has shown that the problem of representation is not just a matter of "negative" stereotypes, of bad personality attributes. Analysis of the interactions between texts and viewers has suggested that issues of diversity and multi-dimensionality are of far more significance in the forging of emotional attachments to portrayals of disabled people. Few, if any people engaged with soap opera depictions of characters with impairments, due to narrative inequalities. Seen as "issues," portrayals of disabled people tend to remain "fixed." Moreover, the placement at the topical level encourages people to turn off from any explicit political messages being conveyed (Gavin, 2000). Rather, participants engaged more with non-disabled figures who reflected recognisable aspects of themselves, particularly as changeable personalities, adapting to a fluctuating range of circumstances.

Crucial narrative inequalities seem to play a fundamental role in the stereotyping of disabled people. Synchronically and diachronically, analyses of disabled characters invariably reveal that characters with impairments are far more likely to be found in supporting or subsidiary roles (Wilde, 2004). Typified by the over-population of disabled characters in the meta-narratives, this point was forcefully made in the group counter- identifications of younger disabled participants:

Beth: [] it's got to be dramatic. (*Group agreement*)

Oliver: Yeah, no disability or a major one.

Andrew: And then it's gone.

It is of considerable significance that few participants question these placements, indicating a naturalization of disabled people as events to be resolved.

Regarding data as performances has illuminated some of the ways that audiences use media. In particular, these examples of soap opera viewing demonstrated how people use characters and narratives to negotiate their own perceptions of, and identifications with, normality and abnormality. These interpretations and viewing performances have varied significantly between group and private contexts. In nearly all cases engagements with characterisations of disabled people seemed to be marginal to these performances and negotiations of self. Nearly all referential discussions of disability and impairment were performed in terms of counter or dis-identification (McNay, 2000) or in critical talk of pathological images. Portrayals of disability contributed very little to the cultural capital of any of these participants, having little or no value as a resource for collective or self-identity, providing little pleasure and reassurances of fears. Remaining within the terms of the negative/positive debate seems to disable us further (notwithstanding the existence of explicitly malicious genres, such as the comedy of Jim Davidson and the late Bernard Manning). The avoidance of some stereotypes, suggested in some broadcasting manifestos⁷ will limit disabled people's roles and viewing opportunities further. Disabled characters should float freely between stereotypes and multiple roles, interwoven on all narrative roles, just as non-disabled people do. Our place within media narratives should be everywhere, affording us the same range of stereotypes as non-disabled people, as angels, heroes, villains, and so on.

If narrative inequalities were redressed, disabled characters would be provided with a greater range of roles and greater fluidity. This way, the degrees of implication that are offered to the audience would be increased. Alongside the counter or dis-identifications, which are currently made with disabled figures, greater narrative equality is likely to encourage more sympathy and empathy with characters with impairments and the messages they are conveying. In turn, portrayals of disability will become increasingly referenced to viewers' own lives, strengthening social and personal identifications with normality and providing reassurances for feelings of abnormality. Hence, like the majority of non-disabled characters, dimensions of likeability (Sancho, 2003) will be optimized, providing recognition for disabled peoples lives and identificatory resources for both disabled *and* non-disabled viewers. Disabled characters receiving widespread audience approval have often been cast in ambiguous or even negative roles. These include abrasive leading characters such as Kerry Weaver of *E.R* and Gregory House of *House*, both medical dramas from the U.S. The benefits of people with fluctuating personality characteristics are clear. The viewing performances of the participants in this project have suggested that viewers do not make simple identifications on the basis of impairment or disability status, or indeed, by gender, class, ethnicity or sexuality. Significant aspects or personal identity reflected in television images undoubtedly have a part to play in processes of identification. But *how* people are depicted on television is of greater significance. Viewers are more likely to seek images that reassure them of their own normality or against private feelings of abnormality, whatever they may be.

Overall, this article has demonstrated how portrayals of disabled people are usually universally read as abnormal others, interpretations that have been performed in a variety of contexts. Focusing on viewing as performance, it has also illustrated some of the ways that characterisations are used to strengthen or weaken cultural identifications and to articulate, negotiate or maintain patterns of exclusion and inclusion between people.

Interdisciplinary, or intertextual, approaches to media such as this are likely to provide us with greater insights into strategies for representational change. Moreover, they have much to offer in understanding significant cultural discourses in the professions and elsewhere, particularly in examining how media contribute to the structuring of social relations (Warner, 2006) and in perpetuating, or challenging the misrecognition (Fraser, 1996) of disabled people as “other.”

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References

- Abercrombie, N., & Longhurst, B. (1998). *Audiences*. London: Sage.
- Alasuutari, P. (1999). *Rethinking the media audience*. London: Sage.
- Barnes, C. (1992). *Disabling imagery and the media: An exploration of the principles for media representations of disabled people*. Halifax, NS, Canada: Ryburn.
- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Oxford: Polity.
- Biklen, D., & Bogdan, R. (1977). Media portrayals of disabled people: A study of stereotypes. *Interracial Books for Children Bulletin*, 8, 4-9.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-192.
- Cumberbatch, G., & Negrine, R. (1992). *Images of disability on television*. London: Routledge.
- Darke, P. (1998). Understanding cinematic representations of disability. In T. Shakespeare (Ed.), *The disability reader: Social science perspectives*. London: Cassell.
- Fenichel, O. (1999). The Scopophilic Instinct and identification. In J. Evans & S. Hall (Eds.), *Visual culture: The reader*. London: Sage.
- Fraser, N. (1996). *Justice interruptus: Critical reflections on the 'postsocialist' condition*. London: Routledge.
- Gavin, J. (2000). Television teen drama and HIV/AIDS: The role of genre in audience understandings of safe sex. *Continuum*, 15(1), 77-196.
- Hall, S. (1980). Encoding/decoding. In S. Hall, D. Hobson, A. Lowe, & P. Willis (Eds.), *Culture, media, language: Working papers in cultural studies 1972 – 79*. London: Hutchinson in association with the Centre for Contemporary Cultural Studies.

- Kent, D. (1987) Disabled women: Portraits in fiction and drama. In A. Gartner & T. Joe, (Eds.), *Images of the disabled, disabling images*. New York: Praeger.
- Klobas, L. E. (1988). *Disability drama in television and film*. Jefferson, NC: McFarland.
- Kriegel, L. (1987). The cripple in literature. In A. Gartner & T. Joe (Eds.), *Images of the disabled, disabling images*. New York: Praeger.
- Lasch, C. (1980). *The culture of narcissism*. London: Sphere.
- Liebes, T., & Katz, E. (1993). *The export of meaning: Cross-cultural readings of Dallas*. Oxford: Oxford University Press.
- Longmore, P. (1987). Screening stereotypes: Images of disabled people in television and motion pictures. In A. Gartner & T. Joe (Eds.), *Images of the disabled, disabling images*. New York: Praeger.
- McNay, L. (2000). *Gender and agency*. Cambridge, UK: Polity.
- Nochimson, M. (1997). Amnesia 'r' us: The retold melodrama, soap opera, and the representation of reality. *Film Quarterly*, 50(3), 27-38.
- Norden, M. E. (1994). *The cinema of isolation*. New Brunswick, NJ: Rutgers University Press.
- O'Donnell, H. (1999). *Good times, bad times: Soap operas in Western Europe*. London: Leicester University Press.
- Oliver, M. (1990). *The politics of disablement*. Basingstoke, UK: Macmillan.
- Sancho, J. (2003). *Disabling prejudice: Attitudes towards disability and its portrayal on television*. British Broadcasting Corporation, Broadcasting Standards Commission and Independent Television Commission. Retrieved from <http://www.ofcom.org.uk/static/archive/bsc/pdfs/research/disability.pdf>
- Shakespeare, T. (1994). Cultural representation of disabled people: Dustbins for disavowal? *Disability and Society*, 9(3), 283-99.
- Shakespeare, T. (1999). Art and lies? Representations of disability on film. In M. Corker & S. French (Eds.), *Disability discourse*. Buckingham, UK: Open University Press.
- Warner, J. (2006). Inquiry reports as active texts and their function in relation to professional practice in mental health. **Health, Risk and Society**, 8(3), 223-237.
- Wilde, A. (2004). Performing disability. In M. King & K. Watson (Eds.), *Representing health: Discourses of health and illness in the media*. Basingstoke, UK: Palgrave MacMillan.

¹For example, in Fenichel's (1999) work (as cited in Hall & Evans, 1999) which uses psychoanalytic theory to reiterate old myths of masturbation and blindness.

²Care was taken to recruit people from different socioeconomic backgrounds and localities, including young people from a fee-paying school and comprehensives, lesbians, and one black person (in a predominantly white area).

³This is seen most obviously in the saturation of television schedules with "Reality TV" programs.

⁴This was before her hip dysplasia operation, in Series 12, "Out on a Limb."

⁵All references to Alison are myself as the group moderator.

⁶See note 4.

⁷Examples of these can be found in Broadcasters Disability Network, at: www.media-disability.org/.

Performing the Pain: Opening the (Crip) Body for (Queer) Pleasures
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Abstract: With a view to interdisciplinary dialogue(s) between queer theory and disability studies, this article discusses the work of Bob Flanagan and his partner Sheree Rose. Specifically, it focuses on their queer S/M practices as a strategy of negotiating disability/pain, but also as a practice redefining notions of (disabled) embodiment. It also discusses Flanagan and Rose's queer/crip politics as an opening for "desiring disability."

Key Words: queer theory, pain, crip

What kind of pain is it? Where and how does it hurt? These are the questions we ask when confronted with pain, in an endeavour to localize, characterize, and define the pain we experience. Central to the questions is the Cartesian binary, issuing a call to our intellectual capacities to explain what is happening to the aching body (Leder, 1998; Bendelow & Williams, 1995). As such, the questions reveal the concept of pain that predominates in modern culture and the ways in which we think about pain. In his classic book *The Culture of Pain*, David Morris (1991) puzzles over the lack of knowledge about pain that, in his assessment, represents the most significant illiteracy of Western culture. In his argument, Morris opposes the tendency to strip pain of its cultural and social relevance. Similarly, Bendelow and Williams (1995) are critical of the tendency to localize pain within specific bodily parts and perceive it *solely* as a result of "an elaborate broadcasting system of signals" activated by a failure or dysfunction in the machine of a human body and its organs, rather than understanding pain as "shaped both by the individual and their particular socio-cultural context" (p. 140). To many, such attitudes to pain are emblematic of its medicalization.

Pain undoubtedly "belongs to the most basic human experiences that make us who we are" (Morris, 1991, p. 1). In concert with the critique towards its overt medicalization, and foregrounding the importance of thinking pain in its relation to social interactions and individual location, the following text explores the art-work and performances of Bob Flanagan (1952–1996), often dubbed the pain artist, pain man (Carr, 1997), or the artist Who Fashioned Art From His Pain (Smith, 1996). Bob Flanagan was an artist, a writer and a performer, whose artistic production was carved around two intricately intersecting subjects of physical disability and erotics. He lived with cystic fibrosis (CF), enjoyed S/M play¹ and fashioned his artistic persona as The Supermasochist (Juno & Vale, 1993). The CF and S/M are thus two very particular locations from which Flanagan and his partner, and dominatrix, Sheree Rose, address pain and pleasure. In other words, in their work (and play) pain and pleasure create two inseparable components indicating that CF and S/M (i.e., disability, sexuality) are negotiated as mutually contingent locations.

Thus, Flanagan's work highlights many of the synergy effects occasioned by the dialogues between queer theory and disability studies. "Perhaps the most significant similarity between these disciplines," Carrie Sandahl (2003) notes, "Is their radical stance towards concepts of normalcy" and the fact that both domains "argue adamantly against the compulsion to observe norms of all kinds" (p. 26). Disavowing normalizing efforts, queer theory embraces the denigration and the stigma attached to "other" sexualities and signifies a novel identity politics that – as Butler (1993) phrases it – construes "a site for collective contestation" of the present and the past (forms of identity) as well as a starting point for (its) "futural imaginings" (p. 228). In analogy, Flanagan's work embraces the abjected disability.

And while the sexual practices of S/M enable Flanagan to transform his physical pain, his engagement with queerness exceeds his individual body (in pain) and stretches to the level of the socially inflected pain of stigma. The transgressive potential of Flanagan's queer gesture thus lies precisely in embracing the *disability* and *sickness* to become Sick/Crip.²

Queering pain/disability in Flanagan's S/M performances entails conjoining pain/disability with desire, or even outright "desiring disability" (McRuer & Wilkerson, 2003, pp. 13-14), which challenges and eventually collapses the ablist logic of the question: "In the end, would you rather *not* have cystic fibrosis?" (cf. McRuer, 2006, p. 8; emphasis added). Flanagan's love of (some kinds of) pain, and his provocatively ostentatious reveling in being S/sick is a part of his "crip resignification" (McRuer, 2006) of disability. That is to say, queering disability establishes the ground on which sickness can be embraced, desired, welcomed and "crippled." It is the (sexual) desire and pleasure that the CF marked body brings to Flanagan and his mistress that transforms "disability" into self-affirmative crip position. Flanagan's form of desiring disability is a form of the future imaginings Butler has envisioned in critical queerness; it suggests that "another world [might be] possible" (cf. McRuer & Wilkerson, 2003) – that is, a "crip" world beyond the norms of "compulsory able-bodiedness" (McRuer, 2006).

Visiting Bob

Discussing intersections between the queer and crip positionalities, I have foregrounded their shared challenge to normalization and disciplination of both sexuality and disability. Politics of visibility count as one of the most powerful vectors of disciplination of (disabled) bodies (cf. Foucault 1979; Garland-Thomson, 2001). It is also the site where queer/crip reconfigurations most acutely occur. Hence, I commence with discussing Flanagan's crippling the politics of visibility and his challenges to the (medical) gaze.

As an introduction to Flanagan's art of pain and pleasure, we might tour one of Bob Flanagan and Sheree Rose's best-known and biggest museum installations, *Visiting Hours*, which opened in Santa Monica Museum of Art in 1992.³ The exhibition starts in a "waiting room," and though references are made to a hospital setting, soon enough it is clear that Flanagan and Rose initiate the visitor into a very different version of a hospital. Sitting down on the waiting room couches, the visitor finds the usual magazines splayed out on the end table. Children's magazines on first sight, on a second, however, they give out the clue to the difference of the cure this hospital offers. It is not cartoons but S/M visuals that one finds between the covers. Posters of S/M instruments that hang on the walls next to the medical images that adorn the room. Cacti in suggestive phallic shapes with no less suggestive thorns stand in one of the corners.

Already the naming and the structuring of the show ("visiting hours," "waiting," and "hospital room") position us as "visitors," making it clear that our initiation into Flanagan's pleasure and/in pain involves a dialogue with medical discourse and, in particular, with medical ways of seeing and disciplining a subject's body as an object of medical investigation and cure. (Different/Crip) visualization of pain/disability therefore represents one of Flanagan's strategies of countering the medical gaze. Gaze is also a key component of the S/M practices and erotic investigations of the body. As Munster argues, the S/M play practice "is literally saturated by a desire to understand and pose the body as raw material...unmediated by the form and consumption of spectacle" (as cited in Hart, 1998, p. 134). Even if we remain fully conscious of the utopian streak in the search for the "raw" and

“unmediated” material of the body, it is possible to perceive Flanagan and Rose’s erotic and S/M performances as (crip) investments in reinventing the body outside the medical spectacle and gaze.

An art piece that illustrates this investment is a simple x-ray image of Flanagan’s chest. It depicts his cystic lungs, but the familiarity and authority of the medical code of visualization are invaded by the unmistakable shades of nipple piercing. In this piece, two radically different modes of *knowing* and *living* the body in pain collide. The rings in Flanagan’s nipples – the visual traits of Flanagan’s pain/pleasure – recontextualize his ‘disabled’ and pained body as a site for ‘sick’/‘crip’ pleasure. An elaborate installation of a 12-foot-high video scaffold is another of the *Visiting Hours*’ art pieces engaged in reinvesting visuality of a disabled/pained and yet desired body. It consists of 7 video monitors positioned “where [Flanagan’s] face, chest, genitals, hand and feet should be” (Juno & Vale, 1993, p. 96), and each of the monitors runs a video loop of Flanagan’s body being whipped, flagellated, slapped, beaten, tortured.⁴

In their different ways, both artifacts speak about the medical gaze and its practice of dissecting bodies into individual and seemingly unrelated parts. While the scaffold counters and appropriates this visual logic of breaking up the body for its own purpose of multiplying the seats of pain/pleasure, the x-ray image of Flanagan’s cystic lungs comments on the urge to localize pain in the single (diseased) part of the body. In this respect, Flanagan’s commentary strikes a similar ground with scholars engaged in a critique of the “specific centre” paradigm (Leder, 1998) or, as Pedro Laín-Entralgo coins it, a “molecularisation of medicine” (as cited in Cassell, 1992, p. 237),⁵ which perceives the body as a mechanic system and reduces the experience of pain to “an elaborate broadcasting system of signals” (Bendelow & Williams, 1995, p. 140). While the “specific centre” theory reinvents pain as a potentially endless shuttle of electrochemical impulses, it threatens any prospect of inner coherence of the subject’s experience of pain (Bendelow & Williams, 1995, pp. 140-146). Similarly, Morris (1991) pleads for reestablishing the ties that link pain to its meaning – meaning that for him emerges “only at the intersection of bodies, minds and cultures” (p. 3). *Visiting Hours* voices a matching challenge to the medical knowledge of pain. The complex meaning of pain, meaning that would enhance rather than threaten “inner coherence” of the experience of pain, and that accommodates Flanagan and Rose’s mutuality is found in the queer S/M desire embracing the CF pained body.

Pain as a Practice of Mutuality

So far, I have focused upon the ways in which Flanagan and Rose challenge and crip the medicalized concept of pain. It has been essential to approach pain not as a localized sensation, but rather as a complex emotion encompassing both the body and mind. However, Flanagan and Rose’s work bring out a further challenge to our thinking about pain. Their S/M performances highlight that pain is not located solely in/on the individual body, but in contrast involves the overall situational context and a complex interaction between those who are *in* pain and those who are *out* of pain. In this sense, the performances reveal that pain is a practice, both in the sense of being carried out, as well as in the sense of bringing about some effects, changes, or response. Briefly, pain is both *done* and *does something*. This performative aspect of pain is the subject of my following discussion.

In her book, *The Cultural Politics of Emotion*, Sara Ahmed (2004) addresses this question of what emotions do and comments:

“Emotions shape the very surface of the bodies, which take shape through repetitions of actions over time, as well as through orientations towards and away from others. Indeed, attending to emotions might show us how all actions are reactions, in the sense that what we do is shaped by the contact we have with others” (p. 4).

Inspired by Ahmed’s conceptualization of emotions as performative actions that shape our subject positions, I ask what positions are produced by pain, and how pain ‘shapes the surface’ of social bodies. In approaching pain as cultural and social practice, the question no longer focuses on what pain is and how or where it is felt. Rather, it shifts into the area of what pain does. What effects does pain bring about? Further questions follow: What embodiment does pain produce? How does pain relate to materiality of bodies both in and out of pain? Most importantly, how does the concept of performativity of pain lend itself for queering/cripping?

In the Western, “civilized” cultural context, pain is predominantly referred to as the experience of intense and uncomfortable unfamiliarity, even estrangement from the self. Pain is felt “as something ‘not me’ within ‘me’” (Ahmed, 2004, p. 27). According to Elaine Scarry (1985), this estrangement also encompasses the level of interpersonal and inter-social relations. Pain is not only bodily trauma, it radically affects the possibility of communication. Feeling pain, being in pain, she thinks, is an extreme state of existence that literally shatters the possibilities of language (cf. Ahmed, 2004). Pain, in this sense, represents a “place beyond words” (Hart, 1998, p. 134). On a similar note, Joseph A. Kotarba (1983) concludes his studies into chronic pain by defining pain as a lonely experience; as a feeling that the subject has and others cannot have, or vice versa as a feeling that others have, yet the subject him/herself cannot approach. Again, it is the breach in the possibility of sharing and mutuality that for these authors defines the experience of pain.

Contemplating this strain on interpersonal relations caused by pain, leads Ahmed to recall her mother’s pain. She describes her mode of reaction as ‘living with’ her mother’s pain and as “witnessing it.” The act of “witnessing” was equally important, she says, to her mother’s experience of pain, as well as to herself and to their mutual bond. It transformed the pain from mere sensation into an “event” and gave it “the status of...happening in the world” (p. 29). “Through witnessing, I would give [my mother’s] pain a life outside the fragile borders of her vulnerable and much loved body” (p. 30). Nevertheless, at the same time Ahmed notes: “I lived with what was, for me, the unliveable” (p. 30), thus revealing that not even the acts of witnessing allow her to transgress the estrangement of pain.

But, if pain is a practice, we need to explore how it *does* the estrangement and solitude, and whether there are not new/crip possibilities opening for thinking/living through pain. Ahmed’s words offer a clue. Witnessing, perceiving it as an event, Ahmed extracts, transfers her mother’s pain *outside* the depths of her body and transforms it into a situation, a happening. In this, pain ceases to be the mere matter of the materiality of her mother’s body and comes to *affect* its very materiality, it affects the very way of how her mother’s body is turned into “matter” (cf. Butler, 1993). Accentuating, in fact *creating*, the “fragile borders” of the mother’s body, pain (re)construes her body’s very material presence. The act of witnessing somebody else’s pain, then again, is a performative act that affects all involved bodies, both *in* and *out* of pain. Ahmed argues that the sensation of pain is instrumental in revisiting and redrawing the bodily boundaries, the “pain surfaces” (p. 23). Likewise, Lynda Hart (1998) notes that pain intensifies a body’s surface and borders (p. 134). It is this

increased consciousness of borders between individual bodies that informs the emotion of ungraspability of pain. Against this, I want to reflect on Flanagan and Rose's practices of pain carried out at the intersection of CF and S/M, to argue that their crip investments transgress the isolation and estrangement of pain.

Audre Lorde (1984) has famously argued for the revolutionary power of the erotic; within the context of S/M interactions, the power of erotics radically recontextualizes pain so that it consequently produces different effects.⁶ One of the aspects of this recontextualization concerns modes of embodiment. In contrast to other contexts, in S/M the through pain intensified and emphasized body surface does not mark out the impenetrable territory and the body in pain does not represent a liminal point of strangeness, and of the incommunicable unknown. Rather than a rupture of communality, Flanagan's body affected by CF and pain becomes transformed into a body of shared, eroticized pain that gives pleasure both to him and his dominatrix.

There are at least two aspects that are worthy of further pondering. The first concerns the implications Flanagan and Rose's queer practices of pain raise for the concept of crip embodiment and materiality of bodies. The second centers around the curiously direct and unproblematic link between CF (disability) and S/M that Flanagan, as well as most critical essays on his art, produce.

As to the aspect of embodiment, I have first referred to the characteristic Cartesian mind/body duality which lays at the foundation of the "specific center" paradigm. Secondly, another of the classical pitfalls of the Western concepts of subject/ivity has come to the fore. The literature I referred to when outlining the cultural responses to pain has illustrated that the issue of independence, or conversely, interdependence of subjects is of central importance to our thinking about pain. Both Hart and Ahmed emphasize that in pain, the bodily surfaces become intensified, in fact re-created, while intensely re-lived. We might hence infer that among themselves, Flanagan and Rose retrace, that is *re-construct*, their bodies. Within the S/M performance, the body pained through CF is transformed into a body that gives pleasure as well as pain, both of which Flanagan and Rose share. This line of argument, however, presupposes an important shift in thinking about bodies and embodiment. Both of the bodies (Rose's as well as Flanagan's) need to be seen as situational, defined by encounter and mutual dependency/interaction.⁷ The queer pleasure of S/M deconstructs the borders of their individual bodies. As Janet Price and Margarit Shildrick (2002) have argued, it is the acknowledgement of "permeability between bodies and between embodied subjects" that might move disability studies forward (p. 62).

I return now to discuss the intersection between CF and S/M. As we have seen, Bob Flanagan provides a curiously straightforward connection between both kinds of pain. For him, the two, even if perceived as two different kinds of pain, appear unproblematically connected and fused in a simple cause and effect pattern. As he repeatedly says, the propensity to search for (and find) pleasure in pain was initiated by the doctor's own hands (note the jeer) in the very same moment as the CF was recognized:

"[W]hen the pediatrician spanked my ass to get my diseased lungs sparked into life, that also sent a shock through my sphincter, up my tiny rectum and into the shaft of my shiny new penis which ever since then has had the crazy idea that sex and pain are one and the same" (Juno & Vale, 1993, p. 77).

This narrative is duplicated in many of the essays on Flanagan and his art (cf. Kauffman, 1998; Meiners, 1999). However, amid all this, an essential distinction gets lost: in Flanagan's own narrative, we encounter a strategy of his self-fashioning, or "practice of the self" (Foucault, 1988; cf. with Greenblatt, 1980). As such, it cannot be taken as a matter-of-fact statement. Not only would we take the artist's own word as a key to the analysis of the work itself; more importantly, this would silence the immense energy and hard work Flanagan and Rose invest in refashioning and in fact queering/cripping pain, their embodied selves and their relationship.

"Why?"

I will open the last section of my discussion with a brief quote from Bob Flanagan's poem entitled "Why?"

"Because it feels good; because it gives me an erection; because it makes me come; because I'm sick; because there was so much sickness; because I say FUCK THE SICKNESS;...because of Christ and the crucifixion; because of Porky Pig in bondage:... because of cow-boys and Indians; because of Houdini; because of my cousin Cliff:...because I had time to think; because I had time to hold my penis;...because I still love Lent" (as cited in Juno & Vale, 1993, p. 64-65).

Obviously, the poem responds to troubled questions about the source for Flanagan's queer acts of masochism. The answer Flanagan gives here is poking fun in many directions. Even though it lists biographical details that are absolutely credible, perhaps even "true," and that may well justify "why" Flanagan loves to torture his (disabled) body, as a whole the poem mocks the very urge to rationalize and explain away the "sick" nature of his acts. As the discussion of *Visiting Hours* has already documented, Flanagan *perverts* the logic of cure and of the medical discourse.

"Sick/ness" refers both to Flanagan's clinical condition, and his excessive sexual activities and his exhibitionism – which, he makes clear, are conditions beyond cure. The ambiguity encoded in the notions of "sick/ness," symbolizes the joyful dialogue between the queer and the crip. Flanagan's enjoyment of being S/sick stands in stark opposition to medical rationality; he expressly does not want to be cured of his sickness.⁸ The hospital, the medical practices to which he has been subjected throughout his life become recontextualised in Flanagan's performances of S/M. Instead of humiliating, hurting etc. they become sensually, sexually and emotionally gratifying. Or, to keep in concert with the S/M logic/erotics, I rephrase: these practices become pleasing as they are humiliating. In *Visiting Hours* Flanagan and Rose put together their alternative version of hospital and alternative treatment of pain and cystic fibrosis. However, a "treatment" that would not be ambitioned to "cure." Bob Flanagan wants to be and to remain Sick!

The alternative treatment Flanagan suggests for himself comes close to Morris' (1991) notion of *meaning* of pain, however, again, not a meaning that explains the pain away, ascribes it a metaphysical quality, or sets it into a teleological framework of any sort. Rather, Flanagan and Rose produce meaning that sustains Flanagan's life with and in the disabled body and opens the possibilities to enjoy this body and to derive pleasure from it for both himself and his partner. Cultivating the (eroticised) pain in the S/M practices (both public and private), becomes not a matter of simple domination or control of the pain, but a much more complex strategy of transforming and integrating the pain into a life's purpose (cf. Cassell,

1992), and of turning it into a subject-matter of his “technologies of the self” (Foucault, 1988). In this aspect, I propose, Flanagan’s deployment of pain allows for inspiration to other means and strategies of negotiating pain/disability, not necessarily those that resort to a nail or a whip.

In conclusion, I retrace my argument about the ways in which Flanagan and Rose’s practices of pain provide inspiration for interdisciplinary dialogues between queer and disability studies. Despite its extravagant character, Flanagan’s embracing of CF/disability, as well as Flanagan and Rose’s S/M interactions, contribute a lot to critical re-conceptualizing of disability in a broader social and cultural context. The concept of pain that Flanagan and Rose present and perform is valuable in several respects: pain transpires to be a contextually defined, complex relationship rather than a bodily sensation that we need to decode through our brains. Flanagan and Rose’s (artistic) performances detach pain from the concreteness of the body and re-localize it in the sphere of mutuality and personal encounter, as a situational relation of two embodied subjects. In brief, their performances clearly manifest the inadequacy of thinking about pain as a static *situation of the body* and offers a way to think of pain as *a body in situation*. Here, I see a powerful parallel to definitions of disability. If bodily disability, or impairment, is unfortunately still often enough seen as the indisputably material and thus factual condition of body, Flanagan and Rose’s work on pain transgress this notion.

Furthermore, pain being and happening in a relationship, pain/disability is not lodged only on/in the body that is most acutely affected by it, but concerns all bodies involved in the interaction. Flanagan and Rose thus manifest radically the point Price and Shildrick (2002) and have made in their theoretical essay: “From [a perspective of embodiment], disability clearly cannot be conceptualized as the property of an[y] individual” (p. 63), and thus in “giv[ing] up ownership of [their individual] bod[ies]” Flanagan and Rose open “new social and ethical possibilities” for thinking about pain and disability (p. 65).

Last but not least, it is to foreground the futural imaginings that Flanagan and Rose’s strangely and slightly perverse, queer and crip politics initiates for us and for the possibility of desiring disability.

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References

- Ahmed, S. (2004). *The cultural politics of emotion*. Edinburgh, UK: Edinburgh University Press.
- Bauer, R. (2005). When gender becomes safe, sane and consensual: Gender play as a queer BDSM practice. In E. H. Yekani, & B. Michaelis (Eds.), *Quer durch die Geisteswissenschaften. Perspektiven der Queer Theory* (pp. 73-86). Berlin: Querverlag.
- Bendelow G. A. & Williams S. J. (1995). Transcending the dualism: Towards a sociology of pain. *Sociology of Health & Illness*, 17(2), 139-165.

- Butler, J. (1993). *Bodies that matter: On the discursive limits of "sex."* London/New York: Routledge.
- Carr, C. (1997, November 18). The pain artist. *The Village Voice*, p. A1.
- Cassell, E. (1992). The body of the future. In D. Leder (Ed.), *The body in medical thought and practice* (pp. 233-249). Dordrecht, Netherlands: Kluwer / Springer.
- Deleuze, G. (1989). *Venus in furs, and coldness and cruelty*. New York/London: MIT Press.
- Foucault, M. (1979). *Discipline and punish: The birth of the prison*. London: Penguin.
- Foucault, M. (1988). Truth, power, self. An interview with Michel Foucault. In L. H. Martin, H. Gutman & P. H. Hutton (Eds.), *Technologies of the self*. London: Tavistock.
- Garland-Thomson, R. (2001). Seeing the disabled: Visual rhetorics of disability in popular photography. In P. K. Longmore & L. Umanski (Eds.), *The new disability history: American perspectives* (pp. 335-374). New York: University Press.
- Greenblatt, S. (1980). *The renaissance self-fashioning. From More to Shakespeare*. Chicago/London: The University of Chicago Press.
- Hart, L. (1998). *Between the body and the flesh: Performing sadomasochism*. New York: Columbia University Press.
- Juno, A. & Vale, V. (Eds.). (1993). *Bob Flanagan: Supermasochist*. San Francisco: RE/Search.
- Kauffman, L. S., (1998). *Bad girls and sick boys: Fantasies in contemporary art and culture*. Berkeley, CA / London, UK: University of California Press.
- Kotarba, J. A. (1983). *Chronic pain: Its social dimensions*. Beverly Hills, CA: Sage.
- Leder, D. (1998). Pain and the 'dys-appearing' body. In S. J. Williams & G. Bendelow (Eds.), *The lived body: Sociological themes, embodied issues*. London: Routledge.
- Lorde, A. (1984). Uses of the erotic: the erotic as power. In *Sister outsider: Essays and speeches by Audre Lorde* (pp. 53-59). Trumansburg, NY: The Crossing Press Feminist Series.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York: New Yorker University Press.
- McRuer, R. & Wilkerson, A. (2003). *GLQ: A Journal of Lesbian and Gay Studies*, 9, 1-23.
- Meiners, E. (1999). Sick and twisted: Reading revolting research. *Qualitative Studies in Education*, 12(5), 565-586.
- Morris, D. (1991). *The culture of pain*. Berkeley, CA: University of California Press.

- Price, J., & Schildrick, M. (2002). Bodies together: Touch, ethics and disability. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 62-75). London: Continuum.
- Rubin, G. (1993). Thinking sex: Notes for a radical theory of the politics of sexuality. In H. Abelow, M. A. Barale, & D. Halperin (Eds.), *The lesbian and gay studies reader* (pp. 3-45). New York/London: Routledge.
- Sandahl, C. (2003). Queering the crip or crippling the queer? Intersections of queer and crip identities in solo autobiographical performance. *GLQ: A Journal of Lesbian and Gay Studies*, 9, 25-56.
- Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. New York/Oxford: Oxford University Press.
- Smith, R. (1996, January 6) Bob Flanagan, 43, Performer who fashioned art from his pain, *New York Times*. Retrieved from <http://www.nytimes.com/1996/01/06/arts/bob-flanagan-43-performer-who-fashioned-art-from-his-pain.html>

Endnotes

- ¹ I work with Jay Wiseman's definition of S/M: "SM is the use of psychological dominance and submission, and/or physical bondage, and/or pain, and/or related practices in a safe, legal, consensual manner in order for the participants to experience erotic arousal and/or personal growth" (as cited in Bauer, 2005, p. 75). On the relationship between sadism and masochism, see the enlightening discussion by Gilles Deleuze (1989) in *Venus in Furs, and Coldness and Cruelty*. On Bob Flanagan's use of S/M see also Erica Meiners, (1999).
- ² For an articulation of the relationship between the disability and crip politics, as well as between queer and crip see McRuer (2006, 2003)
- ³ In 1994, *Visiting Hours* was installed also in the New York MOMA. It is worth noting here that most of Flanagan and Rose's works had the character of onstage performances.
- ⁴ The reference to Christ and crucifixion is – of course – acknowledged and fully intended.
- ⁵ See also e.g., Bendelow & Williams (1995), Cassell (1992), Morris (1991).
- ⁶ Flanagan himself makes a conscious distinction between the bodily pain/discomfort experienced as a direct cause of his medical condition and the pain experienced and staged in their S/M plays, suggesting clearly that he and Rose understand the performances as a part of the recontextualizing strategy (Juno & Vale, 1993).
- ⁷ Conceptualizing the body as situational and as contextually contingent is important here while it precludes the risk of absolutism and false and shallow optimism. If I am trying to imagine and interpret Flanagan's body as "body in situation" which would allow for accentuating the various strategies of negotiating of the body's sensations, I am in no way trying to postulate that Bob Flanagan's body is no longer pained through CF. Neither should this essay be read as in any way belittling this difficult aspect of Flanagan's (and Rose's) life with disability.
- ⁸ See also McRuer's (2006) intriguing reading of Flanagan's "Why?" McRuer reads it as a part of Flanagan's gesture toward new/different future temporality of the crip (pp. 183-194).

Disability by Design
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Abstract: Given the primacy of global economics and marketing mind-sets, this article interrogates disability as a phenomenon of design and branding. We begin by briefly reviewing relevant design and branding concepts, proceed to apply them to the creation of a disability identity and set of responses, and then demonstrate the power of design and branding as subversive or facilitative of advancing transformative global inclusion and human rights.

Key Words: identity, design, branding, disability

Over the past decades, definitions and understandings of disability have expanded and increased in complexity. Looking beyond medical diagnosis as the defining element of disability, disability studies has brought important interdisciplinary thinking from humanities, arts, social science, and natural science fields to bear on interrogating, explaining, and guiding responses to disability. It is therefore curious that given that design, branding, and marketing take center stage in the 21st century, these important contemporary lenses have not been vigorously applied to analyzing and responding to disability. In this paper, we suggest that a synthetic lens of disability studies, design, marketing and branding scholarship provides a potent scaffold for the analysis of disability and for crafting meaningful intellectual and social change in an advanced capitalist world (Habermas, 1973).

Background

As an initial departure from the impairment approach or what we refer to as the medical explanation for disability, scholars and disability activists in the late 1970s posited the social model of disability. This model countered medical explanations by suggesting that those with atypical bodies were the objects of social and cultural discrimination and exclusion (DePoy & Gilson, 2004). By bodies we refer to the broad corporeal as well as experiential elements of humans, including but not limited to the physical, social, economic, intellectual, expressive, spiritual, and emotional human. The introduction of the social model of disability was an important initial impetus in conceptually relocating disability away from medical deviance into the discourse of human construction, diversity, and discrimination. However, an unintended consequence of this theoretical shift was the creation of a multitude of opposing explanations which DePoy and Gilson (2004) classified into two overarching explanatory categories: medical-diagnostic and constructed. This binary fractured the study of disability (Siebers, 2008; Albrecht, 2001) polarizing disability scholars from one another and from disability professionals whose domain is the provision of services. In an effort to end the conceptual duel, Depoy and Gilson (2004; 2008) advanced an axiological lens through which to understand disability. The lens parses category formation and response to category members into three overlapping modes: description, explanation, and legitimacy. What is considered a legitimate disability and viable responses are determined through a complex set of value judgments on multiple explanations that are posited for the atypical, and which can inhabit the same explanatory space as friends or foes. This axiological framework provides a discourse platform on which many explanations can be laid and then examined for their legitimacy in locating explanations within the category of disability and engendering the concomitant responses that are bestowed upon category members. One explanation that only recently has entered disability discourse and thus is nascent and ripe for intellectual

development (Riley, 2007) is what we have named “disability by design.”

What is Design?

Design is a complex construct that has been increasingly used to describe abstract and concrete human intention and activity, and to name a property of virtual, physical, and even abstract phenomena. As reflected in its diversiform definitions, design emerges in multiple disciplines including art, architecture, computer programming, fashion, business, and marketing just to mention a few. While the term, its many homes, and its implications are diverse, what is evident in the contemporary use of the term is the broad scope of phenomena to which design applies, including but not limited to the activities of conceptualizing, planning, creating, and claiming credit for one’s ideas, products, and entities as well as the inherent intentional or patterned characteristics of bodies, spaces, and ideas (Munari, Eames, Eames, Guixé, & Bey, 2003; Margolin, 2002). Of particular note is the contemporary commonality in all definitions of design as purposive and intentional. That is to say, design is not frivolous but rather is powerful, political, and is both shaped by and shapes notions of standards, acceptability, membership, and desirability (Munari, Eames, Eames, Guixé, & Bey, 2003; Foster, 2003).

What is Branding?

In contemporary western economies, design is closely related to branding. Given the emergence of branding from the fields of marketing and advertising, brands within this conceptual framework are defined as the purposive design and ascription of logos or markers to a product for the intent of public recognition, addition of value, and consumption. Of particular importance to our analysis is the construct of value-added. Interpreted broadly, the addition of value does not necessarily imply an increase or elevation, but denotes inscription of value that can span the continuum from extremely pejorative to most desirable (Lusch & Vargo, 2006). Throughout the article, we use the terms *value-added* and *de-value added* to clarify positive and negative valuation respectively.

More recently, scholars have expanded their definitions and analyses of branding beyond the purpose of product recognition and profit. This enlarged scope has positioned branding as a mechanism that commodifies and reciprocally represents and shapes value, ideas, identities, or even cultures (Lusch & Vargo, 2006). Brands are design stories that unfurl and take on meaning as they are articulated and shared by multiple creators and viewers. Because symbolism and dynamism both inhere in branding, Holt (2004) has suggested the term *cultural branding*, which denotes the elevation of brands to the status of icon, marker of identity, and idea. While Holt’s term is relatively new, the notion of branding as definitive of one’s cultural, social, and individual identity--and of one’s comparative social worth--was originated in the early and mid 20th century by thinkers such as Horkheimer, Adorno, Noerr, and Jephcott (2002) and McLuhan and Fiore (2005). Although divergent in ontology and scope, these scholars were seminal in introducing branding as a symbolic means to assemble and project identity. Through the process of choosing and adopting cultural iconography in the form of products, fashions, food, music, and so forth, one ostensibly defines the self and displays value to others (Holt, 2004).

Classical theory suggested that consumers followed a logical sequence of identity branding: (1) selecting a brand from a menu of options, (2) adopting, and (3) displaying the brand to reflect one’s identity. Contemporary literature reveals a more complex analysis and

debate about the directionality of this sequence. Some scholars adhere to the classical view that choice of style and design brand is a self-determined effort to align one's identities with preferred value-added cultural-media images (McLuhan & Fiore, 2005) while others suggest that branding is surreptitiously ascribed to groups and individuals by market forces. We suggest, however, that the purposive nature of design and branding manipulates individuals and groups into believing that they can and do autonomously choose their identities, but in effect they do not, regardless of the icons they select.

Building on design and branding theory, the conceptual portal of design and branding is potent for unpacking and analyzing the purposive, political, and profit-driven nature of embodied labeling, identity formation and recognition, stereotyping, and responses that span tolerance through exclusion and discrimination. The importance of this conceptual framework lies in the processes and purposes of design and branding as deliberate, complex, and potentially able to manipulate the thoughts and behaviors of individuals and groups about themselves and others who sport particular brands. Moreover, we see branding as both explicit and tacit representation of ubiquitous contemporary design within a specified context. Thus, branding is not restricted to a logo designed for a product, but rather occurs through the design of signifiers that function as iconic simulacra in multiple arenas including but not limited to products, spaces, ideas, services, and even sounds (Licht & O'Rourke, 2007).

While product branding through logo is central to popular culture, particularly in developed economies, the tacit branding and thus commodification of groups and individuals through other mechanisms is more insidious. Logos do not have to be present in order for individuals and groups to be "branded." As noted by Lefebvre (1991), physical space is not neutral, but rather carries value or devalue-added meanings in its design, purpose, and use. For example, the streets denote home for some, accompanied by devaluation of those who live on the streets by those who do not. The term *brandscape* (Sherry, 2000) has been coined to denote the role of spaces in designing and assigning both identity and value. Understanding disability through these powerful contemporary lenses provides the opportunity for media activism and the creation of positive social change within global economic environments through iconic design (Pasquinelli, 2005).

Disability by Design: Application to Disability Identities and Responses

As noted in the introduction, over the past several decades, disability studies has been grappling with the definition of disability. Theoretical attempts have sought to replace deficit medical understandings of atypical bodies with views of disability as imposed by economic, political, and social factors. We have suggested that the medical-constructed fracture is not useful for a complex understanding of disability and thus have posited disjuncture theory (DePoy & Gilson, 2008) as a synthesizing explanatory foundation. Through this scaffold, disability is viewed as an ill fit between bodies (defined broadly) and environments (defined broadly as well). Disjuncture allows us to examine the interaction of physical, virtual, and abstract environments and diverse corporeal and experiential elements of bodies, and thus brings us to query the universe of environmental design and signifier as significant contemporary forces in delineating the category of disability and affixing the value of those who fit within it. If ignored, the market economy and its practices leave atypical bodies vulnerable to the obfuscated forces of commodification, tacit design, and branding (Adair, 2002).

Through our research, we have found that evidence of "disability by design" is

ubiquitous, as is illustrated in the marketing terminology and practices of design and branding in **Figures 1 and 2** below.

Figure 1-The Disability Debate

June 2005 Synergy Communications has unveiled a new brand identity for a national debate on disability by the Disability Rights Commission UK.

<http://www.brandrepublic.com/news/480462/Synergy-creates-identity-promote-disability-rights-debate/?DCMP=ILC-SEARCH>

Figure 2-Logo to Recognize Employers of Disabled People

The logo for Employment for Disabled People (N.C.P.E.D.P.) indicates synergy between disability and responsible corporations; affirmative action must have at least 3% disabled employees among other criteria in order to display this logo. Logo is intended to identify companies “who care.” <http://www.ncpedp.org/>

These two examples represent the increasing awareness and use of marketing terminology (e.g. the usage of brand logos and of the word *synergy* in both figures), design, and branding in particular in the world of disability-related initiatives.

Similar to Fussell (1992), whose classic work asserted that owned, displayed, and used objects are definitive of social class, we posit that products, and specific to this paper, “disability” products (or what we refer to as designer disability items), are designed as functional, recognizable, identity-assigning, and manipulative of those who use them and those who view them. In essence, these products by their aesthetic design and distribution outlets brand the user as disabled, as illustrated in the following photos of shower seats. Despite identical functionality, Seat A in **Figure 3** is designed as prescribed durable medical equipment while Seat B in **Figure 4** is designed for commercial sales and voluntary selection and universal use. The family sporting the medical equipment is often branded as the object of pity, with lexical symbols such as caregiver, assistive technology, and health insurance further reifying and providing devalue-added status to the “designer disability” brand.

Figure 3-Seat A

Figure 4- Seat B

Conversely, a perusal of websites and catalogues of commercial companies reveals that they sell “high brow” (Foster, 2003) designed and marketed household and lifestyle products that were originally branded and in some outlets (rehabilitation, assistive technology, and medical products) yet still are “disability- branded.” In comparing the products, differences in the functional use are not discernable but the design distinctions are often obvious (see **Figures 3 and 4**) and thus ascribe, sub rosa, a defining brand label to those who have and use “designer disability” products. Moreover, the brand in turn manipulates meaning, behavior, and value and serves to institutionalize and maintain segregated status quo between disabled category members and their non-disabled counterparts. Consider two examples: headphones and attire.

Bodies diagnosed with conditions that contain the symptom of distractibility (e.g. Attention Deficit Disorder) are often met with medication and medical products to filter out irrelevant stimulation and aid in concentration. However, those same distractible people, without diagnostic labels, were the subject of a recent article in the NY Times (Sunday, June

8) reporting use of mainstream, high-tech noise canceling headphones to eliminate ambient noise, help people focus, and reduce noise related stress in urban environments (Walker, 2008). Different from the devalue-added signifier of assistive technology, this genre of technology is referred to as fashionable technology by Seymour (2008) and adds value to those who use it.

As part of a current exhibition at the Royal Ontario Museum entitled, *Out from Under: Disability, History and Things to Remember*, Phillips (2008) draws our attention to attire, not haute couture but another type of fashion. She displays a photo of adults clothed in identical, drab gray sweat suits (called track suits) next to the actual suits themselves. What becomes clear in the visuals and further elucidated in the textual explanation is that this attire not only homogenizes those who wear it, but strips them of individual identity and brands and devalues them as disabled institutional litter regardless of where they live or what they do.

The examples above depict devalue-added status. However, disability product design does not always carry a negative connotation. As shown in **Figures 5 and 6** below, items such as racing wheelchairs and futuristic prostheses often brand those who use them as superhuman, inspirational and remarkable, but never fashionable.

Figure 5-Racing Wheel Chair

<http://sports.webshots.com/album/52401758gvadWk>

Figure 6-Racing Prostheses

<http://www.spectrum.ieee.org/print/2189>

Regardless of the value or devalue-added contribution of products that are designed and branded for the disabled body, disability by design serves as a segregating mechanism. As product design and explicit or tacit branding imbue identity, meaning, and value, so do geographies.

The foundation for current architectural standards institutionalized by Le Corbusier harkens back to the elongated measurements and proportionality of Vitruvian Man (Gilson & DePoy, 2007). Bodies that stray too far from the mythic standards of human size, locomotion, sensorium, and behavior do not fit well in geographies that are built according to Vitruvian bodies. It is curious to note that rather than being designed for a larger range of human diversity, contemporary methods and policies guiding new construction and retrofitting of existing built environments provide guidance for partitioned and clearly labeled spaces for disabled bodies. The result is that segments of public spaces and locations are not only designed for disabled bodies, but serve to contain them as well (Sherry, 2000; Butler & Parr, 1999), branding them as atypical and different by the very space that ostensibly was designed for greater access and participation. **Figure 7** below demonstrates the cleavage of space into distinct and separate locations for standard and atypical bodies with accompanying simulacra in **Figure 8**, the cultural icon that denote “spaces” exclusively for “disabled” bodies whether or not those bodies use wheeled mobility. We refer to the wheelchair symbol as a simulacrum because of its diffuse and often empty meaning coupled with its recognition and “devalue-added” component. As ridiculed in Mitchell and Snyder’s (1997) classic movie, *Vital Signs*,

Crip Culture Talks Back, an example of the wheelchair as a meaningless branding simulacrum is the practice of airlines to accommodate embodied difference (in this case deafness) with a wheelchair.

Figure 7-Parking

Figure 8- Disability Icon

While the media have been frequently thought about with regard to shaping attitudes toward actors, their power in designing and branding spaces cannot be understated. As noted by Scott (2008), science fiction films are potent in creating design imagination and actualization, as exemplified by films such as *AlphaVille* and *Blade Runner*. These two films along with others depict “fables of the future” that provide templates and conceptual blueprints for urban designers.

Now turning to more abstract and complex designer-disability phenomena, on first examination, one typically sees disability services as altruistic, professional, and “helping.” We do not dismiss or vilify these important aspects of disability services that are so critical for increasing participation and access to some extent in our current world. However, the picture is not that simple. As early as 1992, Gill published scholarship that revealed the economic advantage derived from disability by providers, professionals, product manufacturers, and so forth. DePoy and Gilson (2004) referred to this phenomenon as the disability industry in which economic survival and profit too frequently trump the goals of facilitating meaningful, full participation in community, work, recreation, and civic life for people who are considered or identify themselves as disabled. Our more recent thinking asserts that in the current global context, economic advantage and value-added services not only can co-exist but must do so in order to be viable.

For analytic and guidance purposes, we turn our attention to the phrase *environmental simulacra*, originally coined to describe theme parks that are not easily distinguished from the “reality” they represent (Galician, 2004). Rather, these spaces and what occurs within them are designed for the purpose of shaping and encouraging consumerism. Given the current economic and socio-political context of the service environment, we suggest that this term and its principles are relevant to “disability” environments and the disability by design signifiers that are explicit or inherent within them. The service environment or what we refer to as the “disability park” is comprised of all physical and abstract spaces and activity within them as well as explicit and implicit sign, product, and signifier. Besides service delivery as the articulated purpose, implicit branding both influences and reflects the value or devalue-added partitioning of these spaces and the relative groupings that interact within them (e.g. consumer or provider). For the short-run, we are suggesting that without the service and market orientation becoming friends with one another, that services will continue to be devalue-added and thus devalue disability category members. But our longer longitudinal gaze posits a generic environment that responds to the full diversity of humans, and thus designed disability services and products, that brand and segregate humans into arbitrary and punitive categories as they exist today will not be necessary.

Aligned with disability products, spaces and services that serve to brand those who use

and inhabit disability geographies and parks, disability policy is an abstract exemplar of branding through segmentation. Typically, disability policy has been categorized into two areas: policies that guide the provisions of designed disability services and resources, such as the Social Security Disability Insurance Act (SSDI) (established by the Social Security Amendments of 1956, in the United States), and more recently those, such as the Americans with Disabilities Act (ADA) and the UN Convention on the Rights of Persons with Disabilities that purport to protect and advance the civil rights of populations that are considered or identified as legitimately disabled.

Building on this taxonomy, we suggest that policy is much more complex than its explicit verbiage and articulated outcomes. As noted by Kymlica (2007) in his recent analysis of multiculturalism, global human rights policy is plagued by two overarching problems. The first is the failure of current categorical frameworks to do viable work in dividing humanity into useful categories. The second is the time sequence of designing and implementing targeted and generic policy. We acknowledge the importance of targeted distributive and protective legislation to exist before generic policy can be democratically and efficaciously applied in the current global context (Nussbaum, 2007). However, we caution the long-term perpetuation of such policy that continues to serve the economic process and outcomes of the disability park. Working to locate special policy designed for the populations that identify or are considered as disabled adjacent to generic human rights and distributive policy rather than seeking to globally enforce these existing policies for all (Kymlica, 2007) is a method that perhaps inadvertently separates, differentiates, excludes, and ultimately causes intergroup friction, competition and segregation. Separate policies institutionalize and brand the disability park by partitioning abstract principles and language and applying them differentially to disabled and non-disabled individuals. Above, for example, we noted that people who are considered disabled use “assistive technology” while non-disabled people who use identical products use technology or as Seymour (2008) asserts use “fashionable technology.” The need for help is implied in the word *assistive* and the institutionalization of this branded concept in the Assistive Technology Act passed in the United States in late 20th century.

Another consideration regarding the sequencing of targeted and generic policy was illuminated by Badinter (2006) in her discussion of gender equality. She suggested that the maintenance of “specialized rights and policies” negates their articulated aims of equality. This insidious process occurs by surreptitious design in which recipients of resources and rights only granted by specialized policies are required to remain as victims. Those who are covered under disability by design policy therefore must remain vulnerable, in need of specialized assistance, and in the disability park that provides employment and economic opportunity and advantage to providers and disability designers. Analysis of disability by design policy reveals it as a grand narrative, a brand of designed disability policy that on the surface speaks of resources and equity, but in essence serves up populations identified or identifying as disabled to the disability park. Similarly, The UN Convention on the Rights of Persons with Disabilities, while theoretically enacted to raise awareness and reduce discrimination and disadvantage experienced by populations identified or identifying as disabled, is often persuasive in the abstract but lacks substantive content, enforcement, and thus is policy simulacra as well. Many terms that are at the heart of the policy are often undefined and the mechanisms for enforcement are absent, designing a grand narrative at the global level.

So What is Next?

To summarize, this paper has identified the central roles of design and branding as powerful, political, and potentially evocative of social change. Given the primacy of these market strategies in the contemporary global economy, we have applied design and branding theory to the category of disability and responses to members, with an axiological gaze. This analysis reveals the subversive, segregating, and devaluing use of disability design and branding, often for the planned or unintended purpose of economic advantage for those who are not disability category members.

Examining disability through the synthetic lenses of axiology, design, and branding may paint a contemporary picture that is not complimentary. However, we suggest that this view does not have to be pessimistic. On the contrary, using contemporary practices that are aligned with larger powerful global trends, typically not thought of as disability and human rights scholarship, provides the opportunity for significant change while attending to devaluation of disabled groups. We draw on Holt's (2004) work to guide our conclusions. He suggests that the current reactive, outsourced method of branding maintains the status quo rather than facilitating cultural opportunity and advancement. Holt calls on cultural activists to take the reins of design and branding for the purpose of global social development. According to Holt and relevant to disability by design is the realization that iconic branding has activism inherent in it if it is conducted by those to whom he refers as cultural activists and to others who have been named media activists (Riley, 2005).

Building on this important work, we identify the first step in harnessing the power of the global market and its related practices as recognizing them in the disability park. We have attempted to begin that recognition in this paper.

The second step requires careful and complex analysis of design and branding as value or devalue-added. Design and branding may be destructive, facilitative, or both of human rights and equality. Carefully interrogating disability products, places, images and abstracts through an axiological lens foregrounds the economic and social functions inherent in design praxis and branding. This detailed attention creates an opportunity for using design and branding to replace devalue-added status with value-added symbols.

Thus, disability scholars and activists are in a position to capture and use design and market strategies to make positive change in several areas. We refer back to Kymlica (2007) here to identify two that contribute to the unwanted and pejorative maintenance of designed disability: useless categorical taxonomies, and sequencing and timing of targeted and generic policies and practices.

The category of disability itself is simulacra as its meaning is vague, differentially defined, and contains assumptions of homogeneity among members in a group that has no clear substantive boundaries or content (Depoy & Gilson, 2004; Titchovsky, 2007). Moreover, axiological analyses reveal that nature of value implicit in the lexical symbol, disability. Furthermore, this symbol obfuscates its own potential for economic exploitation by those who are not assigned to it. Redesigning categories and their brands is a conceptual and practical movement that is critical for advancing equality, participation, and human capabilities (Nussbaum, 2006).

Our final point is that the timing of designed disability policies and practices is essential to consider. What we mean here is that targeted praxis may be warranted

temporarily, but in the long term it perpetuates and obscures the disability park. New categorical concepts and timing by cultural and media activists using market-based strategies along with other human rights methods of change have the potential to harness design and branding for significant and lasting global improvement.

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References

- Adair, V. (2002). *Branded with infamy: Inscriptions of poverty and class in the United States*. Chicago, IL: The University of Chicago Press.
- Albrecht, G. (2001). *Handbook of disability studies*. Thousand Oaks, CA: Sage.
- Badinter, E. (2006). *Dead end feminism*. Cambridge, UK: Polity Press.
- Butler, R., & Parr, H. (1999). *Mind and Body Spaces: Geographies of illness, impairment and disability*. New York: Routledge..
- DePoy, E., & Gilson, S. (2004). *Rethinking disability: Principles for professional and social change*. Pacific Grove, CA: Brooks-Cole.
- DePoy, E., & Gilson, S. (2008). Healing the disjuncture: Social work disability practice. In K. M. Sowers & C. N. Dulmus (Series Editors) & B. W. White (Vol. Ed.), *Comprehensive handbook of social work and social welfare: Vol. 1. The profession of social work*. Hoboken, NJ: Wiley.
- Foster, H. (2003). *Design and crime*. New York: Verso.
- Fussell, P. (1992). *Class: A guide through the American status system*. New York: Touchstone.
- Galician, M. L. (2004). *Handbook of product placement in the mass media: New strategies in marketing theory, practice, trends, and ethics*. New York, NY: Routledge.
- Gill, C. (1992, November). Who gets the profits? Workplace oppression devalues the disability experience. *Mainstream*, 12, 14-17.
- Gilson, S. F., & DePoy, E. (2007). Da Vinci's ill-fated design legacy: Homogenization and standardization. *The International Journal of the Humanities*, 5(7), 145-154. Retrieved from <http://ijh.cgpublisher.com/product/pub.26/prod.1150>

- Gilson, S. F., & DePoy, E. (2008). Explanatory legitimacy: A model for disability policy development and analysis. In I. Colby (Ed.), *Social work practice and social policy and policy practice*. Hoboken, NJ: Wiley.
- Habermas, J. (1973). *Legitimation crisis*. Boston, MA: Beacon Press.
- Holt, D. B. (2004). *How brands become icons: The principles of cultural branding*. Cambridge, MA: Harvard Business School Press.
- Horkheimer, M., Adorno, T., Noerr, G. S., & Jephcott, E. (2002). *Dialectic of enlightenment*. Palo Alto, CA: Stanford University Press.
- Kymlica, W. (2007). *Multicultural odyssey*. Oxford, UK: Oxford University Press.
- Lefebvre, H. (1991). *The production of space*. Oxford, UK: Blackwell.
- Licht, A., & O'Rourke, J. (2007). *Sound art: Beyond music, between categories*. New York: Rizzoli.
- Lusch, R., & Vargo, S. (2006). *The service-dominant logic of marketing*. Armonk, NY: M. E. Sharpe.
- Margolin, V. (2002). *The politics of the artificial: Essays on design and design studies*. Chicago: University of Chicago Press.
- McLuhan, M., & Fiore, Q. (2005). *The medium is the message*. New York: Ginko Press.
- Mitchell, D., & Snyder, S. (1997). *Vital signs: Crip culture talks back*. Marquette, MI: Brace Yourself Productions.
- Munari, B., Eames, C., Eames, R., Guixie, M., & Bey, J. (2003). *Bright minds, beautiful ideas*. Amsterdam: Netherlands: Bis.
- Nussbaum, M. (2006). *Frontiers of Justice*. New York: Belnap.
- Pasquinelli, M. (2006). An assault on neurospace (misguided directions for). In M. Grzanic & G. Heeg (Eds.), *Mind the map! History is not given: A critical anthology based on the symposium*. Frankfurt/Main, Germany: Revolver. Retrieved from <http://matteopasquinelli.com/docs/neurospace.pdf>
- Phillips, S. (2008). *Out from under: Disability, history and things to remember ~ Dressing*. Retrieved from http://www.rom.on.ca/media/podcasts/out_from_under_audio.php?id=5
- Riley, C. (2005). *Disability & the media*. Lebanon, NH: University of New England Press.
- Scott, A. O. (2008, June 9). Metropolis now. *New York Times Magazine*. Retrieved from <http://www.nytimes.com/2008/06/08/magazine/08wwln-lede-t.html?ex=1370491200&en=17c9264ae41f03ae&ei=5124&partner=permalink&expd=permalink>

- Seymour, S. (2008). *Fashionable technology: The intersection of design, fashion, science, and technology*. London/New York: Springer.
- Sherry, J. (2000). Place, technology and representation. *Journal of Consumer Research*, 27, 273-278.
- Siebers, T. (2008). *Disability theory*. Ann Arbor, MI: University of Michigan Press.
- Titchosky, T. (2007). *Reading and writing disability differently*. Toronto, Canada: University of Toronto Press.
- Walker, J. (2008, June 8). The silence generation: QuietComfort headphones. *New York Times Magazine*. Retrieved from <http://www.nytimes.com/2008/06/08/magazine/08wwln-consumed-t.html>

Book Reviews

Title: *Victorian Freaks: The Social Context of Freakery in Britain*
Editor: Marlene Tromp
Publisher: Columbus, OH: Ohio State University Press, 2008
ISBN: 978-0-8142-1086-4
Price: \$49.95, Cloth, 328 pages
Reviewer: Charles Folk

The freak shows of the nineteenth and early-twentieth centuries in the United States and Great Britain are stark reminders of the change in western societal perceptions of human differences. The so-called 'freak' is often recalled as an unfortunate individual, usually with a severe disability, who through exploitation by the unscrupulous, was subjected to ridicule and mockery in feeding the public's voracious insensitive curiosity. The emergent sub-field of Freak Studies reconsiders this phenomenon using current thought on disability, gender, race, ethnicity, and societal norms. *Victorian Freaks*, a collection of twelve essays edited by Marlene Tromp, is a substantial new contribution to this sub-field.

These essays reveal the social process of "enfreakment" whereby those possessing unusual bodies, abilities, and disabilities were recreated as spectacles for consumption. By drawing on a variety of compelling historical sources and documents, each essay attempts to situate these spectacles in the context of the social tensions in Great Britain as it underwent extensive economic, political, scientific and social changes. In "Poor Hoo Loo" by Meegan Kennedy, the botched and ultimately fatal operation to remove a large tumor in the genital area of a Chinese man became a spectacle for the medical establishment striving for a new standard of clinical objectivity, and the society's concern at the "unnatural growth" in the British Empire. Another essay, "Our Bear Women, Ourselves" by Rebecca Stern, convincingly argues that Julia Pastrana, whose face and body were covered with long hair, presented a challenge to Victorian categories of femininity and the erotic, and inflamed Victorian anxieties about class, race, and particularly gender.

The issue of personal agency repeatedly arises in these essays. Hoo Loo apparently faced a forced choice of either going to London for an operation thereby unknowingly subjecting himself to the spectacle his life and death became, or resigning himself to staying in China, where doctors refused to operate. Joyce L. Huff's "Freaklore" describes the career of Daniel Lambert, who exhibited himself at fairs and theatres and accepted fees from curious visitors to his home to offset the expense of having his furniture and clothing custom made to fit his unusually large size. The aforementioned Pastrana seems to have collaborated quite cleverly with her husband/promoter, though she did not likely contribute to the decision to be embalmed and displayed posthumously along with the newborn who only briefly survived her. Each of these individuals made choices from a limited set of options based on the information, qualities, and skills they possessed, in the hope that their circumstances might be improved.

While these are academic essays, any student or scholar of the humanities or social sciences will be quite familiar with the jargon and theoretical frameworks employed, and the forward by Rosemarie Garland-Thomson and introduction by Marlene Tromp offer an adequate grounding in the foundations of Freak Studies. The overlap between the collection's subject and that of Disability Studies is considerable, and where there is difference in focus,

as with questions of race and gender, there exists a useful space for mutual engagement. *Victorian Freaks* is a valuable contribution to scholarship in the areas of disability, race, gender, and class, and offers an interesting perspective for understanding the social history of Victorian Britain.

Charles Folk is a freelance writer with a B.A. in Anthropology from U.C. Berkeley.

Title: *Living with Low Vision and Blindness: Guidelines That Help Professionals and Individuals Understand Vision Impairment*

Authors: John M. Crandall, Jr., Ph.D. and Lee W. Robinson

Publisher: Springfield, IL: Charles C. Thomas Publishers, 2007

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Cost: \$49.95

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Cost: \$34.95, 220 pages

Reviewer: Beth Omansky

Take two parts developmental psychology; add one part special education; sprinkle with one part blindness/low vision rehabilitation and you have *Living with Low Vision*. Chapter subjects address concept, growth, cognitive development; science and the visually impaired; measurement and assessment; learning theories; the senses and perception; motivation, emotion, attitudes, self-concept, and memory; orientation and mobility; advocacy; transition; mainstreaming; and psychology of blindness. Even though authors Crandall & Robinson claim to challenge negative attitudes toward blindness, unfortunately their text perpetuates 'individual' medical model notions of 'limitation,' 'weakness,' and 'overcoming.' For example, they ask, "[t]he question for professionals who work with the blind, 'Can the effects of vision loss be totally overcome and if so, how?'" (p. 92). As a social model advocate, I would much prefer the question be framed, "How can education and rehabilitation best understand and adapt to students and clients' lived experience of blindness and low vision?"

Some blind people have mannerisms unique to blindness which rehabilitation negatively labels as blindisms--behaviors rehabilitation seeks to eradicate while training clients to act sighted. While many blind activists and scholars resist this model of 'lack' or 'loss,' Crandall & Robinson do not challenge the rehabilitation viewpoint. They write, ... [blind people] "often lack facial expression, engage in repetitive rocking, light filtering, and other 'blindisms,' dress inappropriately, and lack personal care. These are socially limiting behaviors" (p. 105).

Considering their extensive expertise and experience in psychology, special education, and blindness rehabilitation, it is not surprising Crandall & Robinson heavily rely on traditional psychological concepts, theories, and scientific research. However, I was disappointed to find copious use of the language of 'normality': "handicap," "vision limitation," "normal," "deficits," "overcome," as examples, belying their stated desire to help change negative public attitudes toward blindness and blind people. Another shortcoming of the text is how often the authors state "studies have shown..." but fail to provide citations to back their assertions. For example, they write, without supporting evidence, "[o]bservers have noticed that blind children seem to lack 'normal' motivation (p.102), and... "[I]n the

end, most people would rather be remembered as a friend and mentor than as a blind person” (p. 128). Crandall & Robinson also conjecture as to why sighted people are more afraid of blindness than any other impairment, “... many individuals, as children, played ‘Blind Man’s Bluff’ and felt foolish because they could not do even simple tasks when blindfolded” (p. 112). This is a rather reductionist explanation which ignores complex social processes that construct blindness, such as charity’s perceptions of blindness as tragedy, negative media images, and segregationist methods of blindness education.

Living with Low Vision contains much more information about psychology and special education, in general, than the topic of blindness. It reminds me of books marketed as specific to particular dog breeds when, except for photographs, the material, in fact, is applicable to any and all breeds. If you are interested in developmental psychology concepts and theory, or if you want a refresher intermediate level education research methods course, then this book is for you. But, if you seek a practical “how-to” about living with vision loss, as the title might lead you to expect, look elsewhere.

Beth Omansky, Ph.D., is an activist and disability studies scholar in Portland, Oregon. Her book, *Borderlands of Blindness*, will be published by Lynne Rienner Publishers in April, 2011.

Title: *Disability in Twentieth-Century German Culture*

Author: Carol Poore

Publisher: Ann Arbor, MI: University of Michigan, 2007

Cloth: ISBN: 978-0-472-11595-2

Cost: \$70.00

Paper: ISBN: 978-0-472-03381-2

Cost: 24.95, 432 pages

Reviewer: Katharina Heyer, Ph.D.

“Why has disability remained outside of the focus of most cultural historians in German studies?” asks Brown University German studies Professor Carol Poore in her comprehensive and nuanced new book, *Disability in Twentieth-Century German Culture*. While cultural representations of disability have been central to specific topics in German history – most notably the development of eugenics and the social welfare system for disabled workers – there has been no comprehensive study weaving together the different discourses of disability in German society until Poore’s important contribution. Informed by critical disability studies, Poore uses an impressive range of texts and resources to match the cultural representations of disability with the way that Germans with disabilities themselves responded to and resisted that representation. The result is an intensely readable, richly illustrated, and thought-provoking read for students of disability studies, German culture, and contemporary bioethics.

A large part of the book’s attention goes to the development of the Nazi eugenic ideology. This is perhaps an inevitable focus of a book on disability in Germany, even though much has been written about the subject already. Poore provides the important cultural background to understanding National Socialism’s contempt for “useless eaters” and “lives unworthy of life” by tracing metaphors of the disabled body back to the Weimar Republic, where images of the disabled veteran in both art and politics symbolized both Germany’s humiliating defeat in World War I as well as Germany’s fascination with modernism. It is no

coincidence that this period provided the foundation for Germany's unrivalled leadership in physical and vocational rehabilitation. The compelling image here is that of a quadruple amputee war veteran wearing state of the art prostheses on both arms and legs while working as a skilled craftsman (p. 11).

Continuing chronologically, Poore's analysis moves to the postwar Allied occupation and the founding years of the two German states, both grappling in different ways with yet another generation of disabled war veterans. In contrast to the Weimar model of rehabilitation and generous pensions, the Allied occupation of Germany discouraged the privileging of war veterans in their attempts to "impress upon the public that a military career bears neither honor, profit, nor security" (p. 171). Just a year after the end of the occupation, however, the young West German state re-instituted employment quotas for disabled workers and social welfare benefits that became emblematic of Germany's postwar economic miracle (Heyer, 2005).

When it came to accountability for bringing the perpetrators of disability-based euthanasia and forced sterilization to justice, however, the German state fell miserably short. Similarly, the East Germany state's ideal of social justice and a classless society failed to include disabled citizens in meaningful ways. Thus, Germany's eugenic legacy continued to haunt the country's thinking about disability for decades to come. Attitudes began shifting in the late 1970s, spearheaded first by the student's movement and then by disability activist protests against the UN Disability Decade, challenging the medical model that continued to inform Germany's extensive but still segregationist rehabilitation system. The U.S. civil rights approach to disability became a powerful model for German activists eager to embrace notions of inclusion and equal opportunity while at the same time critical of the American social welfare system (Heyer, 2006).

Poore's analysis covers an ambitious range of topics and historical periods. It is thus understandable, but ultimately frustrating, that her chapters can read like a list of events without conclusion or deep analysis. Readers may be left feeling deprived of a larger theoretical argument, or deeper case studies into the lives of activists and artists she introduces. Poore's book is most successful when it is explicitly comparative, as for example her insightful comparison between FDR's "splendid deception" (Gallagher 1999) and German contemporary politician Wolfgang Schäuble's inability to escape disablist assumptions about the meaning of his disability for public office. She also offers powerful comparisons of the way Germany's eugenic past informs contemporary debates about gene technology in both countries. Not to be missed is her last chapter's personal observations: an "American Professor" with a visible disability navigating two worlds.

References

- Gallagher, Hugh Gregory (1999). FDR's splendid deception: The moving story of Roosevelt's massive disability and the intense efforts to conceal it from the public. 3rd ed. New York: Vandamere.
- Heyer, K. (2005). "Rights or quotas? The ADA as a model for disability rights" In L. B. Nielson and R. Nelson. Eds. *Handbook of research on employment discrimination: Rights and realities*, p. 237. New York: Springer.
- Heyer, K. (2002). "The ADA on the road: Disability rights in Germany. *Law and Social Inquiry*, 27(4), 901.

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Title: *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals*

Author: Terri Couwenhoven

Publisher: Bethesda, MD: Woodbine House, 2007

ISBN: 978-1-890627-33-1

Paperback: 8 ½ x 11, 400 pages

Cost: \$24.95 USD. Order through Woodbine House www.woodbinehouse.com

Reviewer: Martha M. Guinan, MPH

Talking to your son or daughter about sexuality and their bodies is difficult for many parents. What do you say? For parents of children with intellectual disabilities it can be even harder. Talking about the birds and the bees just leads to greater confusion for concrete learners. How can you be sure your son or daughter understood what you said? Can they apply what they've learned to their lives? Protecting your children means preparing them for the unknown—a scary prospect at best.

Today's parents are more accepting of their children's sexuality and the role they play in educating and helping their children than they used to be. However, they need ideas and strategies to teach their children about these issues in ways that are respectful and understandable. They pay close attention to their child's physical and emotional growth but they are never sure how much to explain about sexuality to their child. Terri Couwenhoven has written a wonderful resource that answers many of these questions. Having worked as a sexuality educator and taught people with disabilities even before she had a daughter with Down syndrome, she has practical experience and a depth of knowledge. The writing is approachable, understandable, and well referenced. Body parts and sexuality are talked about candidly without excessive medical jargon. The author is respectful of differing beliefs and perspectives. She introduces thinking points that allow you to reflect on your own feelings, values, and attitudes about specific topics so you present a clear message to your child. The reader is informed about concepts they may have overlooked and key messages that affect goal behaviors.

Reading through sections about pelvic exams and periods made me appreciate having had a son. I don't recall if my mother ever tried to talk to me about these things. If she did I am sure I cut her off with my embarrassed teenage know-it-all attitude. As a parent I can appreciate how necessary it is to move past embarrassment, as people with intellectual disabilities might not be able to learn about these topics on their own. They live in a more sheltered world than the rest of us.

My son had a well-meaning teacher when he was in elementary school teach him about "shame" when he was really trying to teach about "modesty." I spent a lot of time having to differentiate between the two concepts with my son. I wish this book had been published then, as it would have helped in explaining to my son as well as to the teacher what my objections were!

This is a book that should be read by all parents of individuals with intellectual disabilities as well as the professionals that assist them with their daily lives. It would be

helpful for anyone with young children but addresses adult and disability-specific issues that may not be relevant. It is organized by issues rather than age and includes illustrations that help open dialogue between you and your child. This book really is the starting point for discussions about freedom, responsibility, maturity, and becoming an independent adult.

Martha Guinan is a PhD. student in Exceptionalities and works for the Center on Disability Studies at the University of Hawai`i. She is also the mother of an exceptional young man named Ryan.

Disability Studies Dissertation Abstracts

Editor's Note: The information for this section of RDS is provided by Jonathan Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at: www.hsls.pitt.edu/guides/histmed/researchresources/dissertations/index_html.

Cultural differences and perceptions of autism among school psychologists

Tasby, Calissia Thomas. Proquest Dissertations And Theses 2008. Section 0803, Part 0525 156 pages; [Ph.D. dissertation].United States -- Texas: Texas A&M University; 2008. Publication Number: AAT 3348040.

The retention of college students with learning disabilities

Huger, Marianne Seabrooke. Proquest Dissertations And Theses 2009. Section 0075, Part 0514 207 pages; [Ed.D. dissertation].United States -- District of Columbia: The George Washington University; 2009. Publication Number: AAT 3344873.

Human service students' perceptions of people with mental retardation

Bennett, Dianne M.. Proquest Dissertations And Theses 2009. Section 1351, Part 0534 94 pages; [Ph.D. dissertation].United States -- Minnesota: Capella University; 2009. Publication Number: AAT 3344907.

Who's being left behind? A study to determine the progress of students with disabilities and nondisabled students in Georgia urban elementary schools

Booker, Rasheen G.. Proquest Dissertations And Theses 2009. Section 1351, Part 0524 122 pages; [Ph.D. dissertation].United States -- Minnesota: Capella University; 2009. Publication Number: AAT 3344645.

Infusing self-determination into the curriculum for young adults with significant disabilities: One teacher's journey

Held, Mary F.. Proquest Dissertations And Theses 2008. Section 0093, Part 0529 205 pages; [Ph.D. dissertation].United States -- Indiana: Indiana University; 2008. Publication Number: AAT 3344574.

Self-beliefs in high school students with learning disabilities: Interaction and intervention

Mitnick, Ethan Samuel. Proquest Dissertations And Theses 2009. Section 0055, Part 0529 125 pages; [Ed.D. dissertation].United States -- New York: Teachers College, Columbia University; 2009. Publication Number: AAT 3348359.

The meaning and means of inclusion for students with autism spectrum disorders: A qualitative study of educators' and parents' attitudes, beliefs, and decision-making strategies

Sansosti, Jenine M.. Proquest Dissertations And Theses 2008. Section 0206, Part 0524 392 pages; [Ph.D. dissertation].United States -- Florida: University of South Florida; 2008. Publication Number: AAT 3347368.

The role of caregiving on quality of life of parents with children having autism in Taiwan

Hu, Hsiu-Shuo. Proquest Dissertations And Theses 2008. Section 0128, Part 0628 157 pages; [Ph.D. dissertation].United States -- Michigan: Michigan State University; 2008. Publication Number: AAT 3348121.

Promoting resiliency in families of individuals diagnosed with an autism spectrum disorder: The relationship between parental beliefs and family adaptation

Warter, Elizabeth Hill. Proquest Dissertations And Theses 2009. Section 0016, Part 0620 252 pages; [Ph.D. dissertation].United States - - Massachusetts: Boston College; 2009. Publication Number: AAT 3344740.

The grief process in children with cognitive/intellectual disabilities: Developing steps toward a better understanding

Trueblood, Sonya. Proquest Dissertations And Theses 2009. Section 1009, Part 0620 87 pages; [Ph.D. dissertation].United States -- Wisconsin: Wisconsin School of Professional Psychology, Inc.; 2009. Publication Number: AAT 3348804.

Double jeopardy: Disabled and black disability, race, and their interaction

Maeder, Evelyn M.. Proquest Dissertations And Theses 2009. Section 0138, Part 0325 147 pages; [Ph.D. dissertation].United States -- Nebraska: The University of Nebraska - Lincoln; 2009. Publication Number: AAT 3344515.

Enjoyment and physical activity levels of students with and without disabilities in physical education

McClain, Zane D.. Proquest Dissertations And Theses 2008. Section 0172, Part 0523 178 pages; [Ph.D. dissertation].United States -- Oregon: Oregon State University; 2008. Publication Number: AAT 3336394.

Bimodal bilingualism in hearing, native users of American Sign Language

Bishop, Michele. Proquest Dissertations And Theses 2006. Section 0505, Part 0290 304 pages; [Ph.D. dissertation].United States -- District of Columbia: Gallaudet University; 2006. Publication Number: AAT 3337513.

Meaning-making in chronic disease: A qualitative study of how adults with epilepsy create a meaningful concept of illness

Gatt, Maureen Theresa. Proquest Dissertations And Theses 2008. Section 0669, Part 0339 156 pages; [Ph.D. dissertation].United States -- California: Institute of Transpersonal Psychology; 2008. Publication Number: AAT 3336644.

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