Between the therapeutic and the democratic? Mediating disability memories online[1]

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ABSTRACT

Disabled people constitute the "largest minority in the world" (United Nations, 2006). As such, a study of contemporary memory-making practices around disability can provide a crucial lens through which to engage with ongoing issues of socioeconomic and cultural marginalization. This article examines two digital memory projects which showcase the life stories and creative outputs of people with disabilities: the *Museum of the Person USA* (Bloomington, US) and *Envisioning New Meanings of Disability and Difference* (Toronto, Canada). I argue that a close analysis of these projects illustrates a current tension between autobiographical, self-expressive memory narratives and those orientated by wider sociopolitical claims. Significantly, gendered aspects of disability discourses also work to unsettle the boundaries of what we understand the "therapeutic" and "democratic" to be. At present there is scant research taking people with disabilities' own testimony and experience as its core sources. The rise of networked technologies and the opportunities this creates for marginal memories to be publicly shared and witnessed therefore provides a compelling context through which to examine the mediation of disability stories online, and the ways in which these memories can act as tentative resources for social justice claims.

Introduction

As scholars in the social sciences and humanities have theorized, we are currently experiencing the rise of an auto/biographical society tied to new forms of digital

technologies and consumer culture in which "life stories are everywhere" (Plummer, 2001:78). In this new "confessional society" (Bauman, 2007), boundaries separating the private and the public are being blurred, with citizens demonstrating an increasing sense of obligation or virtue in sharing personal information about themselves in the public realm, including through much frequented social media sites. In turn, public institutions in the West are increasingly inviting citizens to "tell your story" in cooperation with them, drawing on new media technologies and platforms to do so (Cameron and Kenderdine, 2007; UNESCO, 2003). Explaining this shift, museum and heritage scholars have suggested that facilitating audiences to present narratives and images about their own lives can demonstrate "social inclusion" pathways— of particular importance to engaging otherwise marginalized groups such as those from low socioeconomic backgrounds, ethnic minorities and people with disabilities. Notably, such groups have historically remained outside of the core audience (and representative agents) of museums, archives and galleries in the West and demand new strategies for inclusion and engagement (Dodd et al., 2008; Sandell, Dodd and Garland-Thomson, 2010; Tlili, 2008).[2]

In her study of several museums in the UK and US, Thumim (2010, 2012) scrutinizes the aims, functions and outcomes of recent museum projects incorporating public self-representation activities in their cultural programming. She identifies two main drivers behind these projects: a *therapeutic function*, focusing on issues of self-expression and identity building for diverse audiences, and a *democratic function*, based on assumptions that greater visibility of marginalized communities, using online technologies, equates to greater democratic participation and active citizenship. Appeals to such drivers are woven throughout museum mission statements and policy documents. While therapeutic and democratic drivers are invariably intertwined, Thumim highlights how such practices may nevertheless end up competing with each other, with the less politically transformative, self-expressive therapeutic function taking precedence. In this vein, Thumim questions how far "visibility" and "democratic participation" can be achieved in top-down museum initiatives that mandate people to perform their "ordinariness" (perhaps even their marginality), without connecting these initiatives to broader social and political processes of democratic participation. The manner in which public institutions maintain their control of representations, by compiling certain narratives and frameworks to mediate public self-representations, must also be considered. Thumim provides the example of museum initiatives that ask participants to upload their photos and memories of particular museum objects, while the authority and expertise to select and curate these objects remains with the institution (2010:296). For Thumim, merely

participating in public-facing initiatives is not enough to substantiate democratic claims: there needs to be a more manifest engagement with questions of power and agency.

Engaging critically with Thumim's findings, this paper draws on empirical research on two projects re-mediating disability life stories online: the Museum of the Person virtual museum (www.museumoftheperson.org, Bloomington, US) and the Envisioning New Meanings of Disability and Difference project (www.envisioningnewmeanings.ca, Toronto, Canada). These initiatives can be mapped within a broader shift in museums and galleries in particular re-engaging with disability issues and forms of representation (Dodd et al., 2008; Sandell et al., 2010; Sandell and Fraser, 2014). These two case studies have been selected for their focus on people with disabilities self-representing themselves within an institutional context.[3] Both university-based projects use arts-methods and storytelling approaches, including oral history, digital storytelling and photographic workshops; and both use digital platforms to showcase the resulting audio-visual outputs. After first considering the relevance and resonance of "therapeutic" and "democratic" discourses to disabled communities in the US and Canada, I then examine the ways in which "democratic" and "therapeutic" (Thumim 2010, 2012) discourses of disability, impairment and disablement are constructed via my selected case study sites, alongside the role of memories within this.[4] As I demonstrate, nominally the Museum of the Person USA site has a stronger democratic orientation and the Envisioning New Meanings of Disability and Difference project is more therapeutic-led. However, I argue that an analytical framework referring to "therapeutic" discourses needs to be further contextualized, in light of different communities' varying relationships to "therapeutic" practices as a site of regulation and social control (Goodley, 2011), and repositioned through contemporary discourses of postfeminism and neoliberalism that call for subjects—especially women—to perform "projects of the self" in publicly mediated sites (Gill and Scharff, 2013). Through a discourse analysis of the two case study sites, I also attend to the blurred lines between the "therapeutic" and the "democratic" when considering participants' vernacular engagements with the politics of redistribution and recognition (Fraser, 1996; Loja et al., 2013) in their life story projects. Through this article I argue that while a therapeutic-democratic framework for understanding publically mediated life story projects remains a useful analytic, this framework can be further repositioned and critiqued precisely through the marginalized memories of excluded citizens, such as people with disabilities.

Disability, citizenship and the democratic

In terms of democratic practices and discourses, disabled people have been historically maligned and excluded from the category of citizenship. In the United States, hegemonic discourses have posited people with impairments as "deficient" and "dependent." These attributes are further shaped by practices of colonialism and capitalism, which sit in tension with foundational American national myths of "independence" and "autonomy." The disabled person is therefore constructed as an "incapable citizen" (Nielsen, 2012). Within a Canadian context, Prince (2009) examines the policy contexts through which people with disabilities are rendered as "absent citizens," facing numerous barriers to social, economic, legal and cultural participation and recognition in society. Shaped by such horizons of marginalization and exclusion, the rise of disability testimony has become a potent site of intervention in hegemonic discourses of ableism, as well as a potential site for education, policy and social connection.

Caveats are needed, however, to temper any overly positive claims for new media as a site for expanding citizenship practices. If digital media has been celebrated as a means of increasing democratic representation—through sharing voice and challenging hegemonic power structures (see Carpentier, 2011; Jenkins and Thorburn, 2003)—the use and role of ICTs and digital technologies in disabled peoples' lives has been contested. Online technologies can act as a "lifeline" as well as a site for acquiring cultural and social capital for the person with an impairment, circumventing the loss of physical capital that many disabled people experience in real-time settings and locations (Loja et al., 2013; Seymour and Lupton, 2004). Recent studies, however, also highlight how structural concerns, such as the digital divide, accessibility limitations regarding the world wide web and the prevalence of digital illiteracy, delimit the use of digital culture as a site of personal, social and political engagement for people with disabilities (Dobransky and Hargittai, 2006; Macdonald and Clayton, 2013). Such factors intertwine to create and delimit the horizon for potential citizenship practices and digitally mediated memory work, and they create the context through which institutionally mediated disability life story projects take shape.

Disability, therapeutic discourses and social control

There are also significant tensions with regard to what constitutes the "therapeutic" within this analytical framework, especially when considered through the context of disability. As a textual repository of historical meanings and interpretations, the Oxford Dictionary—itself an institutional memory

text—defines "therapeutic" as "to treat medically." The prevalent model of understanding disability since the nineteenth century has been through a medical lens, where disability is treated as an "inherent attribute of deviant bodies" (Goggin and Newell, 2003:xvii). Consequently, the medical model categorizes some bodies as "wrong" and in need of special measures and segregation. The term "therapeutic" is discursively haunted by disability histories and memories of marginalization. Such an awareness of disability histories can draw attention to the various tensions of appeals to "therapeutic" discourses: people of color, queer, women and the working class have all been historically subjected to the therapeutic gaze in Western societies as a form of social control (Goodley, 2011; Oliver, 1995; Reeve, 2004).

We can see this evidenced in Pelka's (2012) recent documentation of the disability rights movement in the US. Alongside oral history, Pelka attends to the institutional contexts where people with disabilities have been positioned through "therapeutic" discourses as a form of control and oppression. In the aftermath of World War Two in particular, people with disabilities (including returning veterans who had been disabled by war) were forced through "rehabilitation" programs in an attempt to move them into the workplace. (It is worth noting that historically, as well as in contemporary times, the ability "to work" has been used as a governmental discourse and presumed measure to define disability.) As Pelka recounts, rehabilitation programs adopted a "whole man" approach, where people needing aids such as wheelchairs and prosthetics were subjected to the disciplinary gaze of medical experts who deemed people with disabilities as having maladjusted personalities that needed to be corrected in order for them to "get on" (2012:14–17). Across the twentieth century in the US, people with disabilities, or people who were seen as "deviant" to the "norm" and thus labelled as disabled in some way, were incarcerated within mental institutions where "structure," "direction" and "therapy" were prescribed. As Pelka details, in many instances incarceration in these institutions were thought to provide "milieu therapy," where "just being confined in such a place was alleged to be therapeutic" (2012:77). Remembering such historic practices, and remaining open to similar practices being carried out today, alerts us to the need to be critical about the term "therapeutic" to best describe initiatives drawing on public self-expression and self-narration—precisely because some communities have a different historical relation to "therapeutic" discourses and practices than others.

Case study 1: Museum of the Person USA

As part of my case study analysis, I have sought to understand how "democratic" and "therapeutic" discourses are being constructed and contested in contemporary disability life story projects. The Museum of the Person (MoP) USA hub is an online portal dedicated to the production, dissemination and sharing of autobiographical memories of everyday "common people" (Worcman, 2006). Developed by the Center on Aging and Community (CAC) in the Indiana Institute on Disability and Community at Indiana University, Bloomington, this project is dedicated to collecting stories of local residents with physical and/or learning difficulties, alongside non-disabled community groups and participants (Stafford, 2005).[5] The MoP hub positions itself as part of a global network of life story initiatives in Brazil, Portugal and Canada, all branded through the name Museum of the Person.[6] What ties these networked projects together are common goals and methodologies, with each portal "concerned with using the power of life stories to bring communities together, and to create a different social memory" (Worcman, 2006:2).

Autobiographical memory is highly valued within the Museum of the Person network, especially when social memory can be turned into what the co-founder Karen Worcman articulates as "social information" (Worcman, 2006). As the MoP USA mission statement states:

- Every life story has value and should be part of social memory.
- Listening to others is a way to offer respect and act as a peer.
- Every person plays a role as an agent of historical change and an author of history.
- Memory is an instrument for social and cultural development.
- Understanding through exchange will lead to peace (www.museumoftheperson.org/about).

Above and beyond a therapeutic function of identity building and self-affirmation, there is a clear social transformative driver articulated here: memory is seen as "an instrument for social and cultural development" with the potential to "lead to peace." An emancipatory function is strongly embedded in the MoP's wider objective of "mak[ing] our society a more democratic and fair one, where people who would normally be 'invisible' have the chance to be included and respected as history makers as we all are" (Museu da Pessoa, 2012). Crucially, this democratic approach is aligned with the chosen MoP methodologies of oral history and digital storytelling, which are geared towards "creating an agentic self" for participants (Hull and Katz, 2006) through the co-production of mediated life stories and creative memory work. Through such methods, everyday memories of "ordinary people" become counter-narratives to hegemonic accounts of history and agency,

with the potential to draw attention to embedded structures of discrimination and marginalization (Perks and Thomson, 2004; Thompson, 2000).

The choice of the term "social memory" in the MoP mission statement—rather than public memory, cultural memory or collective memory, which are other common monikers—is striking. We can read this terminology as putting an emphasis on the social acts of *telling, preserving and accessing* lived experience and testimony, as a site of shared articulation. There is a resonance with the concerns of social justice and social transformation, which would not be present in the same way if "public memory" or "cultural memory" were deployed as operating terms. With regard to personal testimony as a democratic resource, it is a truism that historical narratives of the past routinely fix themselves to the accounts of the elite and privileged, particularly with respect to gender, class and race axes (Hall, 2002). The non-disabled/able-bodied must also be included in this scope of hegemonic power relations. The MoP mission statement rhetoric that "every person plays a role as an agent of historical change and an author of history" foregrounds a democratizing vision of history, in which memory can operate as "the connective structure of societies" (Assmann, 1992:293). Such an approach calls for a radical revisioning and revaluation of individual, everyday testimony, including who counts as a historical agent and what can be learned from embodied memories and experience.

To understand how life stories are re-mediated online in the MoP USA project, a brief visual account of the website will help to establish the interface of this site (see Figure 1). Alongside the top section of the web page is the MoP logo of three interlinking circles. Beside this logo are three information tabs: Projects (listing the memory projects undertaken by the MoP USA), About (including the background information and mission statement for the MoP network and the institutionally mandated privacy and terms of use statements), and Contact (providing key contact information for MoP USA staff). In the right-hand column of the page is four sections: a free text box to search archived content of the site, links to other story sites (including the Center for Digital Storytelling and the Museum of the Person–Brazil), "share your story" instructions and log-in functions, and "tour the museum" mechanisms, including links to events, news, text stories, video stories, website privacy notices and website terms of use. Situated under the logo is a flash animation sequence of photos, drawn from archived content on the site, and a "Recent Comments" field to show the latest user interactions. Archived content is presented on the home page, with the latest posts appearing at the top of the screen. This content is a combination of text, photos and YouTube embedded life story interview clips. The YouTube videos are also captioned so as to be more accessible. The MoP USA site

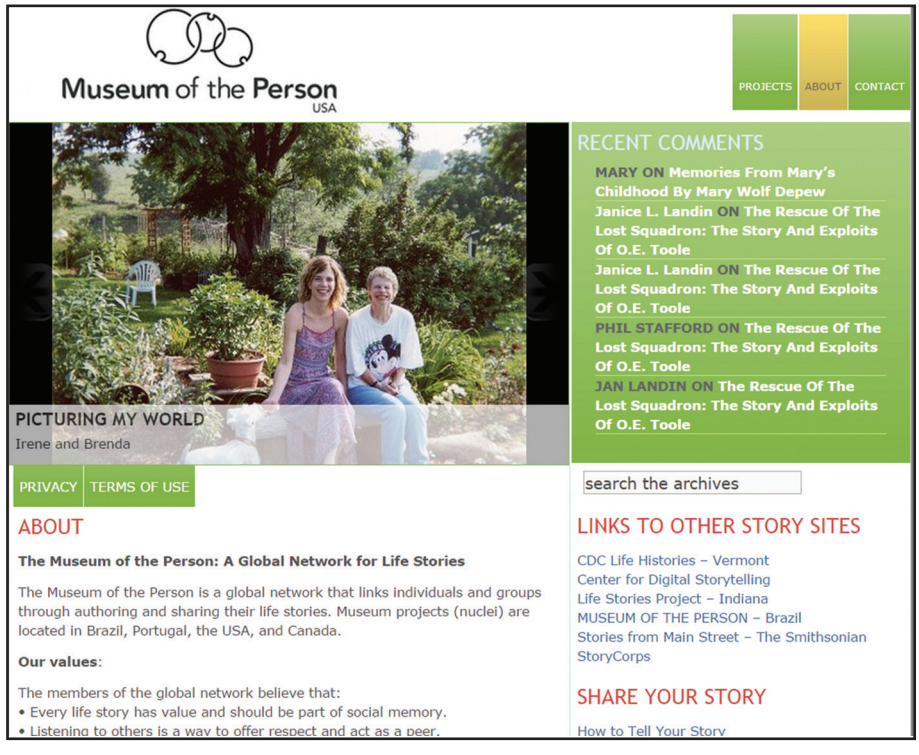

Figure 1. Museum of the Person USA website (www.museumoftheperson.org, January 2014).

can be logged on to—for online story submissions and commenting—from several social media accounts, including Google, Facebook, Twitter, Yahoo and LinkedIn.

At the time of writing this article in the winter of 2013, the most recent post on the MoP USA site offers a short summary of an oral history interview conducted with Indiana resident Katrina Gossett, video-recorded at the 2012 annual conference of the Indiana Governor's Council for People with Disabilities. This interview is thematized around her experience of wheelchair accessibility in the urban environment (Gossett, 2013). A quote from Gossett is presented in the short written summary about living in a downtown Indianapolis neighborhood and how buildings are slowly being adapted to become more accessible to those in wheelchairs. Gossett is cited as saying: "I've noticed that the stores and restaurants have made an effort to become accessible even though the [older] architecture is not ideally designed for it." Within the video clip of her interview—linked at the bottom of the written post and presented in a six-minute

segment—the listener also learns about unsuccessful accessibility measures: such as the entry buttons for automatic doors placed too high for wheelchair users to reach, which Gossett negotiates by having her service dog reach up and press the button for her, finally enabling access to the building.

Gossett's account offers a tacit illustration of the social model of disability in operation. In this conceptualization, a person's impairment relates to their physiological condition, while disability is the socially constructed and maintained phenomenon of exclusion (Goggin and Newell, 2003:21). The social model of disability—although contested in its strongest forms for negating the bodily experience of disability and overly focusing on social attitudes and environments (Shakespeare, 2006)—emphasizes how policies, architecture, legislation and cultural attitudes actively construct the category of "disability" (United Nations, 2006). Social memories around the experience of disability, therefore, can help to illuminate aspects of the social model of disability and provide resources for social change. Life story narratives can serve as effective, situated counter-memories and "subjugated knowledges" (Foucault, 1980:82) through which individual and collective experiences of disability can be named, explored and interrogated. Such accounts carry with them a sensory, arresting character: to hear a voice, to see a face, to listen to a story, can be a powerful mediator. They can be interventional in terms of shaping social understandings of marginalized experience, while also providing knowledge and calls for accountability within policy and legislative contexts.

While life stories are powerful precisely because of their embodied, sensory and evocative qualities, they are nonetheless mediated texts. Institutionally speaking, forms of mediation include the co-creation of life story testimony through the presence and agenda of the interviewer, the process of editing testimonies and packaging them online, and even the tags and meta-data used to label content when presented online (Perks and Thomson, 2004; Thumim, 2012). The ways in which the value of social memories "from below" are signaled as important is a part of the memory work carried out by the institution, as part of their mnemonic framing. In the case of the MoP USA, this is mainly achieved by presenting mediated memories as a site of empathy and affect (Landsberg, 2004), as a site of recognition. Empathy—that state of feeling *as* other to facilitate social connection and understanding (Pedwell, 2012)—is actively performed within the MoP USA site. Seeking to interpellate the reader/listener as an empathetic subject, Gossett's quote about wheelchair accessibility downtown is framed thusly: "Through Gossett's eyes, we understand how unobstructed pathways, smooth curb cuts, accessible shop entrances and automatic door openers within her reach can make a difference." The listener/viewer is asked to share Gossett's viewpoint and experience, to re-situate themselves bodily and imaginatively, indeed, to reach that point of understanding and to see "through her eyes." As a sensory, affective

resource, memory is uniquely placed to create such moments of interpellation and to provoke new understandings of those who experience multiple systems of exclusion.

Numerous life story testimonies on the MoP USA site implicitly invoke a "politics of redistribution" with regard to disability, moving from the personal to the structural. Within Nancy Fraser's (1996) conceptualization, a politics of redistribution focuses on socioeconomic injustices, including exploitation, economic marginalization and deprivation. A politics of redistribution—or at least a vernacular appeal to its logics and analytics—is arguably presented within the testimony of Sylvia Jackson, an older woman with a mobility impairment. In her video-recorded testimony, collected at the 2012 annual conference of the Indiana Governor's Council for People with Disabilities, Jackson describes how she had to sell her home to avoid foreclosure after losing her job within the Nation Able Network's Senior Community Employment Program, a program funded by a US Department of Labor Grant, which seeks to find employment and provides assistance for disabled people over 55. Her loss of employment was due to funding cuts to the program. With a horrible irony, Jackson is now struggling herself to find a job (which she used to help others to do), and she is competing against younger candidates and people without disabilities. She states: "I don't think the federal government understands that when you cut somebody off from this program you're just dumped, you're done" (Jackson, 2013). She explains how she cannot live on disability allowance, especially while being financially accountable for purchasing expensive mobility equipment. Jackson has a policy point to make about redundancy, cuts and unemployment: "My point is that I would like to see that there's some kind of follow on…that they [the government] assist us in some way." Her appeal has a particular resonance in this current economic climate. Since the global financial crisis of 2008, governments have carried out particularly assaultive welfare cuts, which have disproportionately impacted people with disabilities. People with disabilities are reliant on health, social care, housing and transport service; and, as a result of low employment rates and the additional costs of living with an impairment, they are more likely to live in poverty and/or rely on benefits to survive (Clarke, 2013; Grant and Wood, 2010:11). In Jackson's mediated memory, a demand for redistribution is made and documented.

Case study 2: Envisioning New Meanings of Disability and Difference

The Envisioning New Meanings of Disability and Difference (ENMDD) project, my second case study, offers a striking counter-point to the redistribution and democratic-orientated narratives strongly at work in the MoP USA site. The ENMDD project ran between 2008 and 2010 as a collaboration between the Women's Studies Program at Trent University, regional branches of the YWCA, the Women with Disabilities and

Deaf Women's Program at Springtide Resources, and the Women's College Research Institute at Women's College Hospital. This project entailed group-based arts sessions of women with disabilities and physical differences, a public exhibition and a multi-media website for participants to "use photography and digital stories to boldly present themselves in their own words and images" (University of Toronto, 2009).

The main crux of difference between the ENMDD project and the MoP USA site—analyzed at the level of web mediation—includes a greater emphasis on personal reflection and self-created works and a declared engagement with self-esteem, self-image and wider social imaginaries in the ENMDD project. The therapeutic flavor of this project can be apprehended through the project statement posted on the site:

> Visual images shape how we see the world. Stories have the power to change how we view and understand many things: our identity, our body image, our own experience of difference. Sharing personal stories and alternative images is an important part of creating change (http://www.envisioningnewmeanings.ca).

The lexicon of "creating change" is shared with the MoP USA project, but with a notable different sense of location and mode of address. Within the MoP USA mission statement, the tellers of life story are constructed as an "every person" and the audience is shaped as listeners to others' stories. In the ENMDD project, the mode of address is shifted to the familiar and personable, as indicated through the collective "we." The register of social change is also located primarily on an individual, subjective level, as "Stories have the power to change how we view and understand many things: our identity, our body image, our own experience of difference." As common with therapeutic narratives (Illouz, 2007:48), nodes of experience and identity are at the forefront, presented as the very loci through which to make sense of disability experiences. As the introductory blurb to the arts-based project makes clear on the home page: "Workshop activities and discussions explored identity and the meaning we find in our experiences. How do we want to be seen? What is important to us?"

Repetition of the words "identity" and "experience" points to both a therapeutic narrative and a politics of recognition. Within the therapeutic narrative the project is hinged around a collectivity ("we") based on individual self-realization; significantly, one of the principal investigators for this project works within clinical and counseling settings. While the MoP USA site documented testimonies of welfare cuts, unemployment, accessibility options and the built environment, ENMDD turns the gaze inwards: "How do we want to be seen?" and "Can I love myself completely?", it asks.

The bulk of textual space on the website is given over to participants' reflections about their stories and the experience of taking part in the project (see Figure 2). In the top left-hand corner of the ENMDD website is the project's logo. As a header, there

are tabs for Home (taking the user back to the main page), Disability and Difference (outlining the project rationale), Stories (a statement describing the importance of life stories for sharing experience), Reflections (calling on audiences to think about common themes such as love, community and self-esteem), Accessibility (to select viewing options to facilitate the use of the site by the visual and audio impaired), and Contact (to contact a project practitioner). On the left-hand side are the names of fourteen artists—one of whom has chosen to remain anonymous—and links to their series of work produced within the ENMDD project.

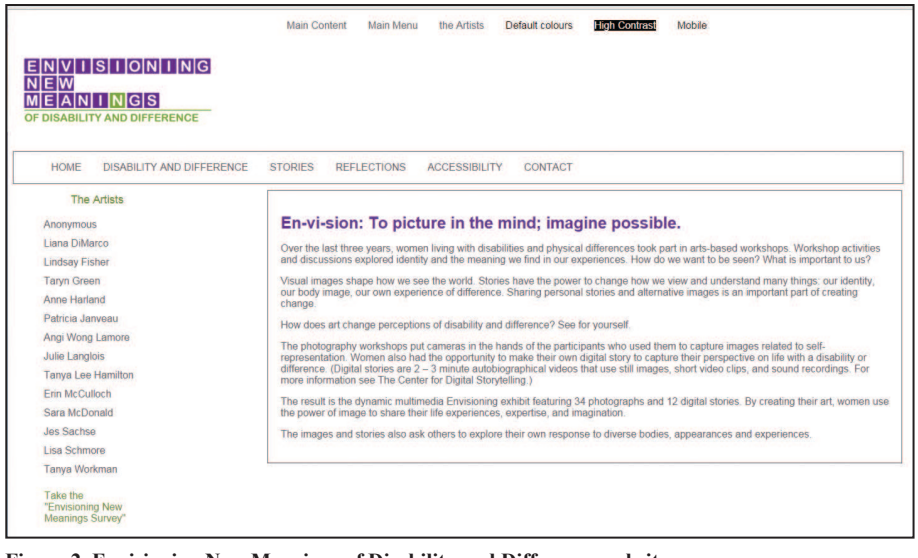

Figure 2. Envisioning New Meanings of Disability and Difference website (www.envisioningnewmeanings.ca, July 2014).

This turn to self-reflexivity and self-esteem can be mapped across wider neoliberal and postfeminist discourses, where neoliberalism operates as a "mobile, calculated technology for governing subjects who are constituted as self-managing, autonomous and enterprising" and postfeminism as the media terrain in which political engagements become subservient and sometimes evacuated in favor of reflexive explorations of identity, body, choice, individualism and self-transformation issues (Gill and Scharff, 2013:5). On the home page of the ENMDD website, an indication of the meaning of the project title is provided: "En-vi-sion: To picture in the mind, to imagine possible." The contours again appear interior, rather than community or collectively orientated. While the MoP USA site posits shared social memories as a resource for building empathetic routes to equality and social justice, the ENMDD website suggests more softly that "Some of the stories and photos ask others to explore their own responses to

diverse bodies and appearances," as "Life is about embracing a range of experiences."

"Memory" is not mentioned on the website but "stories" are. An explanation of the methodology for the ENMDD project is provided: following the pioneering work of the Center for Digital Storytelling (see Hartley and McWilliam, 2009), participants were given cameras to capture their daily lives, and workshops were used to build skills and narratives for a set of short films and photographs. The participants were women from inter-generational age cohorts, with a range of disabilities and non-normative embodiments, including mobility and sensory disabilities, chronic illness, learning disabilities, and facial and physical bodily marks. Memory materials are embedded in the participants' art projects, including the use of family and childhood photos and first-person narration in the 2–3 minute short films.

The video stories, photographs and accompanying written reflections presented on the ENMDD website are wide ranging, with varying esthetic approaches. A common thread running through many is the desire to challenge stereotypes around disability. As a blurb on the website states: "We are often seen only within the narrow confines of two common stereotypes: the tragic, pitied victim, or the spirited survivor held up as a source of inspiration." These reoccurring stereotypes (Loja et al., 2013) are engaged with in the memory works; the videos in particular offer incredibly moving, thought-provoking and at times also humorous and confrontational narratives to unpick the ableist imaginary from which such stereotypes become established. In Lindsay Fisher's video, she uses a series of images of her asymmetric face, posing in different ways and from different angles. Fisher talks about desire, relationships, her connection with her body and her consciousness of how other people look at her ("First impressions"). In Anne Harland's video ("Assumptions"), she addresses how people assume that she is able- bodied, even to the point of shouting at her for parking in disabled spaces, due to the invisible disability of her muscular dystrophy. With the increasing loss of use of her hands, she states: "Like the phoenix, I need to reestablish my self esteem, my identity." In Tanya Workman's video ("Difference"), the maker reflects upon her creative journey in taking up photography, including the experience of seeing images of herself in a medical journal while at a doctor's surgery—framed as Exhibit A and Exhibit B photos, pre and post operation. For Workman, starting to take photos of other people with facial disfigurements—in a kind of talking back to the dehumanizing discourse of medical framings—was about documenting "Not the clinical, but the person themselves."

These videos, reflections and photographs document autobiographical, as well as autobiographically inspired fictions, of lived experiences of disability, including the temporalities of struggle, triumph, connection and isolation. Therapeutic narratives figure strongly in these memory works, but so too does a politics for recognition. Across the testimonies and creative works there are comments about, and attempts to

intervene in, ableist imaginaries, in particular in how the "non-disabled gaze invalidates impaired bodies" (Loja et al., 2013:193). As Fraser (1996) elaborates, a politics of recognition is concerned with forms of symbolic revaluation, encompassing the pluralist recognition of difference and diversity. One way this can be achieved is by creating new legitimacies and symbolic frameworks for respecting and valuing marginalized groups' own forms of cultural production. While a politics of redistribution targets socioeconomic change, a politics of recognition brings to bear the crucial significance of identity, symbolic production, cultural value and participation. "Here the goal, in its most plausible form, is a difference-friendly world, where assimilation to majority or dominant cultural norms is no longer the price of equal respect" (Fraser, 1996:3). For Fraser, recognition and redistribution models of political articulation are analytical, not ontological, categories and therefore inevitably overlap and intertwine.

Crucially, in terms of our discussion of analytical frameworks, a politics of recognition is not about "self-realization" played out along the psychological level—which a therapeutic discourse pertains to. Instead recognition relates to issues of justice in the wider socioeconomic and cultural sphere (Fraser, 1996:24). As Fraser suggests, to be misrecognized

> is not simply to be thought ill of, looked down on, or devalued in other's conscious attitudes or mental beliefs. It is rather to be…prevented from participating as a peer in social life as a consequence of institutionalized patterns of interpretation and evaluation that constitute one as comparatively unworthy of respect or esteem. When such patterns of disrespect and disesteem are institutionalized, for example, in law, social welfare, medicine, public education and/or the social practices and group mores that structure everyday interaction, they impede parity of participation, just as surely as do distributive inequities (1996:25–26).

For the women involved in the ENMDD project, their creative works negotiate ableist discourses of the body–discourses which are also highly gendered, as the female body is assumed to perform and represent in ascribed feminine ways. Rupturing the non-disabled and hegemonic gaze is done both poetically and confrontationally within Jes Sachse's video "Body language." Stating that she has a fused spine and wanted to know what "everyone was looking at," Sachse's video features her first-person narration over a series of beautiful photographs of herself posed nude: by a crane, in an empty room, by a window, on a bridge. She discusses how scared she is to present herself like this—unadorned, exposed—and the soundtrack of a beating heart punctuates the air of the video. In the written text accompanying the piece, Sachse both elaborates on her reasons for creating this memory work, as well as wishing to evade any easy to pin down interpretations. Recognition is intersectional. As she writes:

> This is not just about disability. this is not just about me. this is not about pc [political correctness] and new words to mean disabled without having to name difference. This is not "our time to shine." this is not cripples for a cure. This is not about educating the masses and "pissing on pity." This is not art. this is not "en vogue." this is not an excuse to get naked.
>
> Well, it could be that.
> This is me. This is her pain, his voice, my words, our histories. This is a story.
> This is (www.envisioningnewmeanings.ca).

Concluding remarks

Mediation and re-mediation are vital factors in how shared testimonies are produced and represented in the public sphere. In this article I have understood "mediation" to be the social, cultural and technological practices shaping, disseminating and bringing to interpretation different sets of embodied memories around disability and difference. Processes of re-mediation are multiple: from recording life testimonies (through video-recording, audio-recording and written narratives), to uploading life story documents (including family photographs and other personal memorabilia), to the dissemination and consumption of these accounts. Stories—including memory fragments and materials—are a way to evoke, problematize, imagine and create. Empathy and recognition remain important aims within the storytelling process.

The Museum of the Person USA hub re-mediates life story histories of disability, representing everyday, lived experience. Within this project participants call for a politics of redistribution in terms of accessible urban planning and welfare provision. Democratic drivers are threaded throughout this site, with the conditions for an empathetic encounter being consciously staged within the institutional mediation of site—although wider discourses of austerity and cuts remain under-articulated in the institutional framing of life story narratives.

The Envisioning New Meanings of Disability and Difference project has a manifestly therapeutic aim and idiom; this is captured in the discursive register of the personal deployed within the site and its stated concern with nodes of self-esteem and image. In line with seeking a politics of recognition, ENMDD attempts to shift social imaginaries: with testimonies challenging ableist imaginaries and creating new narratives around disability, beauty, sexuality, agency and moments of confrontation and vulnerability. Although the focus on the personal could be read as complicit with postfeminist and neoliberal discourses, particularly with the gendered life stories of women being presented for the public gaze, the non-normative expressions of embodiment, subjectivity and experience

put forward on this site disrupt too easy notions of the "therapeutic" as a solely self-affirming, politically divorced discourse (while at the same time remembering that the medical model haunts the therapeutic as an analytical term, and that therapeutic values of finding identity and self-esteem are still of vital importance to people with disabilities who have to intimately negotiate ableist imaginaries as well as socioeconomic and legal obstacles).

Through this article I have argued that while a therapeutic-democratic framework for understanding publically mediated life story projects remains a useful analytic, this framework can be further repositioned and critiqued precisely through the marginalized memories of excluded citizens. I adopted Fraser's (1996) framework of a politics of redistribution and recognition as a counter-point to Thumim's (2010, 2012) framework—crucially, not as a replacement, but as a parallel lens through which issues of agency, political demands and transformative politics can be further articulated and interrogated. Deploying these two frameworks in a productive friction—noting points of overlap and distinction—I argue, can help us to understand nuanced systems of institutional and personal mediation and, crucially, of agency. Within the life story projects analyzed in this paper, social memories of disability offer compelling and interventional discourses for understanding the workings of power, society and citizenship more widely. These testimonies bring to the fore interlocking issues of labor, policy, cultural attitudes, human rights, technology, creativity, identity, social exclusion, prejudice, agency and resistance.

NOTES

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2 New projects exploring issues of representation, access and disability agency in museums, universities and arts organizations in the UK, US and Canada have emerged in recent years (see Dodd et al., 2008; Sandell et al., 2010; Sandell and Fraser, 2014).

3 See It's Our Story for a grassroots-led disability life-story project. Launched by the Disability Media Initiative, this project has collected over a thousand life history testimonies with disability activists across the US in advance of the twentieth anniversary of the passing of the Americans with Disabilities Act (http://dmi-us.blogspot.co.uk).

4 The wording of the 1990 Americans with Disabilities Act (ADA) remains contested. This document states:

> The term "disability" means, with respect to an individual: (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.

As Kudlick (2003:767) suggests, drawing on the argument of the activist Mary Johnson, such a definition implies that "disabled" refers to a political or a moral judgement, based not on the individual in question, but also on others' perceptions and attitudes about how society should function.

5 Four main principles shape the work of the Indiana Institute on Disability and Community: (1) People with disabilities exercise choice and control over their daily lives; (2) Persons with disabilities have dignity and are treated with respect; (3) Individuals with disabilities and their families are involved in the design, operation and monitoring of services and supports that affect them; (4) Enhancing the broader community improves the lives of all, including those with disabilities (www.iidc.indiana.edu).

6 The Museu da Pessoa in Brazil was the inaugural Museum of the Person project. This virtual museum and private organization is a highly successful life story project which has been in operation for over twenty years (see Clarke, 2009). Other portals in the network include the now defunct Museum of the Person hubs in Portugal and Canada (see Gillespie et al., 2005).

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