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Parry, M.S.; Tijsseling, C.; Trigt, P.W. van; Chynoweth, A.; Lynch, B.; Petersen, K.; Smed, S.

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SLOW, UNCOMFORTABLE AND BADLY PAID

DisPLACE and the benefits of disability history

Manon S. Parry, Corrie Tijsseling and Paul van Trigt

Framing culture as a curative

The cultural spaces of museums and archives are a primary arena in which a society's values are defined, preserved, reified, and shared, shaping who is valued and included in a country's notion of citizenship. The movement of museums for health and well-being builds on the idea that culture plays a significant role in society to investigate how museums can contribute to wellness – by combating loneliness or isolation, challenging stigma and inequality related to disabilities or mental illness, and condemning discrimination related to race, gender, or sexuality (Chatterjee and Noble 2013). While such work can be helpful, emerging critiques are raising questions about some of the strategies used and the assumptions behind them. Ideas about the 'therapeutic museum', for example, often rely on notions of inclusion and access that are inadequate to address the complex interaction of prejudices, policies, structural and attitudinal barriers that shape everyday life (Silverman 2010).

Initiated for people with disabilities, rather than with or by them, projects are more likely to embrace the goal of increasing access to institutions rather than undertaking a more radical rethinking of how collecting and exhibiting habits may be unhelpful, and even unhealthy, for diverse audiences (Niciu 2019). A more participatory and transformative, disability-led methodology could address these problems, as we discuss here. We begin with a brief overview of some of the major factors limiting the representation of disability in museums, drawing on recent research as well as Parry's own curatorial work. We then turn to a collaborative project we are involved in, to build a digital archive of disability history in the Netherlands, to examine some of the lessons learned and the challenges that remain. DisPLACE is a digital platform for the collection and interpretation of experiences of disability, past and present, by people with disabilities in collaboration with other students, researchers, disability service organisations, and the creative industries. The project prototype was launched in 2019, and the site is intended to serve as the first archive in the Netherlands to gather and analyse a broad range of historical sources on disabilities together, the first shared virtual environment to utilise the cultural heritage of disability, and the first to make these accessible online to people with a wide variety of disabilities. The project is part of a larger initiative by the BIB Network

(*Bronnen voor Inclusief Burgerschap*), working to stimulate the collection and interpretation of disability history. Throughout, we draw on the ‘social model’ of disability proposed by critical disability studies scholars, which focuses on the ways that difference or impairment become disabling through the design of institutions and infrastructures to suit some and which exclude others.

The underrepresentation of disability

Until relatively recently, disability and disfigurement were a much more visible part of public life, and would have been encountered by the majority of society even if not directly experienced (Ott 2005). Yet this history has gone largely uncollected, contributing to the absence or invisibility of disability in archives and museums. When relevant objects have been collected, they are sometimes catalogued without information that illuminates their connection to disability, obscuring their relevance for subsequent use. Moreover, museum professionals have reported anxiety about exhibiting such materials, for fear of offending people with disabilities (Dodd *et al.* 2008).

Currently 15 per cent of people worldwide have a disability, and many more will know a family member, friend, or colleague who does (World Health Organisation 2011). The demographic changes underway in aging societies ensure that growing proportions of populations will be living longer, and thus living with age-related disabilities. Museums have only recently begun to address the institutional barriers that exclude many of these potential visitors, although such efforts are gaining momentum as funders, consulting groups, and the sector’s professional bodies increasingly highlight the issue (e.g. Disability Cooperative Network, no date). However, activities that address physical barriers, by installing wheelchair access ramps, organising sign language interpretation tours, or sensory experiences for blind and visually impaired visitors, usually fail to account for other obstacles such as transportation to the venue and the fees to enter, as well as underdeveloped connections to the target groups. As we and our colleagues in the field have experienced, if resulting visitor numbers do not match expectations, initiatives evaluated simply on the costs incurred may be deemed unsuccessful or discontinued as too costly for the (low) level of impact.

Furthermore, these projects rarely address the content of collections to consider ways in which experiences of disability are, or could be, represented in exhibitions. Alongside limited holdings and a lack of knowledge about them, as well as a lack of confidence in exhibiting on the topic, many museum professionals also underestimate the relevance and appeal of disability-related histories for a diverse audience. The assumption remains that disability is a marginal category applying only to a small group in society. In fact, ideas about disability are also implicated in the identity of ‘non-disabled’ and influence virtually every aspect of how we organise our society. Like categories of races, genders, and sexualities, disability and able-bodiedness are mutually constitutive, deeply entangled, and meaningful precisely because of their interaction.

The widely held misperception of disability as a burden discourages cultural venues from engaging with the subject. In Parry’s previous role as a curator of exhibitions on the history of medicine, on a scientific research campus where you might logically expect a focus on disability as part of the range of activities, some stakeholders were reluctant to allow such a project, arguing that the subject would not attract an audience and would be ‘too depressing’ for the general public. Institutions that do take on the topic are then limited either to tragic

narratives of disability as a terrible fate in history, or to celebratory examples of people with disabilities overcoming their challenges (Sandell *et al.* 2010).

All of the factors above contribute to a cultural silence that misrepresents the presence of disability in the past and contributes to a narrow view of the roles of people with disabilities today – which in turn limits expectations as well as opportunities (Ott 2005; Haller 2010). Overall, this fuels negative assumptions that can lead to discrimination against others as well as personal anxiety about becoming older or disabled. Both can have life-threatening consequences, from denying treatment or opportunities to someone deemed ‘too disabled’ to benefit, to depression or difficulty coping with the changes associated with aging or following an accident or injury (Corrigan 2014).

Strategies for overcoming some of these obstacles include reframing disability history within narratives more commonly featured in museums, linking projects to national or international anniversaries and events, and developing activities beyond the museum walls. Smithsonian curator Katherine Ott curated an exhibition on the history of polio, for example, to mark the 50th anniversary of the development of the Salk vaccine. She suggested a war-related exhibition, for example, as one way to bring disability in under a more ‘popular’ topic, and indeed Parry gained approval at the National Library of Medicine for the onsite, online, and travelling exhibition *Life and Limb: The Toll of the Civil War*. At the same institution, Parry incorporated aspects of disability history into a travelling exhibition on the definition and treatment of mental illness in the nineteenth century (*The Literature of Prescription: Charlotte Perkins Gilman and ‘The Yellow Wallpaper’*). The 60th anniversary of the World Health Organization provided another opportunity to address disability, in *Against the Odds: Making a Difference in Global Health*, a major gallery exhibition and travelling version hosted by sixty venues across the United States on the theme of health and human rights (Parry 2016).

Although each of these projects provided an opportunity to temporarily incorporate missing perspectives, none of these interventions permanently altered collections or ways of working. Like other short-term activities, which over time may contribute to an accumulation of new approaches, individually, they risk being overlooked and forgotten about. In fact, occasional activities may be used as a substitute for more substantial change, as decision-makers can argue they have already addressed an issue or a group and move on to focus on something else.

In the rest of this essay, we turn to a digital project intended to address some of these issues by carving out a new platform and process for collecting and interpreting disability history. DisPLACE is a Dutch digital archive project, intended to make the collection and interpretation of historical objects accessible to users with a diverse range of disabilities. The project is an initiative of the BIB Network (*Netwerk Bronnen voor Inclusief Burgerschap* – meaning ‘Sources for Inclusive Citizenship’), a cooperation between people with disabilities involved in a range of institutions and history projects, including the National Museum of Education, the network leder(in), the website Canon Social Work, and university-based researchers. The prototype was developed by Driebit, a digital heritage company, and funding was secured from the Netherlands Organisation for Scientific Research (NWO) through a joint application by academics Parry, van Trigt, and Paul Bijl, supported by DSiN/Disability Studies in Nederland, a foundation with public and private partners for the advancement of disability studies in Dutch institutions. Tijsseling and van Trigt are co-coordinators of the BIB Network. Parry participates as a network board member and public historian teaching at the University of Amsterdam. The prototype was launched in March 2019 and led to positive press coverage

highlighting the importance of disability history both in the national press and from the country's leading organisation for professional historians (Mudde 2019; Wiersma 2019).

DisPLACE: a digital disability archive

In the absence of a commitment within (unhelpful!) institutions to permanently shift their approach, digital tools offer a means to present alternative narratives online, using material already digitised by archives and museums but underused or narrowly framed in existing projects. A digital initiative can also draw on diverse collections from a range of museums and archives, compensating for silences in specific collections and creating new resonances by juxtaposing objects from very different origins and initiatives. DisPLACE also includes materials from the personal collections of individuals, as a way to draw attention to historically significant assets that have been overlooked by heritage institutions. The website will be the first archive in the Netherlands to gather a broad range of historical sources and interpretations in one location and the first to make these accessible online to people with a wide variety of disabilities, going far beyond the basic standards of universal design.

The design as well as the content of the website are being developed in consultation with people with disabilities, and the narratives included will prioritise their reflections on the past. The first phase of the project focused on the theme of 'living', with short entries featuring photographs, archival materials, and the reflections of people with disabilities (interviewed by public history students), combined to address key issues from personal perspectives. Topics included innovative independent living projects, navigating sexuality as a young person living with parents or in university housing, and community life. The narratives often feature multiple viewpoints, to highlight the range of opinions on a particular policy or housing system, for example, as BIB Network members stressed the importance of illustrating the diversity of opinions across communities rather than aiming for more simplistic evaluations of 'good' or 'bad' strategies. The texts are written for a broad audience, and presented in an uncluttered style with clear options for navigating back and forth or accessing other related materials.

Other themes will be explored in future phases, such as work, parenting, and leisure. With additional funding, we hope to develop an expanded interpretive zone with online exhibitions, digital documentaries, scholarly essays, policy proposals, and teaching resources. The third component will be a networked community forum, linking members affiliated with the project as well as people interested in contributing or using the material, so that they can exchange information and advice.

The collaboration is complex and has revealed how existing social inequalities are reinforced by the structures in which the project is being undertaken. In the discussion below, we focus

FIGURE 10.1 Logo for the DisPLACE website.

on three main aspects of this: funding, design processes, and the practice of content development. For this last topic, we draw on our experiences leading a group of master's students as part of a practical course on digital public history, taught by Parry. While the context is educational, the lessons learned are equally applicable to collaborative projects between museums, creative industry partners, and the broader public.

Funding

After the financial crisis of 2008, government funding for museums was substantially reduced in the Netherlands. In addition, the allocation of funds for cultural work related to health and well-being is less developed there than in the UK, for example, where there are established networks of museums and art galleries undertaking such projects (e.g. Culture, Health and Wellbeing Alliance, no date). National investment in academic research is increasingly tied to specific 'societal challenges', largely driven by priorities set at the European level. Although disability is an underrepresented topic in the range of funds allocated for cultural heritage and humanities research, collaboration between universities, creative industries, and the cultural sector is actively encouraged as a means to disseminate research results and benefit society.

While this helps to motivate cooperation between the different groups, the allocation of resources *within* projects heavily favours the academic partners. Although the team was successful in securing funding from the government-funded NWO, the main applicant was required to be a researcher employed at a university on a permanent contract (Parry 2016). A co-applicant on the grant, historian Paul van Trigt, plays an instrumental role as co-coordinator of the BIB Network, but as he is employed on a temporary contract as a postdoctoral researcher, he cannot serve as the lead applicant or primary investigator on the grants we have targeted so far. This is particularly unfortunate because his credibility with the network of partners with disabilities has been crucial to the project, and his coordination of our collaborative activities depends significantly on his skill at parsing opinions, navigating conflicting views, and building agreement to move forward with particular activities.

Equally important is the role of the fellow co-coordinator Corrie Tijsseling, who is deaf, as she connects the project to a wide community of people with disabilities as well as service and advocacy organisations. Tijsseling completed a doctoral degree in philosophy and history of education, but was not able to follow her PhD with a university career 'because academia these days is disabling'. The pace of grant-writing has proven a particular challenge in our collaboration. As she noted during a hurried scramble to submit a proposal, quick turnaround times between the publication of the call for applications and the deadline limit the participation of team members who cannot meet at short notice as they need time to arrange sign language interpretation. For participants with other disabilities, such scheduling also makes it difficult to organise accessible travel.

While we would hope to attract young researchers with disabilities to the project, there is clearly a 'pipeline' problem at earlier stages of university education too, although institutions are now focusing on this as an area for improvement. However, the ableist character of an academic career identified by Tijsseling is increasingly hostile to people with disabilities as workloads intensify and expectations for output increase. Levels of stress, depression, health problems, and burnout are rising across the sector, making an academic career particularly unhealthy for those who may require more support services or time to complete their daily

activities, and who are likely to encounter discrimination and barriers in the process (Dolmage 2017).

The academic historians in the group are able to undertake their roles in the project as part of their salaried research, creating another imbalance as others, who are for the most part themselves disabled, volunteer their time to ensure that their histories are collected and preserved. While we strive to pay these participants for their role in specific parts of the project, such as advising on the design and testing of the website, the funds that are most likely to finance the work prioritise 'scientific researchers', must cover large overhead costs for the university, and have limited scope for paying for other kinds of expertise. As with marginalised groups, some of these volunteers already have extensive leadership responsibilities in other, often underfunded, projects. Funds administered by the university are also highly bureaucratised, meaning that payments are hard to request and slow to process.

In general, it is difficult to pay individuals who are not employed by an institutional partner (such as a museum or web design company) with these kinds of grants. As a result, the amount that can be allocated for such participants is fairly small, and embedded within general categories of funds for travel or meetings. This poses an additional problem as these then become 'hidden costs', while grant reviewers with expertise in participatory research are likely to look for a fairer allocation of the money as part of their evaluation of a project proposal. We hope that by drawing attention to these issues they can be taken into account in the design of funding in the future. At the project level, our aim is to secure funds to build career tracks instead of occasional opportunities to work together.

The prototype addresses one of twelve themes as a way to organise the range of potential histories that will be collected in the website. Once the format is finalised and the technical tools for uploading new content are built, funding can be sought to address other themes, meaning that the process should become smoother over time as the group repeats similar steps even as they need to reach new contacts and locate historical assets and perspectives on different topics. This structure also means that sustained work can be planned over years even before the money is available to undertake any of it, rather than proposing new projects whenever another funding opportunity arises. We hope to be able to select themes that map with new funding calls, while reusing the overall framework for multiple types of funding bids, from museum collection digitisation funds to PhD research opportunities and public engagement or digital humanities grants. This strategy is especially important as other projects have suffered due to the late awarding of funds too close to the project delivery deadline, meaning that once again, the most excluded groups are not reached in time to participate, especially given the need to build relationships and credibility, to adapt ways of working, and then to collaborate to refine the project proposal.

Design process

The majority of the project funds were allocated to the design company Driebit to develop the prototype website (www.displace.nl). Driebit has worked on museum and commercial projects. Because the founder, Bram Opdam, was interested in supporting a socially oriented activity, he agreed to take on the scope of work for a more limited budget than usual. Although accessible digital design is an increasingly important area of development in the Netherlands, there has not been much creative specialisation in this realm. There is great potential to develop expertise that goes beyond simple functionality and is more aesthetically innovative with

greater scope for user interaction. The BIB Network could thus provide Driebit with advice and testing by people with a range of different disabilities, greatly increasing their knowledge of key issues, and helping them to develop techniques that they can apply to other projects.

In order to facilitate this process, Driebit had to adjust their way of working significantly from the outset. First, we negotiated for a larger group of people to participate in the kick-off session than is preferred. The session was also lengthened, to accommodate the larger amount of input that would be generated by a bigger group, as well as time for breaks needed by participants as they had to translate, rethink, and adapt to working in a non-disabled-friendly environment. Interpreters also needed regular breaks. As in other meetings of the BIB Network, Parry is the only non-Dutch participant, and while she can understand (most of) the Dutch discussion, she speaks in English. Sign language interpreters thus listen to alternating Dutch and English to sign for deaf participants, while other attendees translate her remarks into Dutch summaries for those who do not understand English. As a result, all our meetings invariably take longer and move more slowly than if these processes were not involved.

It has been interesting to experience the shifting dynamics that this creates. At first, as some participants adjust to the different pace, there is often a sense of impatience or frustration. It may even seem inefficient as a way of working. What is becoming more apparent as the process continues, however, is that pushing through quickly is a sure-fire way to exclude some perspectives, and that by moving more slowly, another ideal of efficiency can emerge – it is more efficient to test ideas with intended audiences and refine them together, rather than deliver something finished more quickly but that has limited appeal or relevance to a group assumed *for* but planned *without*. By slowing down, participants also have more opportunity to exchange skills, building the capacities of the group during the process. Instead of trying to create ‘buy-in’ for ideas that are pitched by a designer to the clients they are working with, for example, the designer breaks down the processes of development for the academics, the community representatives, and organisational partners, who then collaborate in development of the project plans.

Other points of tension stemmed from the complexity of designing the structure and functionality of the website for a very diverse audience. At the initial design meeting, it was clear that the usual method of categorising target users was problematic. If our aim was to challenge the categories that separate people with different kinds of disabilities, as well as between people with and without disabilities, how could we still define target groups clearly enough to shape our approach? ‘Design for all’ was deemed too broad to be useful, while designing for people with disabilities encompassed a range of different, and sometimes incompatible needs. It is difficult, for example, to keep web pages clean and uncluttered but still provide the navigational options that will suit a range of users. We have concluded that the public launch of the prototype will have to become a next step in testing the impact of the compromises made. This will allow us to assess the impact over the longer term, where we maybe can evaluate the preferences of a larger group of users.

Accessibility consultants to the museum sector have frequently noted that they are brought in too late in the design process to have much influence. Indeed, user testing for digital tools is often the last stage of exhibition development and frequently cut short or cut out due to lack of time or funds. Building this process from the outset was crucial, although we suspect the time subsequently spent on the development greatly exceeded the expectations of the team at Driebit.

Content development

The design process is also usually much more closely integrated with the intended content for a project. In that way, the form can be tested for how well it suits the assets used, such as images or video, as well as the flow of the narrative and its organisation into themes, subsections or interconnected storylines. However, due to the underrepresentation of disability history in archives, museums, and academic scholarship, we began the project with very little source material. In addition, every member of the content team was engaged in other work – meaning that this was not the sole project, or even priority project, as each of us juggles other jobs, teaching, or research responsibilities.

Although we had anticipated that our other relevant activities could feed into the DisPLACE website, it became clear that a more consolidated period of work was needed to research storylines, identify assets, finalise and review the scripts, and then input the material into the online content management system. Our solution was to integrate the project in a master's-level practical course on Digital Public History, which Parry teaches over two months every autumn, following an introductory course on the topic. Students were provided with readings on the significance of disability history and museum approaches to the subject, and met with BIB Network members to discuss potential topics. The students worked in pairs (in groups formed by the teacher), and were responsible for two storylines for the website, on the theme of living. In class sessions, we discussed strategies for representing the experiences of people with disabilities, including the strengths and weakness of existing approaches. In one exercise, students rewrote entries from the *Encyclopedia of American Disability History*, and researched potential images or historical documents to incorporate in a shorter script suitable for online use. The exercise demonstrated that although students had taken on board the importance of telling these histories from their subjects' perspectives, they usually reverted to their own priorities – beginning their narratives with the type of disability and how it was acquired rather than the accomplishments or experiences of their chosen historical figure.

In an effort to avoid this, students tended to focus on interviews with members of the BIB Network or their contacts, rather than archival materials. This also reflected the scarcity of known historical sources, but as van Trigt noted, raised additional complications regarding how to integrate individual perspectives in a larger historical context. There were practical problems too, in finding interviewees in the short timeframe of an eight-week course – and without an existing website available to show people how their stories would be used. The situation was also shaped by inequalities and their legacies. The managers of an institutional living facility, for example, would not allow students to present their requests for participants to residents, citing privacy concerns but also rather paternalistically declining participation on behalf of their clients without consulting them. A practising psychiatrist deferred, concerned that their work might be harmed by publicly discussing their activities. Students also struggled to find people willing to reveal the most intimate aspects of their lives, such as sexuality and personal relationships, while more were happy to talk about the impact of laws, welfare systems, and services. Illustrating these latter, more bureaucratic, issues in compelling ways and with an appealing array of primary source material was also a challenge.

A positive outcome of these difficulties was the need for students to draw on their own networks – this process made several aware of existing connections to people with disabilities whom they had not previously thought of in this way. This served a larger goal of the project as a whole, to challenge assumptions about who is designated as disabled and the tendency

to see the worlds of the disabled and non-disabled as completely separate spheres. Another benefit was that almost every student reported new awareness of the importance of collecting and representing disability history. As future public historians they can potentially advocate for or implement such work in their own careers. While several expressed anxiety about offending people, using the wrong terminology, or asking questions that were considered offensive, all who raised this issue in their final assignments stated that the interactions they had were positive and made them more confident that they could do such work successfully. A couple said it was upsetting to hear people's personal stories of discrimination, with one reflecting that she then felt it was inappropriate to show her emotional response, but struggled to hide it. For most, this was their first exposure to these kinds of experiences, perhaps especially confronting due to the general presumption of Dutch society as relatively progressive or notions of charitable benevolence towards people with disabilities (Brants *et al.* 2017). We had also talked about the tendency in media and culture to represent life with a disability as something to be pitied, making students anxious about appearing to do the same (Haller 2010). Although Parry emphasised the value of authentic responses and discouraged the suppression of emotions, we recognise that encounters that expose the very different lived realities of participants can be problematic.

Overall, both the BIB Network and the students were extremely pleased with the end result – with both groups also expressing great satisfaction from having worked together and sharing in the excitement of developing the first material for the prototype. However, when Parry read the final assignments, she was shocked to see that one had found the process very difficult but felt unable to raise this during the course. This student wrote that she has a disability, that she would have hated to be one of the people interviewed for the project, and that the activity went against her values by forcing her to put someone else under the kind of scrutiny she herself would avoid. She and Parry met to discuss these comments, and with permission, we include her remarks here.

This student considers her 'high-functioning depression' a disability. She has been frequently 'studied' by healthcare providers and those in training, especially psychologists, as she is able to function well in public but can be extremely depressed when alone at home. She found it difficult to tell her teacher about her reactions to the project proposal, as she felt she was the only person in the group struggling while classmates talked excitedly and appeared very motivated. She was also wary of discussing her depression as she has previously lost friends and relationships following such disclosures. She and her project partner did not work closely together, and although she tried to explain the reasons for her misgivings, her teammate did not seem to listen or recognise what she was saying. These issues were exacerbated because other students from the same class were bullying her by excluding her from group work in another course, and criticising her skill set.

This situation is not specific to a classroom setting but rather, highlights the challenges of transforming deeply entrenched attitudes within any context where there are likely to be participants who have been negatively affected by the same values the project is intended to revise. While some participants gained a new appreciation for the experiences of people with disabilities, this appreciation may remain confined to the specific people they met during the project, or encompass only their particular types of disabilities. Awareness of the invisible disabilities, especially within the students' own peer group, has been harder to address. Overall, a more fundamental shift, recognising the range of abilities and roles that exist throughout society, may not have occurred.

Conclusion: beyond inclusion

In our view, this is precisely the reason to keep engaging in such work. The goal should not be one moment of transformation but an ongoing range of activities, building the capacity of a broadening group of participants to work together. In the process, by encountering problems, the various stakeholders gain valuable experience, strategies, and confidence. This is unhelpful, however, if we fail to reflect on the potential harm caused in the process – by making assumptions about who should do these activities, or what they can contribute; by underestimating the range of approaches that can result in a successful outcome; and by expecting the process to be painless or problem-free. In the spirit of this edited collection, we have described some of the uncomfortable truths made apparent by this project, as a means to critically reflect on the realities of doing undervalued work in an imperfect world.

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