Archiving Dutch disability activism: what can digital culture do?

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07. ARCHIVING DUTCH DISABILITY ACTIVISM: WHAT CAN DIGITAL CULTURE DO?

ELINE POLLAERT & PAUL VAN TRIGT

Introduction

In 2022 *De Groene Amsterdammer* stated that the work of disability activists in the Netherlands is fragmented, faceless, and mostly forgotten.[1] Dutch anti-ableism activism is one of the most invisible forms of activism, struggling to achieve recognition comparable to that of feminist and anti-racist movements. No Netflix movies such as *Crip Camp* (2020) are created about the Dutch disability movement, although recent television series such as *Wheelchair Road Movie* (2019) and *Mari Stands Up* (2021) are starting to reach a broader audience.[2] Actually, the fact that the Netherlands has a rich history of disability activism since the 1970s (and even before) remains largely unknown and unacknowledged.[3] In this respect, digital culture holds great potential for the disclosure of historical disability activism and the activities of current day disability activists, but also comes with challenges because the accessibility of digital culture is not self-evident. The central question of this chapter is therefore: in what ways can digital culture play a role in archiving Dutch disability activism?

In this chapter, we use three case studies to reflect on current and past archival practices relating to disability activism in the Netherlands and the potentially transformative role of digital tools and networks for archiving disability activist practices. Before going into these case studies, we critically conceptualise dominant perceptions of activism in general and the implications they have for the recognition and visibility of disability activism. We then introduce our cases with specific attention to the role of 'the digital'. Firstly, we discuss the activities of the disability justice collective Feminists Against Ableism. We will demonstrate how they use digital tools for maintaining their networks and participating in activist initiatives. In particular, we consider the role of these tools and potential obstacles in archiving practices. Secondly, we consider how digital culture has been used to archive disability activism, showing how the website DisPLACE.nl has been used to address the exclusion of disability (activism) in Dutch archives and to stimulate heritage institutions to 'crip' their collections. Thirdly, we reflect on a community project with the Kreukelcollectief (Crinkle Collective) on eugenics. In this project, we have tried to connect different histories, collections, and types of activists to create an interface in which activists and archives could interact.

Just as 'the digital' has implications for archiving practices, so does our positionality as researchers writing this article. Therefore, we finish this introduction with a short description

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[1] Naïm Derbali, 'Men is tevreden met de kruimels', *De Groene Amsterdammer*, 13 August 2022, https://www.groene.nl/artikel/men-is-tevreden-met-de-kruimels

[2] 'Rolstoel Road Movie' website, https://www.npostart.nl/rolstoel-roadmovie/VPWON_1296793; 'Mari Staat Op' website, https://www.npostart.nl/mari-staat-op/VPWON_1321256

[3] Jan Troost, *Troost Over Leven; 50 jaar belangenbehartiging en ondeugd*, Amsterdam: Inclusie Verenigt, 2022.

of ourselves and our involvement with archiving disability history and activism. Eline Pollaert (they/she) is a disabled, neurodivergent and queer 32-year-old PhD student in disability history. In addition to their academic work, they are a member of Feminists Against Ableism and the Kreukelcollectief, combining research and activism as a public historian. Paul van Trigt (he/him) is a 43-year-old assistant professor, does not identify as disabled and is involved in public history collaborations with activists such as the Kreukelcollectief and DisPLACE.nl. We are both involved in the NWO research project 'Disability and Self-Governance: a Global Microhistory of Het Dorp Community and its Cultural Heritage from the 1960s' which started in 2022 at the Vrije Universiteit Amsterdam.[4]

Problematizing dominant perceptions of (disability) activism

On March 12, 1990, dozens of people with physical disabilities gathered at the foot of Capitol Hill in Washington D.C. Inside, Congress was discussing the passing of the Americans with Disabilities Act (ADA). Although the ADA was well on its way to becoming law, progress had been stalling and disabled people worried about the outcome of the vote. Suddenly, about 60 people in the crowd threw aside their mobility aids and spontaneously started crawling up the 78 marble Capitol steps. The activists wanted to draw attention to the physical and social obstacles they faced every day in the face of an inaccessible world, cheered on by others at the bottom of the stairs. Some got down on their hands and knees, others pulled themselves up by their arms, dragging their paralysed and atrophied legs upwards one step at a time. Videos and pictures of the crawlers spread far and wide, especially of the then 8-year old Jennifer Keelan wearing an ADAPT[5] bandana, telling ABC News: 'I'll take all night if I have to'. The day after, a smaller group returned, determined to start a sit-in inside the Capitol Rotunda. The Capitol police, dressed in full riot gear and unsure what to do, started dragging activists out after strapping them to their wheelchairs and using chain cutters to separate them. The protests had a major media impact and the ADA was passed shortly after.

Over 30 years later, the Capitol crawl still is an iconic image of disability activism.[6] The protest was bold, powerful and photogenic – people all over the country were taken aback by the images of the Capitol police restraining and forcibly removing peaceful disabled activists. In other words, this event lodged itself in the public mind because it was 'ready to remember'.[7] But at whose expense? What other activist initiatives get overlooked because they are less spectacular and hence less archivable? Although it is understandable that provocative and photogenic actions tend to etch themselves firmly in the public's mind, we argue that

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[4] Rethinking Disability project website, https://rethinkingdisability.net/projects/disability-self-governance/

[5] ADAPT (formerly American Disabled for Attendant Programs Today) is a United States grassroots disability rights organization with chapters in 30 states and Washington, D.C. They use nonviolent direct action in order to bring about disability justice.

[6] In the context of this chapter, we define disability activism as any initiative relating to anti-ableism and the advancement of disability liberation – be it individual or collective, in person or online, planned or spontaneous. We point here to the distinction between disability activism (in which nondisabled activists can also engage) and the involvement of disabled activists in other forms of activism which are not directly related to disability and anti-ableism. The scope of this chapter does not include the latter.

[7] Alexandra Juhasz, 'Forgetting ACT UP', *The Quarterly Journal of Speech* 98.1 (2012): 72.

conceptualising disability activism based on direct action initiatives actually obscures and excludes less visible and spectacular, but nevertheless equally important disability activism initiatives. Reiterating conceptions of 'classic' protests such as the Capitol crawl 1. excludes large numbers of disabled activists who are unable to attend in-person protests, 2. adds to the dismissal of online activism as inferior 'armchair activism' and 3. defines disability activism in terms of in-person protest, thereby enhancing its archivability (and in turn diminishing the archivability of other types of activism). The remainder of this section elaborates on these three consequential pitfalls.

Pitfall 1: Exclusion of disabled activists at in-person protests

The first pitfall of focusing on activism defined as in-person protests is the fact that those types of events are only accessible to certain body-minds (fig. 7.1.).[8] In-person protests not only require certain levels of physical strength, emotional self-regulation capacity, and sensory processing, but also financial resources and privilege (i.e. not being at risk for losing benefits, care, medical devices or citizenship when arrested). Marginalised people are even more at risk of experiencing violence and police brutality. Very few in-person protests take into account disabled body-minds and their access needs, let alone the realities of multiply marginalised disabled people. In practice, this excludes many disabled people who want to raise their voices in support or protest from participating in in-person activist initiatives.

Fig. 7.1. Zoomed-in photograph of a disability activist whose wheelchair is stuck in tram rails, during the Women's March on March 8, 2020 (Amsterdam, the Netherlands). The person is wearing a dark blue wheelchair blanket and is surrounded by other activist using mobility aids. Photographer: Rebekka Mell.

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[8] We follow Eli Clare's use of the term body-mind here: 'I followed the lead of many communities and spiritual traditions that recognize body and mind not as two entities but as one, resisting the dualism built into white Western culture… I settled on *body-mind* in order to recognize both the inextricable relationships between our bodies and our minds and the ways in which the ideology of cure operates as if the two are distinct – the mind superior over the body, the mind defining personhood, the mind separating humans from nonhumans'. Eli Clare, *Brilliant Imperfection: Grappling with Cure*, Durham: Duke University Press, 2017, xvi-xvii. See for instance Annemarie Mol's work on the body for an attempt within the west to rethink (and redo) body-mind relations: Annemarie Mol, *The Body Multiple. Ontology in Medical Practice*, Durham: Duke University Press, 2002.

Johanna Hedva, a Korean American contemporary artist, writer and musician, lives with a chronic condition that regularly incapacitates them for months at a time. They live in a predominantly Latino neighbourhood in Los Angeles, which is often an active place of protest. In their essay ‘Sick Women Theory’, they describe their experience with the Black Lives Matter protests in a nearby park in 2014 and they were unable to join due to their health:

> I listened to the sounds of the marches as they drifted up to my window. Attached to the bed, I rose up my sick woman fist, in solidarity. […] So, as I lay there, unable to march, hold up a sign, shout a slogan that would be heard, or be visible in any traditional capacity as a political being, the central question of Sick Woman Theory formed: How do you throw a brick through the window of a bank if you can’t get out of bed?[9]

Are you less of an activist if your health does not permit you to physically attend protests and rallies? Does your body-mind matter less politically if your access needs are not met by the majority of activist initiatives? If most activist groups do not even consider ableism and disabled perspectives in their work in the first place? If the few disability advocates that are being invited into broader activist initiatives are so often white, educated, straight, and middle-class? Hedva’s response is a resounding no. Instead, they offer a radical shift of perspective:

> Sick Woman Theory is for those who are faced with their vulnerability and unbearable fragility, every day, and so have to fight for their experience to be not only honored, but first made visible. For those who, in Audre Lorde’s words, were never meant to survive: because this world was built against their survival. It’s for my fellow spoonies,[10] my fellow sick and crip crew. You know who you are, even if you’ve not been attached to a diagnosis: *one of the aims of Sick Woman Theory is to resist the notion that one needs to be legitimated by an institution,* so that they can try to fix you according to their terms. You don’t need to be fixed, my queens – it’s the world that needs the fixing [emphasis added, EP].[11]

Pitfall 2: Dismissal of online and hybrid activism

As a consequence of inaccessible in-person protests, many disabled activists turn to online activism. Since it became available to the public in 1991, the internet has greatly impacted

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[9] Johanna Hedva, ‘Sick Woman Theory’, *Mask Magazine*, 19 January 2016, 1 and 5, https://pocatech.org/sites/default/files/digital_resources/Sick%20Woman%20Theory_0.pdf

[10] Christine Miserandino came up with the spoon theory in 2003 while sitting in a restaurant, wanting to explain to a friend her experiences with Lupus. She used the spoons on the table as a metaphor for the limited amount of energy chronically ill and disabled people have. Compared to nondisabled people, everyday acts such as washing oneself or cooking take more spoons, forcing disabled people to meticulously plan their activities. Since then, ‘spoonie’ has become a term of endearment amongst disabled and chronically ill people. Christine Miserandino, ‘The Spoon Theory written by Christine Miserandino’, *But You Don’t Look Sick*, https://butyoudontlooksick.com/articles/written-by- christine/the-spoon-theory/, 2003.

[11] Hedva, ‘Sick Women Theory’, 8–9.

organisers and activists in general. Maintaining (international) networks, organising activities and sharing knowledge became much easier with the rise of websites, social media, and video conferencing tools. Disability activism, and disabled activists in particular, profited from the low-threshold and accessible possibilities that the internet opened up, because online options allow people to (partially) bypass physical, emotional and cognitive constraints to participation in in-person activism. However, attitudes towards digital activism have not always been positive. Activist groups, and also society in general, used to in-person organising have dismissed online and hybrid activism as inferior, not the 'real deal' or armchair activism/'slacktivism' (referring to people talking about social justice issues online but not taking concrete action).[12]

The limitations of in-person activism became apparent all of a sudden when the coronavirus pandemic hit. Almost one third of the world population found themselves in lockdown, unable to carry on with life as we knew it. For most people, this meant a radical shift in terms of work, social life and pastime activities. Apart from key workers, most of us became more or less housebound – just like many chronically ill and disabled people have been for months, years or even decades. One crucial difference, however, was that those who had been living house-bound or even bed-bound before had all kinds of strategies and mechanisms in place to manage their daily activities and needs. While nondisabled people were scrambling up the walls in boredom, panic and frustration, the disabled community relied on online tools and communities that often had been years in the making.[13] All at once, online activism became the new normal for everyone: individuals, grassroots activist communities and even NGO campaigns.[14] Ironically, disabled activists did not receive credit for sharing their experience and knowledge of digital organizing. In fact, an onslaught of online discussions erupted, questioning the value of the lives of so-called 'vulnerable' people.[15] Many disability activists felt that not only their way of organising was dismissed, but that their online activism strategies and cultures were appropriated by nondisabled organisers.[16]

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[12] Nolan L. Cabrera, Cheryl E. Matias and Roberto Montoya, 'Activism or Slacktivism? The Potential and Pitfalls of Social Media in Contemporary Student Activism', *Journal of Diversity in Higher Education* 10.4 (2017): 400–415. See also Kai Doran 'The Problem with Armchair Activism', *The M-A Chronicle,* 12 June 2021, https://www.machronicle.com/the-problem-with-armchair-activism/; Muhammad Jazli Adam, 'Armchair Activism: Social Media during Social Unrest', *UKEC*, 18 June 2020, https://www.ukeconline.com/armchair-activism/

[13] Kerry Dobransky and Eszter Hargittai, 'Piercing the Pandemic Social Bubble: Disability and Social Media Use About COVID-19', *The American Behavioral Scientist* 65.12 (2021): 1698–1720.

[14] Megan Elias, 'Armchair Activism: How Social Media Changed the Way We Make Change', *The Current*, Winter Issue (2020–2021): 38–42.

[15] Andrew Pulrang, 'What Disabled People Are Thinking and Feeling About The Pandemic, One Year Later', *Forbes*, 21 March 2021, https://www.forbes.com/sites/andrewpulrang/2021/03/21/what-disabled-people-are-thinking-and-feeling-about-the-pandemic-one-year-later/?sh=511604113277.

[16] Covid-19: Appropriation of disability culture & movements, Asian American Arts Alliance (AAARTS), 10 May 2022, https://www.aaartsalliance.org/events/covid-19-appropriation-of-disability-culture-movements

Pitfall 3: Domination of in-person protests when it comes to archiving

So far, we have concluded that in-person protests are often inaccessible and that online or hybrid initiatives from disabled organisers regularly have been dismissed for being ‘slacktivism’. This plays into a third pitfall: because in-person protests are continuously presented as actual activism, they become dominant in representation because they are perceived to be more archivable. Focusing on photogenic protests and charismatic leaders shifts the focus away from less public, popular, and visible forms of activism. Think for example of lobby activities, community work, and research projects. Although explicit in-person protest initiatives are sometimes highly effective in gaining public traction for certain topics, ‘behind the scenes activism’ is just as important to achieve social justice. However, this kind of activism is considered to be less archivable, adding another layer to the exclusion of disability activism and disability activists from archives. The invisibility of ‘soft activism’ applies to all types of activism, of course. Because disabled people in the Netherlands tend to be viewed as in need of (medical) support instead of civil rights and emancipation. Therefore, they are more often forced to move in policy and law contexts compared to other marginalised groups.

In addition, we might ask ourselves who is considered archivable enough to be remembered as a charismatic disability activist and why. Curator Katherine Ott of the National Museum of American History remarked that highlighting disability rights movement figureheads such as Ed Roberts, who started the Center for Independent Living in Berkeley in 1972, overlooks many others who were instrumental to the movement. One practical obstacle in the way of crediting all individual disability rights activists is a lack of (personal) objects relating to these persons and their activist activities, which could be used to showcase them in a museum exhibit. More importantly, she points out that the main takeaway should be that the disability rights movement ‘. . . was a grassroots movement and it was people inspiring each other all over the place’.[17] We have to ask ourselves what kind of socio-cultural biases affect the representation and archivability of dominating figureheads (who are often white, male, and middle-class) compared to others involved in disability activism.[18]

In the Dutch context, a critical engagement with dominant cultural and archival perceptions of disability activism is necessary. It is noteworthy that the archiving of social movements in the Netherlands is quite well developed in terms of dedicated archives related to women’s rights, queer emancipation, and the civil rights movement of Black Dutch people.[19] The International Institute of Social History (IISH), located in Amsterdam, is even dedicated to the preservation of often oppressed social movements.[20] However, no formal Dutch archives relating to disability history exist. Prior attempts to deposit private disability activism collections in the ISSH and secure their future as archives within the IISH were turned down, because disability was viewed

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[17] David Serlin, ‘Making Disability Public: An Interview with Katherine Ott’, *Radical History Review* 94 (2006): 205.

[18] Juhasz, ‘Forgetting ACT UP’: 72.

[19] Institute on gender equality and women's history, https://institute-genderequality.org/; IHLIA LGBTI Heritage, https://ihlia.nl/en/; The Black Archives. https://www.theblackarchives.nl/home.html

[20] Mission statement, International Institute of Social History, https://iisg.amsterdam/en/about/mission

as a medical topic rather than a social history topic; thus not archivable. Digital culture has the potential to crack open this impasse on several levels. The following case studies trace various roles digital culture might play in archiving disability activism, including potential challenges.

Digital disability activism and archiving practices

With these general critical remarks about (disability) activism in mind, we will now take a closer look at digital culture in relation to archiving Dutch disability activism. Due to the sometimes ephemeral nature of sources, coalitions and initiatives, digital activism poses challenges to historians and archivists of activism.[21] This rings especially true for disability activism in the Netherlands, as grassroots disability activists tend to engage with issue-centred initiatives in a fragmented way (rather than in long-term, overarching collaborations). In addition, disabled activists oftentimes have limited time, energy and resources at their disposal. This significantly increases the risk of activist overwhelm or even burnout, causing short(er)-lived activist engagement. With regard to the latter, digital and online realms offer much needed tools and accommodations to 'crip' disability activism. In this section, we present three cases of disability activism in the Netherlands today (partly) relying on digital and online tools. We argue that the conceptualisation of activism is enhanced by taking digital activism into account in addition to in-person activism. We also use the three case studies to investigate various ways in which digital culture can aid in archiving disability activist practices.

Case study 1: Disability justice collective Feminists Against Ableism

When a number of disabled activists found each other online in 2018, they started a Facebook group. Their aim was to draw attention to ableism – the interpersonal and systemic exclusion of disabled, chronically ill and neurodivergent folks. The Facebook group offered an increasing number of people the opportunity to share their stories and experiences with day-to-day ableism. A small core group of activists banded together, noticing that mainstream activist initiatives did not take ableism into account or think about the accessibility of their events. This core group then decided to start the disability justice collective Feminists Against Ableism (FAA hereafter).[22] Their first achievement was taking part in the national Dutch Women's March in Amsterdam in 2019. Disability activist Annika Mell gave a speech and the collective headed the march through the city centre. In addition, FAA organised the Online Disability March for those who were too tired, sick, or disabled to attend the in-person protest. Inspired by the January 21, 2017 Disability March, which flanked the Women's March on Washington they

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[21] Lisa Lindström, *Archiving in the Era of Online Activism: Challenges and Practices of Collecting and Providing Access to Activist Social Media Archives,* MA thesis, Lund University 2019, https://www.lunduniversity.lu.se/lup/publication/8980793

[22] The disability justice movement emerged from the mainstream disability rights movement in 2006, specifically from and for disabled queer of colour communities. The framework was conceived by Patty Berne, Mia Mingus, Stacey Milburn, Leroy F. Moore and Eli Clare. Shayda Kafai, *Crip Kinship*, Vancouver: Arsenal Pulp Press, 2021, 22; Patty Berne, 'Disability Justice – A Working Draft by Patty Berne', *Sinsinvalid*, 10 June 2015, https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne

asked people to share their story of why they were unable to attend, including a picture of themselves.[23] In their entries, participants in the online disability march indicated that both their health and the inaccessibility of the Women's March prevented them from being there. They also called attention to other obstacles disabled people face, such as lack of medical research, stereotypes and additional exclusion based on gender, ethnicity and socio-economic class.[24] Between 2019 and 2021, FAA was a regular at the Dutch Women's March stage (fig. 7.2.). Currently, FAA consists of around 15 core members of varying ages, ethnicities, genders and sexual orientations, all identifying as disabled, chronically ill and/or neurodivergent. The collective focuses on organising (online) events, advising organisations about anti-ableism and accessibility, speaking during demonstrations and meetings and creating social media content.

Fig. 7.2. Photograph of two members of disability justice collective Feminists Against Ableism, during the Women's March on March 8, 2020 (Amsterdam, the Netherlands). Jeanette Chedda (left) is a 30-something brown woman wearing a black hoodie, a yellow scarf and a green jacket. She is holding hands with Mira Thompson (right), a 20-something white woman wearing a green scarf and a brown jacket. They are surrounded by protest signs and smile broadly at the camera. Photographer: Rebekka Mell.

How does FAA go about online and hybrid activist practices? In terms of building and maintaining its networks, the collective organises itself *exclusively* online. The members' communication switched from a Facebook group to a WhatsApp group to Slack and Discord servers. Although FAA is a relatively small collective with only 15 members, only some of them have met each other in person. The members have never been in the same space collectively. Both

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[23] Disability March, https://disabilitymarch.com/

[24] Online Disability March 2019 stories, https://feministsagainstableism.nl/categorie/online-disability-march/verhalen-2019/

their internal and external connections take place almost exclusively in the online and digital realm, even prior to the coronavirus pandemic. The collective also works in a hybrid manner, for example with one or two people co-writing a speech in a shared online document and a third person reading it out loud at a protest march. This does not seem to hinder the growth of their following; more and more individuals and organisations approach them for requests. The activities that FAA (co-)organises often have an online or hybrid character as well. These workshops, protests and events are livestreamed for free when possible, including speech-to-text interpretation to provide access to those for whom auditory information is inaccessible.

FAA in no small part depends on digital and online tools for its anti-ableism activism. This also enables the collective to archive its own work, independent of formal archives. The aforementioned Online Disability March submissions are archived on a dedicated part of the FAA website, for example. The collective has chronicled its own history on their website as well, in addition to an overview of various types of resources featuring contributions by collective members (speeches, news articles, podcasts, etc.) and event recordings.[25] Despite offering a rich overview of its activities, FAA's online archive is incomplete. Although the collective is firmly rooted in digital culture, this does not automatically result in consistent online archiving practices. Several factors play into this. First, the composition of the collective has changed a lot over the years. Founding members left and new members joined, but administrative rights to the collective's online platforms have not always been passed on or shared. That leaves some previously used digital platforms unreachable to current members. Second, structured and consistent archiving practices require a level of expertise that the collective members do not have at their disposal. This includes knowledge regarding the accessibility of archiving services, both for the makers and users of the archives. In order to create a proper archive, ideally one or two collective members would dedicate themselves to crafting a durable archival structure. This ties in with the third factor, namely that the collective must choose wisely in what activities to invest its limited time, resources, and energy. Priority is often given to urgent, immediate matters that have a more direct or noticeable impact. This factor is compounded by the fact that not all 15 members are able to invest in the collective together at the same time due to their health and personal situations, which impacts the collective's load capacity as a whole. Choices must be made and archiving is not a top priority. In other words, disability activism does not only suffer from archival disinterest, but disability activists are not always interested in archiving their work either for a variety of reasons.

Looking at the Feminists Against Ableism case study, it becomes clear that digital culture is crucial in facilitating their disability activist activities. It also grants the collective agency to independently archive its work, despite various obstacles in terms of member composition, knowledge, resources and prioritisation interfering with the collective's archival consistency. In summary, the first role digital culture might play in archiving disability activism is one of *facilitation*.

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[25] Formation of Feminists Against Ableism, https://feministsagainstableism.nl/over-faa/ontstaan-van-faa/

Case study 2: DisPLACE

Archiving has not always been the first priority of activists who tend to focus more on their immediate goals for social change, as we have seen in the previous case study. However, some Dutch disability activists have long been aware of the importance of the past for their activism – and consequently the relevance of archiving practices. Before academics started to write about the history of Dutch disability activism, activists Jan Troost and Agnes van Wijnen already undertook digital initiatives to document the achievements of disabled self-advocates: they launched websites on which they presented a Dutch disability history timeline, bits and pieces of this history, and oral history interviews.[26] These websites were not primarily focused on preserving their individual activism, as is the case with Feminists Against Ableism, but rather on offering a broad overview of disability history and activism in the Netherlands. A website was the ideal medium because of the relatively low costs, potentially broad reach, and the possibility of adding unlimited information. In addition to their digital work, activists Troost and Van Wijnen also maintained non-digital archives and even took over parts of other archives in order to prevent relevant material from being thrown away. In fact, they turned to 'the digital' because it was not self-evident that official archives would include disability activism. Because Dutch disability activism has often been considered as non-existent, archival institutions such as the IISH have not acquired relevant collections in contrast with collected sources from more well-known activist groups such as from workers and anticolonial movements.[27] Disclosure thus was an important function of Troost's and Van Wijnen's websites.

When author Van Trigt became interested in the history of Dutch disability activism and aware of the existence of archives at people's homes or in poor condition at organizations, together with Deaf historian and self-advocate Corrie Tijsseling, and public historian Manon Parry, he started the BIB Netwerk (Bronnen voor Inclusieve Burgerschap, meaning 'Sources for Inclusive Citizenship'), to stimulate the collection and interpretation of disability histories.[28] Once again digital culture was used by the initiators to call attention to the history of disability activism in the first place. They secured a small grant which enabled them to build a website, designed by a digital heritage company with guidance from self-advocates, which was launched on March 20, 2019: DisPLACE.nl (fig. 7.3.).[29] This website was different from earlier initiatives because it has not only presented stories from the perspective of disabled people, but also documented these stories with information and illustrations from personal archives and heritage institutions. Each year, students work with volunteers from the BIB Netwerk to produce histories around a specific theme. In this way, DisPLACE is 'cripping' collections: the

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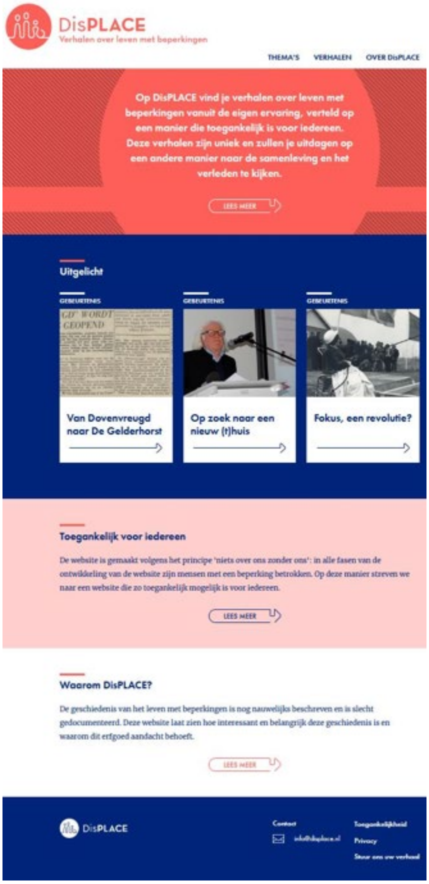
[26] Gehandicapten Schrijven Geschiedenis, https://gehandicaptenschrijvengeschiedenis.nl; Aparticipatie, https://aparticipatie.nl

[27] A notable exception to this rule is the Dutch queer archive IHLIA (Internationaal Homo/Lesbisch Informatiecentrum en Archief), which dedicates a part of their archive to the intersection of queerness and disability.

[28] Corrie Tijsseling, https://corrietijsseling.nl/; Manon Parry, www.uva.nl/en/profile/p/a/m.s.parry/m.s.parry.html

[29] Manon S. Parry, Corrie Tijsseling and Paul van Trigt, 'Slow, Uncomfortable and Badly Paid. DisPLACE and the Benefits of Disability History' in Adele Chynoweth, Bernadette Lynch, Klaus Petersen and Sarah Smed (eds), *Museums and Social Change*, London-New York: Routledge, 2020, 149–159.

website has pointed to the existence of disability in existing heritage collections, has provided these collections with a new interpretation and has presented new, often personal source material that complements official archives. Although the focus of DisPLACE is broader than activism only, it has made the history of Dutch disability activism more visible and has also contributed to its digital archiving. Moreover, the website was designed with disabled people in order to make it as accessible as possible for people with different disabilities.



Op DisPLACE vind je verhalen over leven met beperkingen vanuit de eigen ervaring, verteld op een manier die toegankelijk is voor iedereen. Deze verhalen zijn uniek en zullen je uitdagen op een andere manier naar de samenleving en het verleden te kijken.

Toegankelijk voor iedereen

De website is gemaakt volgens het principe 'niets over ons zonder ons': in alle fasen van de ontwikkeling van de website zijn mensen met een beperking betrokken. Op deze manier streven we naar een website die zo toegankelijk mogelijk is voor iedereen.

Waarom DisPLACE?

De geschiedenis van het leven met beperkingen is nog nauwelijks beschreven en is slecht gedocumenteerd. Deze website laat zien hoe interessant en belangrijk deze geschiedenis is en waarom dit erfgoed aandacht behoeft.

Fig. 7.3. Screenshot of the DisPLACE website. The DisPLACE logo at the top is followed by a short description of the website, three highlighted posts, a section on accessibility and co-creation, DisPLACE's mission and finally the colophon. Screenshot taken on July 18, 2023.

DisPLACE has generally been received well by historians and self-advocates: during the launch of the website for instance, the initiative was praised by the chair of the main Dutch Association of Historians and by an activist employed by the main Dutch self-advocacy organisation Ieder(in). However, it has turned out to be a challenge to maintain the DisPLACE website and further improve it by adding new stories and materials. This is a matter of time and money, in particular because maintaining the accessibility of the website requires extra investment. Despite these practical obstacles, the DisPLACE case study draws attention to the potential that digital culture holds for disclosing Dutch disability history and activism at large. In summary, the second role digital culture might play in archiving disability activism is offering an *interface*, deliberately connecting archival and historical materials to a broad audience of non-historians.

Case study 3: Digital community project on eugenic histories

As has become clear from the previous case studies, we do not consider digital culture to be an active agent, neither do we see it as a simple tool for archiving activism that leaves archives and (disability) activism unchanged. The digital realm presents challenges and offers opportunities, holding potential for rethinking and innovating archival practices. In fact, we have initiated a project that explores the potential of digital culture to archive disability activism in a way that leads to new collections and new insights into past and present. A couple of years ago, we were approached by the D4D research team from the UK that wanted to bring together people from the UK, the Netherlands and Germany in order to explore the complex and troubling issue of eugenics and the impact that 'eugenic logic' imposed on disabled communities in both the past and the present. Because the pandemic made an international gathering impossible, we were asked to organize a Dutch event that would result in audio-visual material for the D4D website or even a virtual museum. We decided to make use of an already existing Dutch network and of an exhibition idea when we responded to the request from D4D and to use this project as a new step in archiving activism.[30]

Together with the so-called Kreukelcollectief (Crinkle Collective, consisting of disabled activists, artists and academics) we approached Dutch eugenics from the perspective of the Second World War and prenatal screening. We selected five stories and objects related to eugenics, including photographs, clothing, and videos, partially based on a forthcoming Kreukelcollectief exhibition called 'Places of Pride and Sorrow'.[31] The stories and objects were presented to the participants as the starting point of the workshop. The first story concerned the biographies of three inhabitants of the Willem Arntsz Hoeve, a psychiatric facility in Den Dolder where many patients died due to neglect and starvation during and right after World War II.[32] The second story presented the memorial that was revealed at the Willem Arntsz Hoeve in 2016, as an acknowledgement of these events.[33] The third object was a worn-out

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[30] Brave New World exhibition, https://d4d.org.uk/workstreams/brave-new-world/brave-new-world-exhibition/

[31] The title of the exhibition refers to the 1996 landmark book *Pride and Sorrow: Disabled in the Netherlands*, which was the first Dutch publication on disability written by disabled people themselves. Yolan Koster-Dreese and Agnes van Wijnen (eds), *Trots en treurnis: gehandicapt in Nederland*, Amsterdam: Singel Uitgevers, 1996.

[32] Marco Gietema and Cecile aan de Stegge, *Vergeten slachtoffers. Psychiatrische inrichting De Willem Arntsz Hoeve in de Tweede Wereldoorlog,* Amsterdam: Boom uitgevers, 2016. The outcomes of a larger follow-up research project investigating multiple psychiatric institutions will be presented in the fall of 2023: 'Mental institutions under pressure', https://www.niod.nl/en/projects/mental-institutions-under-pressure.

[33] VGN, 'Gedenkteken voor vergeten oorlogsslachtoffers Willem Arntsz Hoeve', https://www.vgn.nl/nieuws/gedenkteken-voor-vergeten-oorlogsslachtoffers-willem-arntsz-hoeve

T-shirt from the 1990s depicting a DNA helix centred in a bulls' eye, with the phrase 'FAIR GAME?' underneath (see fig. 7.4.). This T-shirt had been worn during protests against the increasing prenatal screening for disabilities in foetuses. The fourth story was a recorded fragment of a 1995 satirical play entitled 'The Museum 2040' about a museum in a dystopian future where disabled people are exhibited, having gone extinct due to prenatal screening.[34] The fifth and final story was a snippet of the 2000 documentary *Dead End*, chronicling the life and death of the Dutch Jewish and disabled accountant and teacher Alexander Katan.[35] These five stories and objects were used not only to discuss eugenics with the workshop participants, but also to address ways to unlearn eugenics and to explore the 'otherwise' .[36]

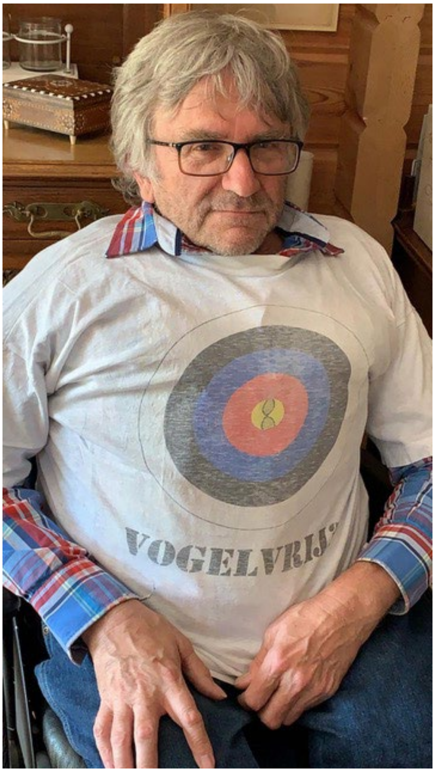

Fig. 7.4. Photograph of late disability activist Jan Troost in 2021, wearing a worn-out white T-shirt depicting a DNA helix centred in a bulls' eye, with the phrase 'FAIR GAME?' underneath. Jan Troost is a white man in his 60s wearing glasses, gazing straight into the camera. Photographer: Paula Boek.

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[34] Jan Troost, 'Theater Aaibaarheidsfactor10: Het Museum in 2030 over genetische defecten en hun hulpmiddelen', *Troost Over Leven*, 22 February 2014, https://troostoverleven.nl/2014/02/theater-aaibaarheidsfactor10-het-museum-in-2030-over-genetische-defecten-en-hun-hulpmiddelen/

[35] Netherlands Film Commission, 'Dood spoor?', https://filmcommission.nl/database/production/dood-spoor-3/

[36] Dagmar Herzog, *Unlearning Eugenics. Sexuality, Reproduction, and Disability in Post-Nazi Europe*, Madison: University of Wisconsin Press, 2018.

In two virtual workshops which took place in 2021, we brought together 13 participants who self-identify as disabled and/or neurodivergent, with lived experiences of disability. During the first workshop a series of objects and documents related to the five cases was presented by members of the Kreukelcollectief to the participants as a starting point for discussion and questions: how might they re-interpret these objects? Which of the materials do they feel are most significant and tell the most powerful stories? Have they got ideas for alternative materials that they would like to see included? For the second workshop, then, we asked the participants to respond to the cases and materials presented and to use creative methods for their response, such as collage, creative writing, theatre performance and song. The workshops were recorded in an unobtrusive way, in order to use fragments for the D4D website about eugenics.

The five starting objects/stories presented during the first workshop were not all produced by activists, but were nevertheless (re)appropriated by them as relevant for their self-understanding as disability activists. This (re)appropriation was possible thanks to the digital availability of historical materials and the fact that they could be made easily accessible through digital tools. The workshops also provided insight in the different ways in which people do (or do not) relate to the past and the implications of this for archiving practices. The workshops as accessible online events made connections possible between activists from different backgrounds and generations. They facilitated a dialogue about these connections: we brought people together by inviting them to the workshop, but this does not mean that their histories are connected or that they experience them as such. It is important to articulate these dynamics, because they make us aware of the politics of archiving. What has to be archived, how, by whom, where and why? Due to the set-up of the workshops, they also resulted in new input for activist archives (fig. 7.5.). Because we asked the participants to respond, they not only produced new archival materials, but they also shared contemporary stories with urgent archival relevance. People told for instance how they were threatened in the recent past with clear references to what the Nazis did to disabled people before and during World War II. This is surprising, given that hardly attention is paid to this aspect of the war in Dutch public remembrance culture. Such stories are relevant to store. The belated appearance into circulation shows that archiving activism is an endless and urgent endeavour.

Fig. 7.5. Photograph of a collage-painting made by Jacqueline Kool. Religious and archival images connected to life and death are placed in a tangle of tree roots, framed by a banner with the text 'Life... Oh... Life'. Multimedia (paper, acrylic paint, flowers from Alchemilla Vulgaris (lady's mantle), plastic). Photograph: Jacqueline Kool.

The presentation of the project on the D4D website is still in progress, but the workshops already showed how this digital format could serve the archiving of disability activism. The workshops enabled the activists to show materials from their personal collections and to share acquired knowledge about disability history with peers. This allowed them to exchange knowledge across disabilities, generations and activist practices. As such, it was in line with the aims of digital archival activist projects such as DisPLACE. Moreover, the D4D case study suggests that digital culture might play a role as a *generative hub* in archiving disability activism. As we concluded earlier, DisPLACE already functions as an interface by connecting public and private collections and by disclosing activism and activist archives. The D4D project then adds an extra layer of functionality to digital culture, by purposely generating interactions between activists and archives and thereby creating new networks and archival materials.

Conclusion

Circling back to the main question: In what ways can digital culture play a role in archiving disability activism and what kind of challenges may arise in this process?

We started this chapter with a few reflections on dominant perceptions of activism in general, in order to position disability activism in relation to other forms of activism. Generally speaking, activism is conceptualised in terms of direct action and hands-on initiatives, usually disruptive in character. As a result of this 'classic' activism blueprint, 1. large numbers of disability activists who are unable to attend in-person protests are excluded, 2. online activism is dismissed as inferior 'armchair activism', and 3. the direct action blueprint leads to the obscuring and even exclusion of less visible and less spectacular disability activist initiatives. A focus on 'classic' conceptualisations of activism leaves disability activism at risk of being perceived as inferior or less effective. This in turn may lead to disability activism being perceived as less archivable, leading to a lack of interest in the history of disability activism on the part both of archivists and of disability activists.

The three case studies we presented suggest that the digital offers opportunities as well as challenges when it comes to archiving Dutch disability activism. Digital and online tools impact both archiving practices and disability activism. In terms of opportunities, these tools offer new venues to make possible partnerships and collaborations between disability activists and others, especially when they are faced with health constraints. Furthermore, digital and online tools facilitate the collection of existing disability activism materials and stories, but also their presentation to the public. These tools also present disability activists with opportunities to produce new archival materials and (re)connect across backgrounds and generations. The three case studies illustrated three potential roles digital culture can play with regard to archiving disability activism: 1. *facilitating* activist and self-archiving activities; 2. providing an active *interface* that connects archival materials to broader audiences; and 3. constituting a *generative hub* that actively stimulates the creation of new archival materials and activist networks.

In terms of obstacles, the three case studies made clear that digital culture is not a 'quick fix' for archival disinterest in disability activism and vice versa. Setting up structured and consistent archives takes time, resources, and knowledge that may not be readily available or a priority to disability activists. Additionally, collecting and sharing archival materials in such a way that is accessible and available in both the short and the long term, requires significant resources which may not always be readily available. An important requirement for advancing the collection and archiving of disability activist histories is thus an equitable collaboration between archivists and activists, in order to alert one another to potential oversights and shortcomings and to strengthen the impact of each other's work.

In conclusion, we think it is undeniable that digital culture has the potential to archive disability activism in a way that leads to new insights into past and present. Formal archives continue to exclude disability history from their collections, especially in the Netherlands. Digital and online platforms offer grassroot activists tools to collect and share their private collections with other (disability) activists and the public, thereby connecting stories and insights which remained fragmented earlier. This may also lead to the production of new archival stories, collections, and materials. However, disability activists must have resources at their disposal to actually be able to develop and sustain their own archives in an accessible way. Taking care of one's communities is a form of participatory heritage activism; archiving can be an act of activism in itself. Both private and formal archival institutions can and should profit from this development, especially when it comes to the acknowledgement of disability activism as an integral part of social movements and history. A critical rethinking of and (re)connection to archiving disability activism is needed for the integration of digital archival activist projects into formal archives. Together we must design ways for heritage institutions to learn from the working methods of disabled (archival) activists and from the way they design access. Otherwise, disabled people and their histories will continue to be shut out of traditional archives as both subjects and researchers.

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