

Toilet Signs as Border Markers

Exploring Disabled People's Access to Space

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ABSTRACT

Signs prescribing our permission to enter or abstain from specific places, such as those on toilet doors, mark murky borders between quasi-public and private space and have profound impacts upon our lives and identities. In this paper we draw on research which centred trans, queer and disabled people's experiences of toilet in/exclusion to explore how the signs on toilet doors shape disabled people's experiences of toilet access away from home and therefore their use of public space more broadly. We argue that the use of the International Symbol of Access (ISA) both delivers a false promise of accessibility and maintains the borders of disability through (re)enforcing a particular public imaginary of disability. We note the forced reliance on toilets in institutional and commercial settings when away from home and argue that, under capitalism, accessibility is persistently restricted by its potential to be lucrative.

KEYWORDS

accessibility; disability; bathroom; restroom; capitalism; public imaginary; charity; non-apparent impairment; invisible impairment

I. Introduction

Considering our orientation to objects, Ahmed (2006, p.31) notes that '[s]ome things are relegated to the background in order to sustain a certain direction'. Toilets outside of the home are one such thing. Despite being something that everybody needs to use and completely necessary for other activities to take place (e.g. work, socialising, travel), they are often considered too mundane or taboo to be discussed and are rarely prioritised in design processes (Slater and Jones, 2018) Ahmed (2006, p.48) writes that objects become those which 'we attend to, or are concerned with' when they fail. Lisney (in Jones et al., 2020, p.227), a disabled

woman, affirms Ahmed's statement, explaining that when she's with disabled women friends, accessible toilets are regularly the focus of their discussion. She reflects that this 'is often disconcerting for non-disabled friends in the group, especially for those who do not understand how that can be a worthy conversational topic, but for us it is a very important access requirement.' Lisney highlights that toilets are designed with certain bodies in mind. Thus, toileting habitus forms a 'largely invisible process of socialisation' (Dimpfl and Moran, 2014, p.721), whereby silence, trivialisation and dismissal is a position only beneficial to those who are already accommodated by current provisions.

In this paper we explore how signs on toilet doors mediate access to (and perceptions of eligibility of access to) toilet spaces for disabled people. To make our argument, we draw on a series of research projects collectively known as *Around the Toilet* (AtT – <http://aroundthetoilet.com>). Since 2015, AtT has used a range of arts-based and interdisciplinary methods to explore toilet accessibility. Within capitalism, where profit is prioritised over equity and justice, accessibility requirements usually rest upon meeting the minimum standards set out (and often hard fought for) in law (Piepzna-Samarasinha, 2018). Making environments accessible is therefore reduced to 'accommodations' or 'reasonable adjustments' made for individual disabled people on a case-by-case basis (Boys, 2014; Dolmage, 2017; Titchkosky, 2011). AtT used the toilet as a familiar 'grounding space' from which we were able to broaden and deepen understandings of accessibility. We were and remain, interested in the questions posed by Titchkosky (2011, p.3): 'What if access is much more than an individual state of affairs? What if access is much more than a substantial, measurable entity? What if it is more like a way of judging or perceiving?' From the toilet, we have considered embodied relations between identity and the built environment and explored how space shapes whose lives are made possible and liveable (Jones and Slater, 2020; Pearce et al., 2019). We have spoken about categorisation, our understandings of self and of each other and the worth that contemporary capitalist societies place on some bodies and ways of being over others.

The project was inspired by the work of Alison Kafer (2013), who makes clear the political nature of toilets. Kafer suggests that because many people are prevented from accessing the toilet, these facilities are a fruitful place to bring together different political movements and help us to think about 'what accessible futures may look like' (p.149). Following Kafer, AtT uses the toilet to find points of coalition and divergence between queer, trans and disability movements by centring the experiences of queer, trans and disabled people in conversations of toilet accessibility. Situating the toilet at the fringes of disability, queer, trans and feminist studies and activism allows us to think about accessibility with, but also beyond, the experiences of disabled people whilst acknowledging the obvious (but often overlooked) issue that disabled people live heterogeneous lives at the intersections of many identity categories and/or axes of oppression.

We write this paper following 10 years of austerity across Europe and North America, which continues to ‘harm the social infrastructures of coexistence’ (Shaw, 2019, p.973). Austerity has both dramatically reduced the number of publicly owned toilets – creating an increased reliance on private business provision (Slater and Jones, 2018) – and has had severely detrimental impacts on disabled people, leading to poverty, isolation and death (Ryan, 2019). By focusing on disabled people’s access to toilets – the ‘matter of everyday life’ (Blumenthal, 2014, p.191) – this paper follows Penny’s (2020, p.928) call for ‘grounded explorations of how austere political dynamics are locally “encountered”, rolled-out, negotiated and resisted’. Whilst the relationship between a lack of toilet access, privatisation and austerity policies has received some recent attention and critical analysis in the media (Hatherley, 2019; Newton, 2021), there is little in the way of theorisation within academic literature. In this paper, we therefore add to this limited body of work.

We focus particularly on toilet *signs*, firstly, because signs have continually emerged as a theme and focus of discussion during data collection. Signs are ‘indicators [. . .] giving information, [and] directing us to the required and the expected’ (Titchkosky, 2011, p.65) and signs orientate us (Ahmed, 2006), ‘represent[ing] a world of meanings in a single image’ (Ben-Moshe and Powell, 2007, p.490). We argue that signs function as borders – or ‘markers of belonging’ (Brambilla and Jones, 2020, p.289) – by drawing lines between who is and is not welcome. The familiarity and working of signs allow us to enter a toilet door with particular expectations of both what and who will be behind it. It is expected that our understanding of a sign is widely shared and indisputable. We will argue that the International Symbol of Access (ISA) – the international marker used on toilet doors (and elsewhere) to indicate accessibility – creates a false promise of accessibility (Fritsch, 2013). Furthermore, it encourages surveillance and maintenance, not just of the borders of the toilet space itself but also the borders of disability, thus impacting upon who is and is not able to use that space and constructing a specific public imaginary of ‘disability’.

Borders are inevitably ‘traversed by resistance struggles’ (Brambilla and Jones, 2020, p.289), thus toilets and their signage have been sites of social contention and change (Jones et al., 2020). In the penultimate section of the paper, we consider how ISA toilet signs have been depicted as inadequate and therefore augmented or replaced, particularly focusing on ‘Not Every Disability is Visible’ signs, which have been used increasingly across the UK. Signs are ripe contenders for what Dolmage (2017) describes as ‘retrofit’. Describing a retrofit as an addition, retrospectively made, in an attempt to render inaccessible buildings accessible, Dolmage argues that although retrofits are important in ‘constructing alternative modes of access’ (p.103), they are also often inadequate, providing only partial access. He explains that the retrofit is a logic of fast capitalism, aiming to ‘extract surplus value with as little investment as possible for the greatest possible return’ (p.108). Signs can be very low in cost but with high visual and practical impact. One outcome of AtT was a list of recommendations; despite the

difficulty we had in composing this list (due to a fear of diluting the complexity of experiences shared with us), we also felt compelled to produce it, as participants told us that sometimes small, even imperfect changes, can make people's lives easier. These recommendations included altering signs (e.g. through removing gender markers or adding further access information) as a low-cost way of improving toilet accessibility (Slater and Jones, 2018). Without denying the impact that small changes can have on individual access, we reflect on how retrofits continue to sit within capitalist frameworks, often relying on arguments of increased productivity or profit and we explore the dangers of this logic for people not considered 'productive' or 'profitable'.

The aim of this paper, then, is not to list barriers and design solutions that allow better toilet access, or to suggest new toilet signs. Whilst we strongly believe in continually striving for better toilet design and accessibility and argue that some toilet design (including signage) is better than others (for project recommendations, see Slater and Jones, 2018), we do not advocate for one particular design that would suit all people. Rather, we use the focus on toilet signs to explore the different ways in which disabled people's access has been represented on toilet doors for capitalist gains and the material impact that this has on disabled people's access to space. Before introducing further methodology and data from the project, we turn now to outline our theoretical approaches to analysis in this paper: disability justice and collective access.

2. Disability Justice and Collective Access

We situate institutional and commercial attempts towards toilet accessibility alongside discourses of Equality, Diversity and Inclusion (EDI), often prevalent within such environments (Ahmed, 2012; Price, 2017). To 'include', 'diversify' or 'welcome' – including through design – inevitably results in Othering and reproducing institutional norms (Ahmed, 2012; Fritsch, 2013; Price, 2017; Titchkosky, 2011). Price (2017, p.156) writes that 'there must be an object to the verb; someone or something must be welcomed, be included'. However, the subjects who need to be welcomed, or the reasons behind this action, are often hidden or unsaid. Ahmed (2012, pp.9–10) explains that 'diversity becomes associated with certain bodies' and that a discourse of 'welcoming diversity' means that some bodies are, by default, considered 'not at home' (Ahmed, 2012, p.43). Similarly, Titchkosky (2011, p.90) highlights that for an effort to be made to 'include' disabled people, they first have to be positioned as 'excludable types'. Titchkosky argues that the ISA (Figure 1) – perhaps the most ubiquitous symbol of inclusion – is only comprehensible because there is the 'social expectation of inaccessibility' (Titchkosky, 2011, p.66). Accessible routes are rare, specific and need to be marked.

Where efforts to include are made, they often fail or fall short for many people. The ISA, supposedly indicating accessibility, often labels a toilet which is inaccessible for many disabled people, for myriad reasons (Jones et al., 2020; Slater and Jones, 2018). There may be inadequate space to turn a wheelchair, no shelf to change a



Figure 1 International Symbol of Access

Source: <http://mutcd.fhwa.dot.gov/pdfs/2009r1r2/part2ithu2n.pdf>

colostomy bag, no changing bench or hoist for those that cannot self-transfer from their wheelchair to the toilet, fluorescent lighting which is painful or lighting that is too dull for navigation, or the toilet may have been re-appropriated as a storage room. A 2007 study found that no ISA toilet facilities in the UK conformed to best practice guidelines (Hanson et al, 2007*1), a situation that is unlikely to have improved given a decade of austerity measures. As such, throughout the research, we have struggled with language around the ‘accessible’ toilet, which may incorrectly suggest these objectives have been achieved.

We have at times explained that we work from the perspective of the social model of disability, separating disability and impairment, where impairment is a perceived embodied ‘difference’ and disability a result of social relations that construct barriers for disabled people’s participation*2 (Oliver, 1990). The social model of disability has been radically significant for disabled people. Yet, disabled women, since the 1990s, have argued that some understandings of the social model of disability and the accommodations and accessibility guidance that follow (an often diluted version of it), can homogenise all disabled people’s needs into that of a ‘young man in a wheelchair who is fit, never ill and whose only need is a physically accessible environment’ (Morris, 2001, p.9). As such, gendered and racialised dimensions of disability and impairment, the experiences of those with fluctuating, intellectual or invisible impairments, living with incontinence, pain or illness, or experiencing trauma or distress, are not always accounted for (Garland-Thomson, 2011).

In a move away from focusing on a single identity, disability justice approaches instead attend to the implications of multiple social positions (race, class, age, gender, sexuality, migration status, etc.). Disability justice was first coined in 2005 by members of the Disability Justice Collective as a way to consider interdependencies between bodies, communities, movements and the environments which they inhabit (Piepzna-Samarasinha, 2018). Sins Invalid (2019) write of the importance of disability justice movements being led by disabled people of colour and queer and gender non-conforming disabled people, whose experiences have not been prioritised in disability rights work. They note that ‘able-bodied supremacy has been formed in relation to other systems of domination and exploitation’, including ‘heteropatriarchy, white supremacy, colonialism and capitalism’ (Sins Invalid, 2019, p.18) and need to be understood in relation to those contexts. To do disability justice work is not to settle at individual rights but to ask whose safety may be compromised, or rights further revoked, in order for another’s right to be achieved.

Whilst AtT does not meet the benchmarks of a disability justice project due to our own positionalities and its relationship with the academy, in this paper we draw on disability justice approaches to understand access as collective and interdependent (Mingus, 2011; Sins Invalid, 2019). In an exploration of what collective access means for design, Hamraie (2013) calls for designers to consider the multiple and intersectional use of toilets. Hamraie highlights that narrow cubicles are inaccessible for many wheelchair users, but also for others who need more space for their bodies. AtT research found similar: standard, binary gendered toilet provision is inaccessible or inadequate for reasons other than disability or impairment (Slater and Jones, 2018). Participants told us that cubicle spaces were too small to accommodate their body, the items they had with them or people they were caring for; that their gender did not fit neatly into male or female categories (or others did not judge it as doing so); that necessary amenities were missing, such as sanitary bins and baby changing units, particularly in men’s toilets; that they required private washing facilities to rinse reusable menstrual products or perform ablution in a non-judgemental space. For many of these scenarios, the enclosed, non-gendered room with private handwashing facilities, designed for the use of disabled people, made a more accessible (although not necessarily perfect) space, regardless of whether or not the user was disabled (Jones and Slater, 2020; Jones et al., 2020; Slater and Jones, 2018). Whilst the ISA-marked toilet is designed to account for a ‘misfit’ (Garland-Thomson, 2011) between disabled people and standard toilet configurations, there is in fact a continued misfit between many disabled people and that particular toilet space. At the same time, the ISA-marked toilet, supposedly created *for disabled people*, grants a more accessible space for some non-disabled people, who are not formally acknowledged as misfitting through rights-based design standards and legislation. We therefore depart from considering accessibility as purely ‘about disability’ and, indeed, refrain from naming any space as overarchingly ‘accessible’. Rather than refer to what is commonly known as the ‘disabled’ or ‘accessible’ toilet, we refer to the ‘ISA toilet’, by which we mean the toilet marked with the International Symbol of Access.

In the following section, we briefly outline the research design of this project before exploring the central themes of our findings. Before doing so, we draw attention to the tensions we have experienced in our citational practices when writing about toilets and disability justice and the implications of citational decisions for politically situating our work and for the reproduction of power. Ahmed (2013) describes citation ‘as a rather successful reproductive technology, a way of reproducing the world around certain bodies’. This process of reproduction is, of course, pertinent to disability justice and to this paper. The social power of toilets is, too, imbued ‘through thousands of repeated acts by which bodies produce and reproduce themselves in everyday spaces and social relations’ (Dimpfl and Moran, 2014, p.736). Here, we add to existing conversations on citational practice within disability justice (and other) work and clarify some of our own choices, with the intention to support greater citational transparency becoming commonplace.

First, in relation to our citation of Hanson et al. (2007), whilst we draw upon valuable evidence from this source, we remain critical of the toilet studies work of some of these authors (Bichard and Greed). As we have illustrated elsewhere, their work rests upon biological determinism and a cis-centric understanding of gender inequalities (Jones and Slater, 2020). We are also concerned that they perpetuate a simplistic and harmful mis-representation of conflict between cis women’s and trans people’s needs in the toilet (Jones and Slater, 2020). These issues are interconnected with disability justice and we believe it is necessary to be attentive to and to make visible, the broader context of these authors’ work. Second, we draw upon Ben-Mosche and Powell (2007). We value this paper and have no criticism of it or its authors. Since 2018, however, there have been calls to boycott the journal *Disability & Society* (where Ben-Mosche and Powell published their article) by those who argue that the Editor-in-Chief, who continues in post, does not support a trans-inclusive approach to Disability Studies (Ignagni et al., 2019; Slater and Liddiard, 2018). After consideration, we decided that raising awareness of the boycott of *Disability & Society* may be more beneficial than not including the citation. Not including the citation (particularly without drawing attention to the reasons why) could harm the authors more than the journal itself. We do not think that this decision is necessarily perfect and welcome further discussion of citational practices.*3

3. Methodology

AtT initially ran between April 2015 and February 2018 to examine the extent to which toilets provide a safe, accessible and comfortable space for everyone, whilst centring the experiences of disabled, trans and queer people. The project later evolved to include people who were not queer or disabled but had other experiences of toilet exclusion to share. In the most recent phase of our research (Beers, Burgers and Bleach, 2020) our focus turned to worker precarity and cleaning labour, particularly during the COVID-19 pandemic. Data used in this paper include interview and workshop transcripts from disabled participants and experiences shared through co-writing (Jones et al., 2020) in our work from 2015–2018 (pre-COVID).

We also analyse photos of toilet signs taken during the project. AtT began with a social media invitation, which asked people to take photographs of interesting toilets and toilet signs and tweet them using the @cctoilettalk Twitter handle and #cctoilettalk hashtag. As with many of the methods employed, project researchers also took part in this process. All photos analysed here are either shared with permission or taken by the research team.

The research drew on collaborative and creative research design principles coming from feminist, disability studies and queer perspectives (Browne and Nash, 2010; Pauwels, 2015). This allowed us to work with diverse participants, organisations and stakeholder groups, some of whom were involved in research design. Around 30 people in the north of England participated in data collection, which included one-to-one interviews, group storytelling, sculpture and performance workshops. Audio and graphic recordings, video and fieldnotes were used to capture dialogue, as well as spatial and embodied dimensions of data. Most people who took part in interviews and workshops had some form of sustained participation, such as attending multiple activities, collaborating in later research design, joining the advisory board, becoming a co-investigator and/or participating in data analysis. As AtT has been consistently outward facing, more project participation occurred internationally through social media, writing for project publications (e.g. Jones et al., 2020) and at public events. Accessible project outputs were made throughout (films, postcards, a zine and interactive websites – available at <http://aroundthetoilet.com>). This allowed for the ongoing sharing and discussion of data with diverse audiences, which in themselves generated more data. Whilst data was initially coded and themes were identified collectively, content analysis of the data was ongoing and iterative as data collection, analysis and dissemination merged and overlapped. Key features and themes were also reviewed at intervals between projects. Whilst the complex and publicly-engaged methodology makes it impossible to quantify how many times toilet signs specifically were mentioned during data collection, they were a recurring theme in both formal and less formal research encounters (e.g. in interviews and workshops, but also at public events, through social media and collaborative writing).

AtT was given ethical approval by Sheffield Hallam University and ethics have been integral to every methodological decision. Our project team, composed of early-career researchers and community partners, reflected a range of disciplinary backgrounds and research interests and sought to consolidate commitments to feminist, queer, trans and disability politics. There was an intuitive and necessary connection between these movements for many of us, who – in some cases – had personal experience of multiple marginalisation across these axes. We sought to be open about structural inequalities and power dynamics within the team and regularly invited input from a range of expertise and experience. All participants gave informed consent around issues of anonymity and confidentiality, although consent was an ongoing process. Pseudonyms and descriptions of participants' identities are used in our writing with their agreement. A project report is available with more detail on the project process, findings and recommendations (Slater and Jones, 2018).

4. The Promise of a Toilet Sign

Toilet design works on the basis that users will fit neatly into prescribed categories and require one of a standard set of facilities (Slater and Jones, 2018). Toilets are ‘orientated’ to certain embodiments and ‘[w]hen things are orientated they are facing the right way: in other words, the objects around the body allow the body itself to be extended’ (Ahmed, 2006, p.51). Correctly orientated toilets ‘[hook] the human body up to technology, individuals to infrastructure and private to public realms’ (Penner, 2013, p.9). Indeed, when toilets are orientated towards a person, there is a ‘fit’ (Garland-Thomson, 2011) between person and toilet space, which allows the person to use the toilet and continue with their day and this fit brings an implicit validation and belonging (Wiseman, 2019; Jones and Slater, 2020). Through toilets and their social protocols, practices of ‘embodied meaning-making’ occur (Dimpfl and Moran, 2014, p.736). We use a sign to tell us who the toilet is orientated towards and to choose the toilet that is designed to be orientated towards us. We (usually) try to choose the ‘right’ one. Whilst in the UK there is no current legislation that dictates who can legally enter a particular toilet, signs on toilet doors dictate the social convention: they tell us about who is allowed to enter that space and what (people and equipment) we can expect to find once we are in there. Yet, disability ‘blur[s] the boundaries between public and private’ (Kafer, 2013, p.40) and the stories of AtT participants continually pointed to the inadequacy of the options available to choose from. As Steph, a disabled woman who uses a wheelchair, put it:

there’s like three options: are you a non-disabled man, are you a non-disabled woman or are you a gender-neutral disabled person? That’s pretty much what our facilities are and that restriction doesn’t help anyone.

Although some disabled people have argued that ISA toilets should be binary gendered (Hanson et al., 2007; Kitchin and Law, 2001), Steph was not advocating for disabled people to have access to more binary-gendered toilets in order to affirm their genders or to separate toilet users. Indeed, such an argument often assumes that all disabled people’s genders fit neatly into male and female categories, denying the existence of non-binary disabled people and other trans disabled people who do not feel comfortable or safe using binary provision (Jones and Slater, 2020; Slater and Liddiard, 2018). Neither does it account for those who may be caring for people of another gender, or have carers or personal assistants who are another gender. Rather, Steph was highlighting the ways in which toilet signs impose forced identification, or ‘getting by’, within a limited set of categories that do not work for many people. Ahmed writes, however, that the point is not ‘whether we experience disorientation (for we will and we do), but how such experiences can impact on the orientation of bodies and space, which is after all about how things are “directed” and how they are shaped by the lines they follow’ (Ahmed, 2006, p.158). As we explore, although signs act as discursive signifiers rather than physical barriers, they nevertheless have profound embodied effects

on who is able to access the toilet space and the shaping of everyday lives and identities. Ahmed (2006, p.159) adds, ‘some bodies more than others have their involvement in the world called into crisis’.

Steph highlighted that despite the ISA toilet visibly displaying a picture of a wheelchair user, the facilities were not orientated towards her, as she required a changing bench and a hoist to use the toilet. Yet, she did not think that the inadequacy of the ISA toilet was something about which most non-disabled people were aware:

Most non-disabled people [...] just see a disabled toilet, an accessible toilet and think there you go, that's everything, you've got it and when you explain, like "OK, an accessible toilet might be in the corner of the room, the left hand corner, well what about if you're transferring and you've had a stroke and you can't use one side of your body?" and they go "oh I never thought of that". Or "what if you can't actually stand to get out of your chair?"; "I never thought of that".

Fritsch (2013) writes that the ISA produces ‘happy affects’ for non-disabled people and institutions responsible for their installation because, once the ISA is in place, disability is understood to be taken care of and therefore no longer a problem that needs attention. Yet, Steph highlights that the ISA homogenises disabled people’s bodies, capabilities and experiences and – by implication – the facilities they require, at the expense of disabled people, such as Steph, for whom the ISA (in this instance) does little. Drawing on Berlant, Fritsch (2013) theorises the ISA under capitalism as a form of ‘cruel optimism’. The ISA toilet makes the promise of a ‘fit’ that may be beneficial to those who can be conducive for the capitalist project (those she calls the ‘abled-disabled’). However, it also sentences those who continue to misfit to a form of ‘slow death’. As Berlant (2011, p.95) explains, slow death is not about a catastrophic event (like military encounters or genocides) but a gradual ‘wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence’ (Berlant, 2011, p.95). In other words, slow death refers to an ordinariness, where capitalism and structural inequalities grind down particular populations of people in slow, everyday ways. A lack of usable toilets under neoliberal capitalism is an invisible but insurmountable barricade, preventing both financial security and engagement with the social world. It subjects those misfitting to a form of slow death because, whilst the ISA sign promises to include disabled people, those that cannot find a toilet to use become invisible through being forced to stay at home, or, if they do go out, reducing what they eat and drink and holding off from using the toilet. This often feels unsustainable and is at a considerable risk to their health (Jones et al., 2020; Slater and Jones, 2018). Steph’s experience of being forced to quit her job as a junior accountant due to a lack of suitable toilet provision reflected this:

I would get up at 5.30, use the loo and then not get home 'til eleven o'clock at night and I was in pain and it was affecting my work, my concentration. It was making me feel ill. It's something you can do as a one off, but you don't want to be doing this three times a week. I could see my non-disabled, particularly male colleagues, they could drink all day, just whack it out, have a quick wee, carry on!

But it's not something I talked about. I didn't talk about it with managers. Looking back now, I wonder whether I should have and whether things might have been different. But I can't regret the fact that at that stage in my career I was junior, I felt replaceable.

Disabled people have highlighted that self-reliance, despite its veneration through neoliberal capitalism, is an ableist fantasy (Graby, 2018). A reliance on paid work is pedestalled above a life using state welfare and mutual support and those reliant on the latter are demonised as burdensome and lazy; a discourse that has become particularly visible through austerity policies (Ryan, 2019; Sandle et al., 2018). The cruel irony for Steph was that, despite the ISA promising otherwise, a lack of accessible toilet facilities meant that she could not continue in her job. She notes that these circumstances were compounded by her precarity and 'junior'/replaceable status, positions which are more likely to be inhabited by already marginalised people.

As Ahmed (2017, p.37) notes, '[w]hen you expose a problem you pose a problem'. Many disabled people have described having to act the 'supercrip', playing down oppressive structures and systems that make their lives difficult and instead appearing to 'overcome' disability without complaint (Clare, 1999, p.2), often by going above and beyond their non-disabled peers. For Steph, pointing out the failed promise of the ISA sign on the toilet door would risk threatening the happy affects of the ISA (Fritsch, 2013) and her employer's satisfaction of having 'included' a disabled person. At which point, Steph herself would become the problem and be replaced with someone whose body is more willing/able to fit; 'such bodies', notes Ahmed (2006, p.159), are taken as 'the contours of ordinary experience'. Sothorn (2007, p.146) describes how neoliberalism demands 'that we become active, entrepreneurial selves, which promises to herald a utopic vision of a perfectly deregulated world without chronic illness and disability'. Steph's workplace – without sufficient accessibility – promoted a specific vision of work, which excluded Steph.

5. Surveillance and Suspicion

In addition to difficulties with limited physical access to toilets, AtT participants, particularly those with non-apparent impairments, spoke of the suspicion they faced when trying to access the ISA toilet. Toilet signs, markers of spatial and identity borders, are based on a binary framing (Brambilla and Jones 2020, p.291) of disability and access. Ben-Mosche and Powell (2007, p.491) highlight that the figure of a wheelchair and user shown in the ISA is supposed to both represent all disabled people (a broad and heterogenous group) and convey an understanding that the symbol is not just about disability but also 'its ameliorating factor, accessibility'. Fritsch (2013, p.137) notes that Rehabilitation International, the body who originally selected the ISA design and promoted its use,*4 described the symbol as 'self-descriptive' and 'with no secondary meaning'. Yet, the experience of disabled AtT participants was that the wheelchair symbol was not understood to be about all disabled people and nor was it understood as an accurate indicator of universal access. A more exhaustive representation of impairments is not necessarily the goal here; not all disabled people require or

use accessible toilets. However, its limitations suggest a concerning criteria of validity. Non-apparent disability, for example, challenges the ‘brittle binary of disabled/non-disabled, which is relied upon as a means of measuring and mapping deservingness’ (Cooper, 2016, p.135–136). Participants told us that passers-by often took it upon themselves to police the marked border of the toilet space. Mikhail described the ‘abuse you get because you don’t look disabled’ when he and his wife, Dahlia, were trying to access ISA toilets. Nicky, who had a bowel condition that meant that she needed to access the toilet quickly, had internalised ‘the disbelieving stare of the normate’ (Samuels, 2003, p.245):

Most of the time I would use a women’s toilet and I wouldn’t use a disabled toilet. If I do [use a disabled toilet] I often feel a little bit guilty about it and I feel like I’m being a bit cheeky, like oh I’ll just sneak in here. But often I will be desperate. They’re a lot more comfortable as well, disabled toilets, ‘cause there’s just a lot more space and you don’t always have the pressure of someone being outside. But then there’s kind of that judgement there as well, like do you look physically able or not.

Not recognising herself within the ISA sign, Nicky questions her right to use the ISA toilet. This is not surprising given the assumed relationship between disability and fraudulence, where disabled people are at once recipients of charity and a constant source of suspicion and therefore must appear or present as ‘needy, weak and grateful’ (Ryan, 2019, p.28) of any accommodations. As Dolmage (2017, p.109) writes, a reliance upon retrofit to provide accessibility ‘holds us captive in a logic of fairness: apportions out access and accommodation in minimal ways, governed by legalistic and medicalized rhetorics that disempower, but also defended by liberal values that seem unimpeachable, even admirable’.

Hospitality and retail workers were sometimes put in positions from which they could grant or deny toilet entry. This gatekeeping was made particularly explicit when additional signs were added to the ISA toilet (Figure 2). In another demonstration of ‘cruel optimism’ (Berlant, 2011; Fritsch, 2013), disabled participants spoke of following signs to the ISA toilet only to find it locked, with another sign directing them back to a reception desk to collect a key to unlock the door. This had implications for those who found travelling long distances difficult and tiring, adding to the distance that they had to go to find a toilet and then return the key. It also posed problems for those who needed to access the toilet quickly. Furthermore, for those with non-apparent impairments, it required declaring disability, for that declaration to be believed and access granted. When discretion is left to gatekeepers, conceptualisations of disability and judgements made about validity and trust, will also inevitably be shaped by other intersecting belief systems and values, such as racism and ideas about who ‘belongs’ inside the building. Business concerns about toilet ‘mis-use’ (i.e. sexual activity, illegal drug use) will be guided by such stereotypes and prejudice. In some cases, unfamiliar or unexpected visitors may be treated as suspicious and forced to leave and the anticipation of such trouble may in turn prevent some people from entering – or for asking for assistance – when they expect their intentions may be questioned.



Figure 2 A toilet door with signs directing the user back to a reception desk to pick up a key

6. Tools of Legitimacy

The failure of the ISA sign to represent all disabled people meant that participants with non-apparent impairments felt like they were ‘on display’ (Butler and Bowlby, 1997, p.417) and this sometimes led them to use tools and develop strategies in order to gain toilet access. This process, however, involved both precautionary planning and spontaneous negotiations, including the management of emotions and potential shame. Those with bowel or bladder conditions that meant they often needed to access toilets quickly reflected on the worry of having an ‘accident’ and feeling embarrassed to share or discuss their health condition (Jones et al., 2020; Slater and Jones, 2018; White, 2019). On occasion, participants used tools, which enabled them to demonstrate their legitimate use of the toilet in a way that was comprehensible to a normative and ableist gaze. Gill described how she had received ‘unwelcoming comments’ when accessing the ISA toilets due to her bowel condition. Yet, she had

not received these comments since starting to use a walking stick due to a mobility impairment. Siebers (2004) highlights the strong ties between understandings of disability and everyday prosthetics that disabled people use (such as wheelchairs, walking sticks, hearing aids and white canes). Bethany, a participant who uses a wheelchair, said that she was never questioned for using the ISA toilet. Yet, she speculated that she may have less need for the ISA toilet than those with non-apparent bowel and bladder conditions, as she was able to use the standard women's toilets and rarely needed to access a toilet quickly. Siebers (2004, p.12) notes that a prosthetic can be used as an 'altered form of disability passing', which 'allows those who improvise on the use of their prosthesis to tinker with the social meaning of their disability'. He calls this phenomenon 'disability masquerade'. Although neither Gill nor Bethany described their use of prosthetics as a deliberate attempt to masquerade, both reflected on how the use of a prosthetic gave them access to that space, despite the lack of correlation between their access requirements and the degree that their impairments were apparent. Like punitive welfare systems (Ryan, 2019) or visas at a border, these narratives illustrate the requirement for proof, whereby it is understood that accessibility should only be granted to those who are deemed deserving.

Another participant, Daisy, a trans disabled woman with a non-apparent impairment, discussed a more deliberate use of tools that may both indicate disability/impairment to others and grant access specifically for disabled people. As we have written about elsewhere (Jones and Slater, 2020), many trans and – to a lesser extent – cis queer people, also face suspicion in relation to toilet use and are often forced to negotiate other people's gendered expectations about which toilet they should use. Often this means making judgements about their own relative safety in each toilet space and, sometimes, the safest option was to use the all-gender ISA toilet. This was rarely done by non-disabled trans people without worry and discomfort (Slater and Jones, 2018; Jones and Slater, 2020). However, Daisy*5 said that because they worked as a personal assistant (PA) for another disabled person, she had a RADAR*6 key, which gave them access to the ISA toilets. Daisy described having a RADAR key as 'possibly the most useful thing as a trans person'. Thus, her reason for accessing the ISA toilet when on their own was not because of her disability or impairment, but needing 'to go into a gender-neutral toilet but also not pay 30p to wee at train stations.' Tools of disability became tools of legitimacy, access and managing other people's expectations around toilet spaces, both in relation to the policing of disability and also gender and cost. This tool – designed for more specific disability access requirements – was strategically repurposed by Daisy to attend to a variety of other accessibility needs that would otherwise be neglected.

7. Alternative Signs in a Context of Fast Capitalism

Earlier in the paper we outlined how a responsible institutional or corporate image, which claims to value equality, diversity and inclusion (EDI), can sit within a capitalist framework, so long as inclusivity is lucrative. We have shown that in a context of

fast capitalism, however, an ‘inclusive’ image does not necessarily correlate with a more accessible space. The ISA symbol on the toilet door both delivers a false promise of accessibility and maintains borders of disability. We have highlighted some of the impacts that this has on disabled people and the strategies that individual participants employed to manage the ISA’s flaws. We now consider how ISA signs – due to their various deficiencies – have been modified. We centre this critique around ‘Not Every Disability is Visible’ (NEDV) signs (Figure 3), a relatively recent but increasingly commonplace sign in the UK, which, when used, is usually displayed in addition to the ISA. This sign is in line with calls to improve the social as well as the physical environment, in order to change ‘social attitudes and behaviour towards disabled people’ (Butler and Bowlby, 1997, p.411). Without denying the significance of NEDV to some users, we argue that NEDV fails to improve wider toilet accessibility for three interrelated reasons. First, it relies upon arguments of profitability; second, it reifies ‘sellable’ images of disability; and third, it fails in delivering a solidarity-building approach to collective toilet access.

NEDV signs, supported and promoted by the charity Crohn’s and Colitis UK (CCUK), have been used increasingly since 2017 in various UK locations, including parliament, supermarkets, restaurants, transport hubs and entertainment venues



Figure 3 The ‘not every disability is visible’ sign in use on a toilet door

(Jones et al., 2020). Many participants with non-apparent impairments or health conditions expressed feelings of relief when they encountered NEDV signs. Nicky said, 'I had a little sort of excited little thing where I was like "oh yeah, you know, things are happening about this now"'; and Dahlia felt 'touched' to see the sign used in a supermarket as 'it was the first time I found a note explaining invisible disability'. On their website, CCUK asks visitors to use an email template to contact UK businesses that have not yet installed these signs. The template states that displaying an NEVD sign can be a 'simple and relatively cheap action' and that 83% of people with Crohn's or Colitis would 'feel more comfortable visiting venues with the signs installed'. People with Crohn's or Colitis are portrayed as a potential consumer group that businesses are currently not profiting from. 'The business case' – arguing that a lack of toilet access means a lack of spending and consumption – is prevalent in toilet activism and campaigning. Hosting a conference called 'Unlocking the Purple Pound', for example, the Changing Places Consortium (the group of organisations most prominently campaigning for more toilets equipped with a changing bench and hoist) argued that increasing the number of Changing Places toilets could generate £12.4 billion. We too have invoked profit as a strategy: in our findings report we highlight the economic as well as ethical implications of accessible toilets for businesses (Slater and Jones, 2018, p.4). Yet, although changing a sign may be inexpensive, not all access considerations necessarily increase profit. Some of our participants highlighted this, particularly in relation to Changing Places toilets, which are expensive to install. Furthermore, successful attempts to modify symbols of accessibility are often only successful because they re-inscribe particular discourses of disability as *sellable*; people not fitting into profitable business models of accessibility remain without toilet access and subject to 'slow death' (Berlant, 2011; Fritsch, 2013), an exhausting and routinised public exclusion.

Disability charities have long been critiqued for using images of disabled children in their marketing in order to connote vulnerability and generate profit (Hevey, 1992). CCUK utilised images of the disabled child by sharing the story of the sign's inspiration, Grace Warnock. Warnock, who was 10 at the time and recently diagnosed with Crohn's disease, designed 'Grace's Sign' after noticing suspicious looks she got when entering ISA toilets. After receiving support from a local MP, Grace's Sign was adopted by the Scottish Parliament. A video about Warnock and the sign was widely shared and Warnock received a number of awards for her work. CCUK used the story and images of Warnock to launch the NEDV campaign. The depiction of Warnock sat somewhere between that of the inspirational/overcoming disabled person (i.e. the 'supercrip') and the 'girl activist'. Taft (2020, p.1) argues that girl activists are 'particularly desirable figures for public consumption because encoding girls as symbols of hope helps to resolve public anxieties about the future, while their more radical political views are managed through girlhood's association with harmlessness'. Taft adds, however, that harmlessness is not a discourse available to all young people as it is 'premised on a racist cultural framework that sees

young men of color as inherently violent, gang affiliated and dangerous' (p.9). Individualising disability to the image of a white, disabled girl, rather than as a set of social relations, neutralises the political nature of toilet access. Furthermore, as it is those most marginalised that are more likely to be challenged in their toilet use (people of colour, homeless people, trans women and femmes – many of whom will fall into multiple categories and may also be disabled), such imagery fails to challenge the disproportionate ways that toilet access is policed, depending upon multiple social positions (Jones and Slater, 2020; Patel, 2017; Slater et al., 2018).

Furthering the potential for business profitability, CCUK encourages businesses that install NEDV signs to share photos on social media and/or partner with the charity. It is therefore not unusual to see the installation of new NEDV signs in the media. In October 2019, for example, UK tabloid newspaper, *MailOnline*, published an article when a major pub chain, JD Wetherspoons, installed NEDV signs (Green, 2019). The article focuses on the story of a student who was challenged by security when using ISA toilets in the pub to change her stoma bag. It employs personal narrative, including selfies of the student – a young, slim white woman – sometimes dressed-up for a night out and at other times wearing a bikini with her stoma bag visible. These editorial decisions fit with the format of the platform. They also reflect wider 'awareness raising' campaigns around Inflammatory Bowel Disease (IBD), such as #getyourbellyout (<https://getyourbellyout.org.uk>), which invited people with IBD to share selfies with their stomachs visible on social media, 'whether you have scars, an ostomy or no visible signs at all', in order to normalise IBD. Whilst anyone with IBD was encouraged to share a selfie, one of the ostomy selfies which went viral was posted by model Bethany Townsend (Rademacher, 2018), another young, slim, white woman. Very *nearly* meeting traditional beauty standards is one of the ways that disability has been commodified and made sellable (Slater, 2012). We see this here: the story publicises the pub chain as responsive, responsible and inclusive, through a model of beauty, commodification and normalisation, which – it has been calculated by both the newspaper and the pub chain – will increase business revenue. This representation of the productive 'able-disabled' person (Fritsch, 2013) contrasts sharply with another frequent depiction of disability in *The Daily Mail* and UK press: that of disabled people as a drain on the welfare state (Ryan, 2019; Sandle et al., 2018).

Slater and Liddiard (2018) highlight that a belief in bodily autonomy and trusting that others are the experts in their own lives are central tenants in both disability and trans activism. On first glance, the NEDV signs could be understood as an example of this, conveying the message that disabled toilet users are best placed to decide which toilet is the best fit for them and to discourage scrutiny from other users. Yet, the compliance of NEDV with 'fast capitalism' ensures that any accessibility gains made are narrow. Indeed, a photo of the newly installed NEDV sign in the pub described in *MailOnline* shows it next to another sign, directing users back to the bar to get a key for the toilet, thus positioning bar staff as gatekeepers to toilet access, despite the newly installed sign claiming otherwise.

Furthermore, the wording of the NEDV sign continues to presume that disabled people are the only people for whom the ISA toilet is more accessible; and the use of male, female and ISA symbols, albeit side by side and on one door, reify, rather than expand or challenge, the three currently available categories. Their attempts to accommodate self-definition and non-judgement in the toilet are also circumscribed. For example, the story of NEDV contrasts with a report in *MailOnline* just a month later, which described the replacement of gender-separated toilets with gender-neutral toilets in an art gallery as ‘disgusting’ and only included the perspectives of those opposed to the change (Johnston, 2019). As we note elsewhere, negative press coverage adds to the precarity and disregard of all-gender toilets, often leading to them being ‘re-gendered’ (Jones and Slater, 2020). The context of fast capitalism means that two retrofits, arguably with shared aims of reducing toilet policing and increasing user autonomy, can generate very different responses: diversity is only accepted or celebrated within a set of parameters drawn through bureaucracy and profitability (Titchkosky, 2011). Whilst ‘Not Every Disability’ fits into the types of EDI discourse outlined earlier in this paper, a context of transphobia renders all-gender toilets a risky business move, especially when trans inclusion and (cis) women’s rights are needlessly framed in mainstream media as oppositional (Jones and Slater, 2020; Pearce et al., 2020).

8. Conclusion

Toilets are deeply political spaces; denying toilet access means denying access to wider space and community. In this paper, we have illustrated how toilet signs are recognised and experienced as objects that can allege, impede and demarcate access in unhelpful ways. Whilst our focus has been largely representational, we have demonstrated the material consequence of such representation. The ISA, placed on the doors to toilets which are designed and widely understood to be ‘for disabled people’, often fails in its promise of accessibility. Furthermore, the ISA sign functions to maintain and encourage policing of both the toilet space and the borders of disability; a policing which is strengthened because disabled people’s access to space continues to be positioned as a charitable endeavour. As a result, all disabled people, but particularly those routinely not recognised as disabled and/or those inhabiting other marginalised identities, are subject to policing and scrutiny in their toilet use and are expected to be grateful for any (partial) access that is granted.

For institutions, corporations and businesses, however, developing a facade of accessibility by using the ISA symbol on toilet doors can be gratifying and produce ‘happy affects’ (Fritsch, 2013) because EDI obligations and accessibility are understood to have been achieved. More crucially, the impression of accessibility can also be profitable and valuable to developing a good corporate image. Toilet access, therefore, cannot be considered outside of the context of capitalism, where – whilst some bodies, minds and ways of being are undoubtedly valued over others – disabled people are at the same time used and appropriated in order to generate profit. Thus, we have shown how the ‘accessible’ toilet provides a fit only for those that are

deemed economically productive, whilst sentencing others to a form of ‘slow death’, a painful and draining exclusion from public life. We have also indicated the volatility of this situation, whereby some disabled workers felt unable to draw attention to insufficient accessibility in their workplace due to their perceived expendability.

The promise of the ISA sign was unfounded for participants – particularly those with non-apparent impairments – who described feeling that their toilet use was under surveillance from the public or gatekeepers within a commercial building and that their legitimacy was in question. The misconception that impairments manifest in particular (and apparent) ways was understood to be exacerbated by the ISA symbol. Some disabled participants noted that precautionary planning and spontaneous negotiations were required to gain toilet access, such as equipping themselves with tools or evidence of ‘dependency’ or ‘weakness’, whilst others avoided using the ISA toilet or felt guilty when they did. These tensions were especially severe when gatekeepers required a declaration of disability before providing access to the ISA toilet (e.g. toilets requiring a key) and could use their discretion in determining a criteria of validity, suitability and trust. Tools were also deployed to assist with other forms of restricted access or surveillance, such as gender and cost, or to bypass the gatekeeper, whose interests may be aligned with the business. This underlines the need for more free, publicly owned accessible toilets, rather than reliance upon the private sector.

Struggles for better toilet access need to work against, rather than functioning easily within, this capitalist context. Whilst we have demonstrated that disabled people’s access to toilets continues to be a struggle, our wider body of work has shown that it is not only disabled people for whom toilet access is limited (Jones and Slater, 2020; Jones et al., 2020; Slater and Jones, 2018; Slater et al., 2018; Slater et al., 2019). Toilets offer the potential, therefore, to bring together fights for collective access and disability justice frameworks give us the tools to do this. To take a disability justice approach to toilet access means not settling at campaigns that, whilst perhaps improving toilet access for some, fail in a collective endeavour which would improve toilet access for all. Toilet access campaigns run by charities, such as Not Every Disability is Visible (NEDV) signs, are unlikely to offer sustainable and comprehensive solidarity-building approaches. As we have shown, whilst they may make gains for some, charitable campaigns risk further committing those not considered profitable or aspirational to ‘slow death’ (Berlant, 2011). Furthermore, the NEDV sign neglects the multiple intersecting bases upon which judgements are made about legitimacy and toilet use and are often used in contexts which implement other evaluations of legitimacy and restrictions on toilet use. We call, therefore, for those engaged in struggles of accessibility to ask who is profiting and whose material conditions are being affected by their work and what potential they offer for building collective approaches to toilet access.

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NOTES

- *1. Please see paragraph on citational practice at the end of section.
- *2. It is following the social model of disability that we use the term disabled people rather than adopting 'person first' language (ie people with disabilities) (see Mallett and Slater, 2014).
- *3. For those who are interested, we are hoping to start a conversation around this as part of a new Queer Disability Studies network. See: <http://queerdisabilitystudies.wordpress.com>; <http://twitter.com/queerdisability>
- *4. For more on the history of the ISA see Guffey (2018).
- *5. The pronouns used in this paper are those used by the participants. Some participants, such as Daisy, use multiple pronouns (e.g. 'she' and 'they') and prefer their full range of pronouns to be used alongside each other within a sentence.
- *6. RADAR keys, also known as NKS keys, can be applied for or bought online and offer people independent access to locked ISA toilets across the UK. They are predominantly aimed at disabled people.

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