PISSED OFF! Disability activists fighting for toilet access in the UK

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This document is the Accepted Version [AM]

Citation:

JONES, Charlotte, SLATER, Tig, CLEASBY, Sam, KEMP, Gill, LISNEY, Eleanor and RENNIE, Sarah (2019). PISSED OFF! Disability activists fighting for toilet access in the UK. In: BERGHS, M., CHATAIKA, T. and EL-LAHIB, Y., (eds.) The Routledge handbook of disability activism. Routledge, 219-231. [Book Section]

Accepted Manuscript of: Jones, C., Slater, J., Lisney, E., Cleasby, S., Kemp, G., & Rennie, S. (2020). Pissed Off! Disability activists fighting for toilet access in the UK. In M. Berghs, T. Chataika, & Y. El-Lahib (Eds.), *The Routledge Handbook of Disability Activism*. Oxon: Routledge.

PISSED OFF! Disability activists fighting for toilet access in the UK

Charlotte Jones, Jen Slater, Sam Cleasby, Gill Kemp, Eleanor Lisney and Sarah Rennie

Abstract

This chapter is comprised of a dialogue between two researchers and four activists about the significance of the toilet in disabled people's personal and political lives. Reflecting on the contemporary context of toilet activism and issues of accessibility in the UK, we situate the toilet within a wider disability justice movement which speaks to issues of austerity, categorisation, in/visibility, and both social and physical marginalisation. We draw on the research completed in the Around the Toilet project (2015–2018) to bridge the divide between academia and activism and critically consider what we should expect from an 'accessible' space. By introducing a range of different ways in which toilet access, comfort and availability is advocated and executed, including social media campaigns, personal blogging, petitions, and the creative re-designing of spaces and signage, we explore the meanings, influence and impact of activism, and consider how these responses fit into the lives of toilet activists.

Introduction

The toilet is a political place. The labels on its doors intentionally include some and exclude others, whilst the space, design and facilities themselves permit certain bodies, needs and actions, and forbid others. Access to a toilet away from home is not only about gaining entry to the cubicle; toilets also grant access to wider community, public spaces and opportunities. The toilet teaches us who is welcome and who is expected. This chapter is about disability activism which focuses on the toilet. We begin by outlining various forms of recent disability toilet activism in the UK. Modes of activism are conceptualised in a broad sense here: from artistic endeavours; to parliamentary lobbying; social media interventions; personal conversations; and direct action. Toilets are stitched into our wider social and material relations, thus strategies for change are multiple, divergent and symptomatic of wider political and personal differences. Toilets are often utilised as an exemplar for social justice claims. The demands of disability activists, for example, do not start or end with the toilet, but toilet access illustrates their broader claims to recognition and social value, and against physical barriers to their use of space and to perform bodily functions. Although it would be impossible to offer a comprehensive list and evaluation of the full and eclectic range of toilet activism, we do spend some time considering contrasts and tensions between disparate approaches. Such a discussion gives context to, and is followed by, four personal accounts from disability and toilet activists and campaigners.

The introduction to this chapter is written by Jones and Slater from our position as researchers on the Around the Toilet project (AtT). AtT is a cross-disciplinary research project based at Sheffield Hallam University, funded by the AHRC Connected Communities programme and involving researchers and community organisations based across the north of England. The project started in April 2015 with an aim to explore what it means to classify a space as ‘accessible’ and the various ways in which toilet spaces can be inadequate, uncomfortable and unavailable for some. The work began through engagement with queer, trans and disabled people, but has since expanded to include others who have experienced toilet exclusion. Using arts based practices, such as participatory workshops involving sculpture, storytelling and performance, and working collaboratively with architects and designers, we produced various creative outputs, including comics, films and a zine, a self-published collaboratively-written mini-magazine (Jones & Slater, 2018), all of which are available at aroundthetoilet.com. We also produced academic publications (Slater *et al*., 2016; Slater *et al*., 2017; Liddiard & Slater, 2017; Slater & Liddiard, 2018) and a project report (Slater & Jones, 2018). Whilst the toilet has been a focal point for the project, the conversations that we have had are broad: who are buildings designed for? Whose bodies and ways of being become normalised and valued through the design of public space, and thus, who is welcome and expected in particular places? Whose bodies and ways of being subsequently become Othered; and at what cost? Whilst this chapter concentrates specifically on disability activism, AtT approaches these questions from a variety of perspectives. We follow Kafer (2013) in viewing toilet access and activism as a fruitful place to begin building solidarities between social movements, and we stress the importance of considering disabled people’s multiple and intersecting identities, including the ways in which the marginalisation of different social groups is often co-constituted and overlapping (Patel, 2017; Schmidt, 2013; Slater *et al*., 2017).

Cutting out the toilet

Threats of violence, discomfort and marginalisation for trans, queer and disabled people transcend the toilet. These experiences sit within a wider context of racism, austerity cuts and capitalism. In the UK, austerity measures have included cuts to public funding which disproportionately impact disabled people (Garthwaite, 2011), especially disabled women of colour (UK Women's Budget Group, 2017). Austerity has also led to closures of toilets formerly financed by local authorities (Penner, 2013). Public toilet closures particularly affect already marginalised people, including, but not restricted to, disabled people. For example, AtT research found that the increasing scarcity of toilets has particular repercussions for people whose conditions or impairments necessitate urgent access to toilets (Slater & Jones, 2018). A growing reliance on private provision (e.g. in shops, bars and restaurants) means that less attention is often paid to accessibility (Greed, 2011; Slater & Jones, 2018). The paucity of public facilities can prevent older people, many of whom may be disabled, from leaving the house (Help the Aged UK, 2007; Knight & Bichard, 2011). As toilets can provide a rare moment of solitude, their reduction also results in fewer places for care and rest for people with mental health needs (Slater & Jones, 2018).

Public toilet closures and an upsurge in 'pay-to-use' toilets are also especially detrimental to homeless people, creating further divisions within communities, as homeless people are positioned as 'problems' for urinating and defecating on the streets (National Assembly for Wales Health and Social Care Committee, 2012), as well as having particular implications for homeless people that menstruate (Vora, 2016). Of course, disabled people do not lead single issue lives, and they often fit within other categories or groups who are also particularly affected by austerity. As Rennie and Lisney point out later in this chapter, disabled and non-disabled women may need longer and more frequent access to public toilets as they are more likely to be caring for others and/or dealing with menstruation and menopause than people of other genders.

Access to toilets and access to wider social care are not discrete problems, but wrapped up in broader ideologies regarding whose bodies and ways of being are valued. In opposition to cuts to social care, Disabled People Against the Cuts (DPAC) highlight that when budgets for personal assistance disappear, so too does disabled people's basic right to make choices, including when to use the toilet (Forrester, 2017). Serlin (2010), in agreement with DPAC, notes that toilets have been an important site of wider disability activism. He observes that a lack of suitable toilet facilities and/or personal assistance at protests, particularly occupations, has meant that toilets have become an important symbolic and material marker of disabled people's exclusion from some forms of direct action, and the public sphere more broadly (Serlin, 2010). As we discuss in the next section, toilet provision can be perceived as an indication of who is expected and valued in a space (Titchkosky, 2011). Facilities are supplied to suit the needs of those deemed 'typical' and important.

(De)valuing the accessible toilet

As we have shown, accessible toilets are limited in number and not always easy to find, but they are also the first to be repurposed. Throughout AtT we asked people to tweet photographs to us of good, bad or interesting public toilets using the #cctoilettalk hashtag. Numerous contributions have shown accessible toilets turned into bins, storage or staff rooms, and no longer fit for purpose. This is a physical reminder to disabled people that they are not expected or welcome in these venues. Other research participants have noticed that, even when considerable effort has been put into making the gendered (and particularly women's) toilets a pleasant experience, accessible toilets are often clinical and bland. Many do not have mirrors at wheelchair height, if they have mirrors at all. The medicalisation of disability has been widely critiqued within disability studies (Zola, 1972) and activism (e.g. Hearing Voices Network, 2018), and the clinicity of the accessible toilet arguably adds to this context. Upon finding an accessible toilet with decoration which conformed to the scheme of the building, one AtT research participant said that this consideration helped her to feel included and wanted in that space. There is also a gendered dimension to this design decision. Underpinned by sexist stereotyping, a sensorily pleasing toilet experience is considered more important for women. Thus, some disabled people's desire to attend to their physical presentation whilst in the toilet is discounted, reifying a discourse whereby disabled people are not gendered or sexual (Thomas, 1999; Wendell, 1996). As a response to this, some have started taking accessible toilet decoration into their own hands: for example, during an Arts Council funded Architecture-InsideOut workshop, a Changing Places toilet at the Tate Modern was transformed into a 'miniature baroque palace' (Boys, 2014; Boys, n.d.).

The planning of an accessible toilet often appears to be a tick-box exercise rather than a considered design decision. Over a three-year study, Hanson *et al.* (2007) audited UK toilets, and failed to find any facilities that conformed to the best practice guidelines. Artist Ju Gosling photographs red alarm cords in accessible toilets as part of her project, 'No Hope of Rescue' (Gosling, 2017). Alarm cords should hang to the floor in order to be reachable if a person falls whilst in the cubicle. Gosling's ever-growing series of photographs shows cords which have been tucked behind pipes, made shorter, or cut off altogether. For Gosling, the collection highlights that emergency systems are a commonly illusory requirement, with no expectation of use. Freely available 'Red Cord Cards' (Euan's Guide, 2015) have also been designed for people to attach to defective emergency cords upon finding one in an accessible toilet to explain the importance of a fully functional and appropriately positioned alarm cord system. Thus, facilities which are intended for the access and support of disabled people often need to be monitored, examined and rectified by the disabled people making use of them. However, these toilet 'audits', as we discuss in the following section, are not only performed upon the facilities, but also the occupants.

Different signs

Accessible toilets, like gendered toilets, are subject to social monitoring and regulation, and request a process of self-identification with the label on the door. Identifying as disabled in the UK is socially, politically and emotionally charged (Wendell, 1996), and situated by various ways of defining disability, concerns around pathologisation and diagnosis, and potential stigmatisation. Not everyone with an impairment or health condition considers themselves to be disabled. However, categorisation can also be a way of 'receiving the acknowledgement and confirmation of his/her reality' (Wendell, 1996, p. 12), thus suspicion or doubt regarding authenticity when using accessible toilets can be detrimental. People with invisible impairments or medical conditions have spoken to us about feeling guilty or under observation when using accessible toilets due to the 'conflation between the radical diversity of embodiment and the single iconic figure of the wheelchair user' (Titchkosky, 2011, p. 81). As Kemp and Cleasby discuss later in the chapter, disabled people not using wheelchairs can be judged by others as less deserving of the accessible toilet. This is exemplified by the relief many disabled people have shown in response to signs recently added to the doors of accessible toilets, which explicitly welcome disabled people whose impairments may not be perceptible to others. A toilet sign designed by ten-year-old Grace Warnock, who has Crohn's disease and experienced 'dirty looks' and people 'shaking their head' when she visited the accessible toilet, led to 'Grace's sign' campaign (Swerling, 2015). Grace's sign depicts 'female' and 'male' toilet logos with red hearts on their chests, alongside the wheelchair-user/'accessible' logo. The sign has been introduced in a range of locations in Scotland, including Parliament. 'Not every disability is visible' signs (Crohn's & Colitis UK, n.d.) also spread across UK supermarkets and other public toilet facilities in 2017, following charity campaigns.

Changing places and contested campaigns

Even when toilets are functioning, 'accessibility' can be characterised in a range of ways, especially as the minimum legal requirements do not take into account many people's needs (Women & Equalities Committee, 2017). A sign by the Changing Places Consortium (CP) highlights this when it states that, 'not all wheelchair users can self-transfer', due to the scarcity of toilets with adult changing beds and hoists (sometimes known as 'Changing Places (CP) Toilets'). Several participants in the AtT project spoke of the need for more CP toilets. One user discussed having to leave her role as a junior solicitor as there was nowhere for her to use the toilet in her workplace. Two parents of disabled children discussed the extra organisation and planning that had to go into a day out with their family due to a shortage of CP toilets. On some occasions this prevented them from leaving the house altogether.

CP use various campaign strategies, encouraging supporters to engage with social and other media, participate in 'stunts' to raise awareness, write letters to MPs and businesses, and write guest blog posts. Other participants in AtT have highlighted that campaigns such as CP, which are sponsored by large disability charities, are inevitably flawed as they work from a charity model of disability, which tends to portray disabled people as deserving of help and pity, and may not be led by and for disabled people themselves. Critiques of CP exemplify larger debates within disability studies and activism around the role of non-disabled parents of disabled children (Ryan & Runswick-Cole, 2008) and charities (Fulcher, 1989) within disability activism.

The popular and high-profile CP branding is used at will by individuals who support the campaign, which means that endorsement from the 'official' consortium is not always discernible. One of the most visible campaigning techniques attached to the CP label is the photographic documentation of children being changed on dirty toilet floors in lieu of a suitable changing bench, shared by the children's parents on Twitter and Facebook. Whilst these photos may have a strong emotional impact, the ethics of this strategy have been questioned. The

Accessible Toilets Project, an online accessible toilet resource, criticises the campaign for sharing ‘undignified’ images of children and young people without their consent: ‘[j]ust because dignity was lost in being on the floor doesn’t mean the indignity should be extended by their image being shared’ (The World of Accessible Toilets, 2016). The Accessible Toilets Project also points out that as the campaign often focuses on those who use sanitary pads, it can alienate disabled people who need the hoist, but do not use pads. In her essay below, Rennie highlights that because the campaign is dominated by parents of disabled children, CP toilets appear more often in ‘family’ venues, rather than in locations more readily frequented by disabled adults. CP campaigns thus highlight the differing, and sometimes contested, strategies used by toilet activists.

Choosing tactics

As well as implementing a variety of activist tools and tactics, the other contributors in this chapter highlight the importance of speaking more freely about toilet inadequacies in order to address stigmatisation. Paralympian and wheelchair-user, Anne Wafula Strike, echoed this point when she spoke out publicly and received national press coverage (Taylor, 2017; BBC News, 2017) after riding on a CrossCountry train which had no accessible toilets, leaving her to urinate in her seat. She commented that her decision to address this publicly ‘despite the personal humiliation’ was due to a desire to ‘bring about change for other people with disabilities’ as they ‘suffer in silence when this kind of thing happens because they feel too embarrassed to talk about it’ (Taylor, 2017). Whilst Wafula Strike made an important contribution to raising awareness of this problem, the expectation of advocacy and the emotional labour involved in continuous divulgence may feel onerous.

This type of labour is almost always unpaid, often unrecognised, usually expected of marginalised groups, and may involve disclosures which feel personal (Campbell, 2012). Furthermore, ‘choosing’ to speak out (or indeed protest in other ways) is always mediated by context. For example, in 2015 another British Paralympian, Susi Rogers-Hartley, was forced into the position of staging a ‘dirty protest’ when she was refused access to a petrol station toilet at 3am. She resorted to urinating in the garage forecourt and, to make her point, chose to position herself in front of the CCTV camera. She said: ‘I was absolutely desperate so I told [the Attendant] I was going to go outside, she said ‘you wouldn’t, there’s CCTV cameras’ so I said I would, and I did and I made sure I did it right in front of the cameras’ (Smith, 2015).

Rogers-Hartley described the act as 'just one of those things when you're out in the wheelchair' (*ibid.*), a position in which an inability to perform an everyday need in comfort led to both a form of self-preservation and of refusal, or 'political warfare' (Lorde, 1988). As Ahmed (2014) writes, '[w]hen you are not supposed to live, as you are, where you are, with whom you are with, then survival is a radical action'. Toilet protest is often interwoven into personal lives, and therefore enacted with urgency, not always planned ahead, and in some cases politicised only with hindsight.

This chapter discusses only a handful of strategies used to campaign for more accessible toilets and address current inadequacies. They demonstrate the breadth of disability activism: whilst some seek adjustments and call for 'inclusion' within the current system; others position toilet access as part of wider ableist discourse and practice, and fight for radical, structural and behavioural as well as attitudinal change. These actions are often taken as part of an everyday imperative to live, to work, and to get about. With this context in mind, we now turn to Sarah Rennie, Gill Kemp, Eleanor Lisney and Sam Cleasby to explain their experiences of toilet (in)accessibility, disability and toilet activism.

Bursting the balloon – *Sarah Rennie*

Toilets have affected my life choices and 'toilet activism' has powerfully influenced my politics. I cannot walk, stand or side-transfer from my wheelchair. Therefore, standard accessible toilets don't work for me because their design assumes that I can. There is neither a hoist to transfer, nor a bench to lie me on to pull up my trousers.

At home and at university, I had access to a suitably designed ensuite bathroom. Out and about in standard accessible toilets, my super-strength Mum would take my bodyweight in one arm and pull my trousers up and down with the other. She's 65 now and still does this, which worries me. Aged 12, my friends Pip and Shiv devised the 'lift and shift' manoeuvre to enable me to use the loo on long days or nights out. It's sort of like a scene from the Chuckle Brothers but with my ass in shot. It goes like this: Shiv starts by shouting, 'I'll lift, you do pants!' She picks me up with in a cradle lift with one arm under my knees and the other around my back, supporting my head. Pip pulls down the trousers, Shiv lowers me onto the loo and I wee. Then Shiv scoops me back up whilst Pip squints to locate the pants and trousers, coordinates the release of Shiv's grip on me in order to yank the lot up whilst simultaneously trying to avoid punching me in the ‘Cumberbatch’. We must complete the exercise before Shiv turns purple. Good friends at university learnt the ‘lift and shift’ manoeuvre which kindly enabled my rite-of-passage student drinking years.

The trouble really started for me in the world of work. A ruthless corporate billing environment doesn’t look kindly on 30-minute toilet trips, and working away from the office would mean 15-hour stretches without the toilet. The Health and Safety Executive would have me banged up if I allowed my support assistants to use the ‘lift and shift’ manoeuvre. I therefore felt I had no option but to change careers and become self-employed. Whilst I rescued my health, it was at this point I started to get angry about toilets.

Around this time, I became involved with Sisters of Frida, an experimental collective of disabled women. One of my first public-speaking events on its behalf was on a panel called ‘Toilets are a Feminist Issue’. I explained how the issues of toilet accessibility are impacted upon by both disability *and* gender. The audience was supportive. I realised that it was a subject matter everyone could relate to and it was refreshing to connect with a non-disabled audience so naturally. On the panel (and every event thereafter) I listened to older women, trans women and women of faith articulate similar experiences of pain, discomfort, exclusion, shame and discrimination. This was to shape my politics forever.

I became aware of Changing Places toilets in my mid-twenties. These facilities include a hoist, changing bench and plenty of space. There are now hundreds around the UK, often in shopping centres and giant supermarkets. There is no legal requirement for their inclusion or national strategy for their locations. As they are often installed after lengthy campaigns by the parents of disabled children, you often find the facilities in family-oriented places. The problem is that I can hardly say to a client ‘could we stop the meeting for a couple of hours whilst I jump in a taxi to use the loo at the local petting zoo?’ Further, the standard places you find them (e.g. shopping centres, town halls and swimming pools) close at 6pm and not when I need the loo around 11pm after a session in the pub. Wherever non-disabled people need to access a toilet, disabled people do too.

As the facilities cost thousands of pounds and must be funded by the building owner, we usually need to present a business case for the expenditure. The first barrier, as adults, to making that case is that we are discouraged from talking about going to the toilet. To correct the misunderstanding that standard accessible toilets are usable by all disabled people, we need to explain why this isn’t the case. This may need to involve terminology like ‘knickers’ or ‘wiping’. We are no longer children! As adults we are conditioned to keep these experiences private, burdened by shame and fighting to be seen as sexual beings. This pressure usually successfully silences us.

I am therefore trying, at great cost, to speak out about my experiences factually at events, on social media and in daily conversations. Each time I speak about it, it feels like bursting a balloon of stigma. This process forces me to think critically about the objectification of women and the stereotypes around disability and sexuality. As a teenager, if I was ever embarrassed needing to be wiped after using the loo my Mum used to say, ‘don’t forget: even the Queen has to poo’. I remind myself of Her Majesty whenever I feel pressure to be embarrassed talking about toilet injustice. In my activism life, it helps to remember that shame about necessary human bodily functions is patently absurd; toilets are designed for, provided for and policed by the privileged few; and shame is used to silence us.

This silence leads to the second barrier for disabled adults like me: if we’re not talking about our struggles, our numbers are unknown, and our collective purchasing power isn’t ignited. I am trying to establish an experimental network of disabled professionals in my city. One of reason for this is that I have a selfish dream that networks of this kind could pop up across the UK and demonstrate the need for these facilities in the adult world. Who knows if it will work? One day I may even boldly livestream a toilet trip with my ‘lift and shift’ buddies on the internet to wake people up to what ‘exclusive design’ really does to us. But, for now, I’m just going to have to keep popping those stigma balloons and have one brave conversation at a time.

Breaking down barriers – *Gill Kemp*

Until an illness left me with Irritable Bowel Syndrome (IBS) it did not occur to me to check whether toilets were available when away from home; I just assumed that they were. That aura of blissful ignorance was dispelled when I found that having IBS meant I could hardly venture out before warning gurgles had me flying back to the house. From then on I vowed only to go out if I knew of toilet locations.

IBS, like a variety of other medical conditions, is ‘invisible’ and sometimes the ‘disabled’ toilet is the only option in an urgent situation which has led me to come face to face with unwelcoming comments. However, the attitude towards me now when I use the accessible toilet has changed dramatically because, due to a mobility problem, I use a walking stick! This has highlighted the dilemma of those with ‘invisible’ conditions who need the space of the ‘disabled’ toilet but people can’t see why. Having an ‘invisible’ condition encouraged me to establish Public Toilets UK (PTUK), a campaign to improve access to toilets for everyone. PTUK also raises awareness of current toilet provision and offers support and information on public toilets issues.

The dilemma of the ‘disabled’ toilet

Thanks to charities such as Crohn’s and Colitis UK, an increase in the use of an additional sign on doors to accessible toilets reminds us that ‘not every disability is visible’. This is a major step forward; but why is it necessary? And is this enough? Should we still be dividing people into ‘abled’ or ‘disabled’ when we need the toilet?

A locked toilet is exclusive – think how many of us have to use a RADAR[i] key to gain entry to the accessible toilet. A gendered toilet is, for many, also exclusive for various reasons. For example, taking a male child into a female toilet (or vice versa) can cause embarrassment and comment, and using the accessible toilet may also be problematic because of entrenched attitudes. An accessible toilet for those of us with certain requirements is a lifeline but until the additional new signage becomes widespread, the current signage is not viewed as ‘inclusive’. On the other hand, it is worth noting that a Changing Places facility is recognised and accepted as ‘exclusive’ to mainstream users as it has specific equipment such as a hoist for those needing additional assistance, thus enabling them and their families to be ‘included’ in their desire to get out and about.

Is it time for change?

The policy to divide toilet areas into Ladies, Gents and Disabled has been with us a long time and a large proportion of the population do not wish this to change; but what does this say about our society when ‘abled’ toilets continue to be divided by gender and ‘disabled’ toilets are mostly non-gendered? There are long standing arguments on this subject but with public toilets closing at a rapid rate throughout the UK we really do need to consider the future.

In some areas where facilities have closed, Community Toilet Schemes (CTS) have been introduced whereby shops and public buildings allow use of their toilets without the need to make a purchase. Participating establishments are paid by the Council to cover the costs of additional supplies and maintenance which avoids the expensive maintenance of toilet blocks. For the scheme to be successful there has to be good signage and up-to-date information on availability. The type of facilities on offer may be less than the Council originally provided and unsuitable for some users. However, with proper management, could a CTS be the way to ensure the availability of toilets and a means of encouraging a society where everyone is welcome?

People power!

There has been a positive increase in the number of action groups who have successfully fought to keep their facilities open or have them reopened; many of which are the gendered style alongside a separate accessible toilet. It is also encouraging to note that in some areas Councils have listened to their public, recognised the importance of toilets and have funded brand new facilities; some of which are gender neutral. However, whatever the age or design of the toilet, maintenance and cleanliness are particularly important to the public alongside useful opening times.

‘People Power’ is certainly on the rise and hopefully, with encouragement and determination, will continue to be successful in increasing toilet availability. However, what is really needed is for toilet provision to become a statutory requirement. That would make a difference to us all.

Talking toilets with one voice

Unfortunately, until we all talk freely about toilet provision in the UK, progress will be slow and closures will continue to affect both our mental and physical health. The need for public toilets to encourage us to leave our homes for work and leisure are consistently ignored by Government and local authorities who have the capability to make a difference. Public Toilets UK is an example of a campaign to raise awareness of the impact of toilet closures. The realisation that we should speak with ‘one voice’ if the current situation is to change, contributed to the recent formation of the Toilet Consortium where charities and other organisations have begun to work together to break through the barrier of our currently ‘exclusive’ society.

Accepted Manuscript of: Jones, C., Slater, J., Lisney, E., Cleasby, S., Kemp, G., & Rennie, S. (2020). Pissed Off! Disability activists fighting for toilet access in the UK. In M. Berghs, T. Chataika, & Y. El-Lahib (Eds.), *The Routledge Handbook of Disability Activism*. Oxon: Routledge.

Refusal and exclusion – *Eleanor Lisney*

From a very young age, I learnt how to restrain my bladder functions. My classroom was upstairs, and the toilets were downstairs at my primary school, and the school day lasted eight hours. When I was a child growing up in Malaysia, we had an outdoor squat toilet that we shared with all the other tenants. A squat toilet is basically a ceramic 'hole in the ground' where you can plant your feet, one on each side, to then appropriately do your business. I have always admired people who can read while they are doing this! As a child, I was given a spittoon type of container as an alternative; potties were not available then. That also needed careful manoeuvring.

It became more and more difficult to find suitable toilets, so I was happy when sit-down toilets appeared in my life. However, I remember when visiting China with my family, I discovered that not only were squat toilets the only facilities available in public toilets, some of them were also open planned (and separated by gender). Total strangers asking if they can help me in public toilets – albeit with the best of intentions – became one of my top humiliating experiences.

Women have complained about the paucity of toilets for them in many places but for disabled women, it can be even more of a nightmare. I know when I am with a group of disabled women friends, the topic of conversation usually turns to the subject of accessible toilets. It 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. In a gathering of friends, there is bound to be consumption of liquid, whether it be tea or alcoholic beverages, so it goes without saying why availability of an accessible toilet is so relevant.

In my role providing advice on travel and accessibility, I often need to research the availability of accessible public toilets. We nearly missed the Eurostar back to London once because I insisted on going to the only place I knew which had an accessible loo, and then could not find the bus stop to take the bus back to the Gare du Nord.

Due to the lack of suitable toilets on airplanes, my own airline travels are now somewhat curtailed by the travel time on the plane, or else I self-impose dehydration. My activism includes insistence that I travel on planes with accessible loos like the Virgin Atlantic, such as when I was invited to Washington DC to a conference on museum accessibility. It can be difficult to explain this access need even when it is an event about access. Luckily, in this case they did not question it. How do you explain the refusal to travel because you would not be able to use a toilet on a long-distance flight? My sister lives in California and this is exactly why I have not gone to visit her there. I could have a stopover flight, but every stopover increases the chances of my power wheelchair being mishandled during unloading and uploading. Any anxiety and stress caused outweighs the pleasure of seeing family it seems, and this is often very hard to comprehend for my relatives.

When I had a stall at Coventry Market selling independent living aids, I did some research on aids that can help disabled women when they travel, things like the 'shewee' (https://www.shewee.com/), a urination device marketed for women. They might work for some non-disabled women or women who can stand, but not for wheelchair users or those who have mobility issues. I maintain that it is still easier for most cisgender men, including disabled men, to have a pee than a disabled woman. It is not just the privacy that is needed, or the fact that the dimensions need to be big enough to accommodate the wheelchair for transfers, but hygiene is also important for women as a toilet seat would often come into contact with flesh – this is not always the case where most men are concerned.

As a member of Sisters of Frida, a collective of disabled women, I have been invited to speak on panels such as 'Why Toilets Are No Joke for Women' at the Women of the World (WOW) Festival at South Bank in London. In addition to the issues I have mentioned above, the lack of accessible toilets is more than an inconvenience: it means being excluded from social, community and professional events. It is not just being able to pee but also the times of the month when we menstruate, and it gets messy. Cultural taboos around menstruation most often impact women, even though not all women menstruate, and not only women menstruate[ii]. One of the reasons we founded Sisters of Frida was because we saw the gap where disabled women's issues were not mentioned or voiced either by disabled people's organisations or women's organisations. It is not a great leap to link the provision of toilet facilities to health, and such services as part of being inclusive into mainstream society. The recent concluding observations from the United Nations Committee on the Convention of the Rights of Persons with Disabilities (CRPD, 2017) were that disabled women and girls' rights 'have not been systematically mainstreamed into both the gender equality and disability agenda' and they recommended the adoption of 'inclusive and targeted measures, including disaggregated data' to prevent the multiple and intersectional discrimination disabled women and girls face. We are currently advocating for a friend who has been isolated in a care home because her Local Authority has not afforded her to have accessible accommodation using a direct payment, which would allow her independent living with choice and control. She has high level needs including hoisting for her toileting needs. For that reason, she was put in a care home with much older residents, where they refuse visits from her friends.

While I moan about the difficulty of finding accessible toilets in social spaces like restaurants and in the workplaces in the UK, it is never far from my mind that it is much worse for our sisters elsewhere, where there is a lack of toilets in general, which curtails their ability to access education and work. There is one public accessible toilet in my home town, I was told. I have not been there for a few years. I cannot imagine what it is like for less developed countries or for refugees, or those in war torn countries or disaster areas.

Speaking out – *Sam Cleasby*

When I wrote an open letter to the people who tutted at me for using an accessible toilet, I never for a minute expected it to go viral. Almost two million views later and after thousands of messages of support, I realised just how important an issue this is to so many people.

I have a condition called Ulcerative Colitis. I have had seven surgeries to date and I have a permanent ileostomy. Ulcerative Colitis causes pain, diarrhoea, bleeding and urgency and so it’s fair to say that for the past 13 years, my life has revolved around toilets.

I became a bit of a toilet expert. I can name you every public toilet on most routes around my home town. If I were going on Mastermind, my specialist subject would be toilets. This is a bit of a joke I tell at dinner parties (because yes, I am that person who talks poo around the table) but the reality is that without access to toilets, specifically accessible toilets, my life would be pretty miserable and I would be housebound.

I started my blog, So Bad Ass (www.sobadass.me), almost five years ago to have a platform to talk about my illness and it quickly found a huge audience; an audience of people who needed to know that they aren’t alone. It is a bit of a taboo subject – talking about poo, toilets and disability is not everyone’s idea of a fun read – but it was important to me to be open and honest about all aspects of my chronic illness and the very real effects on my life.

After my post about the judgement we face when using an accessible toilet as a non-wheelchair user, I decided to start a campaign called More Than Meets the Eye to raise awareness of the many people with an invisible disability and their needs for accessibility and support in society. I was overwhelmed by the response.

It wasn't just people with Inflammatory Bowel Disease who got in touch, it was autistic people, people with cancer, ME, Tourette's and dementia, to name but a few. The heart of everything on my blog is about kindness, openness and acceptance and I was proud to hear from not only the people who have faced the judgment but also the people who have been the ones doing the judging.

People got in touch to say that they were unaware that accessible toilets were needed by so many different types of people, and that when they saw someone who wasn't a wheelchair user going to the toilet they thought it was someone who was taking something they didn't need. Education is key to moving forward, so to be able to teach society about disability and chronic illness is so important for creating a society that is accessible.

Accessible toilets are not truly accessible for all, and companies need to address this issue. The campaign by Changing Places to see more toilets with large changing areas and hoists shows the real-life problems faced by people who need support to use the toilet or to change continence pads. They use images of people being changed on a dirty toilet floor to highlight the need for changing benches, asking the question, 'would you like to lay your loved one on a public toilet floor?'

There are simple ways that accessible toilets can accommodate more people, for example having a shelf and hook to place ostomy products whilst you change your bag would be a massive help. When I use an accessible toilet in a business that could be improved I do make a point of speaking to staff and management about how they can improve their facilities. These conversations need to happen more; we need to speak about and educate the people making decisions about the needs of customers.

When I wrote about being tutted at, laughed at and mocked for using public accessible toilets, I was filled with hurt, anger and sadness. I felt small and humiliated. I wanted to stay at home safely away from harsh words and unkind people and I didn't want to share my experience with the world. But I am so glad that I made a stand, in opening up and speaking about this event that crushed my spirit, I found a way to take that pain and make a difference, not only for myself but for the many.

It still happens now. I have faced similar events over the years and I think I always will. I look like a non-disabled person and unless I flash my stomach, you would never realise the many issues and impairments that I have, but the difference now is inside. I have found the strength to speak out, not to shout, but to have those difficult conversations, to find kindness in my heart to speak to those who hurt me and to try and educate them about disability and chronic illness.

Shaming people doesn't work, it only hurts and so having conversations on a human level with a lot of understanding and patience is how I plan to move forward, I will never stop talking about these issues. I gained the nickname 'the poo lady' and I carry that moniker proudly!

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[i] RADAR keys, also known as NKS keys, can be applied for or bought online and offer people independent access to locked accessible public toilets across the UK. They are predominantly aimed at disabled people, although they are also used by some non-disabled people.

[ii] For example, some trans men and non-binary people menstruate. Gender is not an indicator of anatomy.