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Mara Pieri

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ELEPHANTS IN THE ROOM: CHRONICALLY ILL PEOPLE AND ACCESS TO LGBTQA+ SPACES

Mara Pieri

University of Coimbra

ABSTRACT

The article explores the issue of accessibility for disabled and chronically ill people in LGBTQA* spaces and its implications on a political level. The first part focuses on the theoretical premises that understand able-bodiedness as a system of compulsion: drawing from the insights offered by crip studies, accessibility is framed as a political claim that challenges the supposed normalcy built on able-bodied and heterosexual models. Also, the notion of LGBT spaces as paradoxical spaces is discussed. The empirical context of the research is explained in the second part, which also outlines a brief overview on chronic illness and on some aspects of LGBT activism in relation to intersectionality in Italy and Portugal. In the following section, the article discusses the inaccessibility of some practices of activism: the focus is on how activism happens and how many of the common practices adopted are actually based on presumptions of able-bodiedness. Pride Parades, assemblies, marches all constitute challenging moments in which interviewees are confronted with the difficulty of complying with the expectation of having a "bionic body". In the last section, the focus moves to relations within activist circles in relation to invisibility and coming out as chronically ill: interviews show the tension between coming out or staying in the closet, and the contradictions of doing intersectional politics without including accessible practices within collectives. Through these narratives, I suggest the idea that LGBTQA* spaces are still very much embedded into able-bodied presumptions which result in multiple obstacles for the participation of chronically ill members; also, I argue that, to create inclusive and safe spaces for LGBTQA* people, it is necessary to make advancements in the way disability and chronic illness are thought within LGBTQA* communities.

KEYWORDS: chronic illness; disability; crip; activism; Southern Europe; accessibility; ableism; able-bodiedness.

The elephant in the room is a metaphor commonly used to refer to an issue that is obvious, but nobody wants to discuss, because of embarrassment, either because of its disrupting potential or because it is considered inappropriate. This article unravels the metaphor in relation to an important, yet largely undiscussed, topic: accessibility for disabled and ill people in LGBTQA+ (Lesbian, Gay, Bisexual, Trans, Queer, Asexual and others) spaces. While the debate on safe spaces and intersectional belonging has been largely covered, little of it has been dedicated to the relations between safety and accessibility.¹ At first glance, the topic may seem a merely practical one: in its mainstream understanding, accessibility is often equated with ramps, elevators, and sign-language translation. However, reducing accessibility to a logistic aspect already reflects a structure of power that exists, invisibly but pervasively, and that reinforces able-bodiedness as equivalent to normalcy.

The aim of this article is to discuss the implications of naming, recognising, and including the elephant of accessibility in the room of LGBTQA+ spaces of activism. It is based on an empirical study carried out with young LGBTQA+ people with chronic illness in Southern Europe. The focus on chronic illness constitutes an additional layer of complexity for the discussion, as it is an experience that challenges common understandings of disability and able-bodiedness.

The first part focuses on the theoretical premises that understand able-bodiedness as a system of compulsion. Drawing on the insights offered by crip studies, accessibility is framed as a political claim that challenges the supposed normalcy built on able-bodied, cisgender, and heterosexual models. Furthermore, the notion of LGBTQA+ spaces as paradoxical spaces is discussed to show the tensions between inclusion and exclusion that are at the basis of intersectional safe spaces. The empirical context of the research is explained in the second part, which also outlines a brief overview of chronic illness and some aspects of LGBTQA+ activism in relation to intersectionality in Italy and Portugal. In the following section, the article draws from narratives collected to discuss the inaccessibility of practices of activism: the focus is on how activism happens, and to what extent it is actually based on presumptions of able-bodiedness. Pride parades, assemblies, relations with the media all constitute challenging practices in which interviewees are confronted with the difficulty of complying with the expectation of having what one of the participants to the study defined as 'a bionic body'. In the last section, the focus moves to invisibility and coming out as chronically ill within activist circles. The interviews show the tension between coming out or staying in the closet and the contradictions of doing intersectional politics without including accessible practices within collectives.

The article intends to focus on what is missing, in terms of theoretical, political, and practical levels of activism, rather than on what is already well established. The interviews reveal different perspectives and experiences; however, they are all aligned in confirming the absence of

¹ David Bell, Jon Binnie, Ruth Holliday, Robyn Longhurst and Robin Peace, *Pleasure zones: Bodies, cities, spaces* (Syracuse, N.Y.: Syracuse University Press, 2001); Eleanor Formby, *Exploring LGBT Spaces and Communities. Contrasting Identities, Belongings and Wellbeing*. (Basingstoke: Taylor & Francis Ltd, 2017).

an intersectional, consistent, and committed set of practices regarding accessibility in LGBTQA+ activism. Hence, unravelling the multiple sides of this absence means not only giving theoretical and political relevance to accessibility as a claim but also providing instruments for LGBTQA+ activist contexts to carry out intersectional struggles in a real inclusive way, which does not leave anyone behind. While speaking about the elephant, then, chances are we can learn more about the room than the elephant itself.

Unravelling Paradoxes: Able-Bodiedness, Accessibility, and Safe Spaces

Since the emergence of studies that have investigated the relations between sexualities and geographies, great attention has been devoted to the concept of safe space within LGBTQA+ communities. Various studies researched the different meanings of safety in relation to sexual orientation, gender identity, and sexual practices and provided evidence of how these meanings are created through active relational practices by groups of activists or communities.² Until recent times, the idea of safe spaces was grounded on the need to create homophobia-free spaces and to make room for the expression of all genders, sexualities, and orientations.³ Nevertheless, this approach, based on identity politics, also reinforced a dichotomic conception of safety as opposition between an 'us' and a 'them'. Hence, it proved itself to be insufficient to create safe spaces for people in their intersectional embodiments, such as, for example, queer people of colour, lesbian women or older individuals.⁴ While welcoming a certain form of queerness (white, middle-class, young, fit), LGBTQA+ spaces appeared to be less ready to undo other forms of oppression, based on race, ethnicity, class, ability, gender, age and education. As Kumashiro illustrates:

Ironically, our efforts to challenge one form of oppression often unintentionally contribute to other forms of oppression, and our efforts to embrace one form of difference exclude and silence others.⁵

This contradiction is particularly problematic in activism spaces, where political orientation overlaps with practices involving community creation. Activists face the challenge of building inclusive spaces that are potentially safe for everyone who wants to join without (un)intentionally generating grounds for other forms of oppression. These brief premises are fundamental to understand how accessibility for disabled and chronically ill people is articulated within discourses on safe spaces.

² David Bell, Jon Binnie, Ruth Holliday, Robyn Longhurst and Robin Peace.

³ Eleanor Formby.

⁴ Matthew Chin, 'Making Queer and Trans of Color Counterpublics: Disability, Accessibility, and the Politics of Inclusion', *Affilia Affilia*, 33 (2017), 8–23.; Robin Peace, 'Producing Lesbians. Canonical Proprieties', in *Pleasure Zones: Bodies, Cities, Spaces*, ed. by David Bell, Jon Binnie, Ruth Holliday, Robyn Longhurst and Robin Peace (Syracuse: Syracuse University Press, 2001), pp. 29-54.

⁵ Kevin K Kumashiro, *Troubling Intersections of Race and Sexuality. Queer Students of Color and Anti-Oppressive Education* (Lanham, Md: Rowman & Littlefield, 2001), p.1.

Generally, accessibility may be initially perceived as a merely practical problem, since its mainstream representations involve ramps, elevators, proper restrooms and sign language translation. Nevertheless, the presence or the lack of accessible facilities for people with disabilities or illnesses is harnessed, in the first place, also in being able to acknowledge ableism as a pervasive and widespread form of oppression. In LGBTQA+ activism this aspect is particularly relevant, as it is connected to the recognition of the multiple connections between ableism and heteronormativity as similar systems of power. Crip studies show how the dichotomies of health/illness and able-bodiedness/disability mirror the binary of normalcy/deviance, which also lies at the basis of heteronormative assumptions.⁶ Through an intersectional reading of compulsory heterosexuality formulated by Adrienne Rich,⁷ Robert McRuer initially put forward the notion of 'compulsory able-bodiedness', arguing that:

the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: [...] in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa.⁸

As Adrienne Rich argued, heterosexuality is everywhere and is so normalised that it is seldom questioned. Nevertheless, it is at the basis of a system of privileges and exclusion which has a direct implication on all levels of social life. Similarly, able-bodiedness is constitutive of the very idea of what is normal, which places all those who do not have the abilities considered integral to a human being in a position of deviation. Therefore, heteronormativity and able-bodiedness, as mutually complicit systems of compulsion, reinforce each other to confirm heterosexual, able-bodied, cisgender normalcy. Furthermore, they are also mutually complicit in generating multiple forms of discrimination, exclusion, and stigma directed at all those who fail to be normal, such as institutional violence, everyday language, de-humanised representations, verbal or physical aggression. Kafer notes that 'perhaps the most basic manifestation of this system is the cultural presumption of able-bodiedness': the assumption that everyone is able-bodied, if not otherwise stated or displayed, indeed, overlaps with the general assumed normativity for which there is no need for a coming out unless you are not heterosexual.⁹

The lack of accessibility in LGBTQA+ spaces can be framed because of a difficulty in intervening in the contact point between heteronormativity and able-bodiedness; the failure to acknowledge the common roots that different systems of oppression share; the inability to take on board the consequences of one system of compulsion (able-bodiedness) while fighting against others (heteronormativity and homo/bi/transphobia). Formulated this way, accessibility should not be a logistic individual issue, but a conscious action of opposition to ableism which recognises

⁶ Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013).

⁷ Adrienne Rich, *Compulsory Heterosexuality and Lesbian Existence* (Denver Co.: Antelope Publications, 1982).

⁸ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006), p. 1.

⁹ Alison Kafer, 'Compulsory Bodies: Reflections on Heterosexuality and Able-Bodiedness', *Journal of Women's History*, 15 (2003), 77–89 (p. 8).

it as a form of oppression linked to the others experienced by LGBTQA+ people: a collective shift in the inclusion of disability 'not defined by our bodies, but rather by the material and social conditions of ableism'.¹⁰

Since the presumption of able-bodiedness is embedded in the presumption of visibility - understood as the presence of visible signs of bodily non-conformity, such as wheelchairs, sticks, braces, marks on the body - the work for inclusion is multi-layered. In the first place, it needs to be based on the acknowledgement that accessibility is an *a priori* condition and not as an *ex-post* one. In other words, LGBTQA+ spaces should be always made accessible, not only and not just as a consequence of a specific need expressed by one or more people that wish to access that space. However, it needs to promote openness to all kinds of invisible disabilities, chronic illnesses, and mental illnesses, through the inclusion of different bodies which do not mirror medical and social representations of what a disabled or ill person should be or look like.

The turn to accessibility as an intersectional political feature of LGBTQA+ activism leads to questioning the contradictory character of these spaces themselves. Bell speaks of gay places as 'paradoxical spaces', held within the 'ambivalence of queer inclusivity'.¹¹ The struggle experienced in these spaces is rooted in the difficulty to find a balance between the attempt at inclusivity and the need for protection through the creation of a safe space. In evidencing this paradox, Bell offers a way to look at LGBTQA+ activist spaces in their tension between political claims of liberation and actual practices of exclusion of some identities or bodies. By reclaiming freedom and inclusion, activist spaces are expected, more than others, to actually make this freedom and inclusion viable for all the intersectional positionings embodied by those wishing to participate. Nevertheless, the persistence of able-bodiedness as an unquestioned system of compulsion has practical consequences in the reproduction of exclusionary practices that reinforce a cultural disavowal regarding the issue of disability and illness. As evidenced by Fox and Ore,

the problem, then, is not lack of diversity in LGBTQA+ spaces but resistance to knowing differently in these spaces, a resistance that is circulated through an epistemology of ignorance.¹²

This same epistemology of ignorance is reproduced whenever accessibility is constructed as a single-person issue or not included in the priorities of LGBTQA+ activism. Making spaces accessible for different bodies (with various bodily and mental abilities) is a form of contrasting epistemic violence that silences and discriminates those same bodies (and minds) on a daily basis. Therefore, the exposure of the contradictory politics carried out by LGBTQA+ spaces of activism about accessibility is paramount in order to create a generative debate on what constitutes a safe

¹⁰ Eli Clare, *Stolen Bodies, Reclaimed Bodies: Disability and Queerness*, 1–2 (Duke University Press, 2003), p. 360.

¹¹ David Bell, 'Fragments for a Queer City', in *Pleasure Zones: Bodies, Cities, Spaces*, ed. by David Bell, Jon Binnie, Ruth Holliday, Robyn Longhurst and Robin Peace (Syracuse: Syracuse University Press, 2001), pp. 84–102 (p. 86).

¹² Catherine O. Fox, and Tracy E. Ore, '(Un) Covering Normalized Gender and Race Subjectivities in LGBT "Safe Spaces"', *Feminist Studies*, 36 (2010), 629–49 (p. 640).

and hence accessible space. Moreover, it holds the political promise of improving intersectional work on theoretical, epistemological, and political engagement with able-bodiedness as a pervasive form of oppression in every context. Through this work, it is fundamental to unravel to what extent a safe space is also an accessible space and how an accessible space is likely to be a safer space.

LGBTQA+ Activism in the Context of Southern Europe: Brief Contextualisation

The article is based on interviews collected within a broader study focused on the experiences of young LGBTQA+ people with chronic illness. The study consists of twenty-four interviews conducted between 2017 and 2018 in Italy and Portugal with people aged between twenty-four and forty years of age, who self-identified as LGBTQA+/non-monogamous and who have chronic illnesses. Illnesses considered involve common features, namely chronic pain, daily need of care, frequent hospitalizations, consistent medicalisation, difficulties in everyday activities such as working, walking, eating, sleeping, having sexual relationships, or going out. The study was complemented with six further interviews with experts from LGBTQA+ activism and organisations involved with chronic illnesses at a young age. This set of interviews had the aim of scrutinising to what extent grassroots organisations work in an intersectional manner with regard to LGBTQA+-related issues and illness-related issues.

The stories of chronically ill LGBTQA+ young adults were collected through the qualitative method of narrative interviews, focusing on semi-structured questions oriented towards the topics of research: management of time in everyday life, issues related to (in)visibility of illness and of LGBTQA+ positioning, and networks of care. The choice of conducting narrative interviews allows for the creation of a space where each interviewee can tell their story of multiple, overlapping, and often inseparable belongings through their own personal perspective, not forcing any epistemological separation between the experience of illness and LGBTQA+ positionings. The sample is diverse in terms of sexual orientation, gender identity, relational identity and reflects a variety of positionings that fall under or question the notion of LGBTQA+. Although within the structure of the interviews these were not specifically addressed as topics *per se*, the issue of activism and accessibility were brought up by most of the participants as aspects which cut across their everyday life. As I myself am a chronically ill, young LGBTQA+ adult, I employed a self-reflexive approach that enriched interviews with moments of shared empathy, mutual exchange of informal knowledge, and the recognition, by several participants, that the space of the interview had felt like a truly safe space.

As introduced in the previous section, chronic illness occupies a challenging place within the able-bodiedness/disability dichotomy. It implies a prolonged, irreversible, and long-term experience of illness, characterized by frequent oscillation between acute and stabilization phases, medicalisation, need for assistance and limitation of everyday activities, and all these features make it comparable to certain aspects of disability. However, chronic illness mostly does

not imply visible signs of impairment or disability: chronically ill people experience disabling conditions without being visible, thus often ‘passing’ as able-bodied people.¹³ Some chronic illnesses are disabling but not socially recognised as disabilities; furthermore, chronically ill people may live as disabled, without claiming their experience as one of disability, because of the stigma attached to this or because they do not consider their condition politically. What is chronic illness and how it differs from disability is indeed connected to the socio-cultural definitions of both more than to a universal meaning ascribed to specific conditions. Therefore, as that which emerged from the interviews, chronic illness complicates the issue of accessibility with blurred lines between visibility and invisibility, embodiment and (dis)identification.

Before moving to the narratives collected, it seems necessary to also briefly outline some of the salient features of LGBTQA+ activism in the Portuguese and Italian context. Although several advances have been made in this sense in recent years, both countries achieved recognition of certain LGBTQA+ rights only in the past decade.¹⁴ In Portugal, LGBTQA+ activism has been successfully focused on conquering basic LGBTQA+ rights, such as the right to marry, to adopt and the recognition of self-determination of gender-identity. In Italy, a wider and more fragmented context, the recognition of civil union was only achieved in 2017, after a difficult negotiation between activist organisations and political institutions. The struggle for the recognition of these rights absorbed most of the active work in both countries, leaving little room for other issues. Activities related to a more intersectional understanding of LGBTQA+ activism were conducted in particular by more radical groups and organizations, such as the *Sommovimento NazioAnale* in Italy and the *Panteras Rosas* in Portugal. Nevertheless, both in Italy and in Portugal, homophobia, biphobia and transphobia are still rooted in society and politics, additionally as a consequence of the strong influence of Catholic culture and values. Disabled people’s movements in both countries are completely disconnected from LGBTQA+ struggles with the exception of two small groups of activists, *Gruppo Jump* in Italy and *Sim, nos fodemos!* in Portugal.¹⁵ In recent years, these two groups have attempted to build intersectional politics, such as the visibilisation of disabled people within Pride marches and initiatives to raise awareness of issues connected to sexuality and sexual life within the disabled community.

These general comments hopefully constitute a general outline of the situation in order to understand the complexities that chronically ill people experience within LGBTQA+ activism.

The Bionic Body of Activism: (In)Accessible Spaces and Practices

¹³ Susan Wendell, ‘Unhealthy Disabled: Treating Chronic Illnesses as Disabilities’, *Hypatia*, 16 (2001), 17–33.

¹⁴ Ana Cristina Santos, *Social Movements and Sexual Citizenship in Southern Europe* (Basingstoke: Palgrave Macmillan, 2013).

¹⁵ Ana Cristina Santos, and Ana Lúcia Santos, ‘Yes, We Fuck! Challenging the Misfit Sexual Body through Disabled Women’s Narratives’, *Sexualities*, 3 (2017), 1-16.

‘How do you throw a brick through the window of a bank if you can’t get out of bed?’. This question is the starting point that Johanna Hedva uses to put forward the Sick Woman Theory.¹⁶ The theory questions the significance of physical presence in public actions and protests, contending that ‘many whom these protests are for, are not able to participate in them - which means they are not able to be visible as political activists’.¹⁷ In most common practices of activism, the visible presence of people is the first fundamental way in which to make the action relevant. However, the alleged overlap between visibility and relevance also stems from the presumptions of able-bodiedness, which assume that being present is not the result of an effort or a burden. Disability and chronic illness challenge this connection, urging the re-thinking and re-framing of the way activism takes place and the way it is expected to happen.

A first recurrent topic emerging throughout the interviews focuses on the practices of LGBTQA+ activism and the ways these exclude disabled and chronically ill people. Narratives relate to the arena of public action, with examples of collective activist gatherings, such as protests, marches, rallies, sit-ins and Pride parades. Some also mention media exposure and meetings with institutions/organizations as part of routine activist work. In terms of accessibility, all these practices represent a possible obstacle, since they require not only the presence of activists but also consistent bodily engagement through physical actions such as walking, shouting, singing, standing or talking. There is a shared expectation that the good activist will participate in an operative way - perhaps the similarity between the words ‘activism’ and ‘active’ is more than a coincidence, if many reported it as a reiterative (although often silent) pressure in all collectives and assemblies. Nina, for example, a queer cis-woman, says:

Actually, I think that the body of the activist is a sort of bionic body, and when I began to do politics, politics [...] in a totalising way, I think I felt invincible for a long time. This is true, I mean [...] even in the spaces that [...] to say so, in the spaces that most work on these issues, the number of things you are required to take care of is enormous, both in terms of time and possibilities (Nina, twenty-four – twenty-nine years old, Italy).¹⁸

In Nina’s view, a good activist is expected to have a bionic body, to overcome difficulties and to engage in highly demanding activities which involve fatigue, hard work, and the ability to do multi-tasking work. This expectation seems to also point to the ability to overcome different limitations in terms of time, economic resources, and availability. As Nina points out, the sense of being invincible is a reward for the ability to juggle with money, work, free time and success in effectively marking a presence in the activist schedule. However, the bionic body is possible only

¹⁶ Johanna Hedva, ‘Sick woman theory’, *Mask Magazine- The Not Again issue*, <<http://maskmagazine.com/not-again/struggle/sick-woman-theory, 2016>> [Accessed on 12.01.2018.]

¹⁷ Ibid.

¹⁸ All the interviews have been anonymised and the names of interviewees changed with fictitious ones of their choice.

for an able-bodied individual, to the extent that activism 'still assumes a consistently energetic, high-functioning body and mind, and certainly not a body and mind that are impaired by illness'.¹⁹

The connection between able-bodiedness and good activism is so ingrained and unquestioned that it becomes evident only when something in the equation changes dramatically. The case of Maria is paradigmatic in this sense. After being a front-line activist for LGBTQA+ rights for several years, she fell ill and had to reduce the amount of time and dedication given to activism, while deciding not to announce her illness publicly:

So, I don't have any energy, to the point that, for example, there was a protest these days against gender-based violence and I didn't go, because I get tired when staying for a long time and walking a lot. But people [...] you know, there's this thing that I need to explain to people why I am not there, why I cannot make it, because people think I don't care, that I'm like that, and I did feel this burden (Maria, thirty-five – forty years old, Portugal).

When Maria fell ill, several people within activist networks noticed her absence from important active practices, such as protests and Pride marches, and they started to gossip about the reasons of her disappearance. While some suggested she had lost interest in the cause, others imagined conflicts within her organisation. Maria felt this pressure as a burden, to the point where she decided to go public about her condition:

And at a certain point, there was a moment in which I wrote, for example, on Facebook, and said 'Look? I didn't say exactly what I had, it wasn't worth it, but I said I had an illness that caused me fatigue and limited me sometimes, so that people would know that if I was not there much anymore, if I didn't show up, it wasn't because I didn't care, it was because I couldn't make it (Maria, thirty-five – forty years old, Portugal).

Maria's story highlights two important aspects. In the first place, the initial reduction of her contributions within the activist environment was met with suspicion and disagreement, as if Maria was naturally expected to be present at every event with the same intensity and there were no good reasons to take her away from this level of commitment. This shows the strong power of the implicit expectation of the 'bionic body'. Moreover, Maria was led to make a public announcement through the pressure felt in that environment, in what may be read as an (implicitly) forced coming out. The context in which it happened - an LGBTQA+ activist environment - makes this contradictory and, to some extent, problematic, as choice over the disclosure of sexual orientation or gender identity is at the core of any LGBTQA+ activist practice and is claimed to be one of the absolutely fundamental aspects of self-determination. If Maria had been (implicitly) pressured to come out as a lesbian, this would probably not have been welcomed as a sign that she was in a safe space.

¹⁹ Susan Wendell, 'Unhealthy Disabled: Treating Chronic Illnesses as Disabilities', *Hypatia*, 16 (2001), 17–33 (p. 24).

The issue of accessibility also emerges as central when it comes to actual spaces of activism. A narrative of frustration related to the difficulty in attending Pride parades is particularly recurrent. Traditionally, Pride parades involve a long route of walking through streets that are not always accessible and which are often packed with people. The obstacles highlighted are of two kinds: the lack of investment from organisers in choosing accessible routes and the difficulty encountered by people with other types of needs besides reduced mobility. Historically, organizers of Pride parades both in Portugal and Italy have ignored the issue of accessibility for disabled and ill people. This was undoubtedly a product of the lack of connections between LGBTQA+ movements and disabled people's movements. However, a deliberate ignorance about the issue or a cultural resistance to including ableism amongst the intersectional forms of oppression that involve *also* the LGBTQA+ community also seems to have had an influence in the choices made by organizers. Only in June 2018, for the first time since its first edition in 2001, did the Lisbon Pride Parade, the biggest in the country, introduce measures to include people with reduced mobility. In Italy, in 2017, a long negotiation was carried out by Gruppo Jump, the only Italian organisation for LGBTQA+ disabled people, and the organisations involved in the Bologna Pride Parade. It was actually the very first time that accessibility was discussed as a non-negotiable requirement to organise the parade. Negotiations lasted months in order to find the best route that would accommodate all types of mobility. However, only a few weeks before the parade, the organising committee opted for a route that was only partially accessible but had the economic advantage of passing by some of the cafés which had sponsored the event. As a consequence, Gruppo Jump dissociated itself from the organising committee and did not participate in the parade. However, as a matter of fact, this event did not lead to any significant national protest.

These events suggest how LGBTQA+ activism is embedded within the presumption of able-bodiedness and how hard it seems to produce important changes regarding the inclusion of accessibility in the demands of the LGBTQA+ community. Interviewees told stories about the difficulty of actually taking part in Pride parades due to mobility issues. The difficulty does not concern only actual participation: for some, it is important to know in advance the characteristics of the route, such as the presence of steps, type of pavement, localisation of benches, in order to make an informed decision about their participation, as they cannot afford the risk of exposing themselves through participating in an event in which they would not be safe in the event of difficulty.

The second type of obstacle which emerged in narratives is related to needs that are different from mobility issues. Some interviewees, for example, pointed to the difficulty of being in a festive crowd, where human contact can become excessive and careless in the event of dancing, singing and jumping, thus putting those who do not feel comfortable with close contact in a situation of stress or even fear. This applies, for example, to people that struggle with chronic pain or mental health conditions. Participants suffering from epilepsy and chronic migraine also

signalled the danger of being caught in the middle of a crowd while stroboscopic lights are used in the floats or on the stage. High volumes and loud noises were also mentioned as trigger elements of stress.

It is important to note that for many people in both countries Pride parades constitute one of the very few LGBTQA+ opportunities to attend an LGBTQA+ event during a year, if not the only one. Hence, for many, being physically present and participating is particularly important to actively contribute to the visibilisation of the LGBTQA+ community. Interviewees agreed that the decision to participate is difficult and is a mixed one between a strong desire to be there and the awareness that it may imply risks for their health. Furthermore, the shared feeling is that strategies to cope with the lack of accessibility are implicitly left to the individual, once again reflecting a cultural understanding of disability and chronic illness as one's own issue.

It is arguable that some of the difficulties mentioned are also applicable to other types of spaces, such as shopping centres, concerts, bus and train stations or non-LGBTQA+ activist events. However, the fact that LGBTQA+ activism does not seem to be aware of the existence of a vast array of differently functional bodies and consistently reproduces oppression concerning them is at least surprising. For some interviewees, it is even disappointing, and it gives rise to contrasting feelings of belonging and exclusion, pride and loneliness. Ellie, for example, a pansexual woman, reveals her doubts over the opportunity to volunteer in an LGBT organisation which she recently joined:

I admit I felt it immediately [ableism] and it is the reason why I'm not postponing but [snorting] let's say I am not enthusiastic either. I've seen they're looking for volunteers for the next parade, which could be a possibility, since I like to engage in challenges and do things, but [...] but I feel there is a resistance (Ellie, thirty – thirty-four years old, Italy).

Besides the special events, such as Pride parades or specific protests, the everyday life of activism is often managed through collective assemblies, camps, seminars or gatherings. Undertaking such events, though, presents other types of challenges in terms of accessibility. In fact, rhythms and timings tend to be flexible, with schedules that can change or that are not respected. Tove, a non-binary person with chronic migraine, reports:

And disorganisation, disorganisation often comes back on those few people that have to do all the work and then, if one of them is like me, with a health problem, nobody cares. And then assemblies, as well [...] long assemblies, five hours sometimes, full of interventions from people that just can't stop talking (Tove, twenty-four – twenty-nine years old, Italy).

The management of time within the context of assemblies is difficult for people whose time is already subject to unexpected changes and unpredictable ruptures. In the case of Tove, migraine attacks may occur at the most unexpected times, in particular after long hours of activity or changes in the food routine. The fact that it is quite common that assemblies have a starting hour but not a set finishing one is a factor for stress. Disorganisation has an impact on the way

chronically ill people manage their time, given that, in several cases, illness rules over everything else and requires people to stop their activities to take care of a migraine attack, an epileptic seizure or a peak of pain.

Comfort is also a fundamental element of accessibility to activist spaces. Interviewees mentioned the importance of properly heated spaces for activities in cold seasons, a condition that is often not respected. Furthermore, for people with mobility issues or rheumatic conditions, the presence of comfortable chairs, sofas or areas to take breaks, is often paramount in relation to the possibility of participating in assemblies. Sofia, a young woman with extrinsic asthma, highlights how the rule of not smoking in the collective space was only achieved thanks to the fact that other people in the assembly suffered from respiratory problems:

It's not that easy, right? I mean, especially in contexts in which there are a lot of people, that need to share a small space with many others, and they need to share survival rules, that can be very variable. Last time I was at an assembly, it was a place [...] on the top of a mountain, with no central heating; everything was heated through chimneys and wood stoves, and everyone smoking inside, there was a level of smoke that was just a nightmare. And this was difficult to explain. And three of us met outside, all of us with respiratory issues, and I remember thinking 'Thank God, it's not just me', [...] and I said, 'I'm going away in half an hour, I can't take this here', so then we went back, opened windows, raised the issue, talked about it (Sofia, thirty – thirty-four years old, Italy).

Although acknowledging that in collective spaces there is a need for shared rules, Sofia's first reaction to the 'nightmare' situation would have been to leave the venue. The conversation with other comrades with the same issues was important to validate her discomfort and reassure her that her difficulties were a collective problem. Moreover, thanks to a shared condition of discomfort, the three activists found the courage to raise the issue in the general assembly, an act of disclosure that they would probably not have engaged in had they been by themselves. Although in Portugal and Italy smoking in public places is forbidden, it is not uncommon that in activist spaces, assemblies and marches people smoke due to a general liberal attitude towards rules.

A final aspect of accessibility emerged which is related to presence in the media: part of activist routines does indeed require liaising with radio, television, press and constant updates on social media. These multiple fronts are challenging due to the speed at which everything happens but also for the need to be present when things happen. Momo, for example, explains:

I was invited to [...] to respond to an interview, and things like these [...] farther from home. They would have required me to travel to Lisbon, or to Porto [...] these are things for which I have no energy. Just the journey would mean I'd have to stay in bed for a week after to recover, so [...] No! (Momo, thirty – thirty-four years old, Portugal)

The difficulty of keeping up with the times and rhythms of communication, social media, and public exposure, in the experience of Momo, inasmuch as in the experience of other interviewees with a more active role on the public stage, often leads them to give up on important

participations in events. This happens when the organisation is small-sized and a large number of tasks is required from a small group of people, who cannot provide back up for the ill or disabled activist. In these cases, it is likely the organisation will suffer, at times, with implications for the inability to be visible and accountable to its collaborators.

In conclusion, the interviews show a generalised difficulty for people with chronic illness to align and fit in with the practices of activism, or, to rotate the perspective, LGBTQA+ activism appears to be moulded on a general, unquestioned presumption of able-bodiedness. This presumption constitutes the basis of practices both in the public sphere and in the more intimate space of assemblies, where venues do not offer basic standards of comfort. The lack of accessibility or, even, of a debate on the possibility of making spaces/events accessible, creates negative consequences not only concerning the ability to participate in activism but also the commitment deployed as activists.

Between Invisibility and Politicisation: Inside Activist Spaces

Compulsory able-bodiedness at the basis of practices around (in)accessibility is connected to a dichotomic form of universalism: the opposition of illness versus health, disability versus able-bodiedness, which is reproduced in the same way as homosexuality being opposed to heterosexuality. One of the consequences of this system is that chronic illness is perceived as a grey zone between two universal and recognisable categories: disability and able-bodiedness. The absence of readable marks of disability and the apparent well-being of chronically ill people makes it very common for them to 'pass' as able-bodied.²⁰ Ironically, the mechanisms of discredit and preconceptions against those who try to 'pass' work very similarly for invisible disabled and trans people, to the extent to which they are all expected to prove some sort of authenticity in the face of suspicions and prejudices.²¹ One of the reasons why dichotomic thought is so hard to challenge is that it creates no room for in-betweens: those who do not belong to a visible category are questioned and pressured to show signs of affinity to one of the two sides. Hence, another side of the able-bodied assumptions ingrained in LGBTQA+ activism is the widespread idea that illness is a private issue which does not have a political place in wider struggles. In the interviews collected and in the perspectives enunciated by experts, a narrative of complete separation between sexuality and illness emerges. Most people speak of a rigid division: on the one hand, LGBTQA+ activist spaces, where issues related to sexuality, gender and sexual orientation are discussed; on the other hand, organisations centred around illness and health professionals who are the interlocutors for issues related to health. In all these cases, the two worlds do not mix: while within LGBTQA+ activism there is almost no mention of health conditions and illness is considered a private issue (with the only exceptions being HIV and STDS), other groups related to

²⁰ Mara Pieri, 'The Sound that You Do Not See. notes on Queer and Disabled Invisibility', *Sexuality and Culture* (2018).

²¹ Ellen Jean Samuels, 'My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse', *GLQ: A Journal of Lesbian and Gay Studies*, 9 (2003), 233–55.

health and sexuality represent a taboo that is rarely mentioned. Therefore, for people that share a multiple belonging to LGBTQA+ activism *and* to the experience of chronic illness, the challenge is to strategically manage visibility between different worlds. Logan, a twenty-four-year-old non-binary person with a heart-related illness, expresses it strongly: 'Yeah, let's say it's like [...] there are two groups, ok? I know I have the people of the heart and the trans people. And they don't meet' (Logan, twenty-four – twenty-nine years old, Italy).

Separation and strategic (in)visibility create another type of division. In the case of Logan, the invisibility of their non-binary gender identity to the 'people of the heart' is counterbalanced by the invisibility of their chronic illness within the LGBTQA+ activist groups they attend. Sexuality and chronic illness are both interpreted as stigmatizing embodiments. However, while the latter is socially constructed as a private issue, the former is reclaimed for its political significance. Interviewees confront the discomfort created by this double embodiment using different strategies. Some choose to stay in both closets, although not so comfortably; very few remain in the closet of activism while disclosing themselves as LGBTQA+ to health professionals or other ill people; others take the opportunity to come out as being chronically ill within LGBTQA+ activism, as they acknowledge that, at least in theory, this should be a symbolic space in which to discuss intersectional embodiments.

There are multiple reasons that lead people to stay in the closet as chronically ill in LGBTQA+ activism. The first is related to the internalisation of a sense of responsibility towards their own condition. The idea that illness is an individual experience, a private one, combined with the actual absence of signs of potential openness coming from the collectivity discourage people from coming out. Visibility always involves an investment in terms of energy, time, and emotional distress. Especially in contexts that seem to be moulded on an ideal 'bionic body of the activist', coming out may imply too much investment. Hence, some feel it is just easier to stay in the closet and adapt to uncomfortable situations and inaccessibility within a step-by-step strategy. Tove relates a situation which happened during an LGBTQA+ camp:

It happened to me that I needed to eat, but in those situations, you can't eat, first there are six hours of workshop, and then you can eat, all together, only all together, because food needs to be equally distributed, you have to stand in the line and wait [...] I mean, maybe it was also my problem, I mean, if I had communicated, 'Guys, I have this problem', for sure someone would have been more careful, but I am uncomfortable in telling everybody [...] there are people I don't know, I'm afraid to disturb, I don't know, I just don't like the idea. (Tove, twenty-four – twenty-nine years old, Italy).

In this situation of discomfort, Tove's strategy, was to try to adapt as best as possible. With their condition being an invisible one, they would pass as able-bodied and nobody seemed to suspect they were having a hard time during some moments of the collective experience. Tove was aware of the fact that, in the event of a coming out, the environment was likely to have been understanding, but they did not feel encouraged to do that. The dynamics of invisibility work as a

circle: when the environment does not show clear signs of openness towards the accommodation of special needs in terms of accessibility, some people may feel discouraged in coming out, thus feeding the collective feeling that there is no need to address accessibility as an issue, since no one, *apparently*, needs it. Furthermore, this dynamic may encourage the idea that accessibility is an *ex-post* determination, an adjustment that needs to be made when someone specifically asks for it, rather than a basic political choice that brings benefit to all the community *a priori*.

Another reason for choosing invisibility is connected to the specific power relations existing in the collective space. Within LGBTQA+ activism, relationships between comrades are often strong and go beyond mere common political activity. Complex networks of friendship, romantic relationships, cohabitation, co-working and mutual support are often at the core of collectives. In some ways, this aspect complicates the feeling of safety in relation to multiple belongings for newcomers or people who lie outside these complex interconnections. Nina narrates her passage from a previous collective, where she was well connected within a relational network, to a new collective in a different city:

So, in the previous collective, the only, the only conquest we made was to have a non-smoking space: no one ever smoked in there. It was also due to the fact that there were several people that suffered from asthma [...] But here, here in every single space, people smoke inside, and I really don't understand why! So, for me, they are basically forbidden spaces, but so far, I haven't had the courage to ask them to stop smoking, because [...] because I've just arrived, and I need to take it easy (Nina, twenty-four – twenty-nine years old, Italy).

Nina's experience highlights how coming out as chronically ill is also a matter of power, to the extent to which it implies the need to share special needs which will become new rules for the whole collective. Those who are not alone, not shy or know the specific dynamics of the collective (in other words, those who have some sort of privileged position in the group) will feel more confident in making their condition explicit, which is otherwise considered as an individual, private, de-politicised matter.

Some interviewees did speak about their visibilisation strategies within a group. In these cases, the incongruity between theory and practices emerges in all its contradictory aspects. Safo, for example, highlights that:

Because [...] it's all very cool when it's only in theory. Mental illness, illness [...] 'I accept your mental illness very well, as long as it doesn't show visible symptoms'. And the issue of chronic illness and chronic pain, is similar, like 'Yes, ok, I understand. But how come you can't go up the stairs now?' (Safo, twenty-four – twenty-nine years old, Portugal).

Safo did come out about her condition and about the importance of accessibility in LGBTQA+ contexts, in an unapologetic and outspoken way. However, while in theory, through conversations, fellow activists seemed generally aware of the importance of supporting her, in practice few were actually able to make any significant intervention in deconstructing ableist assumptions. For example, some seemed surprised she could not go up the stairs, as she did not

show any visible sign of impairment, despite the effort deployed in repeatedly explaining her specific limitations.

Similarly, some interviewees report the feeling that LGBTQA+ activists are not (yet) ready to include disability and illness within the intersectional politics they claim. Maia, who joined a radical LGBTQA+ collective in the past year, recalls the difficulties experienced at the very beginning, when she first introduced the issue of accessibility in assemblies, together with another friend who is also chronically ill:

I'd like to speak about it, it is extremely difficult, still. We tell each other that [...] we are anti-racist, anti-sexist, anti-speciesist, but we still can't deal with disabled or ill people, and at the beginning it was very hard. I remember that, at the beginning, people at the assembly would snort and complain, because we had a slow rhythm, because they couldn't do everything they wanted, because our illness was a hindrance. Everybody would say 'Yes, cool', but then they wouldn't help. [...] I think we need to work very hard, insist and never stop insisting (Maia, twenty-four – twenty-nine years old, Italy)

When she first came out as a person with special needs with the collective assembly, Maia was welcomed with suspicion. She recognises that she felt she could come out because there was someone else, a close friend, who was chronically ill as well. However, she was also confident that the collective would be ready to embrace and discuss a different layer of intersectionality, given the anti-racist, anti-sexist, anti-speciesist orientation at the core of its politics. The act of coming out implied a demand that the collective took on board a shared responsibility in making spaces of activism more accessible for their special needs. However, difficulties were multiple, since some people would ostensibly complain because of the limitations they were faced with. Maia adds that things slowly changed with time and with their constant insistence. The group became more and more aware that collective support was needed in order to adjust to everybody's rhythms and some changes were accomplished. However, it is significant to note how these changes implied the extra orientating task for those who came out, which probably resulted in an additional amount of energy, time, and emotional investment being spent.

The main difficulty, in Maia's and Safo's case, did not arise from the fact that people do not know how to intervene in practice. This began with a step back, with resistance in acknowledging the type of oppression exercised by ableism and the renunciation of self-critically analysing the dynamics of exclusion within the group. Although discourse on intersectional inclusion may be explored, discussed, and embraced, the passage from theory to practice may fail faced with the pervasiveness of able-bodiedness. In these cases, visibilisation strategies of what is, definitely, an elephant in the room, imply extra costs for those who have envisioned the importance of coming out.

The Elephants and the Room: Concluding Remarks

The aim in unravelling the metaphor of the elephant in the room through the article was explored through unravelling several issues. The theoretical framework, combined with narratives collected within a specific context such as Southern Europe, made up a complex picture in which there seem to be more elephants and more rooms than expected. While the main topic of the discussion is and remains accessibility in its political significance, these narratives showed that the meaning of accessibility itself may vary from space to space, from illness to illness, and also in relation to the power relations on which activist spaces are constructed. Therefore, accessibility is a fundamental aspect of discussions about safe spaces: forgetting that safety for LGBTQA+ people should regard also those that are LGBTQA+ *and* disabled/chronically ill means to reproduce oppression and multiply exclusion. However, because ability is only one of many systems of power that oppress LGBTQA+ people, it is important to highlight that a safe space is not only an accessible space: a space can be accessible and still not be felt as safe for people that embody multiple other intersections, hence it can still be a racist or ageist space. On the contrary, if a space is not accessible, it is already, automatically, not safe for LGBTQA+ disabled or chronically ill people.

As the article showed, accessibility can be delineated in different ways and this does not only consider issues of reduced mobility. In all ways, it arises from the recognition that disability and illness are not problematic in themselves when ableism is not included within criticism. Given this, the reproduction of able-bodied assumptions within LGBTQA+ activist spaces should be discussed thoroughly in the same ways with which other forms of oppression have been confronted. The elephant in the room, therefore, is also linked to the difficulty of LGBTQA+ activists in recognising that there is something missing in the intersectional work that has been carried out so far. Narratives which have emerged have offered clear insight into the difficulties of coming out, the pressures concerning invisibility and the expectations over a 'bionic body'. Activism needs to face the limits and lacunae in discourses on inclusion and safe spaces. The challenge is to critically explore the issue of accessibility in order to understand what there is to be improved and what the lines of inclusion or exclusion are that are produced within these practices. This debate has the potential to challenge some of the ways activism is carried out, in order to create other practices that question, for example, physical presence in the action as a sign of importance, as Hedva suggests.

Finally, I'd like to conclude by turning to the literal meaning of the metaphor that guided these reflections. If an elephant enters a room of elephants, it will produce no reactions. The figure of the elephant in the room triggers discomfort because it is related to a room implicitly assumed to be full of humans. Its presence, its size, its difference are the elements that generate unavoidable reactions: the elephant is a misfit within a context of assumed humanity. Through its unsettling presence, the elephant reminds us what the assumptions are that constitute a supposedly normal human being and which embodiments have been left out of the definition of humanity. Hence, the debate on accessibility reveals that the exclusion of disabled and chronically

ill people from spaces of activism is equivalent to their implicit reduction to a condition of non-humanity.

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