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## Sexuality and disability in Portugal: perspectives from a disability rights activist movement

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### ABSTRACT

This study explores the intersection of disability and sexuality in Portugal through the experiences of a disability rights social collective. Historically, disability has been framed by models that often disregard sexuality, leading to the desexualisation and stigmatisation of disabled people. The Independent Living Movement, while addressing sexuality, reclaims self-determination and control over one's life. The research was conducted with members of a feminist anti-ableist activist collective established in Portugal in 2020, selected for its critical approach to the intersection of gender and disability. Data collection between October 2023 and July 2024 occurred across three phases - initial exploratory interviews, semi-structured interviews, and collaborative discussion of preliminary findings. The discussions focused on models of disability, terminology, sexuality, corporalities, and the theoretical and practical aspects of support for the expression of sexuality. Data were analysed using reflexive thematic analysis. Two central themes were developed: 'multiple oppressions' and 'dissident bodies,' highlighting systemic barriers and resistance strategies to achieve sexual autonomy. Findings provide insights into the importance of inclusive public policies and intersectional frameworks, offering a situated perspective on how collective agency can promote sexual rights as a matter of social justice.

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## Introduction

Throughout history, disability has been conceptualised in many ways, including through religious, medical, and charity models, reflecting the dominant perspectives of different periods. Oliver (1990) drew an important distinction between individual and social models of disability, highlighting the contrast between personal tragedy theory and the social construction of disability. The first attributes the 'problem' of disability to the individual's functional limitations or the psychological losses assumed to emerge from the disability experience, while the second attributes the issue to society's failure to integrate and accommodate the needs of disabled people.

The shift of the narrative from the internalisation of deficit and damage to the recognition of disabling barriers as a social and political concern has shaped the development of collective disability consciousness and has strengthened the social movements characteristic of disabled people (Oliver 2013). Throughout this article, the term 'disabled people' will be adopted, considered identity-first language, to align with terminology in line with the social model of disability, which is commonly used within the disabled people's movement.

The social model of disability not only highlights the environmental barriers confronting disabled people but also brings awareness to the pervasive nature of discrimination based on disability – ableism. Ableism is the social oppression of individuals with any form of disability, encompassing physical, intellectual, and psychological impairments (Goodley 2014). It operates similarly to other forms of

discrimination, relying on a set of beliefs and practices that uphold a perceived superior standard of ability, productivity, and capacity among those who are said to be 'able'.

As a form of conscious opposition, disabled people have started to challenge dominant social ideas and reclaimed their right to live on an equal basis with others. Linking disability experience to oppression has enabled the disabled people's community to advocate for change using the language of social justice (Shakespeare 2014). Alongside the social model, independent living defends the idea that disabled people must have the power to control their lives, to make decisions about their future, and to set goals for themselves (Tarrant 2022). It is both a philosophy (Morris 2004) and a goal in itself (Brisenden 1986), and it arose from inside the community in the 1970s and 1980s as part of a fight against institutionalisation and segregation.

Even though the social model has been a key framework for addressing economic and social failures by exposing the numerous barriers in transport, employment, and education, it requires further development to effectively include issues of sexuality, intimacy, and relationships. Sexuality is one of the topics addressed by the Independent Living Movement, but it remains one of the most stigmatised areas in the lives of disabled people. Society's denial of their right to pleasure, intimacy, sexual exploration, and sexual expression arises from a pervasive disregard for disabled people's privacy, individuality and self-determination (Santos and Santos 2018). The social construction of the impaired body as fragile, dependent, and powerless perpetuates the myth of disabled people as asexual, undesirable, lacking sexual agency, and eroticism (Morales et al. 2016; Shakespeare 2000; Siebers 2008). In contrast, disabled people may also be stereotyped as hypersexualised and unable to control their sexual desires (McRuer 2006; Shuttleworth and Mona 2002). The cumulative impact of these ableist discourses is the desexualisation of disabled people, which in turn results from the historical dehumanisation, infantilisation, and medicalisation of their experiences (Shakespeare, Gillespie-Sells, and Davies 1996; Shakespeare and Richardson 2018). As Vitorino (2024, 56), wrote, 'disability has never prevented anyone from fully experiencing sexuality – society has!'

For members of marginalised communities, the process of identity formation is heavily influenced by hegemonic narratives about them. These narratives frequently rely on a singular, biased perspective of their experiences, disseminated by those in positions of power, leading to feelings of isolation, Otherness, and internalised shame (Hall 1996). The lack of diverse representation and relatable role models can hinder the development of a positive self-concept and a sense of belonging (hooks 1992). Moreover, dominant social constructions of sexual life are inherently oppressive, imposing rigid standards of perfection that encompass physical appearance, sexual performance, the individuals involved, and the expected sequence of a sexual encounter, from the initial stages of seduction to orgasm and climax. Within this context, lack of accessibility and representation has had major impact on the intimate lives of individuals with disabilities. The barriers they encounter in their public life are as complex and multifaceted as those within the private domain (McRuer 2006; Shakespeare 2000; Siebers 2008).

Within the disability rights movement, the voices historically heard have been predominantly male, with men often leading the fight for disability rights. Conversely, other social movements have largely failed to incorporate the experiences, realities, and bodies of disabled people into their agendas, even though they strongly challenge heteronormative societies (Garland-Thomson 2002; Morris 1993). Discussion of 'simultaneous oppressions' (at the time, not yet termed intersectionality) (e.g. Nogueira 2017; Platero 2012; Rodrigues et al. 2018) was initiated by the Combahee River Collective (1977/2012), highlighting how class, gender, race, and sexualities interconnect to shape the concrete conditions of people's lives (Combahee River Collective 1977/2012). However, intersectionality as a critical framework, as developed by Crenshaw (1991) and expanded by Hill Collins (2019), involves not merely the addition of identities. It is a lens to understand how systemic power structures – such as ableism and heteronormativity – interlock to produce unique modes of discrimination.

Within the Portuguese context, this means acknowledging how the 'normative body' is constructed through a Catholic, conservative lens that marginalises those who fall outside the standard of productivity and reproduction. Feminist disability theory (Garland-Thomson 2002) and crip/queer approaches (McRuer 2006) have further exposed how ableism intersects with other systems of oppression, producing forms of marginalisation that are simultaneously material, symbolic, and affective. As a response to the single social identity-based disability advocacy, the disability justice framework has emerged,

contributing to an understanding of disability as a complex, interconnected, and multidimensional experience (Goulden et al. 2023). This anti-ableist perspective invites people to rethink their research and professional work. By putting principles – such as interdependence, collective access, and the leadership of those most affected – into practice, people can work towards liberation for everyone (Sins Invalid 2016).

The intersectionality of oppression in contemporary societies means that individuals with multiple marginalised identities experience a compounded form of discrimination, which is not simply additive but more complex (Coll-Planas 2012; DeFrancisco and Palczewski 2007; McCall 2005; Nash 2008; Nogueira 2017). Each attributed social position, along with these interlocking systems of power, shapes unique experiences of privilege or prejudice (Crenshaw 1991). Within the disability community, individuals who hold multiple marginalised identities face an increased risk of having their bodies and needs marginalised and subjected to discrimination. The ableist model of normalcy and cure, which defends a binary of broken and fixed, also tends to medicalise and pathologise non-normative experiences. Therefore, the medicalisation of disability acts as a potent tool of disempowerment. By reducing the disabled body to a biological ‘problem’ to be fixed, the medical model strips individuals of their sexual agency. This biologising reading shifts the focus from social rights to clinical rehabilitation, where the person’s desire is often pathologised or ignored in favour of functional maintenance. Nonetheless, within an oppressive system, dissident bodies resist and challenge hegemonic narratives surrounding disability and normative sexuality.

While the concept of ‘coming out’ is often associated with the queer community, Shakespeare, Gillespie-Sells, and Davies (1996) and Myers (2004) have suggested that it can be applied to disabled people as well. The ‘coming out’ process involves the external act of disclosing one’s identity and the internal journey of reconciliation and affirmation. It points to a pivotal moment where individuals recognise themselves as political subjects, individually and collectively, and celebrate their authentic selves, contributing to a broader feeling of joy and pride.

The experience of disability can contribute to the process of re-sexualisation by enriching sexual practices and bringing into them the creativity that so often is developed by disabled people through overcoming daily obstacles (Shakespeare and Richardson 2018). While social structures neglect their sexual needs and rights, advocating for access to both public and private spaces, as well as agency over their own body, is essential (Santos and Santos 2018). Ensuring that disabled people have equal opportunities to experience bodily autonomy, intimacy, sexuality, and pleasure is a fundamental human right (WAS 2014). Therefore, rejecting the notion of a singular ideal of beauty, ability, and attractiveness should also be a priority of the Independent Living Movement, as an act of narrative reconstruction through which sexual identity is reclaimed and agency developed and empowered (Hyvärinen 2007).

Against this background, this article contextualises the history of the disability movement in Portugal before engaging with activist voices concerning the ‘multiple oppressions’ and ‘dissident bodies’ of disabled people and proposing transformative pathways for public policy and academic research.

### ***The disabled people’s social movement in Portugal***

Similar to other countries, disability in Portugal has historically been framed as a personal tragedy, typically associated with charitable dependency. The revolution of 1974 provided crucial impetus for the development of the social movement of disabled people (Loja, Costa, and Menezes 2011), due in part to the significant return of disabled veterans from the colonial wars in Africa, who did not accept the limited of the Portuguese government when they returned home (Fontes 2014). Subsequently, the influence of international activists, public events and conferences, and the ratification of the United Nations Convention on the Rights of People with Disabilities inspired the organisation of independent living-based initiatives and demands.

In 2010, a group of disabled people came together to create the *(D)eficientes Indignados* [Outraged people with (dis)abilities] collective who mobilised social and political actions to fight for disability rights on the streets, including through demonstrations, debates, [later] online mobilisation, and vigils. As a result of the political pressure from within this community, the first pilot project offering personal assistance<sup>1</sup> was created in 2015, funded by the public authorities in Lisbon. This led to the foundation of the first Centre for Independent Living<sup>2</sup> in Portugal. This successful experience in Lisbon laid the foundations

for a later national pilot project (Decree-Law 129/2017 2017), the *Modelo de Apoio à Vida Independente (MAVI)* (Independent Living Support Model), funded by the European Social Fund, that enabled people to apply to *Centros de Apoio à Vida Independente (CAVI)* (Independent Living Support Centres: the bodies responsible for managing personal assistance) for personal support, in multiple cities across the country. When the pilot-projects finished in 2023, Administrative Regulation 42/2023 guaranteed the continuity of the Independent Living Support Model in Portugal and led to cooperation agreements being signed between the Instituto da Segurança Social<sup>3</sup> (Social Security Institute) and a number of Independent Living Support Centres (Fontes and Martins 2023).

However, public investment is not enough to meet the everyday needs of disabled people, undermining the principles of autonomy and self-determination. Disability policy continues to be dominated by a traditional institutional framework at both national and local levels. These structures are often led by non-disabled professionals and remain focused on a rehabilitation-centred approach rather than policies shaped and managed by disabled people themselves with a focus on human rights, which contributes to the ongoing neglect of disabled people's interests and agency. One example of this imbalance can be seen in the structure of Independent Living Support Centres: 35 of these centres are operated by traditional organisations for disabled people, whereas only four of them are managed as Centres for Independent Living by disabled people themselves. This disparity raises concerns about whether the core principles of the independent living movement are being upheld (Fontes and Martins 2021).

Given the limited number of disability rights organisations in Portugal that adhere to independent living principles, one collective was invited *via* email to participate in case study research so as to foreground their feminist and critical approach. The collective concerned – *As DEsaFiantes* (The DEFiantes) – was established as an anti-ableist social movement in 2020. Its mission was (and is) to address issues arising from the intersection of gender and disability and its members engage in political activism and other actions to draw attention to the lack of public policies tailored to the needs and experiences of disabled people as well as measures that might ensure a life of freedom, safety, and self-determination.

## Methods

### *Sample selection and data collection*

A variety of online platforms, including social media and websites, were used to identify disability rights advocacy groups, and four groups were invited to contribute to the study. A national-level collective – *DesaFiantes* – was chosen for inclusion in the study given its history of organising initiatives and demonstrations advocating for independent living. Importantly, *DEsaFiantes* had a history of collaboration with other groups and social movements, including participation in a national platform of feminist collectives and a group of LGBT organisations.

The ages of the five *DEsaFiantes* members ranged between 29 and 40 years. They were geographically distributed across different cities, ensuring territorial representation. All identified as cisgender; the majority had physical impairments, often associated with chronic illness. Most were single, with one member being in a civil partnership. The majority identified as heterosexual, with one member currently exploring their sexual orientation. Their professional backgrounds include psychology, design, and computer engineering.

Members of the collective were briefed about the purpose of the research and the chosen methodology and invited to identify two persons as representatives of the group. The representatives selected for interviews were two disabled women (hereafter labelled P1 and P2) chosen by the collective itself based on their experience in intersectional activism and civic participation. Their perspectives concerning the sexuality of disabled people were informed by ongoing internal discussions and sustained engagement in listening to community needs, and therefore reflected shared, collectively developed viewpoints rather than solely individual positions.

Following the verbal informed consent, two members of the research team (ARP and LR) conducted data collection in three distinct phases: initial exploratory interviews (I1), followed by semi-structured interviews (I2), and finally, a collaborative discussion of the preliminary findings (I3). All interview/discussion sessions were audio-recorded, transcribed, and anonymised. The discussions centred on terminology

and models of working related to disability, sexuality, and corporality, as well as the theoretical and practical aspects of supporting sexual expression. Data collection took place between October 2023 and July 2024, with each phase averaging two hours.

To ensure rigour, research team engaged reflexively with the process and data elicited. This involved integrating the interview data with the collective's public manifestos as well as collaborative discussion and member-checking to ensure the findings reflected the organisation's political stance. Such an approach has been used in other research to capture organisational memory and the ideologies that underpin a social movement's work (Bogner, Littig, and Menz 2009). Importantly, by focusing on the experiences of the chosen representatives, this study does not aim to offer a generalisable account of all disabled people's organisations in Portugal, but rather the political and intersectional discourse of one leading activist collective.

### ***Analysis***

Reflexive Thematic Analysis (Braun and Clarke 2019, 2022) was used to identify both stated and underlying meanings within participants' narratives. The analysis followed the six-stage process recommended by Braun and Clarke (2006): 1) immersion in the data; 2) application of codes to the narratives; 3) development of initial themes and sub-themes to capture broader meanings; 4) refining these themes to ensure they reflected recurring patterns of meaning connected to core concepts; 5) clearly defining and labelling the final themes; and 6) generating a comprehensive account, supported by illustrative excerpts from participant narratives. These excerpts were translated into English by members the research team. Two main themes were developed – multiple oppressions and dissident bodies (Figure 1).

### ***Ethics***

This study protocol was reviewed and approved by the Ethics Committee of the Faculty of Psychology and Education Sciences at the University of Porto (Reference: 2023/06-11c).

## **Findings and discussion**

### ***Multiple oppressions***

This first theme comprised three subthemes: intersectional sexuality; oppression and the construction of subjectivities; and dependent lives due to social oppression. Within this theme, all sub-themes were permeated by ableism, a power structure that relegates the sexuality of disabled people to secondary status, and fails to recognise it as a priority compared to other domains of life.

### ***Intersectional sexuality***

The subtheme intersectional sexuality documented the multiplicative impact of intersecting social forces on the sexual experiences of individuals with disabilities. Within the Portuguese context, it illustrated the interplay between disability, gender, sexual orientation and/or gender identity (LGBT+), and class.

In Portugal, the dictatorship (from 1933 to 1974) and the influence of the Catholic Church have contributed to the development of heterosexist ideologies (Amâncio and Oliveira 2006) which powerfully affect discourses of sexuality. For members of the collective, this history was of profound importance since its impact on sexuality was such that, 'To embrace your sexuality is practically a revolutionary act. In Portugal, you can't just take that for granted' (P1, I1). The intersection of disability with sexuality amplified this challenge because of the double taboo it creates. Members of the collective described how disabled people were often hypersexualised if they showed any interest in sexuality. However, if they did not express desire, their sexuality was ignored, and they were desexualised. Both of these negative responses are ableist mechanisms to control the sexual lives of disabled people (Shakespeare, Gillespie-Sells, and Davies 1996; Shakespeare and Richardson 2018). The invisibility of disabled people extended to exclusion from sexuality education and medical appointments concerning family planning. Gender also played a key role; the women interviewed felt invisible, especially in activist circles where their sexual and reproductive rights were often ignored:

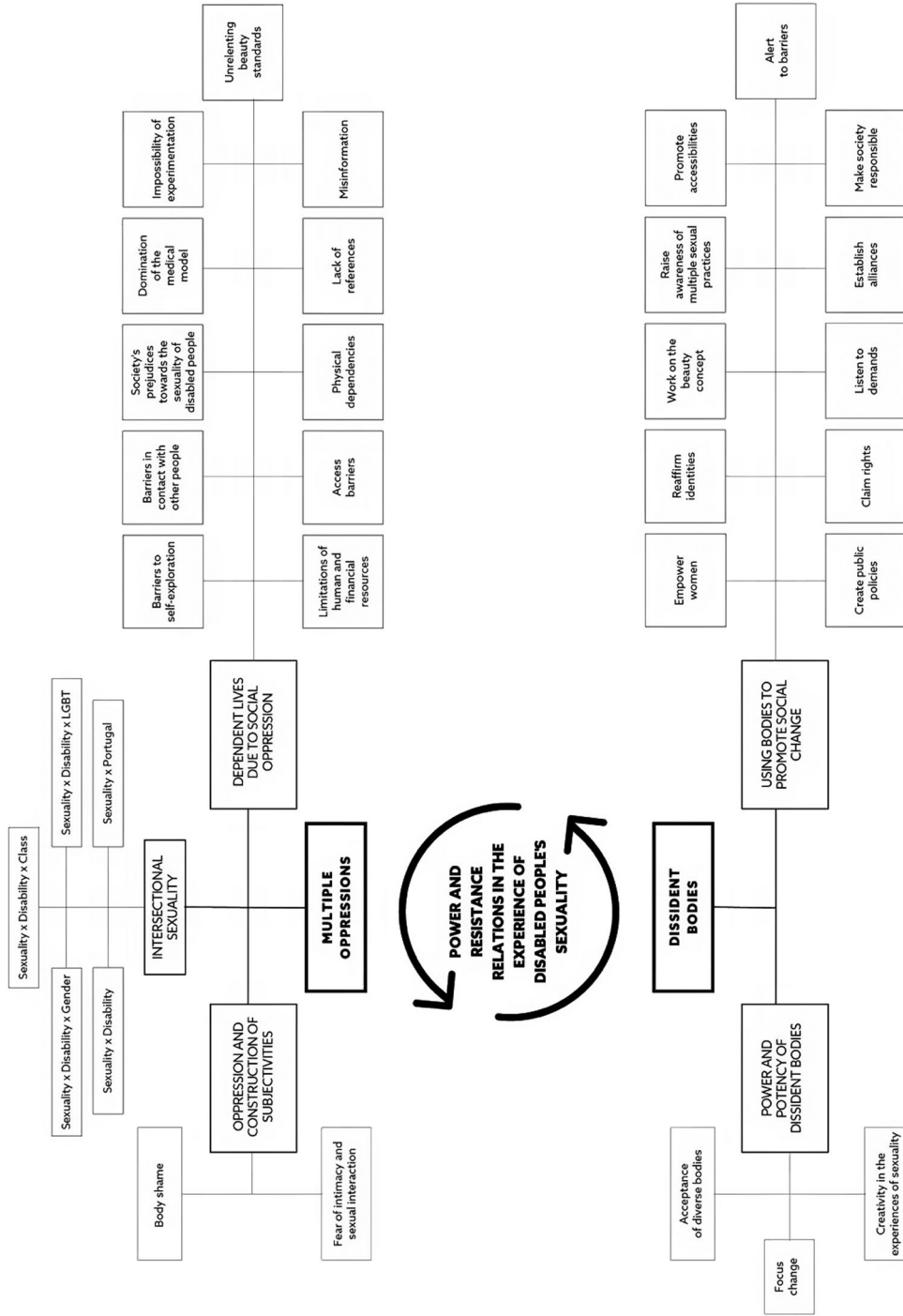


Figure 1. Thematic network of the analysis..

Through our collective work, I've noticed that women's normative demands are never remembered. When they [other social activists] demand sexual and reproductive rights, because of our invisibility they [other social activists] never remember that disabled women also have the right to access sexuality and parenthood. This is very evident within activism. It's a constant fight for us within other communities to remember that we are also women. We too must access all the other rights, in addition to accessibility, which everyone already knows is insufficient for disabled people (P2, I2).

Such comments highlighted how other social movements often failed to include the needs of disabled people as part of their agendas (Garland-Thomson 2002; Morris 1993).

Members of the collective also described significant barriers to disabled people exploring their sexual orientation and gender identity, citing limited access to LGBT+ spaces and social interaction, hindering pre-coming-out experiences:

(...) it cannot just be about having an accessible march; it must also include the parties and the spaces where posters and banners are made. Everyone needs to see whether they feel at home in the [LGBT+] context or not ... you have only just caught a glimpse of it (...) That makes coming out difficult because you cannot truly see what it is like, can you? (...) [Real inclusion] requires more than planning and logistics; it is not simply about letting someone scratch the surface. (P1, I2)

For the collective, accessible spaces where people interact with others are essential, so individuals can begin to understand themselves and what different experiences feel like. Otherwise, the isolation and lack of access to affirmative spaces can impact well-being (Russell and Fish 2016).

Concerning social class, the collective pointed out the disproportionate impact of poverty on individuals with disabilities. Access to resources, such as personal assistance, education, and finance, significantly influenced disabled people's ability to navigate social barriers and access opportunities for sexual expression, including the use of sex toys and sex services. Members of the collective claimed that the financial burden of meeting basic needs should not preclude access to sexual rights.

Taken as a whole, the effect of these intersecting oppressions was to place a substantial burden on disabled people. Sexuality and disability's intersection with other social divisions (such as social class, age and gender) resulted in a complex experience of social exclusion and marginalisation for the people *DesaFiantes* advocated for, and worked with.

### ***Oppression and the construction of subjectivities***

The second subtheme - oppression and construction of subjectivities – described the impact of oppression of disabled people's sense of self. Members of the collective described pervasive bodily inadequacy and shame as a result of the incongruence between their non-normative bodies and societal ideals of beauty, a situation further exacerbated by the medicalisation of disability.

I think that even internally, our relationship with our bodies is medically loaded with shame; we're still very stuck, and we feel very attached to our bodies, and we feel that our bodies do not correspond to the standards that society demands and imposes. (P1, I2)

Afear of intimacy and sexual expression was also evident, particularly among individuals with higher needs for support. This fear was rooted in concerns regarding dependency and vulnerability, as collective members expressed apprehension about relinquishing control over their bodies during intimate and sexual encounters. As P1 put it, '(...) we give our bodies in a way we cannot manage, we cannot dress ourselves afterward, and so we cannot say goodbye to a person after casual sex' (I2). The inability to manage post-sexual activity, such as dressing or disengaging from a partner, can create a barrier to subsequent sexual experience. While desiring diverse sexual experiences, the collective acknowledged that disabled people might avoid them due to perceived vulnerability and lack of control, hindering their ability to experience pleasure and engage in sexual encounters as fully as they might wish.

There was a reciprocal relationship between the oppressions caused by society and the construction of subjectivity. For disabled people, the process of making sense of themselves through subjectivation fosters dependency, since societal oppression reinforces experiences of shame and fear. This highlights that because ableism is so deeply embedded in society, addressing it requires dismantling systemic structures through broad, multidimensional change.

### *Dependent lives due to societal oppression*

This subtheme focused on the externally imposed constraints that impede independent living and sexual autonomy among disabled people. The collective considered self-exploration essential to enable people to know their own bodies and experience pleasure. However, there are people who cannot access their own bodies or who are forbidden (by force of individuals or circumstances) to enjoy self-pleasure. Such actions by institutions, family members or others undermine self-esteem through the devaluation of disabled bodies and affect bodily agency (McRuer 2006; Shakespeare 2000).

In addition, disabled people experience barriers and social stereotypes that negatively impact the possibility of interaction with others. Thus, society's prejudice towards the sexuality of disabled people reinforces desexualisation: 'there's infantilisation and this places sexuality as secondaries and as if it were a non-basic need' (P2, I2). Moreover, the prevailing medical model in Portugal, which frames disability as an individual problem that requires rehabilitation, contributes to this perspective. It often prioritises care over self-determination, neglecting the sexual dimensions of the lives of disabled people, even in cases of acquired disability: '(...) everything is rehabilitation, and the sexuality part is very neglected (...). There is no expectation that disabled people are sexually active; therefore, people do not talk about it' (P1, I2). This pathologisation of dissident bodies provides another illustration of the ableism that seeks to suppress the sexuality and autonomy of disabled people (Siebers 2008).

Lack of opportunities for experiencing sexuality also contributes to the construction of the notion that 'for us, sexuality is like an event; when it happens, there is no possibility of simply experiencing it' (P1, I2). Similar to the limited access to LGBT+ spaces previously described, this extends to sexuality in general, since existing barriers are obstacles to people's experience. Because of this, the collective emphasised the need to visibly reclaim and assert their presence within the sphere of sexuality and sexual citizenship if they wanted to be part of it.

This perception was further reinforced by the logistical and financial barriers to accessing sexual experiences, which together deepen the invisibility of sexuality within this context.

Other issues against which the collective struggled were the beauty standards that reinforce the desire to have an ideal body, misinformation concerning people's rights (particularly concerning personal assistance), and the absence of relatable peer role models. Disabled people experience a significant lack of role models during their developmental years. They also experience an absence of disabled individuals—both in media representations and within their immediate social environments—who openly express their sexuality. As a result, participants grow up without relatable examples of disabled people engaging in sexual and affective relationships, which contributes to a sense of isolation and difference.

Physical dependencies, exacerbated by inaccessible environments and limited access to human and financial resources, including personal assistance, were seen as compounding these challenges. The financial constraints faced by many disabled people further restricted their access to leisure activities, dating opportunities, and sexual services, reinforcing a cycle of dependence:

(...) when we seek a paid sexual relationship, like anyone else might, we face all the challenges previously mentioned, compounded by financial barriers. And this financial limitation does not apply only to paid sex, but also to accessing dates and social interactions more broadly. Disabled people are among the most economically disadvantaged groups in society. Consequently, any form of leisure or activity that requires financial resources becomes significantly less accessible. This economic marginalisation, combined with multiple layers of stigma, further restricts the expression and experience of sexuality for disabled individuals. (P1, I2)

The concept of 'dependent lives' therefore extends beyond physical limitations, to encompass emotional and psychological dependencies arising from barriers to self-exploration and self-expression. Reliance on external provision and permission from others restricts individual autonomy and impedes the free experience of sexuality. Therefore, while advocating for independent living, it is crucial to acknowledge the enduring impact of societal-imposed dependencies linked to systemic ableism and structural oppression.

## ***Dissident bodies***

Power relations are pervasive in society but are also associated with different forms of resistance. Two sub-themes were identifiable within this area of subjectivity and practice: the power and potency of dissident bodies; and using bodies to promote social change.

### ***Power and potency of dissident bodies***

This first sub-theme draws attention to the transformative power of self-acceptance, particularly for individuals with non-normative bodies. Representatives of the collective emphasised how embracing bodily diversity could facilitate a reduction in anxiety for disabled people leading to the development of a more positive sexual self-concept: 'I think that when a person accepts their body, the rest becomes much easier. Because when you can accept the fact that your body is different, the rest of the problems diminish just a little' (P2, I3). In these ways, affirmation and self-acceptance become associated with feelings of pride (Myers 2004; Shakespeare, Gillespie-Sells, and Davies 1996).

In relation to this subtheme, collective members highlighted how this change of perspective was also a form of resistance since it also challenged normative paradigms of sexuality and their phallogentric and penetration-centric focus. Collective members advocated for a shift towards the prioritisation of shared pleasures and an exploration of diverse avenues of sexual expression beyond traditional models.

Creativity was seen as another potentiality of dissident bodies. The existence of this dimension was seen as highlighting the resourcefulness of disabled people when navigating sexual experiences. Collective members described using erotic imagination, thoughts, and alternative sensory stimuli to overcome perceived limitations. Such a creative approach allowed for the exploration of desires and engagement in sexual practices in innovative and fulfilling ways. As P1 noted: 'We're forced to use creativity to overcome difficulties (...) Sometimes to shift the focus a little from what we feel as a limitation forces us to be extremely creative' (P1, I2). Creativity was seen as a strategy to overcome obstacles and shift by shifting the focus away from normative practices that tended to highlight genitalia and/or bodily penetration. Such a process was believed to contribute to the enrichment and resignification of concepts of pleasure and intimacy (Shakespeare and Richardson 2018).

### ***Using bodies to promote social change***

This sub-theme underscored the need for collective action and systemic change to achieve sexual autonomy for disabled people. Collective members identified several key areas for intervention. One of these was the empowerment of women with disabilities. Collective members recognised that women already faced challenges in living their sexuality, but women with disabilities, due to the multiple barriers mentioned, tended to disregard sexuality as a right.

A key priority for the Collection lay in challenging societal norms and fostering an environment that celebrated the diverse identities and practices of disabled people, promoting self-acceptance and challenging the construction of subjectivities shaped by systems of oppression. As the collective advocated for dismantling overly narrow standards of beauty, embracing the beauty of diversity was of paramount importance. As part of this work, there was a need to raise awareness of multiple sexual practices, including those that do not conform to traditional norms, to promote accessibility to sexual sphere, to be constantly alert to barriers, and to hold society accountable for the enduring barriers and stereotypes that still prevent disabled people from fully experiencing their sexuality. To achieve these goals, the collective highlighted the importance of building alliances with trusted figures within the medical community, especially individuals who go beyond disability to focus on the sexuality of the person and respect their right to autonomy and self-determination.

In the eyes of the collective, too many health professionals the focus is 'never on pleasure as a way of solving problems. And the truth is that pleasure and well-being are ways of solving problems and not triggering mental illness, for example' (P1, I2). Furthermore, alliances with the sex industry - particularly pornography producers and erotic product manufacturers - can be important to increase representation and accessibility alongside advocacy for the support and training of sex workers to raise awareness about the diverse needs and desires of disabled people.

Members of the collective pointed to some of the important work that needs to be done, such as listening to the demands of the movement, advocating for sexual rights, and creating public policies in line with real and perceived needs:

Sexual rights will be ensured by listening to us and our demands and creating policies based on our experience. Ah... and [also by] talking about these rights with society and bringing the sexual rights of women or men or people to other social movements. (P2, I3)

Key demands included the criminalisation of forced sterilisation, the establishment of a legal framework for the provision sexuality support services, and improving personal assistance programmes using techniques and approaches identifiable in the existing literature (Hyvärinen 2007). These measures were seen as important in facilitating bodily autonomy and self-determination holding the potential 'to a revolution regarding our bodies, what we do with them, and how we get to places' (P2, I2).

## Conclusion

While this study has focused on the specific experience of one activist collective and the findings from it cannot be generalised beyond that context, participants' accounts reveal the importance of adopting an intersectional perspective with a focus on power and resistance when reflecting on the sexuality of disabled people. To study disability in the absence of a feminist and intersectional focus is to adopt an essentialist perspective that fails to recognise its diversity (Carvalho 2014; Rodrigues et al. 2018).

The collective whose work was focused on here identified a variety of structural barriers that simultaneously sustain and perpetuate ableist attitudes and behaviours concerning the sexual lives of disabled people (Goodley 2014; Oliver 1990; Vitorino 2024). Specifically, the dominance of the medical model has given rise to misinformation, social prejudice towards the sexuality of individuals with disabilities, and an uncritical engagement with existing standards of beauty of Shakespeare and Richardson (2018). Furthermore, barriers within the social, cultural, and physical environment, along with the lack of human and/or financial resources to compensate for them, create a higher level of physical dependency and lack of reference to disabled people than might otherwise be the case. Together, these multiple systems of oppression work together to limit opportunities for disabled people to autonomously explore their bodies and/or have sexual relationships with other people (with or without disabilities). Moreover, the assumption that societal barriers are individual problems, tends to influence disabled people's own self-constructions, resulting in bodily shame and fear of intimacy. The fear of dependency during sexual encounters can lead to the avoidance of sexual expression (Santos and Santos 2018).

While the notion of multiple oppressions reveals how dominant social narratives position disabled people's sexuality in a secondary role, through advocacy and collective action social movements are reclaiming disabled people's rights and demanding social justice (Shakespeare 2014). In this study, as shown in the theme dissident bodies, the *DEsaFiantes* collective emphasised the ways in which sexual autonomy might be struggled for in a manner informed the strategies that have been fuelled by the independent living model (Tarrant 2022).

In conclusion, the perspectives of the interviewed activists regarding the sexuality of disabled people in this study reveal the presence of power dynamics and relations that constrain and oppress individuals. The results of the study suggest that, the strategies and actions undertaken by disabled people to resist and subvert these oppressive forces may be seen as forms of agency and resistance, highlighting the key role played by power and resistance in shaping the sexual experiences of disabled people in Portugal.

## Study implications

Findings from this study have important implications for academic work, the future development of social policy, and advocacy. Within the academic field, there is a need to integrate crip approaches more fully into gender and sexuality studies in Portugal. Research should move beyond question of access to buildings and spaces, to engage with access to sex, sexuality intimacy, utilising participatory action research in which disabled people are co-investigators rather than just subjects. In the areas of social policy and social practice, decision makers, governments, and organisational leaders should more fully

acknowledge the role of sex and sexuality in the lives of disabled people. To enable this, serious discussion needs to take place *with* the disabled people's community (not for the community) informed by the experiences and perspectives of activist groups such as *DEsaFiantes*. To promote equity, inclusion and equality, future legislation and social policy must adopt an affirmative approach to sexuality, but it must also provide disabled people with services and supports to promote their sexual rights. For too long sexuality has been treated as an afterthought for disabled people, with important consequences for the development of both individual and collective identities. Ultimately, the changes required are more than mere policy adjustments. They are actions that seek to liberate all who are oppressed by ableism and the ideologies and practices which it promotes.

## Notes

1. Personal Assistance is a state-funded support service designed to facilitate independent living. The service empowers disabled individuals to act as active managers of their own lives, granting them autonomy over the recruitment, training, and scheduling of their assistants to suit their specific daily needs (Beatty et al. 1998).
2. The Center for Independent Living is a national, disabled-led organisation that advocates for the implementation of independent living policies throughout Portugal.
3. The Institute for Social Security is a Portuguese national public body under the Ministry of Labour, Solidarity, and Social Security that manages the country's social security system.

## Author contributions

CRedit: **Catarina Vitorino**: Formal analysis, Writing – original draft, Writing – review & editing; **Liliana Rodrigues**: Formal analysis, Writing – original draft, Writing – review & editing; **Diana Santos**: Formal analysis, Writing – review & editing; **Conceição Nogueira**: Funding acquisition, Supervision; **João Manuel de Oliveira**: Conceptualization, Funding acquisition, Project administration, Supervision, Writing – review & editing.

## AI use

Gemini 3 was used for English language editing. No Generative AI was used for core content generation or data analysis. The authors take full responsibility for the accuracy and final content of the manuscript.

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