ARTICLE

Acting as if: the utopian political thought and actions of the US disability rights movement

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Abstract

This article studies the response of the US disability community to the prevalent assumption that disabled people do not have a future, in the form of the disability rights movement. It provides an exploratory discussion of the key role played by utopianism in the response. In doing so, the article adds to critical theorizing on the importance of utopia to the oppression of non-dominant groups and to transcending that oppression. I use utopian studies scholarship to interpret the activities leading up to the passing of the Americans with Disabilities Act in 1990 as a minor utopia, characterized by an ambiguous, grounded, and provisional effort to imagine alternative ways of being. I articulate the central role played by a positive vision of disability and disabled people for this inversion of the historically negative relationship between utopia and disability. The article turns to disability activists to show that the movement countered exclusionary utopian approaches by acting as if it had a right to envision and enact a different, better future for all from the perspective of disability and disabled people.

Keywords Crip utopia · Minor utopianism · Disability political theory · US disability rights movement · Utopian political thought

Communities around the world tend to construct visions of the hoped-for-future that presuppose the transcendence of disability. The world would be a better place, these visions imply, 'if disability could be eliminated' (Garland-Thomson, 2012, p. 340). This assumption turns disability into something with no, or at least no good, future and has a detrimental effect on the lives of disabled people (Kafer, 2013, p. 3). As one of the key 20th century witnesses to the horrors committed in institutions for the severely disabled, William Bronston, put it: 'No school, no future, no exit. They've got to die to get out' (Bronston, cited in Pelka, 2012, p. 175). Even those living within their families may encounter little expectation from society of achieving a

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fulfilling life or being part of a positive vision of society (Heumann, 2020). This context sits uneasily with the emphasis within utopian political thought that the future is open and can be 'shaped in positive or negative ways' (Thaler, 2022, p. 55). It raises the question of how disabled people are able to (re-)claim the capacity to envision and shape their own and society's future. In answering this question, the article deepens our understanding of the link between disability and utopia and utopia and the resistance of oppressed groups.

Specifically, the article offers a novel approach to disability and utopia by looking at the role that utopia played in the US disability rights movement's response in the 1970s to 1990s to the exclusionary visions of disability highlighted above. A focus on this period is particularly useful because a radical new political discourse about disability emerged during that time which involved significant utopian world-building to re-imagine the role of disability within society. The 19th and early 20th century had seen the formation of several organizations which fought for the rights of specific groups in US society from the Deaf community to psychiatric patients in mental asylums. However, these organizations often sought to distance themselves from the prejudices and barriers associated with being disabled (Patterson, 2018, pp. 410–411). In the late 1960s to early 1970s a pan-disability movement coalesced around three aims that feature prominently throughout this article, even as it retained some of these tensions and differences in perspectives (Bagenstos, 2009, p. 3): the rejection of the medical model of disability (that treats disability as an illness to be cured through medical advancements, and thus 'rehabilitated' into society, or managed in separate medical facilities) and its replacement by the social model (which highlights that it is social barriers and stigma which prevent people with impairments from participating equally within society and the economy); the empowerment of disabled people to make their own decisions and live fully integrated within society (for example, through the establishment of community support centers for independent living run by and for disabled people); the application of pressure through protest, lobbying and other means towards engendering changes to legal and institutional practices and increase the inclusion of disabled people within the socio-economic and political spheres (leading to a series of federal legislations on reducing architectural barriers and prohibiting the discrimination of disabled people). This article gives a sense of the different uses of the utopian impulse within the movement in relation to these three aims that together provide a comprehensive effort to rethink the relationship between disability, disabled people, and utopia.

My account of the utopianism of the US disability rights movement builds on scholarship on the utopianism of oppressed groups within Black, post-colonial and Indigenous thought, feminism, disability studies and queer theory (Allen, 2015; Dutton, 2010; Hardy, 2012; Jones, 2013; Kafer, 2013; Kauder-Nalebuff & Brodsky, 2015; Muñoz, 2009; Schalk, 2018; Wolcott, 2022; Zamalin, 2019). I take from this literature the insight that utopianism plays an important role in the domination of different communities *and* in transcending that domination. Utopianism here is understood both in the sense of a specific literary form dedicated to envisioning alternative ways of being and the broader process of 'social dreaming' (Sargent, 1994, p. 4) of a better society and hoped-for-future within society. The scholarship is in dialogue with and deepens a critical strand within utopian studies that objects to

reducing utopianism to the creation of a blueprint of the perfect society—what Jay Winter (2006) describes as the formulation of major utopias. The strand broadens the definition of utopia to different expressions of a 'desire for a better way of being or of living' (Levitas, 2013, p. xii), and emphasizes that utopian thought and action can avoid creating totalizing visions that exclude change, conflict and difference. To this end, 'minor utopias' acknowledge the ambiguity of their social dreaming and embrace provisionality and groundedness—I will explain each of these concepts later. This article expands the conception of minor utopia to suggest that what makes the disability activists' approach distinct is that they first had to address the de-legitimation of their utopian impulse through pervasive assumptions that disabled people have no (good) future to dream of. The movement was able to reassert its capacity for social dreaming, by acting *as if* they had an equal right to shape the nature and future of society. As I elaborate further throughout the article, this 'acting as if' involved placing what was previously cast outside of utopian thought and action, in this case disability and disabled people, at the very core of what it means to imagine a better future/society.

The article consists of five sections 'Oppressed Groups' Utopianism', 'Acting As If—the Articulation of Different Criptopias', 'The Social Model and the Ambiguity of the Criptopia', 'The Groundedness of the Minor Utopia', 'The Provisionality of the Minor Utopia', and a Conclusion.

Oppressed Group's Utopianism

In this section, I draw two insights from the literature on the utopianism of oppressed communities for my exploration of the disability rights movement's utopian thought and action and show how these have been addressed within disability studies.

Firstly, the literature highlights that utopianism plays a key role in the oppression of specific groups within society in connection with race, gender, class, disability and so on. This role is visible in the classic interpretation of utopia as a western literary and philosophical tradition that began with either Plato's *Republic* or Thomas More's *Utopia*. The domain of educated men, utopias offered large-scale alternative visions of society as a means to critique the status quo, for example by imagining societies without private property (Abberley, 2018; Zamalin, 2019, p. 3). These static imaginings of a perfect order come with, and depend on, a portrayal of society as homogenous and devoid of change, contestation, or imperfection (Herman, 2016). Utopia as a literary tradition actively excluded difference, including rationalizing the colonization and enslavement of indigenous groups and the exclusion or domination of other ethnicities and women (Chan, 2006; Davidson, 2022; Johns, 2010; Rhines, 2003). Disability studies scholarship has shown that disabled people are either disposed of in utopias as a necessary step towards the ideal society (as in Plato's *Republic*), or relegated to its apocalyptic counterpart, the dystopian novel (Curtis, 2015; Garland-Thomson, 2012, p. 340; Kiefer, 2014). Alternatively, the supposedly improved treatment of disabled people within the utopia serves merely as a marker of the enlightened character of the proposed utopian vision (as in More's *Utopia*).

These tendencies in utopian literature mirror, and indeed support, the broader apparatus of social dreaming within western society and its reliance on exclusionary ideas of reason, progress, and emancipation. The consequences are by now well established, including how they justified imperialism (Allen, 2017; Sargent, 2010). As disability studies scholars have argued, these ideas are part of longstanding discourses, institutions and practices that separate society into the able (or 'normal', 'healthy', 'beautiful', and 'intelligent') and disabled ('abnormal', 'unhealthy', 'ugly', and 'stupid') (Goodley, 2018 p. 6). The categories project an image of a perfect body that is eternal and ahistorical and consist in a collective fantasy that the body without imperfection is an achievable ideal against which all humans are to be judged (Hirschmann & Smith, 2016, p. 269). This fantasy positions impairment as a tragic departure from the normal body that could and should be avoided through physical exercise, care routines, and medical intervention.

The utopia of able-ism runs counter to both human variability and the fact that our bodies are continuously changing (Shakespeare & Watson, 2001, p. 25). To ease the tension, society and the able-bodied person have developed sophisticated coping mechanisms, for instance by externalizing one's insecurities and projecting them onto those that seem most visibly different and 'good to mistreat' (Hughes, 2019, p. 6). This helps draw attention away from a person's failure to meet societal standards of beauty and intelligence and, at the level of society, reproduces hierarchies of power and privilege around the distinction ability-disability (Garland-Thomson, 1997, 2012). In the long run, as the introduction established, disability becomes a site of no future, or 'at least of no good future' (Kafer, 2013, p. 3). In both the explicit sense of utopian literature and the more general sense of social dreaming, then, the exercise of the utopian impulse by dominant groups has played a key role in the oppression of those deemed different, including disabled people.

The second insight I draw from the literature is that utopia is equally central to the resistance of non-dominant groups in society to that oppression. Debates are ongoing about the need for utopia in, for instance, the feminist project (Allen, 2015; Johns, 2010). Nonetheless, the fact of the matter is that utopianism has always been an important tool used by oppressed groups within society. Simply put, marginalized groups have to turn to their imagination for ways to think differently, because of the pervasiveness of sexist, racist and ableist beliefs and practices within society. They cannot afford to hold out on the emancipatory potential of utopian thought and action, embedded as they are in conditions that 'make embracing the negative a political privilege or luxury' (Jones, 2013, p. 4). A defining feature of this dissenting utopianism is that it tends to favor a more partial, speculative approach to utopianism that explicitly leaves space for imperfection and difference and centers on the agency of women or ethnic minorities rather than on mapping out fully what a better place or future might look like (Johns, 2010; Rhines, 2003).

The utopian approach tabs into a more general counter-hegemonic current within utopian literature and scholarship. Indeed, utopianism was from its very beginning caught in a tension between the impulse towards abstraction and realization, imagination and prefiguration. This is evident throughout Thomas More's (1685 [1516]) *Utopia*, starting with his original creation of the term utopia. Utopia sits ambiguously between the Ancient Greek terms for no place (*ou-topia*) and good place

(*eutopia*). However, it is in more recent scholarship and literature that the focus on perfect societies has been largely discarded in favor of a broadly used impulse and practice of social dreaming (Cooper, 2014, p. 3f.). The shift in utopian thought is today particularly associated with Ernst Bloch and his heirs within utopian studies, Fredric Jameson, Ruth Levitas, and Tom Moylan, who gave up on a definition of utopia as a universal blueprint of a perfect society, tainted by the claim that utopias are 'idealistic' and 'naïve'. They favor a greater emphasis on the utopian impulse, understood as the 'desire for a different, better way of being' (Levitas, 2010, p. 209). Levitas, Jameson, Moylan (and Bloch) feature prominently in the academic scholarship on oppressed group's utopianism, for example in José Esteban Muñoz's seminal book (2009) *Cruising Utopia*. In a way, then, oppressed group's utopianism expresses a radicalization of a critical strand within utopianism that centers on the utopian projects of specific dominated groups. I contribute to both sets of literature by focusing on disability activism as a neglected subject in utopian studies and political theory (for a recent example, see Chrostowska and Ingram, 2016). In the process, I extend the research into utopia and disability by providing a framework to help capture the important role of utopianism for and within the disability rights movement.

To further distinguish the approach to utopia adopted by social movements, I draw on Jay Winter. Winter (2006) introduced the term minor utopia to move attention onto the rich culture of more fragmented and partial utopian endeavors characterizing the left in Europe and the United States during the 20th century. Minor utopias are not simply more 'realist' or 'realistic' in the sense that they are small-scale and dedicated to tackling 'real world' problems. Otherwise, this would apply similarly to most localized, de-humanizing projects, including the numerous endeavors of the eugenics movement, and the category of major utopia would become untenably narrow. Minor and major utopianism are also not mutually exclusive categories; for both, the exercise of the utopian impulse potentially marks a moment of discontinuity and radical disjuncture to think and act freely, but also the realization 'that we do not live there; we live here, and we cannot but use the language of the here and now in all our imaginings' (Winter, 2006, p. 3). All uses of the utopian impulse are therefore ambiguous and prone to reproducing the exclusionary practices of the present. However, whereas major utopias tend to ignore or reject this ambiguity, minor utopianism affirms the limits of any vision of the future in the way it articulates a desire for a better world. Utopias are not conceived primarily as a goal, in the form of a future world without discrimination towards disabled people, but a practice 'accompanied by a recognition of provisionality, responsibility and necessary failure' (Levitas, 2007, p. 290).

At the heart of a minor utopia must be an acceptance of necessary failure—not any moment of failure but the inevitable fact that our visions of the future will raise further problems and prove inadequate in important ways. Our utopian impulse 'can and will be disappointed', but it is 'nonetheless indispensable to the act of imagining transformation' (Muñoz, 2009, p. 9; Mrovlje, 2023). Minor utopias are therefore intentionally more open and dynamic in their formulation and realization. A focus on provisionality however does not imply deferring judgement or embracing vagueness. Instead, it is by accepting the complexity of reality without shying away from

the need to come up with concrete proposals for changing an unjust world that we take responsibility for our capacity to transform society for the better. Minor utopias are therefore to some extent grounded utopias, which 'strive to actualize the utopian desire for change in the here and now' (Thaler, 2019, p. 1008). Grounded utopias combine a vision of a future world different from our own with efforts to 'excavate emancipatory potentials that are latent in the status quo' (Thaler, 2019, p. 1004) by, for instance, exploring quotidian spaces open for alternative ways of living (Cooper, 2014). Groundedness retains the utopian impulse in that it undermines assumptions about the necessity and inevitability of the status quo and shows that 'radical difference is possible and that a break is necessary' (Jameson, 2005 p. 231f.). It does not give way to the distinction between 'pragmatism'/'realism' and 'utopianism'/'idealism' but explores the break from the status quo to show that what seems impossible and implausible can be a viable alternative to the present power arrangements. Lastly, at the center of these utopias is not the impossible dream of a perfect society, but the thoughts and actions of those who dream it and seek to make it reality (Chan, 2006; Moylan, 2014, p. xvii).

In the following, I bring out how the movement's minor utopian project offers a partial, limited attempt to imagine a better future that is by necessity ambiguous as it is formulated using the perspective of the present, and affirms this ambiguity by relying extensively on a grounded and provisional mode of utopianism that explores the emancipatory potential in the present to make credible the not-yet and playfully extend boundaries of the social imaginary.

Acting as if: the articulation of different criptopias

A keyway in which oppressed groups' utopianism is distinct from other forms of minor utopianism is that marginalized and dominated communities have to seize 'a space of imagination from which they' are historically barred and 'imagine a new humanity from which they' are excluded (Zamalin, 2019, p. 12). Their exercise of the utopian impulse requires an additional effort to move from a position of having no future and no need to shape one's own future, towards claiming one's stake in society's processes and practices of imagining a better world. To fully understand what this effort involves, we need to attend to the fact that the invalidation of people's lives and perspectives works by a sleight of hand that treats '*different than*' as '*less than*' (Zola, 1982, p. 237). Disabled people are not simply different, but disability is perceived as always less than ability. An autistic person or wheelchair user, so the assumption, would always be better off with a neurotypical brain and outside of a wheelchair. It then doesn't take very long before a second move occurs that treats 'less than' as a threat and hindrance to further individual and societal progress. The hoped-for-future gets entangled with the exclusion and domination of different people.

The acting 'as if' brought out by Alex Zamalin above, inverts the process of exclusion. It, too, consists in a sleight of hand which however treats 'less than' as 'different than'. The reversal of the devaluing process works by placing that which was cast at the edge of the social imaginary at the center of the utopian process and treating it as a

natural part of utopianism. Utopia now becomes associated with the projects and imaginations of oppressed groups: queerness, for example, 'is essentially about the rejection of a here and now and an insistence on potentiality for another world' (Muñoz, 2009, p. 1). In relation to disability, utopia becomes 'crip utopia', or short 'criptopia'—a term used for example by Adolf Ratzka (1998) in his science fiction short story of a time traveling Crip van Winkle. 'Crip' is a reference within disability studies and activism to the positive construction of culture and identity around being disabled that intentionally subverts the derogatory word 'cripple' (Sandahl, 2003). Criptopias aim to delineate and push the boundaries of a different way of thinking about disability and society. They can be minor utopias insofar as the utopian visions conjured up remain provisional, grounded attempts to re-structure the world. Crucially, *crip*topias subvert the traditional format and framework of utopia, by (a) articulating better ways of being from the perspective of disabled people and their allies and (b) identifying in the contestation of the concept of disability a resource for (rather than an obstacle to) imagining and enacting a better way of being.

The exercise of the utopian impulse can take at least three forms, and they are all present and vital to the efforts of the disability community to re-imagine ableist society: utopian theory building, practical utopias, and utopian literature. The interrelated, but distinct currents have become known as the three faces of utopian studies (Sargent, 1994). Theory-building entails a critical reflection on the role of utopia in society and for positive social change (Sargent, 1994). I will focus on the theoretical framework central to the US disability rights movement, the social model of disability, which testifies to the flawed utopian dimensions to dominant views on disability and affirms the potential in utopias, in this case the vision of a fully accessible society, to engender positive social change. Practical utopias are characterized by 'living out some portion of a transformed future in the here and now' (Robertson, 2018, p. 241)—they are 'incubators of change' (Thaler, 2019, p. 1007). One such example are the centers founded by the movement to promote disabled people's independent living. They use the successful integration of disabled people into society to support the claim that, with suitable changes to the social conditions, anyone can live a fulfilling life by exercising the right to make their own decisions. Lastly, Sargent suggests that utopian literature 'refers to works which describe an imaginary society in some detail' (Sargent, 1994, p. 7), while also acknowledging the limits of any one definition to capture the sheer breadth of utopian writing. I draw on contributions to the magazine *The Disability Rag*, a subscription-based periodical published between 1980 and 1996. I also draw on Irving Zola's (1982) memoir, a defining text of the independent living philosophy and foundational to disability studies. Their work is part of a sustained engagement with the treatment of disability in (utopian) literature that offers a critical approach to the norm of describing an imaginary society in some detail.

The social model and the ambiguity of the criptopia

My discussion of the movement's criptopianism begins with a focus on utopian theory-building. I trace the move from medical to social model of disability and the latter model's utopian features. The discussion of the social model provides an

opportunity to address the criptopia's ambiguity, the fact that 'minor utopias reflect the material and ideological conditions from which they emerge' (Thaler, 2019, p. 1007).

The medical model was a dominant approach to disability from the early to mid-20th century. It perceived disability as a physical or mental defect attributable to specific bodies (Shakespeare & Watson, 2001, p. 11). The development of a disability was a personal tragedy to be prevented in the future with further scientific advancements, early diagnosis, and appropriate treatment (Pelka, 2012, p. 8). Disability became associated with an unhealthy or even sinful life, and non-dominant identities within society the subject of efforts to 'treat' or separate out non-conforming appearances, attitudes, and behavior (Nielsen, 2012, p. 136; Pelka, 2012, p. 78). Both treatment and segregation presupposed that disabilities should be cured or managed with the least disruption to 'normal' private and public life. Beyond the treatment of their defects, disabled people's needs and desires—particularly of those facing multiple forms of oppression with regards to race, class, gender—were of low priority. By the 1960s, those deemed to have a disability largely disappeared from public life in western society (Hughes, 2019, p. 26).

The medical model performed a sleight of hand by which the identification of real or perceived physical and mental differences often equated to a status as 'less than human'. To challenge this tendency, activists championed an alternative, social model of disability. The model separates impairment from disability and interprets the latter primarily in terms of the social barriers that prevent inclusion and equality (Davis, 2016, pp. 195ff.). It is 'society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (Oliver, 1996, p. 22). 'The problem' is no longer the individual person, but a society that is built to accommodate a body and mind that is 'healthy', 'intelligent', and 'normal'. Curing the disabled section of society cannot solve the problem that the social environment is hostile to human difference, vulnerability, and inevitable decay. In other words, the separation of impairment and disability exposes the sleight of hand to scrutiny, by isolating the problematic, social construction of disability. For instance, if impairment is often a matter of difference then societies face difficult questions about what treatments are cosmetic or necessary—as well as broader questions about what kind of society we wish to live in—that the underlying assumptions of the medical model about disability conveniently assume as resolved/ easy to resolve (Kafer, 2013, p. 6).

The social model helps reverse the negative role of disability within the dominant social imaginary, and in so doing opens the space for alternative uses of the utopian impulse in relation to disability. The model is therefore 'a "utopian" form of political optimism, the starting point of a philosophy and practice of hope' (Hughes, 2019, p. 60). It replaces the hope of transcending disability with disabled people's hopes and dreams of a world in which disability is treated equally or even celebrated: what if 'someone's story began with the words: "I never wished I didn't have a disability"' (Heumann & Joiner, 2020, p. 201). Proponents of the social model envision 'a society where people with impairments live and flourish alongside everyone else but where disabling barriers and disablist values and attitudes have disappeared' (Oliver, 1996, p. 38).

The last quote also brings out a key way in which this criptopian theory-building is ambiguous by reproducing prevalent tendencies towards a static, universal blueprint. For example, the social model retained elements of the medical model in its understanding of impairment as a neutral category. What is considered an impairment, however, is open to change, for instance the impact of corrective lenses on short-sightedness. In addition, the model assumed at times that ableism can be overcome through the complete removal of physical barriers (Shakespeare & Watson, 2001, p. 11). As a more inclusive vision, the strong focus on society as the problem, and on socio-economic barriers to equal participation, at the same time marginalized turning to medicine for solutions and cast 'cure out of our imagined futures' (Kafer, 2013, p. 7).

The tendency is also visible in the disability rights movement's engagement with experiences of social oppression based on multiple social distinctions. Despite disability activists' general sensitivity to racism in US history, and the use of analogies between racism and ableism to further their course, there was a hesitancy to engage in anti-racist struggles (for a detailed discussion, see Erkulwater, 2018). Different historic factors played a role, including the continued impact and legacy of racial segregation in the US. Of note is that the movement was pre-dominantly constituted of white, middle-class, highly educated activists who were able to view disability as the primary source of their discrimination and therefore as the most important or defining feature of identity. The movement further reinforced the sense that 'if you're disabled, that's the only thing, you know, that is important' (Lacy, 1998, p. 110) as they sought to transcend the historically fragmented nature of disability activism, separated by impairments and race and class, by unifying activists around shared goals and a shared positive disability identity. Consequently, the movement was unable or unwilling to account sufficiently for differences within disability and at the intersection of social distinctions.

The issue comes out in the case of the Berkeley Center for Independent Living, a key location of disability activism within the movement (more on this later). Activists such as Ed Roberts had been radicalized at university in the presence of other civil rights movements and were sensitive to the fact that the Center was situated within a largely ethnic minority community (Pelka, 2012, p. 197). There was therefore a recognition of the need to reach out—without however a serious re-evaluation of the concept of disability (Erkulwater, 2018, p. 380). As Johnnie Lacy, a Black disabled member of the center notes: 'I remember the discussion going on for years and years and years about how you served different races from different cultures after the fact most minority cultures regarded the disabled person as part of a whole unit and that independence from the family was not recognized. I mean, wherever you go, your family goes, as a disabled person' (Lacy, 1998, p. 110). The leaders of the center were similarly reluctant to allow different groups to form within the center to represent the interests of different sections of the disability community (Galloway, 2001, p. 77). These issues were only resolved through increased outreach and, importantly, recruitment of people from diverse backgrounds.

We see that minor utopias developed by marginalized groups remain prone to the exclusionary tendencies they challenge. Indeed, they have a particular need to construct unitary perspectives because of their precarious position at the 'ragged edge'

of society (Shaw, 1994, p. xii). While this experience and its impact on disability is not shared equally, many disabled people and organizations experience significant economic uncertainty as well as a particular vulnerability that arises from requiring support in their private lives, for instance to go to the toilet. To become disabled can mean a unique openness to the realization of human imperfection and continuous change, and this can lead to a positive engagement with human existence but also a fear of further physical and social disablement (Shaw, 1994, p. 9). At the ragged edge, security and certainty become particularly valued goods. At the same time, the criptopia is distinct from the dominant culture's utopian approach in the extent to which engagement with different dominated groups was both unavoidable and desirable. As Susan Schweik (2013) shows, frame extension was an important part of how the utopian project operated. The US disability rights movement was inspired by, in conversation with, and profited from the actions of other movements (Heumann & Joiner, 2020, p. 90; Pelka, 2012, p. 418).

The discussion of the social model as a form of criptopian theory-building highlights that ambiguity is part of any endeavor to imagine society differently—which is not to condone any specific failings of utopian theory-building. Where minor utopias, particularly from the perspectives of oppressed groups, depart from their major utopian counterparts is in their focus on these marginalized groups' agency as well as on exploring the groundedness and provisionality of the 'better way of being'.

The groundedness of the minor Utopia

This section articulates how the minor utopia of the US disability rights movement was in at least three ways focused on groundedness, that is, actualizing the emancipatory potential within existing power structures. Each example contributes to a practical criptopia that acts as if, by asserting the right to articulate in practical terms alternative, better ways of being centered on a positive vision of disability.

Firstly, the movement actualized the emancipatory potential within existing power structures by challenging assumptions about what it means to be a member of society. Citizens are supposed to be autonomous, rational human beings that can sustain themselves economically and live without significant support. In overemphasizing the independence of average citizens, society is, in turn, badly placed to judge the ability of disabled people to live as equal members in society. Against this view, the movement's leaders held that there 'are very few people even with the most severe disabilities who can't take control of their own life. The problem is, the people around us don't expect us to' (Roberts, 1989). They founded independent living centers to help spread this inclusive vision of society and provide evidence in support of it.

The 'independent living philosophy' emerged as part of the headway made by disability activists following World War II in their fight against institutionalization and for inclusion into public life (Levy, 1988). As more and more disabled people gained access to urban spaces, this created a need for support of people's life outside of institutions and the family. In response, independent living centers provided practical guidance and support on how to live as autonomously as possible

in your decision-making. As practical criptopias they were not 'totalizing lifelong places' (Cooper, 2014, p. 8) but instead pooled funding, expertise, and information to offer important points of contact in finding suitable accommodation, jobs, or personal assistance (Figueroa, 2000). They also introduced peer-counseling schemes to replace the paternalistic medical framework and became an often-preferred alternative to underfunded state-run services. At the same time, the centers combined the services with teaching radical ideas of the de-institutionalization of disabled people, their self-determination by allowing disabled people to make choices that come with risks, and of consumer control over the services provided by the state (Nielsen, 2012, p. 163). They championed the uniqueness of each disabled person and their knowledge over their own body and needs (Bagenstos, 2009, p. 15).

One of the most famous centers was founded in Berkeley by students under the leadership of Ed Roberts (Levy, 1988). Roberts had successfully litigated his way into further education at the University of California, Berkeley, where he was influenced by the counterculture of the 1960s. The aim of the center was to serve the local community of disabled people, but it also played an influential role at the beginning of the disability rights movement, including in funneling federal and local funds towards supporting disabled people and activism and in forming a normative vision of a better society (Charlton, 2000, p. 132). The center offered one, important, launchpad for the leadership of the disability rights movement to launch protests, inform wider society about the efforts of the movement and changes to legal provisions for disabled people, and coordinate with other groups to develop and lobby for new legislative initiatives. The independent living centers are thus practical criptopias that used the material and ideational structures of their time (such as federal and local funding and consumer ideology) to produce concrete evidence that—with suitable community support for people with physical impairments to overcome social and physical barriers, such as inaccessible housing—a fully integrated society is possible and plausible.

Secondly, the movement pursued a grounded utopia by lobbying for the passing of legislation to enforce equal status as citizens and contributors to the economy. The focus on law may seem antithetical to the utopian project because laws serve to regulate conflict and disagreements which arise in imperfect societies, for instance about the distribution of limited resources. For this reason, classic writers such as More highlighted the absence of a comprehensive body of laws as a notable feature of their utopian society (Herman, 2016; More, 1685, p. 148). I introduced above how utopianism has since broadened beyond the articulation of universal blueprints of the perfect society and this move necessitates a greater concern with how to transform an unjust legal system. A broader conception of utopia also reveals the social dreaming that motivates legislation, most obviously in the articulation of, and struggle for the protection of, human and civil rights (cf. Moyn, 2012, p. 1).

Law's utopian dimension has historically had a negative impact on disabled people. In the early 20th century, immigration and forced sterilization laws reflected societal anxieties about the decline of US society caused by rapid urbanization, immigration, and industrialization, and the subsequent popularity of eugenics (Nielsen, 2012, p. 100). Disability became a threat to the future wellbeing, or 'purity', of society (or specifically, elites) and laws served to manage or ideally

eradicate the 'problem' of disability. However, just as citizenship was defined by excluding and controlling those deemed different, the dominated found in the language of rights and citizenship a framework to voice their oppression and how to transcend it (Nielsen, 2012, p. 133). The expanding welfare state both provided at times humiliating hurdles to a life of dignity and also a way to demand rights, services, and fund activism. Crucially, the emphasis on rights and discrimination within disability activism exploited a tension within the medical model: it assumes a neat connection between impairment, diagnosed by a medical practitioner or immigration officer, and disability; yet disability has a strong socio-cultural dimension to it as it serves to delineate moral behavior in modern mass society, for instance by associating certain disabilities with morally deviant behavior. Disabled people (especially those otherwise privileged) often experience this sleight of hand as they become subject to seemingly arbitrary decision-making on their ability to work or receive federal benefits (Longmore & Goldberger, 2000). Disability activists reverted the sleight of hand by focusing on disability and not impairment and claiming that it is a signifier of discrimination not diagnosis. This is visible in one of the early organizations founded in the 20th century, The League of Physically Handicapped. The name of the organization alludes to the fact that disabled people in New York were disqualified from work through the arbitrary requirement of physical examinations for all jobs—disabled people were stamped as 'PH' in their records (Fleischer et al., 2012). What characterized members was therefore a shared sense of discrimination rather than the specifics of their impairment and it is this discrimination that prevents their equal participation in the economy.

To exploit this weakness in the medical model, The League of Physically Handicapped employed strategies of civil disobedience familiar from the labor movements of the early 20 century—activists however consistently note the additional dimension that disability brings to these strategies, both for activists (e.g. getting to inaccessible places), and judges and police officers unsure how to deal with them. The focus deepened further as new generations of activists engaged with other civil rights struggles. The movement was 'energized by, overlapping with, and similar to other civil rights movements across the nation, as disabled people experienced the 1960s and 1970s as a time of excitement, organizational strength, and identity exploration' (Nielsen, 2012, p. 160). The public protests of the African American civil rights movement and landmark rulings such as Brown vs Education, Topeka, brought home the importance of litigation, legislation, and demonstrations and treating disability in terms of a rights issue (Winter, 2003).

The struggle for equal rights before the law often involved a focus on concrete, immediate issues. The Architectural Barriers Act (ABA) in 1968, for instance, offered the important requirement that buildings leased or built and altered using federal funds be accessible. The Civil Rights Act of 1964, which prohibited the discrimination on the basis of race, religion, sex, and country of origin but did not mention disability, sparked a decade of struggles across US states centered on extending the protections to disabled people (Patterson, 2018, p. 418). Activists used a 1972 reauthorization of the Federal Rehabilitation Act to advance their cause. Specifically, an initially little-discussed addition of section 504 to the legislation by a liberal Democratic Senator, prohibiting discrimination against disabled people by

services and activities receiving federal funds, provided the legislative foothold for disability-centric anti-discrimination legislation (Erkulwater, 2018, p. 375). Cross-disability alliances lobbied for the implementation of 504 and on 5 April 1977 occupied a number of buildings of the US department for health, education, and welfare (Cone, 1996). The eventual implementation of section 504 was followed by other legislations and renewed activism, but the law's provisions remained narrow in focus and weak in enforcement. The Americans with Disabilities Act (ADA) in 1990 promised to alleviate these problems by putting into place protections against discrimination based on, and requirements of reasonable accommodation of, disability (Bagenstos, 2009; Winter, 2003). Again, disability activists used common strategies to influence the ADA's passing, including by setting up sophisticated lobbying networks in Washington and adding pressure through public protest. One example of this is activists in March 1990 'crawling up' the US Capitol steps (Pelka, 2012, pp. 419, 515).

Litigation and legislation offered important means to utilize the toolkit developed by previous civil rights movements to make the utopian visions of the social model concrete. Together with the independent living centers, legislation helped normalize the model's radical assumption that society needed to work towards enabling disabled people's equal access to socio-economic activities. Acting 'as if', the movement helped shift the legislative focus from 'managing', erasing, or separating out disability from society towards changing society to include disabled people.

Thirdly, the movement actualized the emancipatory potential within existing power structures by challenging expectations of what disabled people can do. In their own words, we have 'been through the worst kind of atrocities, attitudes towards us that see us as vegetables, that see us as sick and unable and having no future. I mean that *got* to piss you off' (Roberts, cited in Pelka, 2012, p. 32). To challenge expectations, the activists had to become experts in areas central to the governance of society, from city planning to the lobbying of politicians: 'we really needed to develop expertise. It couldn't just be "we have the right to get on the bus, we have a right to go to school"', 'we needed to become experts in areas that we never thought about, you know, becoming architects, becoming involved in regional planning and things like that' (Heumann, 2020; cf. Shaw, 1994, p. 166). Of particular importance were jobs held historically by non-disabled workers, and dealing with the lives and futures of disabled people. Denise Karuth served on the Massachusetts Governor's Commission on Accessible Transportation, and Ed Roberts was appointed to the role of Director of the California Department of Vocational Rehabilitation. Deidre Davis-Butler and Judith Heumann worked for the US Department of Education. Many others founded and governed influential disability organizations, for example the Disability Rights Education and Defense Fund. The activists often had to learn these new roles and expertise as they went along, not least as disabled people are in many cases thrown into activism by changes in circumstances or moments of social discrimination. They sometimes gained important support and insight from their connections with other movements, while extending these frames of references in turn through the unique focus on disability. Lacy (1998, p. 102), for instance, moved from anti-poverty programs to working for the Center for Independent Living; Kitty Cone (1996, p. 64) helped organize women's movements. The

third example of groundedness speaks to the central role of agency in oppressed groups utopianism. It highlights that criptopias do not just change the world but 'bring about (or seek to bring about) new forms of normalization, desire, and subjectivity' (Cooper, 2014, p. 5). They change the activists in the process of imagining an alternative world.

The practical criptopia outlined in this section differs from the typical example of a practical utopia, the communes of the 1960s. Sargent terms these 'intentional communities' and defines them as consisting of a 'group of five or more adults and their children, if any, who come from more than one nuclear family and who have chosen to live together to enhance their shared values or for some other mutually agreed upon purpose' (Sargent, 1994, p. 15). The practical criptopias meet the criterion that they are not just a matter of convenience, but sustain a communal normative stance centered on the worth of disabled people as human beings. However, their emphasis on integration into society and autonomy necessarily counters the idea of a separate and separated commune. In this regard we may usefully describe them with Davina Cooper as everyday utopias, 'networks and spaces that perform regular daily life, in the global North, in a radically different fashion' (Cooper, 2014, p. 2). Unlike Cooper's everyday utopias, however, these everyday criptopias combine utopian everyday practices with an explicit focus on pressuring and transforming political and legal institutions—precisely because these institutions have such an immediate impact on disabled people's lives and utopian impulse. The divergence is typical of the acting 'as if' of oppressed group's utopianism, which helps rethink the utopian process from the perspective of disability and disabled people.

The provisionality of the minor Utopia

This final section addresses how the US disability rights movement accepted the necessary failure of any endeavor to envision a radical departure from the present through an affirmation of provisionality. This affirmation is visible in the movement's use of literature and engagement with temporality. We once more see how the movement acted 'as if', by centering a positive vision of being disabled to challenge ableism and the conventions of (utopian) literary writings.

Literature is particularly suited for exploring the provisionality of a minor utopia as it provides the most freedom of the three criptopias—theory-building, practical utopias, and utopian literature—to imagine a different world. At the same time, engagement with literature is essential for disability activists because of the role that disability has historically served in literature and the overdetermination of disabled lives by ableist narratives that pervade society (Mitchell & Snyder, 2001). Here magazines such as *The Disability Rag* and memoirs including Zola's *Missing Pieces* played a crucial role in publishing alternative stories of and by disabled people. While I focus on these publications for their link to the disability rights movement, the literary criptopia also encompasses in a broader sense the many attempts to challenge ableism and rethink disability across US society, including by Audre Lorde and Octavia Butler (for important work on this, see for instance Garland-Thomson, 1997; Osbourn, 2013; Schalk, 2018).

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The contributions to *The Disability Rag* were written from the perspective of disabled people. Founded in Louisville, Kentucky, it quickly reached a national audience of up to 30,000 readers and, alongside other magazines, it helped to introduce disabled people to disability culture and to provide a major source of news and opinion pieces for the movement. The reports, poems and personal reflections published in the *Rag* simultaneously presuppose a common identity, knowledge, and experience (of being disabled), and work to bring this shared sense into being. One such experience is of the way oppression narrows the horizon of possibility. Mary Johnson's engagement with disabled people like Kenneth Bergstedt who litigated to secure the right to assisted suicide, epitomizes this focus (Shaw, 1994, p. 194). Johnson reflects on how a mundane economic (and political and social) issue for many disabled people, such as limited funding to pay for attendant services, can turn into an existential crisis when combined with the bias that a disabled life is less worth living: in 'my mind, I see Ken Bergstedt trapped inside his dark room, inside the dark room of other people's minds; other people who see his death as some sort of a release. A release, I wonder, for whom?' (Shaw, 1994, p. 210). In another essay challenging how dominant visions of the future impact disabled people, Edward Hooper confronts assumptions of being 'sexually dead' due to paralysis (Shaw, 1994, p. 83). The text counters these visions by describing disability as potentially a catalyst for imagining an alternative, better future. Hooper suggests that disability 'can teach profound lessons' (Shaw, 1994, p. 83) about pleasure.

Other contributors encourage a retelling of the past in which disabled people take on multilayered and heroic roles. Disabled people are 'no longer the invisible people with no definition beyond "Other", we are more and more proud, we are freedom fighters, taking to the streets and to the stages, raising our gnarly fists in defiance of the narrow, bloodless images of our complex humanity shoved down the American consciousness daily' (Shaw, 1994, p. 18). The reworking of the past serves to imagine an alternative, better future where 'differences, though noted, would not be devalued' (Shaw, 1994, p. 47). Yet, at the same time as some contributors to *The Disability Rag* seek to formulate a vision of the future inclusive of disability culture, others are dedicated to contesting the idea of a unitary future or culture, instead revealing the hidden hierarchies and exclusions implicit within them (Shaw, 1994, p. 160). Overall, there is a recognition that disability and ableism are such complex issues that no feature can easily be resolved, as disability activists grapple across literary mediums with the need to seem brave but also vulnerable, to speak about difference but also show unity.

Another formulation of a literary criptopia can be found in Zola's (1982) classic text *Missing Pieces*. The memoir uses Zola's encounter with a practical utopia for disabled people as the foundation for a critical reflection on his own physical impairment. Het Dorp is a utopian project of a fully accessible neighborhood in Arnhem, The Netherlands, set up to benefit people with physical disabilities. While impressed with the place which he visited in 1972, Zola highlights that the project remained 'rooted in the traditions of long-term medical care institutions' (Zola, 1982, p. 34). Put simply, Het Dorp was made for but not by disabled people. Reflections on the shortcomings of Het Dorp led Zola to the conclusion that impairment is an integral part of our human condition and that anything 'that

separates and negates those with a chronic condition will ultimately invalidate not only them but everyone else' (Zola, 1982, p. 238).

Zola's choice of memoir for the purpose of utopian theory-building and the openness of his reflections highlights a high level of provisionality. The subheading of the book's epilogue section captures this: 'Some Concluding But Hardly Final Thoughts on Integration, Person and Social' (Zola, 1982, p. 238). The memoir conveys a clear sense of right or wrong concerning the practical utopian project and the need for greater integration, but there is no attempt to provide a comprehensive alternative vision of the inclusive society. Instead, as powerfully brought out by Nancy Mairs in her foreword, Zola invites self-reflection by conveying the ambivalence of utopianism. Het Dorp in Zola's hands becomes simultaneously an 'idyllic' place of social welfare provision unheard of in the US, a problematic expression of paternalist attitudes towards disabled people, and almost like a dream or fantasy—a 'no-place' (Nancy Mairs, in Zola, 1982, p. viii).

The second example of the exploration of provisionality in relation to disability and utopia within the movement comes in the form of the 'cripping' of time. Temporality has long been integral to the construction of disability, particularly in the medical model. Familiar 'categories of illness and disability—congenital and acquired, diagnosis and prognosis, remission and relapse … are orientations to time, even though we rarely recognize or discuss them as such' (Kafer, 2013, p. 26). It is hence unsurprising that the response by disability scholarship and activism reproduces this focus on temporality. The strategy finds its sharpest formulation in the concept 'temporarily able-bodied', which was introduced by disability activists to highlight the inevitable movement with age towards being disabled. The term '"crip" time' (Zola, 1988) goes even further and works as a shorthand for the inability of disabled people to meet the temporal expectations within society about how long things should take or when to arrive. Punctuality is a fraught concept for those facing a hostile environment with, for example, no suitable lifts, and those who experience time differently. It therefore stands for a recognition of the fact that, in a general sense, disability represents aspects 'of the human condition that are unpredictable, unstable, and unexpected: in short contingency itself' (Garland-Thomson, 2012, p. 340). Crip time offers an, as yet partial and experimental, affirmation and expression of a desire for a different way of engaging with time (Price, 2011, p. 62).

This different interpretation of temporality had an immediate impact on the approach of the disability rights movement: activists envisioned and enacted a non-ableist future in the process of 'becoming'. Specifically, they developed ideas as the struggle moved along, an observation emphasized routinely by the movement, and experimented with more inclusive ways of engaging with each other. As Judy Heumann remembers from the San Francisco occupation in 1977 to protest stalling legislation, the 'most remarkable thing about our building-wide meetings wasn't their length … but the culture of listening that developed. No matter how long it took for someone to talk, we listened' (Heumann & Joiner, 2020, p. 120). The activists showed an acceptance of the multiple ways in which our bodies are in time, as the source of provisional practices aimed at an improved engagement with the self, each other, and the world.

Conclusion

Utopian political thought has emphasized the disruptive potential of the future: that things could be different. This article considered what the utopian impulse looks like for those who are deemed to have no future. It contributed to critical theory on the role played by utopia in the oppression of specific groups and their resistance to it, through an exploratory introduction of utopianism within the US disability rights movement.

Turning to utopian studies, I identified in the movement's actions the contours of a minor utopia, aimed at a partial, limited conception of a more inclusive world. Each of the expressions, or faces, of utopia introduced in the last three sections adds to the effort to rethink ableism and the negative link between utopia and disability. Indeed, we may best speak of several minor criptopias, but the important thing is that together they capture all the elements needed in developing this minor utopia: the ambiguity, provisionality, and groundedness of a practice of envisioning a better way of being that departs from a positive account of disability and disabled people—a process I termed acting as if. Thus the disability rights movement was and continues to be a site of contestation and reworking of the very idea of what it means to desire an alternative future. As I emphasized, envisioning minor utopias does not protect people from reproducing forms of oppression, but an emphasis on the agency of oppressed groups, difference and change can help make our social dreams more inclusive.

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