

Chapter 10

The (Crip) Art of Reworking Vulnerability—And Perhaps, to Find a Way Out of It



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No one moves without a supportive environment and set of technologies. And when those environments start to fall apart or are emphatically unsupportive, we are left to “fall” in some ways, and our very capacity to exercise most basic rights is imperiled. And we could certainly make a list of how this idea of a body, supported yet acting, supported and acting, is at work implicitly or explicitly in any number of political movements.
Judith Butler, *Rethinking Vulnerability and Resistance*, 2016

Abstract The aim of this essay is to mobilize the concept of disability and vulnerability, especially when they intertwine. For so doing, I will refer to experiments of care collectives as a fertile case study. The concept of interdependence will accompany the analyses of the essay—and I will account both for the richness and for the limitations it entails. First, I will address the debate on vulnerability, mainly within Feminist Theory and Disability Studies. I will take into account the risks of imposing vulnerability upon specific social groups—for example, disabled people—as it can reinforce their disempowerment and minority position. I will then examine vulnerability as an ontological and contextual phenomenon, highlighting how both are especially productive in critically addressing disability. I will also take into account how disability and vulnerability are frequently entrenched in dependence: in this regard, I will underline how care relationships, which are often considered maximum examples of dependency, can both enhance and reduce the vulnerability that can be experienced by disabled people. I will pinpoint how the narrative of vulnerability can produce neglect of disabled people’s knowledge and skills, also in the context of care. Therefore, I will focus on the value of their expertise in this field, examining examples of collective care crafted in recent years and—despite the disabling and threatening nature of the event—even implemented during the COVID-19 pandemic.

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1 Introduction

The aim of this essay is to mobilize the conceptual and practical intercourses between the phenomenon of disability and vulnerability, addressing collective care relationships as a case study. As I will clarify in the essay, vulnerability and disability are not coextensive concepts: it is possible, and rather frequent beyond human rights discourse, to examine the experience of the latter without addressing the former. In this essay, however, it appears epistemologically and politically useful to intersect them, provided that we are faced with a different mobilization of the two concepts as opposed to the most widespread theoretical analyses. I do not aim to flatten both concepts in a homogeneous similarity, but it is relevant to underline how they share a relational nature and how positive social responses can positively bear on both experiences.

I will present some points within the debate on vulnerability that may be useful throughout my analyses. Vulnerability can concern different systems and entities—the environment, technologies, etc.—and it is clear from the topic of this essay that I will exclusively consider human subjects. In particular, I will address the risks vulnerability may entail when it is used to identify certain social groups or individuals, and I will examine the perspectives that underline its ontological and/or contextual nature—especially within disability studies. However, even though it may seem rather surprising from an external perspective, it is important to note that the topic of vulnerability does not play a central role within disability studies, especially in segments more receptive to critical theory and cultural studies. When it is addressed, its controversial nature is highlighted. I will provide some coordinates of the debate and offer possible intersections between disability and vulnerability, which do not position disabled people in a position of minority and disempowerment. In particular, I describe both phenomena as relational and context-related. In this regard, I will refer to feminist theory as well.

The concept of interdependence will guide the essay, as it adequately embodies the intermingling nature of bodies and subjectivities. In this way, interdependence is connected to disability and vulnerability. It also holds, as it will become clear, a peculiar place within theories and practices implemented by disability studies and disabled activism.

The common perception of disabled people as vulnerable often leads to them being seen as in need of assistance, but this can overlook the fact that disabled individuals can also be skilled and trained in the space of *care*. Therefore, it is important to recognize and value the expertise and contributions that disabled people can bring to the field of caregiving, rather than simply assuming that they are the ones who need care. With this aim in mind, I will conclude the essay by examining examples of collective care, which are also crafted in response to social injustices, that *fragilise* disabled

people—especially in moments of crisis, such as during the COVID-19 pandemic. While it is fundamental to consider this event as disabling and life-threatening, especially with inadequate healthcare support, it is also urgent to recognize disabled people's expertise. Not only must they not be framed as *disposable*, but they also represent a resource.

Methodologically, I will explore both disability and vulnerability with a transversal approach, which keeps in mind the cultural, social, anthropological and economic factors and, at the same time, consider the embedded, embodied, and material experiences. Disabled people can possibly experience more pain and challenges due to their impairments or the inadequacy of the environment. They can also experience situated vulnerability, especially when their needs are not met, and the value of their lives is neglected—as often happened during the COVID-19 pandemic. Vulnerability, (dis)ableism, and some negative aspects (such as pain) that may characterize some forms of disability can be minimized by positive social responses and a network of care *crip*¹ kinships, without neglecting the personal and material experience of marginalization and suffering. Within this framework, I will consider disabled people's practical responses to increased vulnerability.

2 Notes on Vulnerability and Disability

First, vulnerability is generally framed as a disposition that potentially exposes a subject to some form of harm or disadvantage. However, there are expressions of vulnerability that inevitably actualize and can therefore be understood as an inherent characteristic of living organisms: every one of them eventually dies and probably at some moment has passed through phases of compromised health. The harm that the subject may endure is not only located in the realm of life and death: vulnerability can qualify as exposure to tangential or different risks, which are, for example, related to sociality, access to education, emotional well-being, financial status, or sharing of data.

Vulnerability has been addressed, on a theoretical level, mostly by Feminist Theory [1–5] or in discourses on human rights in response to crises and social injustices. As shown by contemporary debate, employing the language of vulnerability with regard to specific subjects or social groups can serve diverse agendas, not just progressive ones as it may initially appear but also “paternalistic, racist, misogynist, homophobic, and anti-feminist ones” [6, p. 5, 7]. Even when the intention is to protect specific pockets of society, the outcomes may be unexpected, ambivalent or explicitly unsuitable. It can draw our attention towards injustice and violence but can produce even more vulnerability. Vulnerability can also entail an othering move: some social groups are distanced from a presumably not (or not so much) vulnerable humanity.

¹ Crip, a contract form of the derogative ‘cripple’, is a term reclaimed by some members of the disability community. It is rooted in activism and politicization of disability.

In this sense, it risks further stiffening social positionings, rather than “mobilizing” social change.

The semantic network of vulnerability generally includes, in a non-exhaustive list, dependency, care, marginalization, injury, subjugation, trauma, and risk [6, 8]. Some of them refer more strictly to a materialist experience, recalling how the flesh can violently collide with the world (trauma, risk, injury), whereas others refer more closely to structural violence and injustice (marginalization, subjugation). Dependency and care are not necessarily negative experiences, even though interdependence—a concept I will further examine—may more fruitfully represent our enmeshed lives, without the derogatory aspects sometimes attributed to being dependent. The mentioned key concepts co-assemble each other, entangling in diverse ways, orbiting around vulnerability: for example, marginalized people tend to occupy a space of medical vulnerability too (e.g., members of the LGBTQIA+ community can have worse access to healthcare).

In this semantic network, I include disability as well; throughout the essay, I will explore the possible negotiations with this association. The concept of vulnerability can “react” in different ways in regard to contact with disability. People are inherently vulnerable *to* disability: they age, have accidents, and predispositions and circumstances add up in a certain way throughout their lives. On the other hand, disability and vulnerability may represent two overlapping experiences: disabled people are often seen as a vulnerable population, both because of their presumed “frailer” bodyminds and because of their marginalized position in society: they appear more susceptible to harm and social injustices. The link [5, 9, 10] between vulnerability and dependence has been widely explored, and it is not difficult to understand why disabled people are often seen as particularly vulnerable. Emphasis is often placed on how their very survival may depend on a dense network of trans-individual ties [11, 12]. For example, someone generally framed as more vulnerable, such as disabled or elderly people, appears dependent on others. At the same time, however, care relationships themselves can both *create* and *compensate for* vulnerability, and I will examine the latter case in the last section.

Disability scholars that examine vulnerability tend to define it as an ontological and universal characteristic of human beings: as already mentioned, human bodies are inherently frail, as they may fall ill, be in pain, and be exposed to external threats. Feminist theorists, as well, underline this transversal form of vulnerability, pinpointing the contemporary social and cultural tendency—in philosophical and critical thought as well—to remove it. This unravelment concerning human nature works as a starting point to rethink the subject in its relational dimension against “masculinist fantasies of sovereign mastery” [13, p. 3]. The very embedded and embodied nature of the subject produces her/his vulnerability [14]. In both feminist theory and disability studies, this framework sustains a counternarration with respect to Western ideas of autonomous, autarchic, and self-contained subjectivities, which shape a hierarchy that posits disabled bodyminds on the disadvantageous section of the spectrum [8, 15–19]. Therefore, unveiling the ontological condition of vulnerability helps us to challenge ableist assumptions about bodyminds.

Within feminist theory and disability studies, the ontological perspective of vulnerability tends to unfold parallel to the situational perspective: it is also interpreted as a process, actualized or not, that depends on context rather than being linked to specific individuals. These fields tend to consider vulnerability as *also* an ecological phenomenon: there are vulnerable *positionings* of subjects and not vulnerable subjects. The concept can be framed as a relationship “to a field of objects, forces, and passions that impinge on or affect us in some way” [13, p. 19, 20]. It describes, in a potentially negative sense, the impact that the context (social, public, institutional...) *may* have on a subject. Although there is not a complete rejection of the category, it is highlighted how risky it might be to impose this *identity* on disabled people. This approach, which situates vulnerability in the inadequacy of networks of accommodation, support, and care, is exemplified by activist and writer Alice Wong:

When you are disabled and rely on public services and programs [such as Medicaid], you face vulnerability every day. This vulnerability is felt in my bones and in my relationship with the state... The fragility and weakness of my body, I can handle. The fragility of the safety net is something I fear and worry about constantly. [21]²

As noted by bioethicist and disability scholar Jackie Leach Scully, vulnerability can be associated with characteristics such as lack of agency, “immaturity, weakness, helplessness, passivity, victimhood, humiliation” [18, p. 210], which risk reinforcing the representations already typically directed towards disabled people. As Judith Butler et al. claim, “there is always something both risky and true in claiming that women or other socially disadvantaged groups are especially vulnerable” [7, p. 15]. Associating disability with vulnerability might be dangerous, as it can reinforce a history of marginalization, partial participation in citizenship, and disempowerment. Disabled people have always been subject to various forms of paternalism—by the state, at a political level, in the social arena, in medicine and healthcare—and therefore they challenge any structure not only that excludes them but also that includes them as passive objects (as, for example, associationism led by nondisabled people). I am not claiming that disabled people are never vulnerable, and should never be considered as such: I only wish to reject that they are vulnerable in a *specific* way and that their vulnerability is supposed to be interpreted in *exceptional* terms. This perspective seems to crystallize the already rigid distinction between disabled and nondisabled people [8, 15, 18, 22].

3 First Keyword: Relationality

Disability studies underline from the very beginning how a purely medical and individual account of disability misses the point. In the so-called medical-individual model, disability embodies an individual tragedy and something that concerns the body or the mind of the subject and, whenever possible, must be cured. Disability

² In the USA, Medicaid is the federal and state program that provides health insurance for people and families with low income.

is frequently interpreted as a fixed category: one is disabled, or not; disability is a dysfunction, a cluster of deficits, or a form of noncompliance to a determined standard. *You know it when you see it*. It is rarely presented as dynamic, changing, and subordinating to the context. The social and political-relational models of disability have confronted this predominant perspective, highlighting how it represents a phenomenon that originates in the material encounter of a bodymind in a given context [23–25]. As Alison Kafer underlines, disability is a political concept, open to debate, as opposed to a monolithic truth of bodyminds. It is enmeshed in politics and personal relationships, coconstituted in social and cultural processes, and constantly transformed. This perspective moves it from the mere medical-individual realm—however important—to multiple locations instead.

[D]isability no longer resides in the minds or bodies of individuals but in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being. [...] The problem of disability is solved not through medical intervention or surgical normalization but through social change and political transformation. [23, p. 6]

It is therefore fundamental to frame the experience of disability in interrelational connections and in sociocultural and political structures, rather than in the narrow boundaries of individuality. Disability emerges from specific normative contexts within medicine, psychiatry, and healthcare discourses and disability from the socio-cultural fabric but is also actively metamorphosed by disabled people. It is “experienced in and through relationships; it does not occur in isolation” [23, p. 8]. In addition, it intersects with other axes (such as gender, class, race), which change a subject’s experience in a given society.

Giving disability is *also* a sociocultural and political interpretation; however, it must never produce a removal of individual experiences of loss, pain, difficulty, limitation, and failure. They must remain legitimate and shareable. In addition, disability may still be rejected by the subject and not exclusively because of internalized ableism or structural marginalization [26, 27]. Material experiences of disability, which *can* also include bodily and cognitive sufferance (for example, mental pain; chronic fatigue; the sometimes painful interaction with medical-assistive technologies), must never be overlooked. The fundamental point is that this aspect must be incorporated within a heterogeneous framework, in which it is expected that joy, desire, pleasure, forms of creativity and competence, specific expertise, love for the disabled community, and ways of flourishing occur and are realized as well [23, 28]. Analyses of the sociocultural and economic production of disability should not be raised at the risk of delegitimizing complex and painful individual experiences. Medicalization and anthropologization can both be dehumanizing, favouring the analyses of structures and frameworks upon the experience of the subjects [29].

In addition, the same attention must be reserved for collective experiences of disablist and ableist structure and for global injustices that produce disablement. Disabled people may not receive fair accommodations and accessibility responses and may not be guaranteed appropriate healthcare, education, or assistance. At the

same time, their condition might originate from unsuitable working and living conditions, lack of adequate healthcare assistance, scenarios of war, and environmental crises.

While vulnerability is hardly seen as something to be proud of, as frequently occurs in relation to disability by the disability community [26, 30], the two phenomena can be addressed by moving from similar theoretical and political assumptions. Firstly, they can both be recalled as sources of knowledge and expertise [6, 7, 31, 32]. The same path is followed in this essay, even though with due caution. This attention to adaptation and resourcefulness should be balanced by attention to possible experiences of harm, pain, and difficulties on a material and social level. As Anu Koivunen et al. note,

It is indeed worth asking how productive the approach to vulnerability [...] as simultaneously involving resistance can be when addressing issues like global racism and massive inequalities in basic resources and the ability to live on. What resistance could there possibly be in the utmost realization of vulnerability – death? [6, p. 8]

Within the “massive inequalities” mentioned, it is important to include disablism and ableism. Secondly, at the same time, it is important to consider both individual experiences and social structure analyses.

Last, as already clarified, vulnerability and disability are profoundly relational: the subject’s experience in both regards fluctuates depending on the outer reality. As Rosemarie Garland-Thomson claims about disability, “shifting [it] from an attributed problem in the body to a problem of social justice was theoretically groundbreaking”: vulnerability, as well, can be more productively addressed as such [33, p. 592]. The setting can *disable* us and make us vulnerable: specific worlds can be more accessible than others, and the structure of society dramatically influences bodyminds’ experiences. The experience of both vulnerability and disability can be shaped by the interdependence that characterizes our living as humans: adequate responses can reduce harm, safeguarding personal well-being and guaranteeing a more just society. These responses can include both personal and communal aspects: a fair distribution of wealth, opportunities, and healthcare but also a platform of shared values, which refuse discrimination and reward care, attention, and support.

4 Second Keyword: Interdependence

As already pointed out, vulnerability does not hold a particularly relevant place within disability studies and disabled activism: this does not mean that the experience of it and the surrounding topics are not addressed, but the conventional literature on it is rarely discussed. A key topic, on the other hand, is represented by the concept and *practice* of interdependence, which shapes the disability community. This practical, theoretical and political response against individualism, precarity, and social injustice is privileged over vulnerability because the latter risks being interpreted as a fixed status of the subject rather than a *movement*. In other words, what people do is more

important than what they are supposed to be. The reflection on interdependence—what it implies, how it can be crafted, etc.—is a key contribution of disability studies and disabled activism: as a theoretical analysis but also as a practical skill to be explored and improved within community organizing (for example, through mutual aid networks, collective care, support groups). The term emphasizes the interaction between two or more subjectivities and highlights the flux of empowerment and agency—rather than pushing a hierarchical logic, as ‘dependence’ might do—or giving prominence to individual capacity and willpower—as ‘independence’ might do [34–36]. With the term interdependence, I mean a mobile perspective in which the necessity to depend, sometimes, on others can be recognized but in which the privileged perspective is neither passivity nor autarchy.

Similar to vulnerability, interdependence is first understood as having a *universal* nature. Interdependence characterizes every aspect of human and nonhuman life (in this latter case, it can also be described as symbiosis or sympoiesis) [37]. Disability studies, as Judith Butler highlights, have remarked how every action and movement is dependent on, and is facilitated by, all sorts of human and nonhuman companions [38]. Several members of society contribute to the weaving of our lives, and “infrastructural conditions” can cause “precarity”, “threat”, or favour opportunities and agency [13, pp. 14–19]. Disability studies underline the leaking and unstable nature of subjects and their bodies. We, all, are captured in transversal assemblages [12, 39].

Through the lens of interdependence, it is possible to frame several aspects of disabled people’s lives, for example, the need for care, support and assistance. The concept of interdependence does not ascribe passivity to disabled people and does not draw attention to their supposed incapacity to be independent. Rather, it can reveal that every subject contributes to social kinships, even when this role is not recognized. This concept not only underscores the fact that no one is capable of doing everything in autonomy but also that the areas and the degree of someone’s need for support vary, and in some cases are deeper (and this can be the case with new-borns, elderly people, and people with disabilities or illnesses). Through the concept of interdependence, it is possible to understand that it is more fruitful to insist on the interrelational nature of every life, while at the same time, disabled people, like anyone else, must be guaranteed the possibility of reaching personal goals and carrying out daily activities. As claimed by the poet and activist Eli Clare, “[p]art of claiming disability is choosing this messy, imperfect work-in-progress called interdependence” [36, p. 136]. The examples of care relationships addressed in the last section of the essay are therefore inscribed within the framework of interdependence: disability *matters*, as disabled people are especially skilled in this practice and sometimes have specific needs in terms of assistance and accessibility, but at the same time, this concept transversally refers to our cohabitation as humans.

5 Third Keyword: Resourcefulness

Framing subjects as vulnerable, as I said, can produce a disempowering perspective on the subjects addressed, according to which they always need protection and assistance. This aspect, albeit sometimes true, can make us overlook their resources, capacities and competencies. Given that disabled people are often addressed as needing assistance *because* they come up as vulnerable, the space of care is rarely considered a location in which disabled people are particularly trained and skilled. This general form of disregard is blatant both in cultural texts and in fictional representations concerning disabled people situated in contexts in which infrastructures are particularly precarious, and vulnerability is therefore transversally rampant. For example, it is frequently recalled how in speculative fictional futures—especially post-Apocalyptic ones—disabled people are depicted as burdens and as almost inevitable casualties. It is imagined that they necessarily have to succumb because they are considered from a fundamentally passivizing perspective, or it is imagined that they are left behind to die [28, 40–43]. Their expertise, inventiveness and adaptability are not taken into account. As Alice Wong recalls,

I often wonder how disabled people will survive in a postapocalyptic world [...]. What I do know is that disabled people are creatures of adaptation that design and build worlds that work for them. The skills that we have reimagining/hacking/surviving hostile ableist environments would serve us well in any dystopian future. [44]

These reflections also echo current events that have resembled, in some circumstances, almost apocalyptic contours. As it has been noted by activists and scholars since the uprising of the pandemic emergency, the loss of certain lives is alarmingly considered more acceptable or simply does not cause the same dismay [45–49]. The COVID-19 pandemic has had a significant impact on disabled people, who have been disproportionately affected not only because they presented underlying health conditions that put them at higher risk but also because of ableist narratives and practices that deeply increased their vulnerability. They have faced barriers in accessing healthcare and other essential services. Additionally, measures put in place to control the spread of the virus, such as lockdowns and social distancing, have disrupted routines and support networks that many disabled people rely on for their daily lives. Last, and most importantly, disabled people have been considered, as mentioned above, *inevitable casualties* because their lives are less valued than others. There have been cases where healthcare rationing policies have prioritized younger and healthier patients over older or disabled patients or in which they have been denied life-saving treatment or access to ventilators *because* of their disability [50–55]. In this regard, the pandemic has permitted preexisting inequalities, systemic barriers, and ableist/eugenic assumptions to surface. The increase in disabled people's vulnerability should obviously be addressed, especially as a problem of social justice.

However, another point is also raised: even if attention is given to the fact that the survival of disabled people is often not guaranteed by structural injustices that include inadequate healthcare, wealth distribution, social barriers, racism, inaccessible housing, and environmental injustice, the role that disabled people themselves

play in their own well-being almost always remains in the shadows. One key philosophical claim of the present contribution is that *excessive emphasis on vulnerability can disempower disabled people*, thereby also leaving their resourcefulness unacknowledged. Their vulnerability has been enhanced by the spread of the virus, by ableism and disablism, and by the suspension or fragilization of interdependence: forms of support, care, and assistance, both paid/professional and informal, have been variously disrupted due to self-protection, policies, and inadequate welfare and healthcare systems. At the same time, however, in this moment of higher vulnerability, disabled people have experimented more than ever before collective care. It is therefore important to consider the higher risks disabled people have experienced and at the same time not to overlook their adaptability and competence.

6 Introductory Notes on Care

Before examining collective care, I will briefly consider how disabled people stand in care relationships, broadly speaking. As argued above, disabled people are sometimes assumed to be more vulnerable than nondisabled people because they are particularly dependent. This aspect is especially linked to care and assistance relationships. Susan Dodds clarifies this point:

Dependence is one form of vulnerability. Dependence is vulnerability that requires the support of a specific person (or people)—that is, care. To be dependent is to be in circumstances in which one must rely on the care of other individuals to access, provide or secure (one or more of) one's needs and promote and support the development of one's autonomy or agency. [56, p. 182]

Disability studies help to understand that the dependence inscribed within assistive relationships is not exclusively an expression of vulnerability, *per se*: the *quality* of these same relationships, on the other hand, can both alleviate and intensify vulnerability. Subjects can experience vulnerability because they are receiving *inadequate care*. Care relationships can also *reduce* the vulnerability experienced by a subject in a given historical, geopolitical, economic, and sociocultural context. I will focus precisely on this possibility.

Relationships between disabled individuals and those who provide care can be characterized by power imbalances and forms of (often intersecting) discrimination: sexism, fatphobia, racism, homophobia, transphobia, and even ableism. Disabled people can experience violence and harassment and endure a lack of control over their lives: care, also in its institutionalized forms, can represent “a place of oppression, loss of empowerment, physical and sexual abuse, and neglect” [28, 34, p. 3, 35, 36, p. 136]. Whereas feminist theory is principally focussed on whoever provides care work, disability scholars pay close attention to the perspective of the care receiver as well—also pinpointing how these roles are not always so clear.

My approach to care is rooted in the perspective of disabled people, who will appear both as caregivers and as care receivers, almost always simultaneously. The

concept of “cure”, Eli Clare argues, “requires damage”: something wrong has to be found [57]. Care, on the other hand, even though possibly inscribed into asymmetrical relationships, is a more flexible category that recalls a movement, a flux, rather than cartographic attention to individual “deficits”. Care is a flexible flux of emotions, actions, attitudes, practices, and narratives and can be both liberating and oppressive. Rachel Adams underlines the multiplicity inscribed within the concept:

Care is work, an attitude toward others, and an ethical ideal. I define it as the intimate and necessary labor required to sustain those who are dependent but also the action needed to sustain the lives of vulnerable others. [58, p. 695]

I will emphasize the generative aspects and creative possibilities entailed by relationships that revolve around care but also the uncomfortable positions and the power imbalances that emerge. Disabled communities *mobilize* the nature of care, providing insights into both its necessity on a social base and the complexity that comes with it. In the last section of this essay, care crafted by disabled people *for* disabled people is framed as “a tool with which marginalized communities activate, engage in, and sustain social justice fights” [59, p. 6].

7 A Case Study: Care Collectives

I will take into consideration voluntary relationships in which the disabled participants play multifaceted roles. In collective care networks, disabled people provide physical and emotional support for one another. Disabled people “have always had to improvise when care is lacking”, as Akemi Nishida underlines [59, p. 6]: discrimination and abuse that sometimes characterizes care relationships and the structural inadequacy of welfare and healthcare have forced them to experiment with “alternative support structures” compared to the paid healthcare professional or related to the family environment [28]. “Care collectives”, in brief, are a way to “actively practice interdependence—a principle that disability justice activism advocates for” [28, 55, 59, p. 8, 60, 61].

Disabled people explore forms of community-based collective care for different and often intersecting reasons, already mentioned throughout the essay: because they have experienced abuse, neglect and discrimination in more “traditional” forms of care, namely, by assistance staff and biological family; because they want to establish a more profound connection with other disabled people, based on political affinities too; because they have to obviate inadequate statal support systems and low-incomes force them to do so; because they want to emancipate from family care, and so on. While similar forms of collective care have always been practised, especially within marginalized communities (queer, Black, etc.) [28, 55, 59], I am referring here to examples situated in recent years that have sometimes been accelerated by the COVID-19 pandemic and the urgency to mend the deterioration of support nets and social exchanges.

In whatever ways they came to experience care collectives, these disabled people were eager to collectively endeavor to create different and more-just ways to meet their care needs and honor their caring capacities. [59, p. 127]

Artist and scholar Loree Erickson has been one of the first to launch—in theory and practice—a form of care network, which partly differs from the one I will present later on. In the last twenty years at least, most of her care has been provided by a rotating collective made of friends or other community members (this last case especially concerns her travel needs whenever she moves away from the usual network). This form of care is therefore based on voluntary participation, by disabled or nondisabled people, scheduled in shifts that cover Erickson’s daily needs. Beyond the more settled network of people, Erickson usually posts her needs on social networks, asking to participate in her care and assistance [62, 63].

Writer and activist Leah Lakshmi Piepzna-Samarasinha grapples with collective care as well; she aims to build assistance networks that are not based on “charity” but rather on “solidarity”, “mutual aid”, and “respect”. These concepts, in her perspective, do not “connote moral superiority of the giver over the receiver” [28, pp. 40–42]. In the “collective care” experiments recalled in her dense essay *Care work* (2018) [28] and then depicted again in *The future is disabled* (2022) [55], participants are mostly disabled, neurodivergent, sick, Mad BIPOC (Black, Indigenous and People of Color) and queer people. There are nondisabled allies helping, but these networks are actively handled by disabled people and structured upon their needs and expertise. This structure also functions as a reminder that disabled people can practice relations of care and not only passively receive them. In each network, participants set an agenda and organize diverse activities based on their needs, which may include both physical and emotional support. For example, people help each other in daily tasks (shopping, cooking, dishing, personal hygiene); share knowledge and skills on medicines and assistive technologies; promote fundraising campaigns to help a member in economic distress; elaborate reflections on Disability Justice; plan visits to members temporarily in hospital, rehabilitation, psychiatric wards; and provide emotional care, verbal or not. These experiments found diffusion in Canada and the USA, with a variety of expressions [28, 55, 59, 64, 65].

Care collectives certainly represent a survival strategy but also open up to profoundly political terrains. Whoever participates necessarily collides with disabled people’s advocacy claims and checks out their needs first-hand. Therefore, there are exchanges of theoretical, political, and practical knowledge that centre on the modality of existence and the activism by the people assisted [63]. Consequently, these networks can represent a platform to inform nondisabled people about social changes advocated by disabled people. They also make it possible to craft stronger and more conscious connections *within* the disability community that originate from everyone’s needs and perspectives. The aim is not only to support each other but also to guarantee transversal accessibility. Care can actually represent a space where it is possible to realize “community building” and—unlike the most common narratives of it—can also be “a site of pleasure” and joy [28, p. 41, 56, 136–137, 55, 58]. Furthermore, practising and sharing these experiences contribute to challenging assumptions

of disabled people's passivity and incompetence: they can in fact organize complex and stratified care networks, contributing in heterogeneous ways [65]. They are a form of resistance to narratives about ableism—a system deeply entrenched with capitalism—which rewards self-sufficient and productive bodyminds.

Distribution of care sometimes emerges as critical, mirroring society at large: in care networks, most labour is often “assigned” to specific sections of the population: women and BIPOC. It is therefore necessary to open uncomfortable conversations about care load [28, 55, 59, 64]. Members must learn to set boundaries and respect their mental and physical energy. Within this framework, everyone shall contribute starting from their possibilities, bodies, and relational inclinations. That does not mean, however, that reciprocity within these care webs must necessarily actualize in an even contribution by all members—also because some of them can be difficult to weigh. Is it possible to ponder the support in the writing of a business e-mail, giving information on disability politics, and transferring someone from the bed to the bathroom? This kind of mutuality, therefore, always comes into being starting from a plurality of support activities. These relationships entail exchanges on several levels—for example, affective ones. In Erickson's case, “logistics” that concerns her necessity is interlaced by her giving relationship advice, small talks with assistants, and general conversations about personal and popular matters [36, p. 136].

When the COVID-19 pandemic hit, disabled people found themselves in a terrifying place not only because of the virus itself but also because of forced isolation and the collapse of many webs of support. Since collective care was already an ongoing experiment—it is never a settled track—they already had some tools to organize and make survival possible *without leaving anyone behind* [28, 55, 64, 66].

All the wisdom of disability and intersecting marginalized communities who are always and already surviving crisis after crisis without support from the government, public, and private entities but with each other have been illuminated. [59, p. 182]

Already running interpersonal connections, social media platforms, virtual communities, and local mutual-aid groups, continued to share information about the pandemic, and to support each other on different levels, often check-in in case companions and friends were isolated and anxious for their lives, in pain, sick, needing help [55, 59]. Not only did *they keep each other alive* [55], but they worked together to decrease the vulnerability collectively experienced, mostly by disabled and other marginalized people. They found themselves navigating in a frightening space—but not so unfamiliar. “Crip wisdom” and disabled skills became of primary importance, also beyond collective care—the “disabled people who were supposed to be the first to die, who absolutely refused to be sidelined or forgotten about”. All the care work went in parallel, however, with “grief and terror and uncertainty and loss”, which must be acknowledged as well as an outcome of the pandemic [55, p. 36]. The patterned, complex and coparticipated nature of the moment is described as such by Clare:

We who check in
every day over text, phone, Zoom, Skype,

Facebook, FaceTime: *how are your lungs,*
can you make rent this month, did you lose your job today,
are you hungry right now, do you have enough
insulin, estrogen, Prozac, Klonopin, blood pressure meds?
 We who drive across town to deliver saltines,
 fresh kale, chicken soup, half bottles
 of Tylenol, the last box of face masks
 to ex-lovers and best friends. We who have always
 shared everything we had. We who keep
 each other alive. We who will be turned away
 from emergency rooms and denied
 ventilators. We who will never
 go to the hospital. We who will die
 and we who will live. [67]

As Piepzna-Samarasinha argues, growing mutual aid discourses, from 2020 onwards, seemed not to acknowledge that disabled people were *already* doing this same work for years: since the “pandemic is a disabled event”, it should be clear that the disabled community may have methods, practices and insights to share [55, p. 63].

8 Conclusion

After having addressed the stratified connections between disability, vulnerability, and (inter)dependence, I have proposed a case study, care collectives, in which disabled people have actively engaged with the contextual vulnerability that can emerge in “traditional” care relationships, or within welfare and healthcare framework which reveals adequate—as it has especially occurred through the COVID-19 pandemic. In these cases, disabled people’s lives are not simply rendered harder: their very survival is at risk. As emerged, challenges posed by vulnerable presents and futures may be addressed thanks to the contribution of diverse subjects, as anyone might be a bearer of valuable contributions—and not *despite* disabilities. Relational and survival practices require the expertise of people with heterogeneous cognitive, bodily, and sensory traits. Even in broken worlds, crises, and emergencies, the lessons they can share should be cornerstones in community organizing: disabled people are experts crafting assemblages centred on care and support. Furthermore, these assemblages directly intervene in social and cultural narratives of disability—for example, disabled people are assumed to be merely passive.

Disabled people highlight the interdependence of our lives, with all the opportunities and the limits entailed: since they are frequently more *exposed* and more *extrojected* beyond their individual boundaries, they are also productively engaged with others. I have highlighted the generative potential of this shared dimension:

overcoming disability as an individual experience can benefit disabled people. In the mentioned cases, experiences of illness and disability are not isolated and detached from the relational context but are shared, both emotionally and practically. Disability can become a place of emotional, affective, and care-sharing and can also represent an important piece in building a disabled culture, with knowledge and practices mutualised. The situational vulnerability they may experience can also become, in Butler's words, "a potentially effective mobilizing force" [13, p. 14]. In this sense, vulnerability on the one hand and resistance and action on the other hand do not necessarily diverge but coconstruct each other. Connections and relationships involved in one's experience of disability do not exclusively produce a deepening of dependence (and therefore of possible vulnerability) but can instead function as "supports that shield against or minimize exposure to risks" [18, p. 214]. "Misfitting", as Garland-Thomson argues, can also enhance resourcefulness: an inadequate relationship between the subject and the context (material, social, and so on) can push her/him to imagine a new reality and to negotiate more just and fertile "juxtapositions" [33]. It is important to underline that I do not aim to romanticize vulnerable ecologies but acknowledge that subjects (forced to be) at the margins produce valuable knowledge and must not be cast aside in crises either.

As COVID-19 has been a "mass disabling event", the knowledge of disabled people should be recalled as especially valuable to manage the individual and collective consequences and changes. As Piepza-Samarasinha recalls, "the pandemic has meant that there's a huge wellspring of disabled culture, collective care, communities, love, grief work, joy": this expertise should be valorised on a social level, as "a crippling of the world, more than ever before", is happening [55, p. 325]. It is urgent to incorporate this training within communities: the role of collective care networks might increase in the future because we will probably live longer, state resources may decrease, climate change and pandemics will continue to have disabling effects, and not all disabilities are recognized to receive welfare aid anyway. Collective care has mitigated the exposure to vulnerability in recent years and during the pandemic as well but can also decrease our experience of it as an ontological human condition, as we are all more likely to thrive in interdependence rather than in isolation.

However, it is important to underline once again how these examples also mirror the inadequacy and scarcity of resources that characterized our society, especially when it confronts disabled people: the forms of "resistance" and organizing presented often work as an adjustment of structural lacks, violence, and discrimination. In addition, the emphasis on disabled people's contributions in this sense cannot become a form of social exoneration: it should not turn into a comforting narrative that implies the conservation of the status quo. Disabled people must not be ceaselessly fragilized by the economic, medical, environmental and social context. Therefore, the acknowledgement of their practices must also indicate what is missing on a community level. Last, these skills and knowledge should not be *extracted* from the disabled community and appropriated: the source must always be clear. In the diverse community they imagine and practice, disabled people are not at the margins: they not only actively participate in transformative social change but also guide it.

In conclusion, throughout the essay, I have attempted to show a set of diverse possibilities of what vulnerable positionings may entail. To gain deep insights concerning disability, vulnerability, and care, it is essential to include a *crip* perspective that originates from disabled people's expertise and knowledge and is also willing to destabilize rigid assumptions about all three concepts. As these concepts are often grappled with each other, it seems important to experiment with diversified approaches whenever we address them. Keeping in mind all the cautions and the ambivalences presented in the essay, I hope a multifaceted analysis of their intersections can operate as a starting point to spark several other conversations that place disabled people's experiences at the centre.

— In vulnerable ecologies, disabled people not only are not disposable but also represent a collective resource.

Core Messages

- Vulnerability and disability are not inherently coextensive, but an intersecting analysis can be productive to uncover the relational nature of both concepts.
- Assuming that every human being is vulnerable for her/his perishable, embodied and embedded nature, it is however risky to frame as vulnerable specific subjects. It appears more fruitful considering vulnerable ecologies, social positionings and processual experiences instead.
- The inherent interdependence of our lives can both be a source of empowerment and deepen the experience of vulnerability of the subjects involved in every relational network.
- Disabled people are not exclusively care receivers, but are experts in organizing and managing care, as it emerges for example in care collectives.
- Care relationships, and the space of assistance and (inter)dependence, can be inhabited with joy, political tensions and love for the disabled community.
- Since care is a fraught and ambivalent space, and we will probably need care more than ever (because of longer lives, climate change, pandemics, etc.), it is urgent to valorise disabled people's skills and experiences.

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