

The Neglected Rights of the Disabled

by David Le Breton

Despite the many measures designed to promote inclusiveness, it is a struggle for disabled people to exercise their rights. In the face of these vulnerable rights, individuals protest and seek solutions to escape the feeling that they are treated as second-class citizens.

About: Anne Revillard, *Des droits vulnérables. Handicap, action publique et changement social* (Vulnerable Rights: Disability, Public Action and Social Change), Paris, Presses de la Fondation Nationale des Sciences Politiques, 2020, 233 pages, €23.

In our societies, representations of disability tend to depict a damaged body, a distorted reflection in which we struggle to see ourselves. On an anthropological level, the human body establishes the boundaries of personal identity. If understanding the body is another way of understanding the world and social relations, then a problem with the configuration of the body disturbs the coherence of the world. It is the disabled who suffer for this, due to the unease it causes, the harm it does to their (already hard-won) social status, and the ill-adapted social space that has long hindered their ability to move around freely and access their desired activities. For a disabled person, professional and social integration is a constant battle that requires great personal strength and a conscious effort from those around them. The body is integral to social relationships, and if that body is not as expected, this affects all our interactions, overtly or otherwise. Impairment can be unsettling, except for close

family and friends, because it complicates social relationships and makes us aware of our own vulnerability.

Impairment becomes a social stigma, and difference creates friction. The mirror of the other ceases to sharpen the reflection of the self. In fact, their appearance momentarily destabilizes our own identity, by reminding us of the fragility of the human condition and the inherent vulnerability of any life. This unfathomable threat to familiarity induces anxiety, giving us the troubling sense that the world as we know it cannot be taken for granted. The disabled person is a disquieting reflection of the self. They remind us of the terrifying possibility that we might one day be (or that we might have been) in their place, because they share our human condition, yet they seem different from those around them. Defending disabled rights is one way around this social resistance, but the application of the laws is ambivalent.

Clear and well-written, Anne Revillard's book is a rigorous yet sensitive analysis and a fascinating read. It precisely highlights the vulnerability of disabled people's rights and the problematic efficacy of these rights for those with visual or motor disabilities in France. For a long time, disability was treated as a medical or individual issue, described in terms of physical, sensory and cognitive impairments. However, in the last few decades, it has come to be associated with poverty, poor accessibility, and a subordinate position within social relations. A number of works have drawn attention to populations who were, for a long time, made socially "invisible". These include the works of Erving Goffman (*Stigma: Notes on the Management of Spoiled Identity* and *Asylums*) and Robert Murphy (*The Body Silent*).

In many countries, public policies and legislation have sought to reduce the inequalities linked to the social handling of disability, but not without problems applying these measures. This is the focus of Revillard's book. The concept of disability encompasses a judgement of incapacity, lack of competence, vulnerability and dependence. It often relates to work. It initially developed around a still largely dominant medical perspective, but with a gradual opening to an ecological and social perspective from the 1970s. It primarily refers to the body and the senses, in terms of deficiency, but also to the ability to understand the world (cognitive impairment, etc.). It leads to public policies, and institutional, legal and community measures.

Often, wheelchair users become a model that obscures other forms of disability. However, situations vary widely: there are not only multiple impairments, but also multiple lifestyles and multiple ways of relating to the world. Disability is a product more of social consequences than of a physical attribute. Similarly, the paradigm of

accessibility is essentially about a situation, rather than a person's intrinsic nature. Anne Revillard shows that in recent decades, disability has been analysed above all as a form of social injustice to be remedied, rather than just a personal tragedy that primarily concerns the person affected. Rights have been centered around a desire to create equality with the wider population. Inclusion policies are now based on the principle of making services and sites inclusive and accessible for as many people as possible, which requires specific adaptations.

If disability somehow implies a dissonance between the individual and their environment, then we need to adapt the environment socially and physically so that this individual can negotiate it unhindered. In recent years, our desire to promote inclusiveness has been focused on minimising the inconveniences experienced by disabled people. In all its forms, this approach implies greater social justice and improves quality of life for all. It is universal in its principle, because it takes into account individual differences connected to ageing, illness and disabilities. It promotes independence by expanding people's connection with the world and with others.

Anne Revillard's book is based on robust research into the ways of mobilizing rights in public action, including discourse, laws, public policies and the positions of those involved. It draws on remarkable documentation, but the author has not remained at a distance: she has conducted in-depth interviews with 17 women and 13 men aged 23 to 75 with visual impairments (ranging from partial sight to total blindness) and 15 with motor impairments. For two thirds of them, their disability was diagnosed during childhood or adolescence. Anne Revillard is also transparent about the social conditions of those she met. All the analyses are accompanied by first-person accounts, which are often moving and always provide insight into experiences of difficulty or ease. Anne Revillard successively examines the right to education, work-related rights and social rights. She fittingly refers to "vulnerable" rights, to shift the focus away from the idea that disabled people are a sort of moral category condemned to interventions that are protective rather than egalitarian. The "vulnerable" nature of these rights is a result of the multiple obstacles to their application, which are clearly demonstrated by the accounts. Despite our ambitions for educational and professional inclusiveness, equal participation in the world of work, and accessible sites and transport, we still have a long way to go and a great deal of work to do.

There has been significant progress in education, but access to schools and universities does not necessarily mean these establishments are always inclusive or properly equipped. In practice, the right to education, from pre-school to university,

has not yet been truly won. Questions also arise about social rights: “Labelling, a feeling of strong social control, poorly adapted forms, excessive delays and a lack of information” ¹(198) mean that the reality falls short of intentions. Inclusion no longer only concerns people with reduced mobility and their access to spaces. It is also about use of and access to social and cultural activities, school, university, work, transport, etc. It is about more than just adapting architecture for wheelchair users: we also need to think about other groups in society (the blind, the hearing impaired, people with mental illnesses, those with multiple disabilities, etc.). Buildings often need major adaptations to restore equality of access and use.

However, Anne Revillard emphasises that disabled people are far from passive in the face of insufficient public action. They too are fighting to enforce their rights in their everyday lives and as citizens, through explanations, demands, pressure, legal action, etc. “Beyond the individual situations in which they are battling, ad hoc, to have their rights respected (access to an establishment, provision of a facility, etc.), many people express themselves publicly about the rights they are being denied, particularly using digital platforms such as blogs and social networks” (200). Having rights is not enough. Sometimes, people must assert themselves as subjects of law, thus helping to make these rights a reality, via an everyday politics that uses both public and political action.

Anne Revillard, *Des droits vulnérables. Handicap, action publique et changement social* (Vulnerable Rights: Disability, Public Action and Social Change), Paris, Presses de la Fondation Nationale des Sciences Politiques, 2020, 233 pages, €23.

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