



Anne-Lyse Chabert

TRANSFORMING A
DISABILITY THROUGH
EVERYDAY LIFE
EXPERIENCES

Disability Studies

Collection Editor

DAMIAN MELLIFONT

LIVED PLACES
PUBLISHING



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To the unknown builders of a time-to-come. Its trembling
uncertainty

Beginning over always and always,

May the untiring heart accompany them in their inaudible
daily lives.

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And yet although each of us tries
to escape from himself as from a prison
that crushes us within its hatred,
a great miracle awaits in the world
outside. I feel it: every single life is lived.

Rainer Maria Rilke, *The Book of Pilgrimage*, 1939

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And finally, I pay tribute to my readers, as they take the risk of following my footsteps. Their reading is the one action that will genuinely open up the approaches suggested in this book. It is my good fortune to ask them to think differently about things they have previously taken for granted. I feel grateful to them for having promoted me to the rank of guide.

Abstract

When does the disability start? How to better define it? As a philosopher, Anne-Lyse Chabert uses her own experience of disability to describe the dynamics necessary to overcome the constraints of the body and its environment. She analyzes this rebalancing phenomenon specific to disability, using three conceptual reading grids (normativity, capability, and affordance). The life situation of a calligrapher who became quadriplegic and remained just as demanding of himself, of young blind people learning to play football, or of an autistic person who was able to find a place in society, illustrate the inventiveness necessary to transform disability through life experiences.

Key words

Norm, disability, capability, affordances, lived experience, ethics

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Content warning

This book contains explicit references to, and descriptions of, situations that may cause distress. This includes references to and descriptions of the following:

- Degeneration of the body.
- Incapacity to do.
- Immobility and tetraplegia.
- Vulnerability of the disabled person.

Learning objectives

- Learn to surpass your own current limits, even when the initial predictions are not favorable.
- Allow a certain technical skill to develop from a phenomenon of distress.
- Better understanding of the dynamics found in the environment in order to make it more inclusive.
- Consider the dynamics of care from the perspective of empowerment.
- Question the situations where dialogue is lost between the individual and their environment.
- Consider capabilities as a tool that could allow us to rethink our way of living together.
- Overcome completely absurd discriminations.

Foreword

What it means to be human

I believe I became involved in ethics in order to have the privilege of meeting people like Anne-Lyse Chabert. To become acquainted in that way with a wealth of approaches, the riches of shared experience and wisdom acquired through the exacting encounter with a harsh reality—in her case, a severe physical disability. Over the years I have come to understand that the values of humankind are lived and defended wherever individuals embody and affirm the principles and aspirations that stem, largely, from their confidence in our democracy. At a time when we are so often urged to reinstate the values of our republic, let us make sure that we give them our very closest attention by recognizing those among us who honor those values through a never-ceasing combat, those who never compromise. A life-long combat revealing the very essence of an existence that is fully assumed and explores every possibility available to it, despite the terribly daunting obstacles that often make progress so arduous.

The countless encounters with the vulnerability of existence itself, the demands imposed by daily life that must be met again and again by overcoming the threats of inertia and the torments of renunciation—these relentless tests can give rise to a nobleness, a creativity, and a focus whose significance and scope we underestimate. Anne-Lyse bears witness to such intelligence of

reality, the will to resist, the boldness, and extreme courage that enrich the precarious present. Her capacity for philosophical reflection and the unflinching and meditative gaze with which she observes her everyday experience of living with a disability are the sources of her undertaking: to transform her relationship with the world. Suddenly a whole range of possibilities and unsuspected perspectives are opened up to us.

A disability, in its manifold expressions, is not “a situation.” At least that is not how our philosopher, Anne-Lyse Chabert, looks upon it. The singularity of daily life with a disability cannot be defined in terms that are too often simplistic and pejorative; it confers upon the person living it a position, a place, a role—I would even say a function—that makes it possible to grasp the world differently, to seize it, understand it, shed light on it, and assume it differently. And indeed, Anne-Lyse unveils other territories and reveals other aspects of a reality all too often denatured by concepts that freeze us in attitudes that are incompatible with the boldness and willpower needed to overcome dogmatic rigidities. She recognizes our freedom to embrace non-standard thinking, to be daring and dissident, to embark on an adventure; we will quickly find that it fosters renewal and enables us to open ourselves up to others and, from there, to a certain idea of human benevolence.

Anne-Lyse is truly a philosopher. She has taken on an ambitious intellectual task and rigorously structured it so as to present a practical and methodical analysis of what “Transforming a Disability Through Everyday Life Experiences” signifies.¹ I was there in December 2014 when she defended her doctoral thesis in philosophy at Université Paris-Diderot—a memorable occasion.

Modestly, delicately, with subtlety and precision and a demanding approach, she brings us to the very heart of what it means to experience a progressive neurological disability. She shows us how this “difference” must be thought through and compensated by calling upon capacities, competencies, and other resources so as to alter conditions and achieve a more favorable relationship with the environment, and how in the process, the environment itself changes and even becomes transformed. When a person aims to make the world livable and hospitable so that it can actually welcome a non-standard way of living and being, endowed with experience and knowledge of inestimable value, that person is quite simply creating the dynamic and the strategy of a metamorphosis.

The notion of metamorphosis is a vital component of ethical thinking that revolves around “incurable” ailments like a modality of existence that brings out what the person is and continues to be despite what has altered their faculties. Reinstating a capacity to seize opportunities, along with self-confidence and hope invested in a project and an outcome that nothing must be allowed to hinder for any reason, means being fully engaged in a life project for which freedom is the indispensable support.

People like Anne-Lyse Chabert, who contribute to our approaches to practical ethics, which is both committed and exposed to what defies it², teach us to appreciate the often-ignored resources of their “experiential knowledge,” that unique wisdom that they cultivate like a priceless treasure and sometimes allow us to discover.

What a privilege it is to share a precious existence with figures like Anne-Lyse Chabert. Her book is the fruit of years of exceptional

efforts and anonymous solidarity: how many people transcribed, as she dictated, her account of the various stages of thinking that became ever more precise as her research advanced! The readers of this book will have the privilege of acceding to a rare body of knowledge. I hope they let themselves be surprised and confidently follow a thought process that will lead them to a new region beyond ordinary thought where mysteries wait to be discovered. Entering this new region is a very personal affair. May we live up to what the author hopes to share with us—that is, what is common to us all as human beings. Anne-Lyse Chabert invites us into the very heart of an experience of humanity. I am convinced it grants us a better understanding of what being human means—and what that commits us to.

Emmanuel Hirsch, Professor of Medical
Ethics at Université Paris-Sud-Paris-Saclay
Director of l'Espace éthique de la région Ile-de-France

Introduction: A badly defined problem

“Well then, what is time? As long as no one asks me, I know the answer. But as soon as I have to explain it, I no longer know.”

Saint Augustine, Confessions

People looking in from the outside are astonished as they watch these human beings who exist (just like them) and who try to overcome the difficulties of daily life (just like them). The outsiders are convinced that it is impossible for those human beings to compete in the cut and thrust of this harsh world we all share: “How does she manage to live, with her disability? I mean, really, when you come right down to it?”

If a disability sometimes makes outsiders uncomfortable, that is mostly because it fascinates them. There’s no way they can remain indifferent, even if the history of ideas has often overlooked the question. A disability is a reality that speaks to them, and the first question that arises is, how do we define a disability? What exactly are we talking about when we talk about disabilities?

Who exactly are we talking about when we talk about “a disabled person”?

Like in the quotation from Saint Augustine, I am capable of approximately categorizing what is involved when I talk about a disability, I am no longer capable of grasping the content of the term when I am asked to define its frontiers accurately. Yet the term is so readily and loosely used these days. If a disability embarrasses us so much, that is precisely because we cannot put a beginning and an end to the notion it is intended to convey, and that makes our traditional ways of grasping and knowing reality inadequate.

I looked and looked everywhere for an academic route I could follow in order to make my words about what the notion of disability summons up more fluent. But at last, I realized that the most obvious trail for me to follow was the one that led me back to the singularity of my own life experience as a person who is today heavily dependent when it comes to mobility. That trail was not easier for me, but there was no doubt that it offered a vital lead connecting every aspect of my efforts to reflect.

The progressive illness that gradually made me an invalid has often led me back to the absurdity of a key question. When did my own “disability” begin? Was it when I began falling down so often on the playground and my mother grew alarmed? Was it when my handwriting began to change as the first stages of my pathology set in? Was it when we came home after consulting one doctor after another in the hope of a diagnosis, and I had at last been stamped with the seal, so to speak, of a particular illness that bore a name, even though the period thereafter was

one of grim anticipation? Was it at age 15, when I acquired my first official “Disabled Person” card? Was it the first time I tried on orthopedic shoes? Or when I began to use a walker? Or was it later, at age 20, when I sat in a wheelchair for the first time? Or the first time I ventured out of the house in a wheelchair? When did a vital difference emerge between me and the world of non-disabled people, to such an extent that suddenly I began to be labeled and excluded as “a person with a disability”? Inevitably, readers will ask themselves the same questions. And the fact that there are so many questions shows, in any case, how complex the notion of “disability” is.

When the word disability burst into my life, it seemed to cause a rupture, but was it really a sudden breaking point? Had I felt this rupture regularly in the course of my own life? Each time my disability entered a new phase, had I ever felt there was a “before” and an “after”? Although my breathing space had shrunk, unraveled, been reshaped, deformed, and condensed, and I had had to reconstitute it after each successive phase in my pathology, it had not seemed deficient to me (a word derived from the Latin and conveying the idea of a lack). Even though there were periods of reconstruction to be heeded and respected, I always needed to reconquer the totality of that space. In other words, although the texture of my private space changed as time went by and living within it became more constraining, I was no different from the person I had been before I began to use my wheelchair. Only in a photographable, external way did there seem to be a genuine difference. Nowhere did a typically external vision and an internal one converge so as to perceive the same event in the same way. Wasn’t this lack

of convergence a tragedy of rational thought? How could this aporia be overcome?

Could a new way be found to raise the same question? Would it be possible to reconcile the incoherence of these two visions while at the same time respecting the phenomenon that we want to describe?

For the sake of authenticity, we will not take as our starting point the question of disability, as it is already bogged down in past and present politico-cultural trends, for they can only offer us tools for classifying this and that without ever entering into the heart of a definition. Instead, we will attempt to alter the basis of our approach by aiming at reality from a new angle that will, hopefully, enable a more accurate tone to emerge.

1

Taking a new position on the question

“I consider that the major metaphysical problems are, generally speaking, badly stated; that they often solve themselves once the way they are stated has been rectified; or else that those problems are formulated in terms of illusion and that they fade away as soon as we look more closely at the terms used in their formulation.”

Henri Bergson, *La pensée et le mouvant*

If we feel that the question of disabilities has not been stated in a satisfactory way, that is, a way that would enable us to open a gamut of pertinent responses, this is no doubt because the problem has been poorly formulated from the beginning and is placed on flimsy grounds, just as Bergson suggests. Indeed, stating a problem is the first step toward orienting its mode of resolution. In this first chapter, we will attempt to set out the manner in which events are arrayed, in time and within the individual, once an organic or psychic lesion has appeared on the scene.

We propose a new way of considering what has until now been termed a “disability” by going beyond the traditional scission—internal vs. external point of view—and paying more attention to examining a phenomenon that grows from the vital heart of an individual faced with a disability. What is the chronological texture of the individual’s life? And what is the spatial texture?

A. A disability as “disorder”

The first phase is the one in which the lesion occurs. It may be inborn, acquired, or even likely to develop further. The individual is not only physically wounded; worse still, at first, they cannot find the usual, ordinary way to balance their needs with the limits of the space they inhabit. This is the first rung, so to speak, on the scale of the individual’s own body as a sort of landscape. The imbalance stemming from their awkwardness within their own body extends to higher scales. Encircled by technical objects and the sensory-motor interface with their world, the individual “knocks into” them and experiences them as obstacles. On the scale of human and social relationships, we find this same point of ungracefulness—of “dis-grace”—that places the individual in such a precarious situation throughout the entire intersubjective sphere.

Generally speaking, an observer viewing a situation of disability ceases to think at this point; they project their own paralysis onto the situation they are considering. Clearly, such a state of instability and disorder is of no help when it comes to devising treatment for a situation that is still ongoing. So our sole resource at this juncture is to reduce insofar as possible the disturbances caused by what we call a problem—and which is one indeed

because the individual has not had time to organize themselves and adapt to what they feel as an imbalance.

The individual exhausts every possibility and makes every effort to seem to remain within the space they inhabit; they pretend that all is harmony between themselves and the space around them. This “fake” situation is a sort of struggle to stay in the known world of objects and human beings.

Then comes a point of “non-choice”, where the individual experiences extreme distress and can no longer lie to themselves or to others. They have to acknowledge the situation as it really is; they are expelled from the setting they have always known. From now on, they are obliged to seek a new situation that can welcome them.

B. A disability as a quest for a new order

Thus we are faced with an initial factual situation whereby the individual no longer has any hope of being able to remain within their habitual living space. Usually, all thought on the subject is reduced to that conclusion, de facto assigning a thoroughly negative weight to the disability in question.

Reaching a new balance, or match, requires a real burst of effort, caution, time, and a new logic. The individual must strive to find ways to call forth and coordinate every single means at their disposal, even the most modest, in order to carry out the same task(s) as in an ordinary situation.

This does not mean they will inevitably be imprisoned in their inadequate and morbid situation. On the contrary: the lack that they feel, the imbalance, can become a potent force for change. Paradoxically,

it is because the individual is enjoined to change the setting in which they previously lived their life, because they are expelled from it come what may, that they will turn toward another setting that will correspond more closely to their capabilities and suit them better. They are absolutely required to create. No longer are they an individual subject to too many constraints to be able to evolve; they become an individual who simply must recreate themselves, must choose, and construct a new environment in which to live.

After these preliminaries, let's stretch our minds and look beyond a so-called definitive imbalance. We find that the individual, because of that very instability, casts about for a new equilibrium, in phase with the situation. They take inventory, so to speak, of the new set of constraints surrounding them, the resources available for them to mobilize, and evaluate the feasibility of their new goal. If an individual can no longer dialogue satisfactorily with their environment and is excluded from it, they must recreate more or less reliable types of balance in order to stabilize their existence. Those new types of balance are not readymade and instantly available. The individual will have to recreate, enforce, and sustain new links that they can establish with the space around them. They must take action in roundabout ways since the means that would normally be used in their situation are lacking. How can they go about this?

C. Strategy for creating new types of equilibrium; stages in the process

Thus, the individual is excluded, at this point in time, from the living environment to which they aspired. Within it, links already

exist with the individuals who are part of it; those ties are relatively obvious and comfortable, even though they may seem to be somewhat standardized and not very well suited to each person's conformation. We must never lose sight of this point of departure; the essential link is one of necessity and enables us to better understand the ensuing stages. The individual has lost their orderly pattern of life; they are in search of a new equilibrium and have no intuitive knowledge of what it will be. They are simply nonplussed by the instability that has taken over their life.

One of the major characteristics of living beings would seem to be that they always aspire to a state of stability; they always seek to remain within the homeostatic equilibrium. There is a long and laborious phase: the test of normality, as defined by Canguilhem (Canguilhem, 1991)—the organism's capacity to reconstruct itself, to modify the links that tied it previously to the world. The individual attempts to make them more pertinent, better suited to the new characteristics (corporeal, technical, or human and social) that their environment confers upon them and also to their own characteristics, whose identity changes with time.

In other words (and this perspective constitutes one of the keys to grasping the situation), the individual has no other choice but to create a new environment that they hope will be more appropriate for them and will allow them to navigate as freely as possible.

Two phases seem to emerge within the time scale of this decision: first of all, the individual must choose a new life setting among those available to them. Then comes the slow, painstaking process of creating links with it. Whether they will prove

functional cannot be known until they have been created and made operational.

- First stage: choosing a setting in which to place one's hopes
 The individual must, as we have seen, opt for a new setting since they have been forced back by the old one. But not all choices are open to them. Alone or with the help of people close to them, they must evaluate what they can realistically achieve, given the resources and the constraints of their personal situation as they see it, amid the overall characteristics of the specific context. Those very same characteristics can prove to be advantages or obstacles, depending on the setting and/or the individual's needs. The individual decides, guided by their criteria, the quality of the construction they are aiming for, the amount of effort required, and the time they can allot to their project.
- Second stage: creating links

The second stage is organized very differently, even though it follows from their decision, which becomes a guideline. The second stage is not on the same time scale. Whereas the creation of a life-setting project was intended to be intuitive and connected to an identifiable point in time, the strategy that will now make this new setting habitable will cover several pragmatic stages. How can we break down the process to discover the various moments when the individual devises and implements a strategy that will make possible the actual transfer, in the smoothest way possible, from one inhabited setting to another?

In order to invent (that is, to find a solution), the individual must take into account the parameters of their context, always "with a view to" reconstructing an equilibrium. They

must adapt them to their situation and the goal they wish to reach.

Generally speaking, the schema will include these points.

- **A goal** that the individual considers attainable even if they are not yet certain how valid their judgment may be. Have they truly taken into account all of the pertinent resources and constraints that will be useful to their efforts? They are certainly not in a position to guess those that will only crop up in the course of the action they intend to take. Some resources will develop or diminish in unforeseeable ways, and, similarly, some constraints will only arise as time goes by.
- **The stakes** are problematic: how can the individual reconcile the means at their disposal so as to meet the initial goal? Reconciling them is not at all easy or instantaneous because, in the current state of affairs, where those means are poorly coordinated, the situation becomes dysfunctional.
- **Resources and constraints** arise from the characteristics of the environment the individual aims to create, depending on the situation within which they function and the goal they intend to reach. Both resources and constraints can emerge on different scales that we will describe. Nor are they mutually contradictory; in reality, they are the two faces of one another. Depending on the situation, one and the same characteristic can be a facilitator or an obstacle. The individual must balance these two elements to make the situation operational and devote their efforts to it. They will draw lines connecting the two from their point of view, and from those dynamic lines stems the notion of structure, which reveals the salient features of the lay of the land (the framework of constraints).

- The notion of the organism's **needs** is part of the constraints to be respected, but in addition, it motivates the process that follows by regulating the goals stated and their feasibility so it is not simply a vector of limits. An individual's needs organize themselves hierarchically within their existence; on the very lowest rung are the essential needs that must be satisfied if the organism is to survive. Only then can hierarchically lower needs be satisfied, and so on. In other words, the organism invests all its strength at the most urgent level, and not until that first need has been met will it invest in meeting a lesser need.³
- Lastly, **time** is one of the major factors that shape the general framework. In what time frame is the unity of action inscribed? What is the chronology? Indeed, the entire phenomenon of adaptation will be configured differently depending on its duration, that is on whether the person has a fair amount of time to reestablish points of equilibrium or only a short time.

Thus, the overall structure of this search for a new adaptation is constantly undergoing reconstruction and constantly being reformatted. Using that dynamic, the system seeks an ever more satisfactory state of equilibrium and is always compromised by external stimuli, perceived a priori as so many disturbances. This nonstop reconstruction process can be observed in the constant adjustment between the entities that are taking part in it and interacting completely. They register the overall morphology of the process at every step while remaining somewhat constant; they are adjustable parameters whose purpose is to accomplish a task in a relatively constant manner, give or take a few variations.