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► **To cite this version:**

Eve Gardien. Between Normality and Disability: Sensitive Cognitive Boundaries. *Welfare e Ergonomia*, 2021, 1, pp.104-116. 10.3280/WE2021-001010 . hal-04405318

HAL Id: hal-04405318

<https://hal.science/hal-04405318>

Submitted on 12 Feb 2024

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Between normality and disability: sensitive cognitive boundaries

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Ref : Eve Gardien, "Between normality and disability: sensitive cognitive boundaries", *Welfare e Ergonomia*, special issue "Dis/ability: theories and practices", ed. Jean-Pierre Tabin, 1, 2021, 104-116
doi : 10.3280/WE2021-001010

This work was funded by the Public Health Research Institut. "AAP 2019 – Handicap et perte d'autonomie – session 10" Réf. INSERM de la convention 2011003-00

Abstract: Within the framework of a cognitive sociology of everyday life (Schütz, 1962, Berger and Luckmann, 1966; Zérubavel, 1997), this article proposes to explore the effects of normality and of norms, accepted as reality/truth, on people who are experiencing rare situations. First, we will analyze the practical consequences of these norms on the use of the body and the physical environment. Then, based on the sociology of knowledge of everyday life, we will explain the partial lack of semanticization (Gardien, 2008) of the reality lived by people in rare situations. These analyses will highlight the major role of generally accepted criteria of relevance, and of the poorly recognized perceptual and cognitive boundaries that result from them. The conclusion will lead to courses of action aimed at broadening the field of intersubjectivity to include greater cognitive diversity.

Key words: Disability; Diversity ; Cognition ; Normality ; Intersubjectivity ; Peerjectivity

Introduction

Observations made by Disability Studies (Campbell & Oliver, 1996) and many other non-academic activist movements have highlighted a lack of accessibility in the most ordinary living environments and the disabling barriers (Fougeyrollas, 2010) limiting or preventing the action of some people considered as disabled. This has made it possible to move away from an individual-centered understanding of disability and to focus instead on the role played by the environment. This new perspective has contributed to advancements, notably at the political level, with accessibility standards being required for buildings, establishments open to the public, public transportation, the Internet, etc., or at the theoretical level with the concepts of universal design (Mace, 1998; Case, 2003) and inclusion (Young, 2000), noticeably enlarging the category of the able through *a priori* adjustments to the environment.

Critical Disability Studies reopen the debate on disability, examining hitherto commonly accepted distinctions between the biological and the social, impairment and disability. They shed light on the unquestioned normativity applied to concepts of normality and disability and on their social production. They create the concept of ableism to describe a social process that assigns people with

different potential to the status of incapacitated or deficient (Campbell 2009; Goodley, 2014; Tabin, Piecek, Perrin, Probst, 2019).

The world has been adapted by humans for humans over a few thousand years, if not many more. Forests are now crisscrossed with hiking trails, seashores are commonly developed for swimming or vacationing, the countryside is provided with paved roads, our cities with public transportation and miles of sidewalks, etc. In short, the world has been largely modified to accommodate certain types of potential bodies, generally referred to as functional bodies. There is nothing natural about this arrangement, even if it seems normal and obvious to most. It has been constructed materially and in an ideal manner over the centuries, following the process of the social construction of reality (Berger and Luckmann, 1966). However, not only has the relationship to the material world been socially constructed; experience has also been semanticized (Gardien, 2008) and reciprocally typified (Schütz, 1962) in order to become intersubjective, and consequently shared and normal.

Within the framework of a cognitive sociology of everyday life (Schütz, 1962, Berger & Luckmann, 1966; Zérubavel, 1997), this article proposes to explore the effects of normality and of norms, accepted as reality/truth, on people experiencing rare situations. First, we will analyze the practical consequences of these norms on the use of the body and the physical environment. Then, based on the sociology of knowledge of everyday life, we will explain the partial lack of semanticization of the reality lived by people in rare situations. We will then develop some reflections on factors that contribute to the long-term perpetuation of these poorly recognized perceptual and cognitive boundaries. The conclusion will lead to proposed courses of action.

Practical consequences of a rare situation on the possibilities of acting in the world

The practical consequences of a rare situation are particularly difficult for individuals who suddenly find themselves in a body with new potential, following an accident, an illness, etc. In some cases, this even requires them to learn most of the activities of daily living at the expense of new efforts – usually within the framework of rehabilitation – so that these actions become possible in new ways. An individual with low tetraplegia, having learned to brush their teeth 15 years earlier with an occupational therapist, explains this new socio-corporal arrangement in this way (Vigarello & Vivès, 1983):

First of all, to put the toothpaste on the bristles, it's necessary to put the toothbrush on the sink facing you, bristles towards the ceiling, and try to press the tube of toothpaste over the bristles. After several unsuccessful attempts (toothpaste stuck on the sink, or toothbrush rolling into the sink, etc.), partial victory is achieved by putting the toothbrush with its dose of toothpaste inside the oral cavity. Several attempts are generally necessary before success. That is to say approximately 30 mn/ brushing of teeth; at a rate of two brushings of teeth per day: one hour/day. (Summary of explanations from T., person with low tetraplegia, focus group, April 2013)

This person was greatly surprised the day they observed an individual with approximately the same body potential as their own take a tube of toothpaste, bring it to their mouth and squeeze it, leaving toothpaste on their tongue, then grab the toothbrush, brush and rinse, the whole action lasting two or three minutes.

What can we understand from this example? Many of the body techniques learned in rehabilitation are based on a model of the way a so-called non-disabled body uses them. In other words, there is only one reference concerning the functioning of a healthy body, and it is biomedical. Rehabilitation therefore often, but not always, consists in bringing the new bodily potential as close as possible to the established norm, which implies thinking of it as an insufficiency and not simply as different.

“E: Yes, you have to brush your teeth with one hand, that’s the way it is... [...] They [able-bodied people and especially the care and rehabilitation professionals] don’t see the purpose of the thing. The goal is to brush your teeth! After that, who cares if it's done with one or two hands?” (Excerpt from a focus group among people with disabilities, Paris, April 2013)

More broadly, the internalization of social standards on the uses of the body generally allows each person to function well and effectively in the world. Mauss (1936) highlights the traditional aspect of the transmission of the techniques of the body, society by society. However, these social norms, when taken as normality – as in the case of the biomedical model of the body – and not as a general example of bodily diversity, prevent or limit the exploration of bodily potentials for their own sake and for the sake of exploring and making discoveries about a new bodily potential.

Furthermore, the rehabilitated body does not systematically return to the functionality considered normal for the so-called non-disabled body. In the case of low tetraplegia, the use of technical aids to achieve a certain number of objectives by oneself is common (e.g., the wheelchair). However, these technical aids sometimes require the help of a third party to be installed before they can be used. Also, a technical aid does not always enable true functional independence, contrary to what its function suggests. Moreover, technical aids are usually designed to allow a particular act, just one. They are rarely multipurpose. This suggests that for each act one can no longer perform alone, a technical aid can be invented and manufactured. This implies in turn a large number of technical aids, and space to store them, but also choices that are sometimes difficult to make when leaving on a trip. Which ones are the most necessary? Finally, most technical aids are not everyday consumer goods. They are custom-made objects created in the context of rehabilitation. A damaged or lost technical aid cannot be easily replaced, an appointment with a rehabilitation specialist is required, and financing must be found.

Technical aids, because they are designed to allow an action or a posture similar to that of the so-called able-bodied body – in an approximation of what is considered the norm for the latter – are not often thought of in terms of *design* for everyday life. Their lack of versatility, their sometimes large size, their use requiring the intervention of human aids, etc., are partly explained by this.

We will not reexamine the lack of accessibility of the environment on a daily basis for some people. These facts – and the reflections on norms they elicit – are well known. It’s thus at the level of the body and its uses, of objects and other extensions of the body in daily life, of environmental factors in the sense of the ICF (WHO, 2001) or of the MDH-PPH2 (Fougeyrollas, 2010) that social – and biomedical – norms impose themselves and their effects. This is that rare situation in which the individual can’t appreciate the good fortune of having a body that fits with ease into the world as it has been arranged by and for human beings for many centuries. Their daily life is not quite ordinary, for reasons linked to the interactions between their body and their environment, but not exclusively... Let's examine further the nature of everyday life, and its norms concerning perception and cognition.

Everyday life is based on normative cognitive socialization

For many of us, everyday life is characterized by the relative ease with which we relate to the world. Our daily experience seems to be self-evident. For example, when a person wakes up, they know what they are going to do with their day, or that they will not do anything with it. They know how to get to work, if that is in their schedule. They also know that they have other transportation options and what they are. They have an idea of their breakfast menu. They have done the shopping in anticipation of this moment, etc. A great deal of knowledge thus constructs our way of life, and our relationship to the world, to ourselves and to others. This knowledge is partly inscribed in our routines. It is part of our daily life, without us really being aware of its existence or its involvement in carrying out our projects and meeting our goals of the moment. How can we explain this fact?

Alfred Schütz (1962) shows that everyday life is based on a world shared with others (even though it's possible to become a hermit in a later stage of one's life). While the materiality of things imposes itself on each one of us from the outside (according to one's perceptive attributes), Schütz emphasizes that the meanings of beings and things also largely impose themselves on us from the outside. Indeed, the meanings of beings and things are not innate. They don't result from our genetic heritage or from our instincts. These meanings vary widely depending on the cultures and social environments a person frequents throughout their life. A child learns what reality is, and in particular the meanings to be attributed to the experiences he or she has during early socialization (Berger and Luckmann, 1996 [1966]: 177-188). Learning the meanings of the world contributes to the possibility of an intersubjectivity (Schütz, 1962) that allows sharing this world, communicating with others and acting in concert, and experiencing the feeling of partaking in the same reality, without this impeding the possibility of very personal and private experiences.

Building on Schütz's work, Berger and Luckmann (1966) highlight the importance of the social construction of reciprocal typifications and their transmission from generation to generation in the process of semanticization of the individual's experience of the world (Gardien, 2008). Thus, the understanding of the world, of oneself, and of others is achieved through the use of reciprocal typifications, such as the meanings and words present in the social environments one lives in. They are largely learned and internalized during childhood, but may be so at any age, in the context of secondary socialization (Berger and Luckmann, 1996 [1966]: 189-200). These typifications are models – simplifications of reality – that give one direction, making it possible to understand and to decide and act. This simplification of reality is not an individual or social choice, but a necessity arising from human limitations. Reality is too complex for the human cognitive potential to understand it all at once or in its entirety. For example, human beings are unable to detect ultraviolet light or ultrasound, among other things.

These reciprocal typifications, internalized by socialization, have major perceptual and cognitive consequences. For example, when individuals meet others for the first time, they cannot rely on knowledge acquired here or there to know who they are dealing with and how to behave. This is why, for this new situation, they will use typifications learned previously. In other words, they will employ the relevant distinctions to bear in mind according to their socialization, and probably without really thinking about it. Depending on the societies or social groups they live in, they will pay more or less attention to the fact of being children or adults, men or women, of belonging to this or that social group, of wearing this or that dress or using this or that vocabulary, etc. That said, whether or not individuals have specific *a priori* knowledge about a being or a thing, they nevertheless use typifications acquired beforehand to give meaning to their experience of the being or the thing. Knowing Juliette personally doesn't preclude an understanding of her also as a woman or as a former student of a renowned engineering school.

Thus, a human being's experience of reality is based on – although not limited to – a "comprehensive and given reality confronting the individual in a manner analogous to the reality of the natural world." (Berger & Luckmann, 1996 [1966]: 85). Shared words and meanings – the internalized reciprocal typifications – constitute strong norms and normative expectations, including the establishment of social roles such as those of the able-bodied person and the disabled person. What happens then when the experience of reality is partially and persistently at odds with reciprocal typifications, with the intersubjectivity established as reality?

The partial absence of semanticization of the reality experienced by people in rare situations, and some of its effects

Some people experience daily situations in which both the material world and social reality are not entirely adapted to their specific needs. Let's take the example of a person living in an electric wheelchair. In spite of commitments in public policies and the efforts of institutional actors to make society accessible, the fact remains that on a daily basis, many public spaces, or entire sections of roadways, or even the natural environment designed for winter sports, do not allow for mobility equivalent to that of people perceived as able-bodied.

As far as social reality is concerned, the same is generally true. What does this signify? The meanings available for understanding reality in different social environments are those useful for semanticizing the usual experiences of everyday life (Gardien, 2020). There are, of course, specificities in knowledge stocks (Berger & Luckmann, 1996) that are available depending on the social milieu. The daily experience of mathematics teachers does not involve exactly the same typifications as those of webmasters, even if parts of their daily life are similar. For a person experiencing an exceptional situation – for example with a spinal cord injury and living in a wheelchair – whether they are a mathematics teacher or a webmaster, they will not have the words and meanings at their disposal concerning sensations experienced below the lesion in their injured body (Brunelles, 1992; Gardien, 2008). The vocabulary is not found in any dictionaries.

These are very commonly experienced phenomena¹. Whether they have a biological, psychological or other cause, they have not been given meanings, much less typified reciprocally. Therefore, they don't contribute to a socially constructed reality or to intersubjectivity. This doesn't imply their non-existence or the impossibility of experiencing them. Conversely, an important consequence of this non-semanticization of these phenomena is the absence of meanings in order to recognize them, to observe them, to distinguish them, to think about them, to understand them and to be able to act intentionally on them or their effects. Individuals living with these rare situations – in this precise case, the interaction between rare perceptions and the absence of available categories of thinking within social milieus – are thus helpless when faced with certain segments of their lived experience.

This lack of shared and available words, meanings, and typifications makes it difficult to communicate with people who are not living the experience, including care and rehabilitation professionals who are usually considered knowledgeable on the issue (Goffman, 1963). Some people with spinal cord injuries (for example) nevertheless attempt to continue relying on their sensory experience. This often makes their words inaudible, unintelligible, or of no possible use to their listener.

In the physiotherapy room, a spinal cord injured patient is tested for the sensitivity of his body below the lesion. He tries to answer as precisely as possible to his rehabilitator:

¹ Phantom pains are a well-known example, but the range of these phenomena is much wider, and few are recognized and investigated.

“Physiotherapist: Does that sting?
Patient: No, not really... [Pause]
Physiotherapist: Do you usually feel it?
Patient: Not usually but I feel... [Pause]
Physiotherapist: And there?
Patient: I feel a little more...[Pause]
Physiotherapist: Here?
Patient: Less....” (Excerpt from Gardien, 2008: 169)

Faced with considerable difficulties in describing certain parts of their experience, or faced with a lack of agreement between perceptions coming from the sublesional part of the body and information gleaned from another source (vision, for example), very many people with spinal cord injuries give up semanticizing their experience. They feel they are dealing with sensory phenomena that are incoherent, random and therefore incomprehensible, or even with a sublesional part of their body that has a life of its own.

A patient, lying on a rehabilitation table, talks with a third party while his physiotherapist moves his leg. While speaking to this third party, the patient states, among other things, that the physiotherapist is moving his right leg. His physiotherapist points out that he is moving the left leg. The patient is then very disconcerted – even disturbed – to discover his error, to note that he can experience sensations that do not correspond to the commonly accepted description of the situation in progress, nor even to the description he himself would have made by using his other senses. (Excerpt from Gardien, 2008: 176)

Social factors also contribute to the reluctance of many injured people to semanticize their bodily experience. They fear being classified as somaticizing patients, or as hallucinating or having mental health problems, etc. The risk of a remark concerning some aspects of experience that challenges intersubjectivity being rebuffed – and the risk that the person who made it is stigmatized – are indeed not negligible... As Z erubavel (1991) explains, the cognitive socialization of each individual promotes learning the *fine line*, this subtle line of demarcation that allows differentiating in a relevant way between what is recognized as existing or not, unimportant or not, between what should be ignored or not, etc. By learning these distinctions operating at the heart of everyday life, society applies a certain logic but also its norms, therefore making possible a sufficiently shared way of perceiving and understanding reality. It thus portrays the respective camps of the normal and the deviant, this time in relation to cognitive socialization (Z erubavel, 1997).

However, some phenomena can be observed and reproduced, and even be very significant due to their reliable efficacy for the body and their important functional relevance. The ability of some spinal cord injured people to use their contractures to perform movements that are otherwise impossible is now widely recognized in the field of physical medicine and rehabilitation. Their skills in chair-to-car transfers are also commonly used in rehabilitation centers by professionals to encourage other spinal cord injured people in their learning process.

The cognitive socialization of individuals enables each society to draw the boundaries between what exists and what does not exist, what is red, blue and yellow, etc., and to stamp its fine lines on individuals, their perceptions and their cognition. However, some individuals in rare situations, for health reasons or not, experience sensations but also thoughts, gestures, and postures that deviate from the normative expectations of the surrounding intersubjectivity. They face daily perceptual and cognitive boundaries that distance them from so-called normal.

Going beyond these perceptual and cognitive boundaries: some thoughts

A lack of reciprocal typifications in some cases, difficulty in typifying in other cases – and probably other causes as well – explain the lack of formalization or even the low level of creation of this rare experiential knowledge. In addition, many obstacles limit the transmission of this rare experiential knowledge: it doesn't fit criteria for the production of scientific knowledge, it has only non-systematic compatibility with professional knowledge, it has little recognition and legitimacy in general (Borkman, 1976; Chamberlain, 1978; Godrie and Dos Santos, 2017; Gardien, 2017), it is often overlooked even by those who possess it, it is usually informal in nature, it has limited social distribution, and there is often denial of the possibility that an alternative social construction of reality can exist (Gardien, 2017).

Another explanatory factor also deserves further investigation: general structures of relevance (Berger & Luckmann, 1966). As Z rubavel (1997) notes, our contemporary world grants relevance and legitimacy primarily to cognitive individualism (Downes, 1993) largely driven by the intersubjectivity of individuals, at least those sharing Western reality. It also subscribes to a cognitive universalism based on Kantian rationalism (1990 [1781]) that examines the frameworks of human understanding and is widely used in the field of cognitive sciences. Two legitimate conceptions of our understanding thus coexist: that of the thinker facing the world alone and that of a cognitive potential specific to the human species.

These two concepts both focus on reason, thus following a tradition of thought espoused by Descartes (1637). This dominance of reason neglects lived experience. Without repeating the extensive debates between empiricists and rationalists, it's clear that rationality cannot be exercised without the capacity to discern, define, etc.; all activities that are possible thanks to language. But the latter is a product of the social construction of reality, of the socially constructed relationship with experience. Thus, it's not possible to reason without experience, which doesn't mean that the method of systematic doubt concerning one's own experience is not useful and relevant. But the "I" and the action of "thinking" stated by Descartes shows that his *cogito ergo sum* is based on socially constructed categories existing prior to his reasoning, making it possible to distinguish the fine line (Z rubavel, 1991) between, for instance, his "I" and what is not "I". The "I" is in fact partly the result of a social learning process that presupposes prior semanticization of the experience of a self on the basis of words and meanings available in the social environments one lives in (Gardien, 2008). The object of human rationality always involves an experience essentially mediated by language. For these reasons at least, we disagree with the usually accepted separation between rationality and experience.

Z rubavel (1997) contributes another element to our thinking on the general structures of relevance. He shows that between cognitive individualism and cognitive universalism, there is a lack of a cognitive sociology to study the differences observed between social groups and the cognitive diversity that is socially constituted and distributed. In other words, he introduces a new explanatory factor that goes beyond the simple individual/human universal continuum – cognitive socialization – and that is based largely on the transmission of reciprocal typifications of the experience of reality from one generation to the next (Berger & Luckmann, 1966). However, this important advance does not explain whole areas of lived experience that are not semanticized, and the significant consequences of this for those directly concerned.

According to our present state of knowledge, these areas of experience that are not reciprocally typified are the result of socialized individuals living rare experiences. They are not differences between social groups or societies. These rare experiences concern individuals and not groups, and the semanticization and typification of the experience often remains the work of a single individual or of a few persons, if they are in contact with their peers. These individuals find themselves faced with the immense task of typifying their experiences by themselves, without any real reference points or method, and generally without any support. Thus, the advances in cognitive sociology proposed by Zérubavel concerning the cognition of groups or societies are not sufficient to solve the problem of the reciprocal typification of rare experiences.

There is consequently a need to establish an epistemology specific to cognitive sociology, no longer dedicated to cognitive distinctions between social groups or societies, but to knowledge resulting from experiences of rare situations lived by socialized individuals. This cognitive sociology would examine the social processes underlying everyday situations considered as normal and reciprocally typified, and those rare situations – not ordinary and not well semanticized – that are not reciprocally typified.

One aspect of the general structures of relevance interferes with the semanticization and reciprocal typification of these rare experiences. This experiential knowledge is *a priori* illegitimate because of its subjectivity. This knowledge would only be valid for one individual, the one living the rare experience. Is this assessment pertinent?

The characteristics of this knowledge are not those of the material objectivity of nature, nor of the legitimacy of social intersubjectivity. However, these semanticizations of rare experiences by one or a few individuals show important similarities between people who don't know each other. For example, knowledge generated by people living in wheelchairs concerning the use of buses commonly includes a focus on positioning oneself in the bus shelter in order to be seen by the driver and to obtain the descent of the ramp, and a focus when entering a crowded bus on the firm negotiation of one's place that is already occupied by one or two baby strollers, etc. This is knowledge that an ostensibly able-bodied person never develops. This is knowledge that displays frank similarities between individuals who have never met.

This experiential knowledge is therefore not subjective: it is valid for all peers and not simply for this or that individual. It doesn't derive from individual preferences or habits and is independent of the will of this or that individual. However, this experiential knowledge is not objective in the sense of being valid for all persons. This knowledge is *peerjective* (Gardien, 2020): valid for all people living similar rare situations. These situations have been semanticized and typified by individuals, but the social conditions of their production have not enabled the creation and legitimization of an intersubjectivity confined to peers.

Conclusion

Examining the question of norms and normality from the perspective of ableism implies not only questioning social normativity and its corollary effects of stigmatization, discrimination, exclusion, inferiorization, infantilization, etc. Another analytical line of inquiry is suggested by Bourdieu's (1997) remark on those norms that no longer need to be stated in order to be thought about and applied, because they are the *doxa*.

Theoretically deconstructing the self-evident concepts of disability or impairment can involve analyzing the processes of social cognition. Indeed, as Berger and Luckmann (1966) point out, once socially attributed meanings of reality have become widely shared reciprocal typifications, once they

have been transmitted, learned and internalized by the following generations, they become obvious, they become the socially shared reality. Considered valid for everyone, this intersubjectivity is considered to be objective. During its transmission and learning, it is not presented as a social construction but as the truth: what is. This is why people feel constrained to deal with it as though it were as irrefutable as physical matter.

Once a particular intersubjectivity has become established, it becomes difficult for a group or a society to consider alternative semanticizations and typifications, notably because of the general structures of relevance. Hence the importance of questioning these structures of relevance: are they the only valid ones? Do they account for the diversity of lived experiences and rare situations, or do they standardize perceptions and cognitions? The view of this article answers this question: they normalize perceptions and cognitions.

Therefore, in order to allow cognitive diversity to be acknowledged and accepted by our societies, it is important to examine the foundations of general structures of relevance. Some avenues of research have been suggested: refusing to take for granted the opposition between rationality and experience; building a cognitive sociology that supplements cognitive individualism and universalism by studying social diversity and not just individual singularities or human transversalities; discarding the practice of sociological thinking in terms of groups and societies for an analysis in terms of knowledge derived from the experience of rare situations by socialized individuals. It is through the effort invested in discussing the presuppositions underlying normality and the normal relationship to reality, that cognitive diversity, and in particular *peerjectivity* (Guardian, 2020), can be constructed², adopted and become legitimate.

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² This type of experiential knowledge cannot be produced by monitoring the practices of everyday life, for reasons that are beyond the scope of this paper. The "survey" proposed by John Dewey will certainly not be sufficient, although of some use. A specific methodology dedicated to the production of *peerjective* knowledge should be set up on the basis of this continuing epistemological effort.

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