

# From the Exceptional to the Universal

Charles Gardou

Translated by Goran Đapić

## Introduction

Do particular phenomena such as different disabilities really have anything in common? Is it possible to get access to the core of what is essentially human through such a side track? Is it possible to discover the universal in something “so unique” and exceptional? How can it address grand anthropological problems related to man in society; in the culture, in the world; faced with “the others”...? To what extent could exceptional phenomena such as disabilities serve as a magnifying mirror, as magnification?

## Singular - plural - universal

Among the many significant characteristics of our culture, there is an inclination to put the issue of disability aside. The responsibility to understand the phenomenon is left to different specialists or experts together with sympathisers fighting for their cause. “It is their job, not ours. It is not our field of interest. It is too difficult, and humiliating, too, to focus our activities, work or research on those who are weak!” For the same reasons, they are being placed “somewhere else”; those who are affected by some impairments. Since they are thought to be strange, they must be isolated. “The strangers”, they are perceived as unfamiliar, unclear silhouettes, often distant and weird, being identified only by their syndrome: Down’s, Guillain-Barre’s, Kanner’s or Asperger’s, Prader-Willi, Rett, or Locked-in. They are children, adolescents and adults reduced to one designation, identified with a specific institution and similar centre. They are

reduced to their wheelchairs, to their crutches or prostheses. It is even possible to disembody and regard them as senseless beings instead of thinking of them as children and adults, as living human beings who feel and think; who have urges and desires, plans, passions and will.

However, are the deaf the opposite of hearing people? No! Their eyes are their ears. Their visual sharpness, imagination and intuition are fascinating. They speak with “signs”. Their first language is their sign language, and it functions similarly to other people’s oral language. They are not acquainted with the world of noises. Their culture is one of silence, and their bodies live in the rhythm of vibration. Emmanuelle Laborit remembers how as a teenager, she loved to go out with her deaf friends to a disco-club:

It was the only place where we could switch on the music on full strength regardless of others. I danced all night, with my body glued to the speakers. The hearing looked at me, surprised. They must have thought that I was crazy (Laborit, 1994: 32).

Are blind people half-human compared to those who see well? No! Their eyes are at the tips of their fingers, and they view the world beyond appearances. Beauty is for them something warm, mild, smooth; the softness of a face, the melody in a piece of music, the resonance and colour of a voice and the shape of a sculpture. Evgen Bavčar, a blind photographer, tells how he colours the things and persons that he meets<sup>32</sup>.

I know one woman whose voice is so blue that it can transform an autumn day from grey to azure. I met a painter who had a dark-red voice, and by chance it was the colour that he loved (Bavčar, 1992:10).

He experiences the sun through its warming effect. And as for light, it comes to him through words and music: “I remember”, he says, “a guitar player who sang a *bossa nova* in Portuguese and I barely understood the words, but the sounds were multiplying like glow-worms spreading over her and her guitar; it was so light that I wished to paint them”. He concludes: “We will live in a barbarous world until you understand that without eyes there are other ways of seeing. That is why I am a photographer; in order to join you in your universe and to suggest to you another kind of view” (Bavčar, 2004: 85). He tells how he, during the opening of a sculpture exhibition, was observing “the nudes up close” with his hands. He was asked to leave the gallery because other visitors were

---

32. Born in Slovenia, Evgen Bavčar completely lost his sight at the age of eleven following two consecutive accidents. The first exhibition of his photographic achievements took place in Paris in 1987.

shocked by his touching the bodies. His experience as photographer continuously imposes this question to us: How does a blind man manage to substitute seeing with using his tactile sense and by so doing grasp the reality of that vision in all its details? Photographic art is considered a prerogative for those who can see. But is it first and foremost a mental picture of the world, and only that? Is it an effect of sensuality, whose imprint is only a secondary phenomenon?

Even though persons who are blind or deaf may be perceived as being exceptional or completely unique individuals, by nature there is no fundamental difference between them and others who are not deprived of hearing or seeing. This remains true, even in the case of the most advanced impairments. I think of a boy with cerebral palsy, who cannot control the movements of his legs, hands or speech organs. His words, insane of fury at being trapped within the confines, collide with the walls of his body. While these are difficult moments that reflect the seriousness of his impairment, they still indicate his level of understanding. He recently enrolled in a higher education programme in social sciences. On the table in his room lies the book *The Body Silent (Vivre à corps perdu)* by Robert F. Murphy (1987), an American anthropologist who tested his physical reactions as his body became gradually paralysed day by day. On his computer, which he commanded by means of his chin, is a love message from his darling, asking him to choose the same type of summer vacation as she has done from a brochure promoting adapted tourism.

I also still think about the girl with multiple disabilities due to major and diffuse lesions which had obstructed her entire developmental process. Her cerebral impairment generates a progressive disease, multiplying her difficulties in a downwards spiral. The domino effect of her overall motor impairments creates a host of secondary effects whereof the most serious are hypotonic or pathological lethargy of the spine<sup>33</sup>, paralysis in all four limbs and difficulty swallowing. Against all odds and even though they lack the possibility of reversing the increasingly serious impairments, her parents are tirelessly continuing to encourage their girl's appetite for life and her desire to explore the world; her ability to enjoy others' caresses, experience new emotions and understand certain messages, such as receiving an invitation to a dinner or listening to music. Their relationship with her is like sharing a precious jewel.

---

33. Hypotonia, also called floppy infant syndrome or infantile hypotonia, is a condition of decreased muscle tone.

Regardless of their impairments<sup>34</sup>, each of the memorable persons I have told about contribute to highlight the meaning of anthropological universality, namely the endless diversity of human beings, their polyphony and changeability of appearance, their inconstancy and essential vulnerability. “Just when I am nothing”, wrote Sophocles (1989) in *Edipe at Colone*, “then I am a man”. Therefore, even if disability particularises these individuals’ place in the world, their suffering and strength, silence and dreams as well as tragedies and their surmounting these tragedies are as much intersected in them as in all of us. However, because they are the mirror of our own incompleteness, they evoke poorly controlled reactions in us where the most intimate layers of our consciousness try to exorcise our own fears and deviations. “*Ecce homo*; behold the man!”

As individuals or single persons we are neither extraordinary nor ordinary. The boundaries are vague. We are all – with or without a disability – “singularly plural”. All of us are “singularly plural and plural singular” (Nancy, 1996:12)<sup>35</sup>. No more, no less. We are all intermediary human beings between plus and minus, the best and the worst, above and below. Unfavourable circumstances may without warning smash to pieces the self-confidence we are used to enjoy as unchanging members of destiny’s favourable side. Nonetheless, at any moment it can throw us into extraordinary circumstances. No one is protected from being a stranger in relation to collective norms; to becoming a stranger in relation to life’s normal path; to becoming a stranger in the universe of others, in the eyes of the collective.

## To break isolation and build inclusion and reciprocity

What characterizes the issue of disability is that we talk about this particular phenomenon as if it is universal. A disability seems to carry the entire human destiny of an individual; nothing seems to be left out. In this way the issue comes to represent a closed system. Research on disability should not take place in this kind of closed system of thinking, self-contemplating and dogmatic in nature. Rather, through tapping into the sources of common cultural references,

---

34. In *La naissance de la clinique* (1963) Michel Foucault showed how diseases tend to be conceptually isolated and physically manipulated, regardless of the patient. The disease exists as an object and its prevalence hides the sight of the physician from the subject who is carrying it.

35. “From a singular one”, Jean-Luc Nancy (1996) writes, “there is contiguity (...) each singularity is a different access to the world”.

singularity becomes open to universality, however radical this notion might be. When original thinking or thinking containing originality is desirable, it is all the more legitimate that it maintains as a principle to refuse to reduce the issues connected with disability to “special issues”.

The phenomenon of exclusion is, according to Michel Foucault (1972: 113)<sup>36</sup> recognised through “the manner in which societies get rid of, not their dead, but their living human beings”. His statement is an echo of Montesquieu’s (1739/1998) argument regarding “closing several lunatics in homes in order to persuade us that those who are outside are not lunatics”. These kinds of statements seem to be on the increase. Unfortunately, more than for people with disabilities, whom such statements threaten in particular, they tell us about our world’s difficulty to build a world; “the world sick of the world and of the sense of that world” (Nancy, 1996:12).

For those who are excluded, this mind-set is worthless and inappropriate: Being invited by discreetly insinuating messages, “to be gone somewhere else” when there is nothing else; and to sense that according to some prevailing logic, they live in this world without any reasonable cause. When Joë Bousquet, a friend of Paul Valéry, André Gide, Paul Eluard and Louis Aragon, was unable to move after suffering a serious injury, he formulated this view in the following way: “I live in a fairy-tale that my peers take for life”. He also said: “I owe to my injury to learn that all men are wounded as I am”. The most vulnerable among us are paying a high price due to the contradiction that destroys solidarity in exchange for mutual benefit. The conception according to which a society must exist as an assembly of (non-) equals is at risk. Should we, indeed, still believe in Nietzsche’s (1993: 342) words: “Man and Land are not yet discovered”? How can we rebuild community? How can we learn “to be with” in order to “exist together”? How can we promote permeability and fluidity between them and us?

Nowadays there is increasing debate about the inclusive society, inclusive education and the inclusive school. It would be interesting to clarify the profound meaning of these words and assess their relevance, considering the way they are created on the basis of their opposites. On the one hand, the verb *to exclude* (*exclure*) appeared at the end of the 16th century and originally meant not to allow entrance, not to accept, lock or keep someone at a distance from something he would be entitled to, and, subsequently, to reject phenomena that

---

36. Foucault (1972) continues, “There are arrangements of massacre or ritual murders, for exiling, for repairing or for imprisonment.”

are believed to be incompatible with each other. On the other hand, the adjective *exclusive*, which was developed two centuries later, refers to something that belongs to someone on the basis of special privileges, and which as such does not allow its being shared with others. This terminological evolution shows how words have both meaning and stability. Their authenticity has as a consequence or, better yet, as a condition, a certain amount of integrity. Therefore, merely by offering it to others, it is possible to constitute a relational universe. This is even more true within the field of disability<sup>37</sup>.

Current use of terms such as ‘inclusion’ and ‘included’ clearly reflects a double refusal. Firstly, it is a denial of the mentality considering non-disabled as eligible for arenas such as a company, school, professional group, cultural arenas, sports and leisure; that these spheres are seen as their “exclusive privileges” according to the expression of Montesquieu, or their “exclusive pleasures” in the words of Jean-Jacques Rousseau. Secondly, the terms imply refusal of insularisation or isolation of those who are judged as being unpleasant, strange and incompatible, and their subsequent exile to other cultures.

The terms ‘inclusion’ and ‘included’ are gradually replacing the words ‘integration’ and ‘integrate’ (etymologically: to remedy, resort, remake, redo); integration meaning to introduce into something or to incorporate into a whole. To integrate means taking an element, let us say a person, from the outside and placing them inside, and this transfer requires their adaptation to a system already in existence. Above all, such adaptation may cause difficulties for the single person, who is being integrated. As a contrast, there is inclusion when a social organisation, such as a school or a local society, becomes flexible and changes its function. This changing action is of primary importance in relation to the social context, so that it concretely implies for everyone: “What makes you unique (your cultural affiliation, your sexual identity, your abilities, your difficulties) cannot deprive you of your right to access the joint heritage, to all social welfare benefits: education, work, entertainment... these areas are not exclusive for anybody”.

Thus, inclusion is not related to disability; it is derived from an overall investment, and it expresses the existence of a process of deep cultural change. Our culture is being rebuilt to nothing less than a unification of multitude, *l'unita multiplex*, as Edgar Morin says. The school lays the foundation of this process

---

37. See Eliane Amado Levy-Valensi (1995). *La dignité des mots* (The dignity of words). “The words mean” she said “not the end of the world or close to it, but (they point at) routes to be branched to infinity, with others to rely on”.

within which it must be understood that it is no longer appropriate to think and act in specific terms for specific groups. A more positive approach, one that is humanizing for all and in accordance with the universal principle of access and the concept of quality of life, must be applied. This is the importance of awareness: “We are made to live together; what is easy for some is good for others!” Plans of inclusion are universally beneficial whether they apply to architecture, social services or education.

## Conclusion

To conclude, what is the challenge for the singular as well as universal underlying this discussion? It is simple but immense. The challenge is about granting the rights of the unique and exceptional individual, even in its sometimes extreme expression; to allow everyone to tell his or her own story for the common good. It is about giving each other through our social ties, a sense of belonging to the universal; to recognise that vulnerability is at the root, in the centre and in the most intimate part of every human being.

It is impossible to approach and understand the existing reality of disability without placing it into the universal chain of culture and renaming it again as a simple “ordinariness”. And if we only open our eyes a little bit, it is this ordinari-ness that will appear to us as being truly exceptional.

## References

- Bavčar, E. (1992). *Le voyeur absolu* (The Absolute Voyeur). Paris: Seuil.
- Bavčar, E. (2004). In *Psychologies*, No. 228, March.
- Foucault, M. (1963). *La naissance de la clinique* (The Birth of the Clinic). Paris: Presses universitaires de France.
- Foucault, M. (1972). Standardization et contrôle social (Standardisation and Social Control). Table ronde avec J.-M. Domenach, J. Donzelot, M. Foucault, J. Julliard, Ph. Meyer, R. Pucheu, P. Thibaud, J.-R. Tréanton et P. Virilio. In *Esprit*, No. 413, April-May, 4–5.
- Laborit, E. (1994). *Le cri de la mouette* (The Cry of the Gull). Paris: Robert Laffont.
- Levy-Valensi, E. A. (1995). *La dignité des mots* (The Dignity of Words). Paris: Les Empêcheurs de Penser en Rond (The Troublemakers’ Thinking Round).
- Montesquieu, C.-L. (1998). Considérations sur les causes de la grandeur des Romains et de leur décadence (Considerations on the Causes of the Greatness of the Romans and their Decline), (1st éd.1734). Paris: Flammarion.

- Murphy, R. F. (1987). *The Body Silent: The Different World of the Disabled* (Vivre à corps perdu). New York: Henry Holt.
- Nancy, J-L. (1996). *Etre singulier pluriel* (Being Singular Plural). Paris: Galilee.
- Nietzche, F. (1993). *Ainsi parlait Zarathoustra* (Thus Spoke Zarathustra). Part I, De la vertu qui donne (From Giving Virtue) 2, Works II. Paris: Robert Laffont.
- Sophocles. (1989). *Oedipus at Colonus*. Paris: Belles Lettres.