

Blindness: Cultural and corporal productions of a condition

By

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Since 2000 I've been doing research in Portugal on questions related with disability, a vast and unexplored field for social analysis in that country. My central aim was to understand the complex relation between the cultural representations socially disseminated about blindness and the lives of those who know blindness and its implications in the flesh: the blind persons.

In a country with 10 million inhabitants, the amount of estimated disabled persons lies between 600 thousand and 1 million. Strangely, those numbers don't have any correspondence with the little socio-political importance and cultural visibility obtained by this significant minority. This fact is due largely to the persistence of what was designated as the rehabilitational approach (Oliver, 1990; Striker, 1999), an approach in which the social exclusion of the disabled people is always understood as the result of differences pertaining to the individual body. In Portugal there has been a perpetuation of the exclusion of disabled persons from the several areas of the social arena, lacking, until this day, comprehensive structures at the level of education, employment, public space, etc.

In fact, notwithstanding the work of some organizations of disabled persons, the social transformation to be achieved by a revindication of rights to equal opportunities didn't make an important way yet. A social model of disability, that is, the reconceptualization of disability as a particular form of social oppression, and its articulation with the language of human rights, is a discursive possibility that is still weakly associated to socio-political mobilization in Portugal. As Barnes *et al.* (1999) have told us, the medicalization of social problems always goes hand in hand with their depolitization, a connection that explains in part the invisibility that accompanies the oppressive conditions lived by disabled persons. But if the naturalization of exclusion, brought by the way modernity medicalized disability, can explain the absence of a more strong socio-political contestation, we must also consider the particularities of Portugal, namely the weakness of its civil society. To understand the situation of disabled persons in Portugal and the hegemonic prevalence of a rehabilitational approach, we must address the "lack of social movement" that characterizes Portugal (Santos, 1999). There are several reasons for that reality, reasons that are fundamentally the result of the long

authoritarian regime that existed in Portugal until 1974, an authoritarian regime that was the longest in Europe during the twentieth century. For that reason there is:

- A recent culture of rights and a fragile participatory democracy - reflected in the small mobilization of disabled persons
- A State that remains with some traits of authoritarian centralism – reflected in its relation with organizations of disabled persons: in the refusal of participation in the decision making about social policies, and in a logic of funding that aims to control the life of the organizations.
- A weak welfare-state that obliges the organizations to compensate its deficits in the delivery of social services. So, as a result, the organizations end up directing much of its resources to provide services that the State does not assure.

This is the overall picture for disabled persons in Portugal.

Having done anthropological fieldwork among the national organization of people with visual disability, I tried to understand the conditions to which blind persons are subjected, their life-histories and social reflections. In the hegemonic representations about blindness this condition is strongly associated to the concepts of tragedy, misfortune and inability. This is a widespread construction that owes both to the meanings that were historically linked to blindness, and to the way that modernity reinvented the social exclusion of blind persons. This conceptualization of blindness is well expressed in the arts. We can take for example the movie “Scent of a Woman”, where Al Pacino plays the role of Frank Slade, a military man that had become blind because of a grenade. The central dialogue of the film occurs when Frank Slade is surprised preparing his suicide. Charlie, the boy that assisted him for a trip to Boston, tries to stop him, and says at a certain moment: — go on with your life. — To this Frank Slade replies: — what life? I’ve got no life. I’m here in the darkness”.

The response yelled by Al Pacino can obviously be the expression of the suffering felt by someone recently blinded in an accident. But I want to emphasize how this enunciation, in such an important thematization of blindness, reflects largely the terms by which this condition is socially understood: a disgrace that challenges the value of life. This same ideas are present in the book *Blindness* of the Portuguese Nobel prized author, José Saramago. In that romance the sudden blindness of an entire population emerges as a rich metaphor to symbolize human disgrace, ignorance and alienation. Meanings that are brilliantly resumed in the voice of a Saramago’s character: “blindness

is also this: to live in a world where hope is gone” (free translation). In fact, in *Blindness* the experiences of blind persons are virtually absent, they were replaced by the dominant cultural values and symbolic echoes involving this condition in the Occident.

The same replacement happens in the life in society, where the lives and reflections of blind persons are continually subsumed by the hegemonic constructions that apprehend the experience of blindness. Those constructions reiterate a “personal tragedy theory” as a dominant socio-cultural grammar to address the experience of blindness, a grand narrative. I use the “personal tragedy narrative” from Michael Oliver, as a central concept to understand how the lives of blind persons must be continually confronted with fatalist prejudices about the disgrace and inability culturally implied in blindness.

One of the first ideas I took from my research concerns the way that the lives and reflections of blind persons tend to deny those notions about misfortune and inability. In fact, soon emerged in my research among blind persons the realization of their positive view about blindness, they will to live, their potentialities and capabilities, and their strength to face the many obstacles posed to their self-realization. In the life-histories of the people I knew, the organization of the blind, ACAPO, although it lacks the capability to transform socio-politically the obstacles set in society, constitutes a privileged space for the creation and consolidation of an empowering perspective about blindness. So what we have is a blind persons’ organization that operates in a rehabilitational logic empowering blind persons to face the “world out there”. This empowering is given both through the services provided and the positive discourse about blindness, a discourse that constitutes a contra-hegemonic vision of blindness mobilized for the personal paths of the individuals.

But the observation of a tendency to the construction of a positive and empowering perspective of blindness doesn’t mean that the “personal tragedy narrative” is absent from the lives that were studied. In fact, the power of the disabling and fatalist perspectives about blindness is present in three main ways:

- 1- In the prejudices that blind persons have to confront in their lives, be it in the daily interactions or in crucial moments such as an application for an employment.
- 2- In the difficulty that some individuals have in assuming their blindness, often a difficult affirmation of a subaltern identity. This leads in some

cases to an incorporation of the dominant disabling perspectives, or to an inability to face them (the most emblematic example is that of the persons that refuse to use the white cane to avoid being exposed to an array of prejudices and disabling attitudes).

- 3- In the denial of the social reflexivity of blind persons, where are identified ways to meet their specific needs in the way to social integration and equalization of opportunities

So the “personal tragedy narrative” is a dominant structure of meaning about blindness. A structure that although not being informed by the lives and reflections of blind persons, informs their personal narratives: informing negatively their “conditions of possibility”, their aspirations to self-realization and social integration. So we can say that the “personal tragedy narrative” is inevitably made present in the personal narratives of blind persons, who have to confront the compassionate disabling values that promote their disempowerment and social exclusion. So we can say that the values vigorously associated to blindness, resumed in the concept of “personal tragedy narrative”, far from describing the general forms for coping with blindness that I encountered, constitute an oppressive grammar that is often lived as a “regime of truth”: a cultural prophecy that creates conditions for its fulfilment. The reflections of blind persons express strongly the situation of discrimination and denial of opportunities lived in Portugal. A frame that promotes a vicious circle: the denial of an active social participation to blind persons reinforces the perpetuation of fatalist ideas around blindness.

But if we want to understand the extent to which the cultural representations about blindness are attached to the ideas of misfortune and incapability, we must go beyond the cultural values and forms of social organization. Although Michael Oliver used the “personal tragedy theory” to describe the way that disabled people in general tend to be comprehended by society, there are conditions more strongly associated with the ideas of tragedy and misfortune. Blindness is one of them. This is something that we perceive in social experience, where blindness often evokes personal anxieties that convey the fundamental importance attached to vision.

Trying to follow these questions I was faced with the importance of recognizing embodied experience as an important dimension in the studies on disability. This is an emerging area of inquire in social sciences, who are traditionally uncomfortable in the exploration of such dimensions of experience. To contemplate embodied experience is

to grasp the consequences of the fact that the body is not only objectified with cultural meanings, but is also the condition for being in the world. It is through our bodies that we get access to the world and to others. Bodies feel pain, pleasure, endure sickness and violence, and, as Judith Butler (1993: xi) affirms, this cannot be demobilized as mere representation. So, we can quote Bryan Turner when he sustains that “To believe that the questions of representation are the only legitimate or interesting scientific questions is to adopt a position of idealism towards the body”.

I want to consider here the importance of embodied experience in two different ways. First, as a way to recognize the experiences of suffering and deprivation that can be directly associated to the physical fact of blindness. To this dimension of personal suffering, eminently corporal, that is not totally captured in its relation with social factors, I call the *anguish of corporal transgression*. The anguish of corporal transgression refers to the vulnerability in the existence given by a body that fails us, that transgresses references in the manner of being in the world. I knew this kind of *anguish* in the life-histories of persons that had become blind at a certain moment of their lives. Notwithstanding the narratives of suffering mainly associated to experiences of persons that became suddenly blind, in those stories I also became familiar with peoples’ capacity for personal reconstruction. So, the embodied experience allows us to address some experiences of disabled persons that go beyond the conditions of social oppression. In that sense, the embodiment of experience responds to the criticisms made to the social model of disability for its overlooking of some subjective experiences of suffering associated with disability. Nevertheless, I think it’s important to understand the social model of disability as a necessary political formulation that aims to make visible the conditions of social oppression, denying the established biological naturalization of exclusion. The social model of disability must be analysed with reference to what Mairian Corker defines as the “principle of optimization of social change” (1999: 92).

But I want to consider here also the importance of embodied experience as a dimension that helps us to understand the dominant meanings associated to blindness. This takes us to bodies that think, bodies that produce knowledges. From my research I want to argue that the tragedy associated to blindness also owes to the way persons use their bodies to experience “how it would be if I was blind?” I think it is important to recognize the place occupied by empathic imaginary projections that bring blindness home to the body of people who see. In fact, vision tends to be a central sense for

someone who can use it for the execution of activities and for the construction of the world. As a consequence, the corporal imagining of blindness from a body that lives visually tends to offer the idea of sensorial prison and inability. So the anguish of corporal transgression is not only something experienced by someone that goes blind, that transgression is also known by emphatic corporal projections through which blindness is imagined. This imagination not only produces personal anxieties towards blindness but is also mobilized as a way of access to the reality of blind persons. The question is that such an imagination allows an apprehension of the eventual impact of a sudden loss of vision, but it fails to understand how someone's life can be reconstructed in other terms without vision, fails to comprehend the adaptation allowed by a blindness that comes gradually during years, and fails to comprehend the world without loss of someone who is born blind. What is produced is an empathic identification, partial and erroneous: an identification with loss, disgrace and tragedy.

But to assume the importance of corporal projections is not to support any kind of universalism in the apprehensions of blindness, au contraire. Firstly, because the relevance of such projections can only be understood in its congruence with the values historically inherited in our cultural context. Secondly, because such erroneous constructions only reinforce the idea that the vicissitudes and implications of blindness must be informed by the experiences of blind persons. Experiences that emphasize the place of social oppression, denouncing that the tragedy is not on the fact of blindness, but is, most of the times, a product of a discriminating society that forgets that "any way of seeing is also a way of not seeing" (Lukes, 1973: 149). So, I think that with the use of a social model of disability and human rights there is a long way to be made. A way that must nourish – and be nourished – by the destabilization of the dominant representations about blindness. Hopefully new regimes of truth will be constructed by the voices of blind persons; in that scenario instead on "personal tragedy narratives" we would have narratives of social transformation.

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