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Representations, Metaphors and Meanings of the Term ???Handicap??? in France

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Abstract

In France, as opposed to most European countries the use of the term “handicap” is not only used as a noun, it is also used as an attribute to designate people living with disabilities. Thus, it was of particular interest to understand the representations, the metaphors and the meanings related to the term “handicap”. A qualitative study, using in depth open-ended interviews was carried in France. The material collected was analysed through a content analysis, in order to identify the metaphors and shed light on their underlying meanings.

Our study, has demonstrated that the representations of handicap do not reflect word for word the official classification separating the motor, sensorial, mental and social components of disabilities. In the representations, the various components are restructured in different configurations, which give specific meanings and values to each one in the context of a global representation of human social functioning and its avatars. “Mental handicap” appears to be the most handicapping of all disabilities and functions as metaphor for all the conditions, states, situations and persons designated by the term “handicap”.

Author Keywords Representations ; handicap ; qualitative research

Introduction

Over the past two decades, social, historical and cultural research on representation has brought new perspectives to the study of the psychosocial dimensions of disabilities revealing the origins and historical evolution of this set of concepts as well as other notions used in different historical and cultural contexts (Paicheler & Morvan 1990 ; Stiker 1982 , 2006). It is now taken for granted that scientific inspired notions, and administrative concepts are not totally disconnected from the social world and from common sense (Giami, Korpès, Lavigne & Scelles, 1996). Among the words, concepts and notions used in the social world of disability and in the scientific field of “disability studies” (Albrecht, Ravaud & Stiker 2001), the concept of “handicap” and its use in different spheres of the social world is of particular interest. Whereas this term was widely used in the official language of the WHO in the early 80’ and in particular in the famous I.C.I.D.H. (WHO 1980), in most countries and languages, the term “handicap” is currently considered as offensive towards and by the people living with disabilities, and the attribute of “handicapped” is taken as equivalent of other terms which are now out of use, such as “crippled” (Kriegel 1987). Moreover, it is strongly recommended to avoid the use of the term ‘handicapped’ in scientific papers. Nevertheless, the exclusion of this term is not consensual in the field of research and in the social world, which means that the term continues to be used in certain contexts and situations, and sometimes expresses contradictions between the need for public health and scientific precision and the necessity of not reinforcing stigma among those who are living by these conditions. On one hand, the American Psychological Association recommended a “non handicapping language to maintain the integrity of individuals as human beings. Avoid language that equates persons with their condition” (APA 2001 , p. 69) and on the other hand, the APA recommends to “use disability to refer to an attribute of a person and handicap to refer to the source of limitations, which may include attitudinal, legal, and architectural barriers as well as the disability itself (e.g. steps and curbs, handicap people who require to use a ramp)” (APA 2001 , p. 69). Thus, in the US-English language, as opposed to the UK language, the word “handicap” is not to be totally avoided. Furthermore, one of the major English-speaking journals in the field, “Disability and Society”, which is published in the UK and was previously entitled “Disability, Handicap and Society”, has deleted the term “Handicap” from its title. In a non-anglophone context, the major French social science journal in the field was still entitled until very recently: “Handicap: revue de sciences humaines et sociales ”.

In France the use of the term “handicap” is not only used as a noun, it is also used as an attribute to designate people living with disabilities in the following term: “les personnes handicapées” (to be translated as “handicapped persons”). A recent 2005 French national law contains the same expression: “Loi pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées ”¹. The aim of this law is not only to fight against discrimination but moreover to reaffirm and develop the human rights and equality in citizenship status for those living with disabilities. Despite the obligation for French administrative documents to use French language, it is surprising to see that France is one of the rarest countries where the term “handicap”, a word of English origin, is still used among the official discourse of the government, the state, public policies and among prominent researchers in the field (Ravaud, Letourmy & Ville 2002 ; Mormiche 2003).

Finally, the international logo which represents those living with disabilities contains a symbol of a person in a wheelchair. The logo is based on the assumption that motor disabilities are the central dimension of the image of "handicap" and that the wheelchair constitutes the major legitimate societal response, i.e. a product based on advanced technologies which creates also some limitations when it is used. Thus this logo encapsulates a paradox of societal concerns and modes of intervention around "handicap" and a focus on physical limitations to be repaired through engineering systems.

It is therefore useful to consider what "handicap" represents to everyday people and what common sense ideas are still dominant in French society. The aim of this paper is to identify and analyse the metaphors that are encapsulated in the term of "handicap" in common sense and everyday language.

Attitudes, representations and metaphors

This research is at odds with previous studies that investigated attitudes held about the social and psychological dimensions of disabilities. Such research often considered the conditions and the disabilities to be objective and self-evident facts and therefore as unambiguous stimuli for psychosocial research (Meyerson 1948). In order to give a more precise picture of the disabilities that are considered as the "objective" sources of negative attitudes, and to capture and measure the more precise dimension of disability, Altman and Siller have tried to define more specifically those disabilities. On the one hand, Siller suggested a clear differentiation between the physical and mental disabilities, and the different attitudes these disabilities could elicit from non-disabled individuals (Siller 1988). On the other hand, Altman introduced a distinction between the conditions affecting people with disabilities and the individuals themselves living with these disabilities (Altman 1981). These authors acted as if the individuals reacted to the various disabilities considered as objective stimuli and did not consider how these disabilities were represented by those expressing these negative attitudes. In other words these authors missed the point that individuals do not react to disabilities but to the representations of these disabilities.

The argument developed in this paper is based on different assumptions. First, it is grounded on the idea that disabilities are represented by individuals and are not perceptions of some objective reality. This means that disabilities per se do not elicit psychosocial reactions, and thus do not function as pure stimuli. This approach is based on the theory of representation which considers that the disabilities are socially constructed and elicit meanings and significations related to the way they are represented (Goode, 1994), and that individuals react to the representations and the meanings that the disabilities evoke for them (Gilman 1985 , 1988). Second, this approach differs from the theory of social representations developed by Moscovici (1961 , 2000) and traditionally used to understand how scientific terms and concepts are transformed when they are adopted into common sense discourses. As opposed to this theory, the study was based on the idea that scientific theories as well as common sense notions are representations, which may influence each other but are not reducible one to the other (Gilman 1985 , 1988). This paper, considering representations as social and cultural phenomena (Kuhn 1962), draws on analysis of narratives of "everyday individuals" (Wagner & Hayes 2005). The analysis sought to identify the metaphors and meanings attached to the term "handicap" (Zola 1985 , 1988 ; Kleinman 1988). In other words, it aimed to understand the symbolic logic and meanings that are conveyed by the term. A metaphor can be defined as "Metaphor," Aristotle wrote, "consists in giving the thing a name that belongs to something else." Saying a thing is or is like something-it-is-not is a mental operation as old as philosophy and poetry, and the sprawling ground of most kinds of understanding, including scientific understanding, and expressiveness." (Sontag 1989 p. ??). Using such definition of metaphor, we can argue that language does not fully and always capture situations, persons and events in the most appropriate way in relation to reality, and that, instead it creates a metaphorical reality, if one can use such an expression. The aim of this article is, thus, to identify the metaphors that are conveyed by the everyday and common sense use of the term "handicap" including the situations, events and people who are labelled as "handicapped".

Method

The Sample

The findings reported in this paper are the result of a qualitative psychosociological study based on 12 semi-structured interviews with non-disabled individuals defined as "unconcerned" (n = 12; 5 women and 7 men). These individuals were between 24 to 57 years old and with a higher education. None of these individuals were known to have any actual or current relationship with a person living with disabilities. In some cases, such a relation appeared unexpectedly through the interview.

This sample was constructed to show that even if someone had no specific and actual relationship - professional or family - with someone living with disability, they could be personally and directly concerned by the "problem" of handicap; they could, often or occasionally, find themselves in the presence of people labelled or perceived as disabled; and most importantly they could, like anyone, be brought to use the term "handicap" as a "metaphor in everyday language " to speak of "problems" that may have nothing to do with "handicap" in the strictest sense, and/or to speak about themselves (Sontag 1989).

In addition we collected interviews from parents of children and adolescents living with cognitive disabilities (n=15); and specialised educators working with adolescents and adults living with cognitive and physical disabilities (n=15). The material collected from parents

and professionals is not presented in this study, but it helped us to understand, by contrast, the specificity of the discourse of individuals not directly involved in the community of those living with disabilities. Nevertheless, it is important to bear in mind that even if the parents were related to children and adolescents living with cognitive disabilities and the educators related to persons living with cognitive and physical disabilities, the sample of the “unconcerned” individuals were not supposed to have been in actual contact with any type of disability. All the names of individuals and places evoked in the interviews have been systematically replaced as alias.

The Interviews

The interviews were conducted in a semi-structured fashion starting with the initial question: “What is “handicap” for you ? What does it mean ?”. The respondents were given the freedom to speak of any topic they wished related and even (apparently) not related to the field. We did not ask them questions about topics that they had not already taken up spontaneously in response to our starting question, or in a free association with a topic that they had already discussed. The discursive material produced during these interviews is located in a semantic and ideological space defined by the interviewing situation and its rules of communication, by the real and concrete experience of these people including their experience or not with people living with disabilities by their imaginary representations of what “handicap” is, independent of any social or psychosocial experience and by their personal history. So it is not possible to argue that the representations elaborated by the “unconcerned” individuals were determined by their personal or professional “contact” with persons living with disability. The “unconcerned” participants may have been in occasional contact with persons living with disabilities but this situation was not known by the interviewers prior to the interview. The “unconcerned” individuals were principally exposed to cultural and social and subjective stimuli related or not to the world of disability.

Qualitative Analysis

Even though all the individuals who were interviewed were asked the same question as a starting point, the people selected for the “unconcerned” group replied in a much wider thematic field, covered different themes and organised their discourse differently to the parents and the educators. The interviews with the individuals in this group were much more difficult to analyse, since each story reflected a specific personal experience related to a specific context in which individuals living with disabilities and/or people having psychosocial difficulties may have appeared or not. Unlike the members of the two other groups who all had one dimension in common - having a child with disabilities or working with individuals living with disabilities - the “unconcerned” were recruited with no specific criteria related to “handicap”, and did not, apparently, have anything in common. But it was striking, that despite these important fields of experience, the analysis gave evidence of some common explicit and underlying trends in the representations of “handicap”.

The interviews that were collected were subjected to two kinds of analysis. They were first analysed qualitatively (Strauss, 1987 ; Kirk, Miller, 1986) to bring out the main themes and their structural organisation in terms of ambivalence, contradiction and polarisation (Gilman, 1985 , 1988). During this stage of analysis we aimed to elaborate the specificity and originality of each interview as much as possible in order to understand the underlying subjective organisation. Following the first qualitative analysis, the topics that were identified were organised in a consistent structure and organised in a File Maker™ software to facilitate comprehensive analysis and non exclusion of minor topics (Giami, Korpès, Lavigne & Scelles 1995). This stage of analysis aimed to bring out the disparate nature of the various thematic elements and their organisation as a consistent representation system.

Results

Representations of “handicap” as a field

The term “handicap” does not cover the same area of actual or potential, past, present, future, positive or negative experiences for the individuals belonging to the three different groups of our study.

Parents focused on the description of their own handicapped child and on comparing him/her with other children, as well as describing the dynamics of their experience with the child both within the family and in the social and educational contexts of special programmes. In addition, parents spoke of the evolution that slowly occurred in their experience of having such a child, from the first discovery of their child’s deficiency termed as “traumatic” or “catastrophic” through acceptance of their child as he/she and then to representing some kind of extraordinary achievement and personal growth. One can say that the representations of the parents were organised around their “parental self”. Specialised educators mainly spoke of specific groups of labelled individuals, groups determined according to the type and level of condition, whom they cared for within institutions, as well as their own professional problems in dealing with these individuals. Their representations of these conditions and of the people they cared for were determined by the successes or problems experienced in their professional activity. They seemed rather worried about the invasion of their private lives provoked by the burn-out syndrome experienced in coping with the individuals with whom they worked. Moreover many of them expressed the need to maintain a good level of involvement in their work while preserving their intimacy outside working hours. One can say that the representations of these individuals were organised as a part of their “professional self” in relation to a group of “handicapped individuals”.

The interviews collected among the “unconcerned” individuals did not fall into these two kinds of organisation, which reflect the actual experience of the contact with people living with disabilities. It needs to be recalled that none of the “unconcerned” had any actual experience in the field of disability. This did not prevent them from having occasional and informal contact with persons living with disabilities or at least from talking about such potential contacts. In other words, the world of handicap is not beyond the scope of their social, symbolic and mental universe. In the next section of the paper, only data from the “unconcerned” individuals are presented and discussed.

First reactions to the interview-stimulus

In the early part of the interviews, the respondents felt that it was difficult to talk of “handicap” and to define the term. This may have been related to the fact that the word “handicap” brought out a great many personal specific representations, meanings and experiences for each of the persons interviewed. The term “handicap” covered a wide range of states, situations, events, individuals and relationships concerning almost everyone. All these states, problems and attitudes were represented as a representation of a potential limitation to social performance:

“It’s so vast. It can be a physical handicap, or a mental handicap ... and I’d even say that for most people it can mean someone who has reached their top capacity ... they have a handicap ... I’d say that for someone who is religious, the only being who has no handicap, when you come right down to it, is God ... Everybody has some handicap in life...” (Richard)

“A handicap is any vibrant, expressive person who is stifled from inside. That’s what handicap is, what is stifled in a person.” (Nelson)

“Handicap is a vast subject, in fact, it can be shyness, that can be a handicap, too. I think that there are people who really suffer from shyness, who blush and can express themselves, that’s a handicap for some people.” (Karine)

“It means always needing someone else. That’s what handicap means to me.” (Claire)

In some cases, the term “handicap” referred to a condition or illness that the individual may have experienced in his/her own personal history. The term “handicap” provokes the revival of a painful situation that was experienced by the subject:

“Yes I think that’s the worst ... the loss of autonomy, I think that’s what handicap means to me, that’s really what I felt when I was lying on my bed in the hospital.” (Alex)

In this case, as in many others, the evocation of handicap provokes a process of identification to those who suffer.

For most respondents, at the beginning of the interviews, the term “handicap” evoked some kind of “physical handicap” rather than some “mental handicap” due to its social visibility on the one hand, and on the other, due to the wide array of situations from the most commonplace to the most serious and dramatic that can directly concern a person’s experience. For some individuals, the term “handicap” suggested the human condition as a whole, and for others it reveals the confusion and chaos and the “hidden truth” of society:

“Finally, everything is upside down, and that’s a handicap...in the final analysis, all the marginalized people, the unemployed, they express a certain aspect of society... it’s all a part of our society, that’s what it’s like, that’s what we’ve sown and that’s what’s grown.” (Nelson)

Organising the representation

From an extended and indefinite use of the term, sometimes directly related to the individual’s experience, the respondents progressively narrowed the field of the definition of “handicap”. This thematic narrowing allowed the respondents to describe a certain number of situations, conditions and states - mental, sensorial, physical or social - on the one hand, and, on the other, to make the distinction between their own personal experience and other people’s experiences. The objectification of these different situations and states allowed the respondents to “think out” the question of handicaps, as something external to them and not directly oriented towards themselves. They could then specify the situations and organise and qualify them, finding positive sides to a problem which is difficult otherwise, since handicap is perceived as threatening and hard to define, something that can happen to the respondent:

“There are many types of handicaps, minor handicaps and major ones where people can’t find for themselves, there are many different forms of handicap.” Francis

“That’s true, but I’m convinced that every negative thing in life has a positive side to it...Pain has a positive side, it’s a danger signal. To my way of thinking, a handicap can develop a person’s sensitivity in some ways.” (Richard)

Genetic versus acquired condition

The different domains of disabilities, which are thus objectified are, in addition, organised according to the origin of the condition:

"I think it's different for someone who is handicapped from birth than someone who is handicapped accidentally, like after a car accident or a fire or whatever. It's completely different. For someone who has lived part of their life with a sound body and mind and then, who at 18 or 20 years old is suddenly handicapped, it's more painful." (Alex)

It is interesting to note that the different origins attributed to the disabilities are classified in relation to the person's own experience. A state that cannot affect the respondent himself - "a birth defect" - is represented as being "less painful" than a condition that could affect him or her. The term of "accident" is most often referred to as a "catastrophe", a "blow" or a "stroke of bad luck", the "wrong number".

The respondents illustrated their representations of "birth handicaps" through examples taken from their own experience. In many cases, this meant individuals who had compensated for the motor or sensorial deficiency by developing other skills or senses.

"She was born blind. She did a great many things, she sang, she gave music lessons. I don't know how she did managed to do all she did. I'm sure that it was probably less difficult for her than if she had suddenly lost her sight at the age of 20. She was able to guess nature or feel rocky or sandy ground with her feet. And sensations that we don't have, so that she could tell whether it was sunny or not. Her senses were far more developed than ours." (Francis)

If these types of conditions are not described as overcompensated for, they are, at worst, described as allowing a person to live "normally":

"When I say it was a minor handicap, it's kind of ridiculous, because it isn't necessarily a minor handicap. And if you forget about that one thing, he's someone who can live like everyone else. His prosthesis is well enough made not to be immediately visible. So he can live perfectly normally... despite the visual discomfort he might have." (Luc)

"Mental handicap" versus "physical handicap": the most handicapping condition

In contrast to this, disabilities located as mental problems in the form of Down's syndrome for example, are not represented in the same way. It is a "birth handicap" that is not represented in a positive way, or as having any positive characteristics, i.e. that there is no possibility of improving this state or compensating for it. In this case, the combination of the characteristics "from birth" and "mental" add up to a negative representation.

"I remember when I lived in a building where there really was a handicapped child, a Mongoloid, a child who doesn't grow up, I mean, I don't really know what kind of handicap it was, but he was a child of 17 or 18 and who looked 10, I mean he looked like a little child. He learned how walk very late and when I would go out he didn't talk at all, he made animal noises... you could see he was really seriously handicapped." (Claire)

When the different states, conditions or situations referred to in these interviews are analysed there is a clear differentiation (a splitting) between the two types of handicaps, "mental" and "physical-sensorial".

While "physical-sensorial handicaps" represented as the inability to move autonomously and associated - in the representation - with sensorial deficiencies, were the first to appear in most of the discourses, "mental handicaps", represented by various forms of mental, psychological or emotional dysfunctions, occupy a key position in the interviews in terms of the seriousness of the condition, the fact that the person was affected in his/her integrity and that it is an incurable and irreversible condition:

"I don't know, the mental side has always scared me... whether it's a handicap in the head or the computer, whatever, it scares me because it seems so complex, and I don't think it's really curable. Of course physical handicaps aren't any fun either, but, I don't know, it seems like there's more chance of curing them in general. It's really more something that affects your head that frightens me the most, and to me, the mind is such a fragile thing." (Paule)

The mental component of "handicap" came up in various forms throughout the interviews. First, it was represented as the major causality of many disorders, conditions or problems that were not necessarily mental ones; secondly, as a group of characteristics attributed to others - "the mentally handicapped"; and finally, in the shape of cognitive disabilities, and difficulties with interpersonal communication, which put the respondents in situations where interaction was complicated; this did not only concern the "mentally handicapped".

The "centrality" of the mental component of "handicap" - in the representation - is expressed by attributing behavioural disorders to a cerebral dysfunction and thus provoking fear:

"I don't know if it was a mental handicap or a physical handicap. I saw someone in a wheelchair whose head was twisted sideways and whose fingers were completely curled up, and I couldn't say whether it was a physical handicap because he was in a wheelchair and his hand was atrophied. I was told it was a physical handicap, though I would have said it was also a mental handicap because he couldn't express himself very well..." (Luc)

"Everything that's physical also concerns the mind. When it's physical you see them in little wheelchairs and it doesn't seem to really come from their mind though in fact it does. But you can't see it... maybe the people who work in that field know it well. What's true is that physical handicaps also come from the spinal cord, it's in the cells...How do they reproduce? Everything starts automatically in the brain, too." (Claire)

Two things are expressed to in these quotations, on the one hand, physical or communication disorders are perceived as having mental causes thus challenging the brain's functioning, and on the other, due to this cerebral causality, the person described as "physically handicapped" is basically represented as a "mentally handicapped". One can observe here, a process in which if the disability/condition is perceived as "physical", the person is perceived as a "person with a disability" which does not affect his/her integrity as a person. In the case in which the disability is represented as being of "mental" origin, the person is then considered as globally spoiled due to his/her "mental handicap". If we refer to the language of metaphors, in the case of a "mental handicap", we are faced with a metonymy, defined by that which "takes a small part (to represent the whole) as the whole".

In this context, speech disorders and communication difficulties, which play a major role in interactions seem to contribute to the stigmatisation of the people described, based on behaviour "observed" by the respondents.

"I had a hard time understanding him... I know I even dreaded his talking to me a little...because I wouldn't know how to answer, not having understood what he said... and I was embarrassed, not understanding, I mean, the words...It's not a very easy kind of dialogue to have...and he also had trouble moving around, but the speech problem was really hard. It's for him, mostly, but that's what slows me down in communicating with them." (Sylvia)

Other types of difficult communication are described and assimilated to "mental handicap":

"Life is too hard for some people, it becomes so hard that they become aggressive and that aggressiveness becomes a handicap ... It's a handicap because when you're aggressive you can't talk to people any more, you can't look for work, you can't do anything. Someone who talks to you and is suddenly aggressive, you think he's crazy...but it's just life that's made him aggressive. Can't that kind of person be described as handicapped?" (Francis)

"Mental Handicap": the paradigm of deviance

This brings out the integrative potential of the notion of "handicap" to define many types of deviant behaviour. This use of "handicap" to refer to these types of social behaviour is accompanied by an understanding attitude. The person thus described is presented as a victim of society. The organic aetiology that characterised the first definitions of "mental handicap" is completed by a social aetiology whose effects are visible in terms of communication.

There is, in addition, another line of representations associating the communication and behaviour difficulties of the "mentally handicapped" with child-like behaviour. The "mentally handicapped" person can thus be described as an "overgrown child".

"Let's say that the retarded look on his face and the fact that he obviously doesn't understand what you're telling him, I mean, he asks for explanations... It's someone who has a child-like attitude, like a little child, even." (Claire)

In contrast to these elements, which contribute to the importance of "mental handicap", "physical-sensorial handicap" takes on the appearance of a counter-model full of virtues and the potential for social integration, as well as personal development:

"Somebody who only has one hand to work with, or no legs, or what have you, is still someone who is useful to society, who can work with computers for example. You don't need legs to work on a computer, you don't even need two hands, one is enough. If you put someone in wheelchair in front of a computer, he can get along just fine, as long as his mental capacities are there. You could even say that, in the case of computer science, it's something that can show his worth, I mean in relation to society... There are major handicaps that prevent people from working, or from being autonomous, it just depends on what kind of handicap it is." (Richard)

A doubt remains nonetheless since the respondent felt obliged to point out the necessity of "mental capacities" to hold down a job; as if the fact of being in a wheelchair might somehow preclude this condition. The capacity to work then appears as the way of remaining autonomous.

The topic of work occupies an important place in the responses to the “handicap” stimulus. It comes up in references to fear of loss of work, and invokes metaphors of “catastrophes” and “accidents of life” and in this sense handicap appears as a threat to the individual’s well-being. Work also comes up in the representation of people who cannot work and therefore who are seen to be excluded from society, or as “people who have problems” in relation to their social identity or their behaviour.

Discussion

The analysis of the narratives of the “unconcerned” individuals has revealed the polysemic nature of the term “handicap”, and of “mental handicap” as the central dimension in the representational field of handicap.

First of all, the term “handicap” refers to sets of problems, conditions and dysfunctions of various natures that can be grouped as states or situations, as well as people as individuals or as part of a group (Giarni, 1990 ; Giarni, Korpès, Lavigne & Scelles 1996). In this sense, the term “handicap” can evoke either a set of conditions, which affect the respondents and represent a threat to their personal integrity and their place in society, or people, individuals or groups, who are subjected to these states and conditions and towards whom the respondents expressed mixed and ambivalent feelings. These elements elicit different reactions. The states and situations raised in reference to the term “handicap” elicit fear, specifically fear of unexpected events that can occur in the area of physical, psychological or social integrity of human beings. The individuals and groups evoked in these narratives are represented as a source of strain in social interactions, due to difficulties in communication, as well as pity or condescension, or more rarely, fear of the threat they represent.

On a first level, this “cluster” of representations is structured around an opposition between states and conditions that can affect the respondent and individuals and groups described as bearers of those states and conditions and with whom the respondent has or might come in contact with. This gives an organising principle built on the distinction and the relationship between the “threat towards the self” (Ehrenreich 1989) and the “afflicted other”.

On a second level, which is narrower and overlaps with the area of physical or psychological conditions, the representations are structured around a distinction opposing congenital conditions or deficiencies (“from birth”) and other conditions that have come up or can appear during a lifetime (“accidents”). These physical-sensorial afflictions, whether “from birth” or “accidental”, are perceived as being compensated for or even overcompensated for by the characters evoked in the interviews. The principal distinction rests on the identification with the victims of such “accidents”. The afflictions caused by these “accidents” are represented as having more dramatic effects than the same conditions when they are congenital. Identification with the victims becomes a way to understand and actualise these situations.

On a third level, which can be described as central, we observed a polarity opposing the mental components to the physical-sensorial and social components that characterise “handicaps”. The negative perception of the mental dimension of “handicap” resides in its construction as a threat of a basic and total affliction which could potentially affect the global integrity of the self, as well as its representation as a “mentally handicapped” person who has “problems communicating” and maybe even “physical problems” which cause strain, anxiety and fear during interactions. In addition, the “mentally handicapped” person is never described as being able to compensate for or adapt to his/her condition. The notion of “mental handicap” can thus be seen to condense a number of different aspects contributing to the centrality of its significance for the “unconcerned” individuals. It brings together the “threatened self” and the “afflicted other” through communication problems. It focuses on the anxiety caused by the suggestion of breakdowns over the course of a lifetime: breakdowns in physical and psychological integrity and in social well-being. The breakdown in psychological integrity is seen as having a global effect on the person. It is seen both as a cause and a consequence of all of these breakdowns. Finally, the breakdown in psychological integrity is seen as being both irreversible and not be compensated for.

Our study, which is based on a qualitative methodology, has clearly shown that the representations of handicap do not reflect word for word the socio-nosographic distinctions separating the motor, sensorial, mental and social components of handicaps. In the representations, the various components are restructured in different configurations which give specific meanings and values to each one in the context of a global representation of human social functioning and its avatars. “Mental Handicap” appears to be the most handicapping of all handicaps and a metaphor for all the conditions designated by the term “handicap”. We can, therefore question why the notion and the field of “handicap” are socially symbolised by the logo of a person in a wheelchair.

We may suggest the following hypothesis: the person in the wheelchair symbolises the possibility of an efficient social response to a condition; which is not the case with the mental afflictions and conditions represented under the category of “mental handicap” that can potentially affect every individual and signals something that is beyond possible effective social response. Rather than meaning and interpreting some characteristics of those living with disabilities, we could suggest that the persistent use of the term “handicap” in scientific and public expert discourse refers to the specific incapacity of mainstream society to elaborate specific and effective responses. Following the ideas of the American-Palestinian historian Edward Said, about orientalism (Said, 1978), we could say that the term Handicap may thus reveal the hidden identity of a society rather than the identity of those who are labelled as such.

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References:

- Albrecht GL , Ravaud JF , Stiker HJ . 2001 ; L'émergence des disability studies: état des lieux et perspectives, [The emergence of disability studies: state of the art & perspectives] . *Sciences Sociales et Santé* . 19 : (4) 43 - 73
- Altman B . 1981 ; Studies of attitudes toward the handicapped, the need for a new direction . *Social Problems* . 28 : (3) 321 - 337
- American Psychological Association . 2001 ; Publication Manual of the American Psychological Association . 5 Washington DC APA ;
- Ehrenreich B . 1989 ; Fear of Falling . New York Pantheon Books ;
- Giami A . Editor: Paicheler H , Morvan J-S . 1990 ; L'hypothèse de la figure fondamentale du handicap, [The hypotheses of the fundamental picture of handicap] . Représentations et handicaps: Vers une clarification des concepts et des méthodes. *Représentations & handicaps: towards a clarification of concepts and approaches* . Paris CTNERHI, MIRE ;
- Giami A , Korpès J-L , Lavigne C , Scelles R . 1995 ; Un exemple d'articulation de méthodes d'analyses qualitatives et quantitatives sur des entretiens semi-directifs: les représentations du handicap [An example of conjunct use of qualitative and quantitative methods on non-directive interviews: representations of handicap] . *Bulletin de Méthodologie Sociologique* . 47 : 49 - 77
- Giami A , Korpès J-L , Lavigne C , Scelles R . Editor: Aymé S , Henrard JC , Colvez A , Ravaud JF . 1996 ; La pluralité des représentations du handicap [The plurality of representations of handicap] . Handicap et vieillissement: politiques publiques et pratiques sociales [Handicap & aging: public policies and social practice] . Paris INSERM ;
- Gilman S . 1985 ; Difference and Pathology - Stereotypes of sexuality, race and madness . Ithaca, N.Y Cornell University Press ;
- Gilman S . 1988 ; Disease and representation . Ithaca, N.Y Cornell University Press ;
- Goode B . 1994 ; Medicine, rationality and experience. An anthropological perspective . Cambridge Cambridge University Press ;
- Kirk J , Miller ML . 1986 ; Reliability and validity in Qualitative Research . Newbury Park Sage ;
- Kleinman A . 1988 ; The illness narratives . New York Basic Books ;
- Kuhn T . 1962 ; The Structure of Scientific Revolutions . Chicago University of Chicago Press ;
- Kriegel L . Editor: Gartner A , Joe T . 1987 ; The crippled in literature . Images of the disabled, disabling images . New York Praeger ;
- Meyerson L . 1948 ; Physical disability as a social psychological problem . *Journal of Social Issues* . 4 : (4) 2 - 10
- Mormiche P . 2003 ; L'enquête "Handicaps, incapacités, dépendances": apports et limites [The survey "handicaps, disabilities, dependency] . *Revue Française des Affaires Sociales* . 1-2 : 13 - 29
- Moscovici S . 1961 ; La psychanalyse - son image et son public - Essai sur la représentation sociale de la psychanalyse . Psychoanalysis – its image and its public – an essay on the social representation of psychoanalysis . Paris PUF ;
- Moscovici S . Editor: Duveen G . 2000 ; Social Representations: Explorations in Social Psychology . Cambridge Polity Press ;
- Editor: Paicheler H , Morvan JS . 1990 ; Représentations et handicaps: Vers une clarification des concepts et des méthodes . *Représentations & handicaps: towards a clarification of concepts and approaches* . Paris CTNERHI, MIRE ;
- Ravaud JF , Letourmy A , Ville I . 2002 ; Identifying the population with disability: the approach of an INSEE survey on daily life and health . *Population-E* . 57 : (3) 529 - 552
- Siller J . Editor: Yaker H . 1988 ; Intrapsychic aspects of attitudes toward persons with disabilities . *Attitudes toward persons with disabilities* . New-York Springer ;
- Sontag S . 1989 ; Aids and its metaphors . New York Farrar, Straus & Giroux ;
- Stiker HJ . 1999 [1982] ; A history of disability . Ann Arbor University of Michigan Press ;
- Stiker HJ . 2006 ; Les fables peintes du corps abîmé. Les images de l'infirmité du XVI^e au XX^e siècle . The painted tales of the spoiled body: images of infirmity (XVI^e–XX^e century) . Paris Editions du Cerf ;
- Strauss A . 1987 ; Qualitative analysis for social scientists . Cambridge Cambridge University Press ;
- Wagner W , Hayes N . 2005 ; Everyday discourse and common sense. The theory of social representations . Houndsmill New York Palgrave MacMillan ;
- WHO . 1980 ; International Classification of Impairments, Disabilities and Handicaps. Manual of classification relating to the consequences of disease . Geneva WHO ; 207 -
- Zola IK . 1985 ; Depictions of disability - metaphor, message, and medium in the media: A research and political agenda . *The Social Science Journal* . 22 : (4) 5 - 17
- Zola IK . 1988 ; The language of disability: Problems of politics and practice . *Australian Disability Review* . 1 : (3) 13 - 21