

The Image of Disability Among Intellectually Disabled People

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The work presented in this article is based on the theory of social representations and it is an exploratory study that aims to know the image that intellectual disabled people have about disability. 17 intellectual disabled people of both sexes (ages range from 16 to 44 years old) participated in this study. An individual interview was done about disability and participants were asked to make two drawings: a drawing of a disabled person and a drawing of a non-disabled person. All data were collected by the psychologist of the Center where the participants are service users. After referring to the main methodological difficulties we faced in data collection, we present the results of a content analysis of participants' answers. Essentially, this analysis shows the existence of two images of disability associated with two groups of individuals: those who saw disability as physical or sensorial disability and also as an inability to acquire some school competencies and those for whom the disability is always - and only - the easily visible disability, i.e., physical or sensorial disability. Finally, we discuss the results in the framework of social representations theory, in their links with identity processes and the social imaginary around the disability.

Keywords: *Social representations, intellectually disabled people, image of disability, identity processes*

The present work is a result of the concerns of technicians in the field who have been working with young people and adults with intellectual disability for about 20 years in an institution called *Os Malmequeres*, located in Leiria, a medium-size city in the coastal center of Portugal. This institution is a center that promotes as its main activities a workshop of wooden toy production developed from the drawings of the institution service users and the animation of an ambulant toy library that goes around the schools and kindergarten of the district performing activities with children.

Knowing the image of disability of the Center service users has been object of conversations and discussions between the technicians of *Os Malmequeres* for a long time. The management of this knowledge often intersects with the interactions and daily routine of families and technicians, from the small common situations of the service users' daily routine to the more important matters in their lives. The educational concerns with their well-being and life quality enforces the importance of this question, specially by the repercussions on self-image and by the psychosocial processes associated with it. Actually this matters as an important issue in terms of the individuals (namely by the learned helplessness) as well as in terms of social interactions, by the many opportunities of confirming the low expectations. The effects of "stigma" were studied in the classic work of Goffman (1963/1980) and the psychosocial functioning of the "mentally disabled" label has been explored in terms of the repercussions on the self-concept of disabled people, of their colleagues and their group, specially related to the ways of coping with failure and success as well as the associated motivational processes (Finlay & Lyons, 2000; Gibbons, 1981; Jahoda & Markova, 2004; Jahoda, Wilson, Stalker & Carney, 2010; Mest, 1988; Szivos & Travers, 1988, amongst others).

The richness of these approaches lies in the possibility for intervention, namely the promotion of life quality of these people and their lifelong psychosocial development. Indeed, they allow the development of an array of intervention strategies based on the dignity of their lives and on the respect owed to them in social interactions and in the institutional answers, namely in the support centers for these people and in the work with their families. Promoting knowledge about their own disability may lead to more realistic expectations, but is not exempt

from counter-indications. The advantages and disadvantages of this consciousness raising, as well as the implications for the intervention, are presented by Szivos and Travers (1988).

In one way or another, working in this framework will sooner or later raise the issue of knowing what people with disability think about disability. In fact, knowing the image that people with some disability have of that disability is not a simple matter of curiosity, since this knowledge may sustain interventions that focus on that image, whether focused on the self, their colleagues or their group.

What is disability for a person with an intellectual disability? Do people with intellectual disability see themselves as disabled? Are they conscious of their limitations? Is this information that can and should be used? What psychological and social consequences may this provide? As far as we know, there are not many studies trying to answer these questions. In this area, the research has focused mainly on social representations (Marková & Farr, 1995; Paredes & Carvalho, 2000) and attitudes (Yazbeck, McVilly & Parmenter, 2004) that certain groups have about mental disability rather than the representations that people with intellectual disability have about disability. This relative scarcity of studies centered on the point of view of disabled people is comprehensible if we take into account the methodological adversities deriving from the cognitive and linguistic limitations of this population.

However, certain studies have showed that it is possible to gather the point of view of people with intellectual disability, namely about their self-concept and their perception of stigma and discrimination. In this line, the importance of the pioneering study of Edgerton (1967/1993) should be stressed. It reports that intellectual disabled people are conscious of the stigma related to disability and how they reject it, trying to “pass as normal”. Accordingly, other researches using different methods and theoretical approaches to explore the perspective of people with disability have examined the awareness of stigma, self concept and the associated identity processes (Finlay & Lyons, 2000; Gibbons, 1981; Jahoda & Markova, 2004; Jahoda et al., 2010; Mest, 1988). In a consistent way, these studies show that individuals with intellectual disabilities are conscious of the stigma and discrimination against them, and reject it. However in this work we want to know another different thing: what image do people with intellectual disabilities have about disability?

To answer this, we found the theory of social representations particularly useful, in that it aims to understand the logic and internal consistency of a thought that might not respect the rules of formal logic. Social representations are mingled ways of thinking, in the sense that they present images, perceptions and concepts that are not always coherent. So, regardless of the non-contradiction law and validation through external events, they tend to be supported more by criteria of utility than veracity.

The explanation for this specificity is based on the diversity of regulation demands of the cognitive system, in which social regulations have a role of “control, validation and maintenance of coherence” of cognitive operations (Moscovici, 1961/1976, p. 255), similar to the role of the logic rules of formal thinking. It is possible that different meta-systems of cognitive regulation coexist and one of the major purposes in the study of social representations is “the search for a correspondence between a social situation and the cognitive system” (Moscovici, 1961/1976, p. 289). Or, as Doise points out (1993, p. 157) “the theory of social representations (...) basically is a general theory about a meta-system of social regulations intervening in the system of cognitive functioning.” We think that in the case we are dealing with, the functioning of this meta-system of social regulations tries to ensure knowledge about disability, which allows a positive self-image in spite of all the information that sustains the opposite.

One of the most interesting aspects of the studies exploring the self-concept of people with mental disability is the analysis of the processes by which they try to build a positive identity. This is a point that coincides with our observation over more than 20 years of intervention in this domain. In spite of all adversities related to their public image, disabled people actively work on a kind of psychosocial bricolage in order to keep a positive self-image. Obviously, the success of this kind of processes is far from being granted, contributing their failure to the rise of emotional and mental health problems (Jahoda et al., 2010).

For mentally disabled people knowledge about disability is not something neutral, nor a minor knowledge among others. Rather, at the end of the day, what is at stake here is a definition of the self or, at least, a representation that is not irrelevant or indifferent to the self-definition. This is even more important when the self is defined socially as mental disabled (with the limitations and handicaps it implies), since it is often thus that those persons are defined, in public and in private, with all the negative aspects related to this stigma. That is, we are faced

here with a particular knowledge, since it defines the individual through a stigma (Goffman, 1963/1980).

Since we are trying to know the content of a representation – the disability - we must consider two other fundamental processes of social representations: objectification and anchoring. Through objectification, abstract concepts become concrete; they are transformed into an image, and the anchoring process refers to the social rooted of the concepts at stake, to their insertion in categories and knowledge already available (Doise, 1992; Moscovici, 1961/1976; Palmonari & Doise, 1986).

In this framework, we are not studying the elaboration, re-creation and dissemination through different communication media of the social imaginaries about disability. Instead, we are dealing here with the results of these processes. We try to look – in an exploratory way – at whether some more consolidated aspects of these social imaginaries will appear in social representations under study. In other words, we are trying to see if there are some tracks of the product of the “social fabrication” of the “social imaginary” that could be present in the social representations of disabled people about disability.

METHOD

Participants

17 individuals with intellectual disability, service users of “*Os Malmequeres*” (7 women and 10 men) aged between 16 and 44 years old were recruited as participants. According to standard classifications, their level of disability would be considered moderate and severe. They are used to being questioned about several subjects and very often they are stimulated to give their opinion. They also have some drawing skills, for which they have received training over the years, and use them as a daily practice in this Center.

Procedure

The data were collected through interviews, because it seemed a good solution based mainly on the profound knowledge that the interviewer (the second author of this article) has of the participants. This knowledge is founded on long relationships, (in some cases spanning more than

18 years) and allowed, on the one hand that empathy, trust and even friendship could already be taken for granted, and on the other that the interviewer was able to translate some linguistic and non-verbal expressions of each person interviewed. To overcome the gaps that would probably still persist in the speeches obtained, the interviews included the carrying out of drawings of disabled and non-disabled individuals and also a request for comments on some images.

The images used in this study were the result of a collection of photographs of individual's bodies and/or faces of both sexes, with different ages, physical and intellectual disabilities and images of other individuals with no physical feature indicating the presence of disability. After a trial with a broader set of images, which were examined by different judges (institutional technicians and researchers) to analyze the relevance of each one, 14 images were selected. After exploring many possibilities concerning the method of data collection, we made a rehearsal and a revision of the process with different technicians (in operational and ethical terms) choosing the following structure of data collection.

In the context of an individual interview done by the psychologist working with them in the Center, participants were asked the same questions: 1) *What do you think disability is or what do you think a disabled person is?* 2) *Among your colleagues of the Center is there someone you think is disabled?* 3) *Here you have some cards [14 cards with 15cmx21cm] with photographs of people and I want you to tell me those you think that have a disability and those you think that don't.* All participants, at the end, were *requested to draw a disabled person and a non-disabled person.* These interviews were done on the premises of *Os Malmequeres* during January 2006 and lasted around 40 to 50 minutes. They were video recorded and then transcribed to paper for further analysis.

With the introduction of question 2 (about the colleagues) and question 3 (images) we aimed, by contrast, to discover the elements on which those interviewed find support for the identification of disability. Finally, as a complement to this data, the request of the drawing was aimed at obtaining more detailed information about the image content, especially as this group receives training in drawing and has a strong drawing practice in daily activities in the Center. In other words, we used it as a tool to help overcome the linguistic limitations presented by the participants. On the other hand, the drawing provide pretexts for useful information to explore in

the conversation about some aspects of the image that these individuals have about disability which may have not be captured in the other steps of the data collection.

Based on an anthropological and clinical role of the interviewer, we wanted to obtain by different means, elements that would allow us to analyze similarities and differences in the picture of people with and without disability to better understand the image that the participants have about disability.

RESULTS

In spite of all the procedures we describe above, the answers of the individuals that could be considered as having severe mental disability provided scarce material for analysis. In two of these cases it was not possible to get any relevant information for our study, so they were withdrawn from our data. The speeches about disability of the remaining 15 participants were submitted to an interpretation as a kind of first exploratory content analysis. With this inductive approach we tried to find the main meanings or conceptions of disability in participants' speeches in the answers to the first question of the interview. Furthermore, they were subjected to differentiated analyses: 1) the features of the individuals considered with or without disability, as well as the arguments used in each case, whether concerning their colleagues (second question of the interview), or whether concerning the images presented in the third question; 2) the drawings of people with and without disability.

After a detailed analysis of each one of these elements, we tried to construct a whole framework and this whole framework picture was discussed and reviewed several times by the two authors of this article. At the end of this process, a relatively coherent whole picture was obtained with two images of disability, which correspond to two distinct groups of participants.

The first of these groups consists mainly of individuals presenting moderate disability and who have learned, with the inherent difficulties, the rudiments of reading and writing. To these individuals, disability is linked to physical features, but is also seen as a lack of capacity in the acquisition of reading and writing as well as some individual autonomy or even the inability to "get a job" (reported by one of the participants). They mainly affirm about themselves that they also have some difficulties or problems, but do not see themselves as disabled like most of their

colleagues (“I also have some problems, but there are others with more disability than me”). In the cards with images they identified all the physical disabilities and in the drawing most of the participants drew individuals with a physical or sensorial disability visible in their bodies (e.g., blindness, person in a wheelchair, amputee; cf. Figure 1). In other words, these are individuals who have the notion of mental disability but for whom the disabled are others with physical problems or that have not learned the rudiments of reading and writing. Examples of the speeches from this group are as follows:

(...) they are not quite like the others... they have problems that others don't have... those who are in a wheelchair or can't dress themselves. (man, 43 years old)

Those who are paralysed, those people that also don't talk... can't read, they always have to copy their name. (woman, 31 years old)

They are people who can't do things on their own, they always have to have help, if they go to buy something they need to take something written [by someone else to show in the store] or need to ask for help. (man, 27 years old)

They are people who can't have a job like a normal person. (woman, 38 years old)

A disabled person has a disability... in the hands and feet... or is in a chair for people that can't walk... There are people with disabilities to read and write. (woman, 29 years old)

They are people who don't know to read... a person who can't walk. (man, 28 years old)

They are people with problems like mine and worse... there are people with disability, but... that don't have physical problems that other people can see...

people like these stay more retarded in school and so can't read very well, isn't it?
(man, 42 years old)

A different image is presented by the individuals with severe disability who did not acquire reading or writing competencies and presented with notorious linguistic difficulties. These individuals have an image different from the previous one: the disability is only and always the one that is visible. Regarding their colleagues, they reported as disabled those who have physical difficulties (for example, walking problems with origin in cerebral palsy) or they answer that they do not have any colleague with a disability. Their own disability, "difficulties" or "problems" are not recognized, and do not exist for them.

Regarding the cards with images for identification of disability, the results are similar to the previous group. In the drawing they always represent a visible physical or sensorial disability (see Figure 1). Basically, it seems they do not have the notion of intellectual disability. For them, disability is always only physical or sensorial. Some examples of these speeches are:

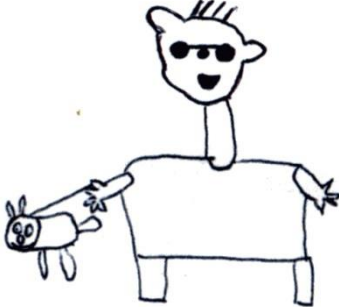



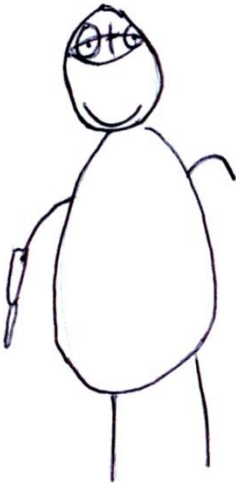
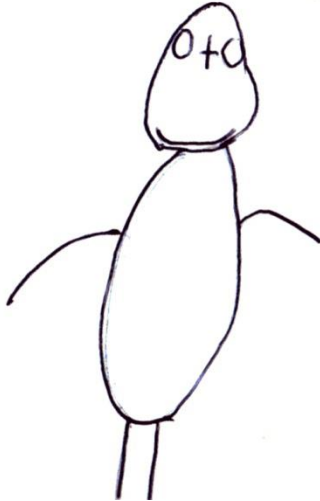
It is a person with a lot of problems... in feet, in hands, in the head, in the hips...in the whole body also. (woman, 29 years old)

It is a person who is "stuck" to a wheelchair...doesn't have arms... doesn't have legs. (man, 21 years old)

Someone who doesn't walk at all. (woman, 27 years old)

(...) they need someone to help them ... they have difficulties. (man, 39 years old)

It is a person who doesn't walk ... who doesn't speak... who has difficulties in eating... someone has to dress him...to wash him. (woman, 43 years old)

A disabled person	A non-disabled person
	
	
	

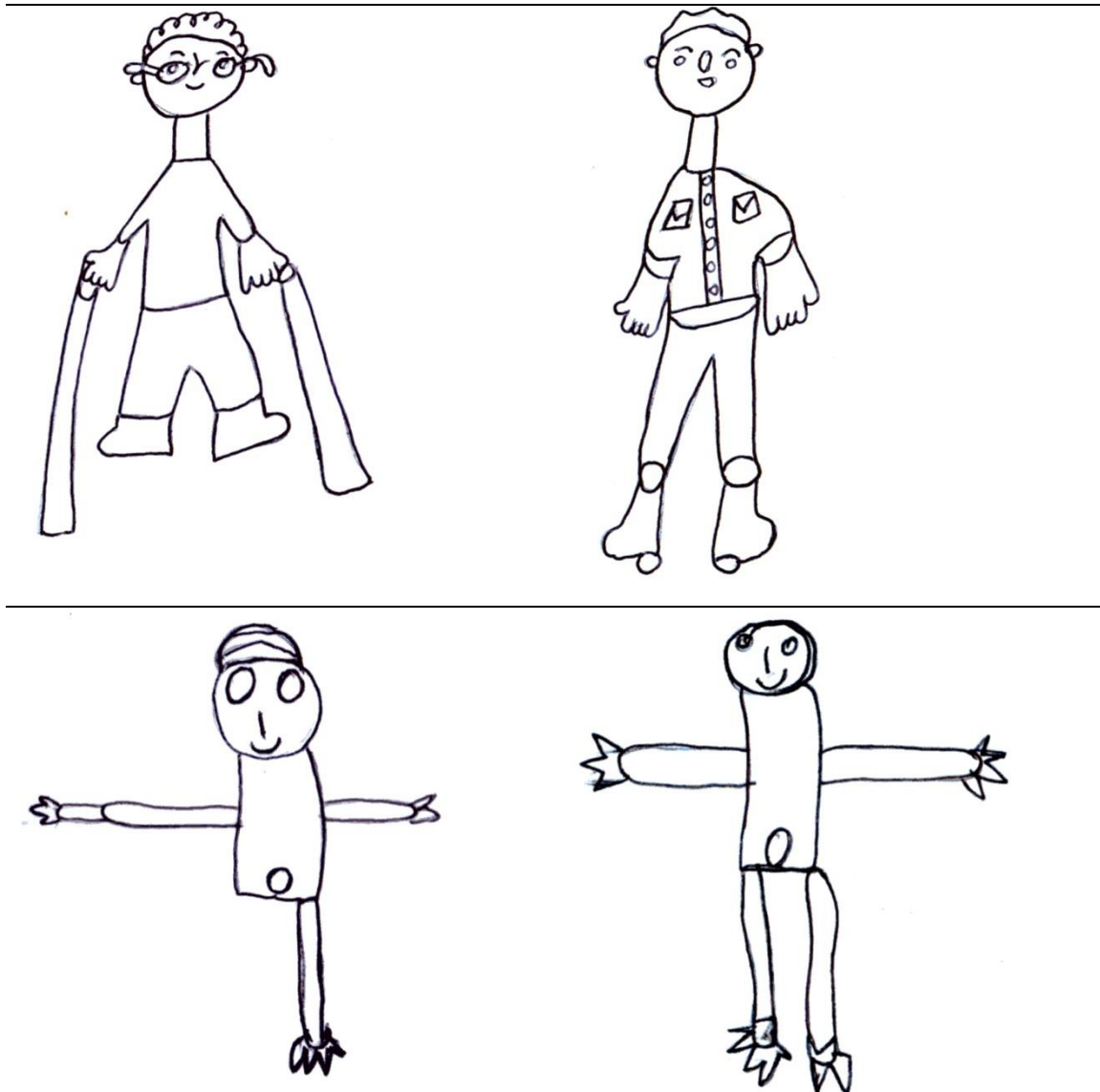


Figure 1 – The five most elucidative participants' drawings of a disabled person and a non-disabled person. Each pair (with and without disability) drawn by the same participant.

DISCUSSION

The major challenge we had to face in this study was to find a proper way of collecting the data from the individuals with an intellectual disability, and overcoming some expected difficulties due to their cognitive and linguistic capacities. That is, we aimed to capture the image that our participants have of disability and, simultaneously, to ensure that these data had the requested features that allows an analysis with the rigor that should characterize a study. I.e., to ensure that

those data are more reliable than the informal collected opinions done by the institution technicians for some years and that inspired this study. This part of the work was particularly difficult, since we did not work with individuals presenting mild intellectual disabilities. This challenged us much more than we expected, concerning not only the researches, contacts with other people and discussions we were obliged to do, but also for an exercise of methodological imagination with the purpose of creating something from the existing methods, but which still permits some validity and reliability of our data. We think that the first lesson to learn from this is precisely this one: the urgency to give a *voice* to these persons is as obvious as the lack of ways to do it. We tried to work out this situation through simple but solid solutions for data collection based mainly on the profound knowledge that the interviewer (the psychologist) has about those interviewed.

It's obvious that the interpretation of our data should not forget the exploratory nature of this study and the inherent limitations resulting from the size and specificity of the used *sample* of our participants.

Considering this, it appears that the results obtained show that the individuals with intellectual disabilities participating in this study have knowledge about disability. They know what we are talking about when we say that someone is disabled. The disability appears here clearly objectified in the physical features of the disabled bodies and also in the inability to read and write. When we ask ourselves about what the foundation is of these different images, we see that they are not only linked to individuals with distinct levels of disability but also with different mastery of reading and writing. In fact, our first group is composed mainly of individuals that have some reading and writing abilities, and the second group by individuals who cannot read or write. The image based on physical characteristics is common to both groups, while the objectification in the inability to read and write appears only among the group of individuals that have learned the rudiments of reading and writing.

In other words, these images of disability show themselves to be anchored in the mastery of school competences of the individuals. Having this abilities, even if they are minimal, may be overrated and taken as a criteria for separating the category of "those who have problems" from those "who are disabled". In the absence of these abilities, the same kind of separation is made through the existence of physical features that work like markers of disability.

It seems that there is here an association with identity processes through the search for a kind of identity protection: the disabled are others almost like me, but I have something that others do not have and that does not make me disabled like them. The tendency to dissociate the label of disabled from her/himself already appears clearly in Edgerton's study (1967/1993) with individuals with intellectual disability. This is a result that other studies have corroborated showing that this population has the notion of the stigma related to disability, rejecting prejudice and trying to get distance from other individuals with intellectual disability (see, specially, Finlay & Lyons, 2000; Jahoda & Markova, 2004).

Even when individuals with disability are confronted with the label of disability applied to themselves, which occurs quite often - and sometimes in an open discriminatory and stigmatizing way - they may develop other and more active ways of knowledge about their own disability than the simple denial of it or passive internalization of its negative features. This information may be appropriated through ways of thought that allow them to be indifferent to the non-contradiction law. We do not know the role that cognitive limitations have in this process. However it is important to point out that this process is not entirely due to the lack of mastery of the rules of the logic-formal reasoning by our participants. It must be remembered that the same type of thought can be found on adults who master formal operations, as Moscovici discovered already in his *princeps* work about the image of psychoanalysis (1961/1976; cf. also Moscovici, 1981, 1994). This is indeed one of the most distinctive features of social representations. As ways of thought they account more for the pragmatic and the utility of a knowledge than for its veracity or error (Moscovici, 1991, p. 72).

Although our work did not focus on the study of stigma or on the self concept of individuals with intellectual disabilities, it is important to highlight the similarities found with the results of other studies which show the existence of a downward social comparisons process (Finlay & Lyons, 2000; Jahoda & Markova, 2004), particularly with other individuals with intellectual disability presenting less capacities. Actually, our participants also distinguish themselves from other individuals with disabilities presenting more severe limitations in a typical process pointed out by Tajfel (1978/1983; Tajfel & Turner 1979/2001) as a social creativity process.

Concerning the relationship between social representations theory and the concept of social imaginary, there is also a speculative point, which we believe deserve to be highlighted here. More than the mere fact of disability being part of the human imaginary inspiring both fear and blessing, it is very interesting to find in the answers of the participants of this study an opposition based on the mastery of the school knowledge, specially reading and writing as a kind of *themata* in the sense of Moscovici and Vignaux (1994). It means a kind of cultural foundation of thought in the form of an oppositional nature. Actually it is worthwhile to note how our data seems anchored in the social memory of the historical process of schooling of knowledge that could also be considered a process of “domestication of the savage mind” (Goody, 1971). The spread of school knowledge is undoubtedly a focus spot of modern societies that marks their imaginary. The separation between literate and non literate people, between knowledge and ignorance done on the basis of who has school culture (cf. Valentim, 1997) is also a finding in our data, in the opposition between those who do and don’t know how to read and write. If in socio-historical terms the school culture was the line for separating educated persons from non-educated persons, it should be pointed out how, curiously, we find here the same line separating disabled from non-disabled persons. It seems that the importance of the domain of the school culture to *pass as cultivated* in a certain sense appears here in the form of *pass as non-disabled*. This is even more interesting since the mild disabilities could be, in part, understandable as a socio-historical construction deriving from the generalization of compulsory school (cf. Zazzo, 1969). As Perron (1969, p. 54) says in a clear way “the [mild] mental disability, historically appears first as a school inability”. And even if this is just a speculative issue it is still curious that those elements are finding here under the shape of this opposition in the knowledge that intellectual disabled people have about what is the disability.

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