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Self-Representation of Students with Intellectual Disabilities in Regular Schools

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Self-Representation of Students with Intellectual Disabilities in Regular Schools

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Abstract

The 20th century was characterized by triggering debates about human rights, citizenship and by the mobilization for the rights of persons with disabilities. This process was intensified in the second half of the 1990, causing significant changes in life and social relations of disabled people. In order to do this research, a group of twenty students from eleven public schools in Goiânia, the capital city of the Midwestern Brazilian state of Goiás, participated in the study. The data collection instruments were in-depth interviews and observations of school documents. The main theoretical framework is based on the ideas of authors such as Berger and Luckmann (1971), Taylor and Bogdan (1987), Moscovici (2011), among others, and also on official documents about the Brazilian school education and documents designed by international conventions and agreements. The bibliographical research showed that the representations are socially constructed, linked to the experiences of social life and sociability of the participant subjects. Empirical research has shown that the group of people with intellectual disabilities is heterogeneous. Thus, the self-representation makes explicit a positive self-image of themselves as students in regular public schools. Moreover, other important aspects are the desire to maintain the process of schooling in regular schools and the ambiguous situation of being in a process where the various representations about the person with intellectual disabilities, their rights, potentialities and possibilities conflict.

Keywords: self-representations; intellectual disabilities; regular schools.

Introduction

The mobilizations and debates about the rights of people with disabilities boosted the opening of the regular schools for all people with or without disabilities. This movement started in Europe at the end of the first half of the 20th century, later expanding to other countries of the world like Canada, United States and Brazil (Mazzotta, 2005). Parents of disabled people, who "founded representative associations regarding their children's interests", led this movement (Faria, 2014b, p. 10), through which they could ask for therapeutic treatment, professional training and research investments.

The collective mobilization concerning rights for people with disabilities integrates the context of political effervescence of the 20th century, in a peculiar way. On the one hand, it differs from mobilizing questions of the first half of this century that revolved around collective and humanitarian rights. On the other hand, it was characterized for being in the forefront of social movements regarding identity, which marked the second half of the century (Alonso, 2009). Many associations that represent the rights of disabled people were created underlying the principles of self-determination and self-advocacy. However, in the case of people with intellectual disabilities, the social process of silencing and despise towards their opinions still prevail (Faria, 2014a).

The disabilities, including the intellectual ones, have been part of debates and international conventions resulting in documents, such as "The Salamanca Statement on Principles, Policy and Practice in Special Needs Education of 1994, the Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities of 2001 and The Montreal Declaration on Intellectual Disabilities of 2004" (Faria, 2014a).

In Brazil, there is the regulation of these conventions in official documents such the Law of Directives and Bases of National Education², National Policy on Special Education from the Perspective of Inclusive Education³ and National Education Plan⁴ 2014-2024 (Brazil, 2014; Faria, 2014b).

Some Concepts: Intellectual Disabilities, Inclusive Education and Social Representations

The concept of intellectual disability is not easy to define. In general, it relates the association between intellectual functioning and adaptive condition of the subject in everyday situations. It is characterized by a slower learning process than the usual one and by difficulties in carrying out everyday activities. Over the years, several terms have been used to designate it, such as mental illness, mental disabilities, mental incapacities, among others (WHO, 2005). Each one of them presents limitations and possibilities in relation to the understanding of intellectual disability and in relation to the factors that it relates to, like the medical and environmental nature.

¹ All excerpts quoted originally in Portuguese or Spanish were translated into English by me.

² Lei de Diretrizes e Bases da Educação Nacional – LEI 9394/96.

³ Política Nacional de Educação Especial na Perspectiva da Educação Inclusiva.

⁴ Plano Nacional de Educação 2014-2024.

The World Report on Disability (World Health Organization, 2011) states that "disability is complex, dynamic, multidimensional, and contested" (p. 3), resulting from established social relations. Besides that, "the disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly" (p. 7). The Montreal Declaration on Intellectual Disabilities (Declaração, 2004) asserts that the understanding of disability is relative, varying from one culture to another. Therefore, it affirms that

2. Like all other human characteristics, intellectual disabilities are an integral part of the human experience and diversity. Intellectual disabilities are understood differently by cultures, and thus require the international community to respect its universal values of dignity, self-determination, equality and justice for all. (p. 2)

The concept of inclusive education emerged in a context where segregation of persons with disabilities started to be questioned and disrupted. Inclusive education can be understood as the practical attitude towards accepting the individual, respecting their specificities and the rights that are inherent to them as a human person. This condition has been the criterion for accepting them regardless of prejudice, discrimination and stereotypes (FARIA, 2014a).

The concept of social representations, in turn, has been developed by authors of various epistemological fields in a transdisciplinary way, building not only a definition but theories about social representations (Jodelet, 2007). Social representations are subjective constructions anchored in social experiences of collective life, of social interactions and of the location of the subject in the world (Dubet, 1994), which are constructed and manifested in discursive spheres, where the ideas are formulated and expressed. Thus, words make representations tangible (Bourdieu, 2000; Moscovici, 2011).

The interactions and the process of socialization implemented by social institutions, mediated by language, decisively influence the process of formation of subjectivities, making possible the attribution of meanings and significances. In the social world, things, objects, people and events do not have a fixed, final and true meaning, for their meanings are produced in society, within human cultures (Hall, 1997).

In that regard, Berger e Luckmann (1971) assert that

Language, which may be defined [...] as a system of vocal signs, is the most important sign system of human society. Its foundation is, of course, in the intrinsic capacity of the human organism for vocal expressivity, but we can begin to speak of language only when vocal expressions have become capable of detachment from the immediate 'here and now' of subjective states (p. 51).

The common objectivations of everyday life are maintained primarily by linguistic signification. Everyday life is, above all, life with and by means of the language I share with my fellowmen. An understanding of language is thus essential for any understanding of the reality of everyday life. (p. 51-52).

In this way, language is capable of becoming the objective repository of vast accumulations of meaning and experience, which it can then preserve in time and transmit to following generation (p. 52)

The concept of social representations can be defined as "images, values, ideas, categories that are easily recognized and resorted to by many people in a group" (Agoustinos; Innes in Leme, 1995, p. 52). Thereby, the aim of this research revolves around knowing the collective thinking of the group studied. The interest of this investigation was not in "the uniqueness of nature - or 'souls' -, but in the particularities of different *collective histories*" (Bourdieu, 1997, p. 15, emphasis of the author).

Methodology

This investigation, conducted in 2013, is a descriptive research, which "primary objective [is] the description of the characteristics of a given population or phenomenon" (Gil, 2002, p. 42). The intention was to know the self-representations that students with intellectual disabilities had of themselves as students in regular schools, in the final three years of elementary school¹, in regular public schools in Goiânia, Brazil.

Besides the theoretical background, which the study is based on, there was the conduction of an in-depth empirical survey, drawing on semi-structured interviews, fundamentally life histories, and observations of the students' school documents (their dossiers). In-depth interviews are qualitative methods of research, carried out by means of the dialogue between researcher and interviewee to "understand [...] informants' perspectives on their lives, experiences, or situations as expressed in their own words" (Taylor; Bogdan, 1987, p. 77). It is worth mentioning that all of the participants were asked the same questions, but for several reasons such as their deviation of thoughts, speech problems and understanding concerning the issue, not all of them answered all the questions.

In the interviews, besides the presentation of questions to help them talk about themselves as students, the presentation and analyses of images that simulated peculiar situations to the school environment were also provided. They intended to simulate their relationship with the group, the formation of mixed groups of people with and without disabilities at school, the performance of activities, the methodology of classes, the participation and commitment in classroom, the satisfaction in being at school, among others.

¹ In the schools where the research was done, these grades are named as cycle III.

There was also a request by the interviewer to make a representation of themselves as students, in order for them to show those people whom they perceived as close to them and those whom they preferred to saty aloof from. The aim of this request was to provide information about the friendly, indifferent or conflicting relationships that took place at school.

In the fieldwork, Laperrière's warning (2008) on the importance of triangulation of data with the use of different sources and perspectives was observed. Thus, the perspectives of family, school and medical reports were considered. Moreover, in order to maintain a reflective attitude, school documents were not read prior to the first interview, ensuring that the subject's representations were made by oneself, avoiding the creation of previous notions and prejudices that could negatively interfere in the process of knowledge of each student. The dossiers were used as support to complement the information on each subject, providing a better comprehension about them. Thus, all the conclusions come principally from the interviews.

By means of triangulation, the goal is to understand both the subject and their perspective, coherence, opinions and personal positioning. From the data collection, it was possible to perceive that the participants were very sincere in their replies to the interviews.

Participants

The group of the study was composed of twenty students from the final three years of elementary school, enrolled in schools from several regions of Goiania, the capital of the state of Goiás, located in the Midwestern region of Brazil. See figure 1.



Figure 1. Location of Goiânia in Brazil

Fifteen of the participants are boys and five are girls. Their ages ranged from thirteen to twenty-two. Most of the students were between thirteen to sixteen years old.

A great disparity in relation to motor functions, oral communication, memory and learning capacities in the group was observed. That shows that the

idea of people with intellectual disabilities as a homogeneous group is inadequate. Vygotski (2012, p. 24) states that "[t]he mentally retarded can never be presented as mentally retarded as a term applied in a general way." According to him, "the child with disabilities does not directly feel their disabilities; [s/he r]ealizes the difficulties that derive from their disabilities" (Vygotski, 2012, p. 18). The group of this study, which is plural regarding the participants' characteristics, diverges significantly from current images that portray them as asexual, passive, docile and childish people.

The map¹ below shows the number of participants by gender and region. This regional distribution simulates the locations of the schools in the city of Goiânia. See figure 2.



Figure 2. Distribution of the Participants in Goiania, By Region

Note: black – boys; red – girls.

From dossiers, it is observable that participants have a long school trajectory, which is favorable for the formation of self-representations of themselves as students.

They presented themselves as people who think, but not immune to contradictions, inconsistencies and insecurity. In the dialogues, some of these aspects were notorious. For instance, there were those who could not even say their own age and/or birthdate. Overall, the discredit to their speech and critical thinking is originated from other people's perceptions regarding these students' confusion over their thoughts, which are considered unusual for their age. These aspects are not unique to people with intellectual disabilities, though for them this is more notorious. Historically, these characteristics of thought and speech of intellectual disabled persons have been the justification for social

² Translation: Noroeste: Northwest; Norte: North; Leste: East; Sul: South; Sudoeste: Southwest; Meninos: boys; Meninas: girls.

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discredit to their speeches, which consequently incites prejudice and social invisibility.

The focus was their discourse as a whole, analyzing it as an expression of a subject who thinks, is multiple and plural. This showed that the thought and discourse of a person with intellectual disabilities have coherence.

Data Analysis

In general, the main representations generated from the data collection are:

- a) the participants' self-classification as good students;
- b) the feeling of appreciation for the school;
- c) their personal desire to go to school every day;
- d) their sense of security to ask classmates and teachers for help and the trust that they will be well looked after, although almost one third usually avoids or denies requesting for assistance;
- e) their concern to carry out the activities, even when they are not able to do them;
- f) their longing for fair treatment in the classroom and school environment, doing the same activities and being with the group during the school term;
- g) their preference to stay in regular schools;
- h) their sociable posture and the establishment of friendly relations with classmates, staff and teachers;
- i) the importance for them of bonds of friendship, respect and trust with classmates and teachers, which can establish positive links with the school and the personal sense of well-being in the school environment;
- j) the students' perceptions of visible conflicts, in which they react by showing self-assertion and not victimizing themselves or feeling inferior; and
- k) the valorization of school environments, which does not come from a naive perception of the school, insofar they perceive and criticize conflicts related to institutional and relational aspects.

The students demonstrated commitment to building a positive social image of themselves as students in regular schools, resorting to postures of discipline or indiscipline to forge a positive social image. For example, some learners adopt the posture of "a good student," demonstrating organization, obedience and dedication, aspects that make their attitudes constantly praiseworthy. Other learners, by taking part in the class disorder, holding conversations in inappropriate moments and fighting with classmates, try to reach equity in relation to other students. Thereby, the self-classification related to typical models of students such as the good student, the undisciplined one, among others, reveals the consistency of self-representations associated with socially

constructed conceptions apprehended in the process of socialization carried out in social institutions, especially by the family and the school.

Problems like indiscipline are not necessarily related to the characteristics of the subject. There is a relation between sociability and behavior. Indiscipline is the result of a relational context, not always caused by the subject, but rather, most times, by reactions to provocations and symbolic aggressions suffered and not always perceived in the school context. Hence, indiscipline integrates and reflects the social context and the interactions resulting from it.

85% of the participants who answered the interview showed that they are not going to school because of family imposition, nor to ease their families' work in caring for them. There is appreciation for the schools and personal willingness to attend them.

In the process of building and maintaining a positive social image of oneself, the withdrawal also has been an important aspect. 31,6% demonstrated inhibition, fear or even refusal to expose their doubts and/or ask for help in classroom, even declaring that when they ask for help they are promptly assisted.

Despite their disabilities, they express confidence in their ability to learn, seeing their own school development with optimism. In relation to carrying out the activities: only one of them said that he does not do the activities; thirteen said they do all the activities, although there are three who are not able to carry out the activities the way it is expected, even because they are not literate, but they do them the way they are able to. Three students did not answer this question.

Two of the participants generally copy the questions from the board and only put the answers after the teacher's correction, or they ask their classmates or relatives (when they are at home) to do the activities for them. Two asserted that sometimes they do not do the activities because they are aware that, even though they try, sometimes they will not be able to do them within the amount of time set.

Concerning the differentiated activities, seven students stated that they do the activities the same way as the rest of the group and prefer it to be this way. Doing differentiated activities is a visible mark of difference, of their learning difficulties and/or cognitive inferiority in relation to other classmates. Hence, rejecting it corresponds to positioning themselves in an equitable condition in relation to the class. For the purpose of exemplifying, one of them said, "If I were given any differentiated activity, something that is only for me, I would ask the teacher why there would be a different activity only for me and the teacher would have to justify." As opposed to it, two students did not reject differentiated activities because they were easier, as they concerned solely painting and drawing. Eleven participants did not answer this question.

With regard to their preference to study in regular schools or special schools, 82% declared they would rather stay in regular schools because in special schools there are restrictions regarding social contact, such as interaction, sociability and learning among students. For the participants, having good relationships with teachers and staff at school is an important factor in order to establish a positive bond with the school.

One participant, who has already been to a special school, argued that people learn, but learn less than when they are in regular schools because there is less social contact with different people. For him, it is possible to learn many things in schools where there are different people. In addition, in his opinion, disabled individuals can learn with those who are not, as those without disabilities can also learn with the ones who are disabled persons.

Seventeen students claimed to like the class in which they study and have shown they can think critically in relation to indiscipline, disorder in class, graffiti, disrespect, among others. Two participants affirm to like their classmates, but that sometimes they feel uncomfortable depending on their classmates' attitudes.

Disagreements among them and their classmates may occur, but friendship, dialogue and good relationships prevail. In some cases it is perceivable that disabled students' involvement refers more to staying in the same environment than establishing a closer bond with classmates, aspect which was revealed in situations of some participants' isolation, both at school and in other social spaces. One participant illustrates this situation. He reported that he had a great relationship with everyone. Furthermore, he stated there was a group of classmates in which he was a member, but that friendship began and ended at the school gate. In his words, "When the group leaves the school, each person goes their own way. It is not a group that is together until the moment to go home. It is not a group that gets to each other's door".

The coexistence of people with intellectual disabilities with other individuals in school environments has allowed mutual learning concerning how to behave in such places and towards people who attend them. However, attitudes of ridicule and disrespect for the human dignity of persons with intellectual disabilities still happen. Harassment and attitudes of physical or symbolic violence are not widespread practices in all schools, but still happen with alarming frequency, especially in relation to those who have disabilities in more severe levels.

In spite of that, except for one of the participants, there is not a posture towards victimization. Attitudes of harassment and violence are seen as arising from conflicting attitudes among all classmates who provoke each other and, thus, not as a unique attitude related to persons with intellectual disabilities. Some students exemplified, mentioning as instances prejudice against those who wear glasses, people who are homosexual, disabled people, among others. Apart from one participant, they presented themselves as individuals who hold no prejudice and that do not see themselves as victims of prejudice.

There is discrepancy concerning learning expectancies between families and the group researched. While families and schools focus their expectations around the school learning, mainly on learning how to read, write and do math, the participant group seems to understand school learning beyond content, perceiving learning how to socialize and interact with classmates, teachers and staff as extremely meaningful aspects for their lives.

When asked if there was something they did very well, perhaps even better than their classmates, the disabled students provided several responses. According to them, their skills were not restricted solely to the school environment, though most were school related. Considering all the information obtained, they declared themselves skilled at studying, writing and doing activities. Nevertheless, this does not mean that there is a level of achievement with regard to learning and understanding of activities as expected by schools and in accordance with their ages. In some cases, there is even conformation of students with intellectual disabilities as copyists, not just due to their learning disabilities, but also due to lack of methodological and pedagogical work structured in the perspective of an effective intellectual engagement of all students. It is important to point out that there is still a need, not widespread, of meaningful activities and the serious involvement of some of these students in the execution of non-schoolwork.

By presenting a positive image in school, they see themselves as "adequate" to what is expected from them in regular school environments. They work on a social positive image in order to seem polite, kind and responsible. They face prejudice and discrimination, but they do so according to the "rules of the game", i.e. not necessarily through school learning, but through skills of sociability and interaction.

When asked what their main difficulties were, their response was mostly related to school nature, that is, difficulties to perform school activities. For example, they recognized that developing skills like reading, writing, doing math is their great difficulty.

They showed to be creative, to have sense of humor, to like attractive and dynamic school activities. With regard to creativity, Vygotski (2012) elucidates that "[f]rom a psychological point of view, also, it is incorrect to deny the existence of creative processes in children with mental retardation" (p. 35), corroborating with the understanding that disability is not a synonymous with alienation, critical incapacity or lack of creative ability. This assertion explains that disability does not mean a homogeneous reduction in all structural and brain capacity, and that there is actually a qualitative diversity of their functions.

There is the appeal for attention, for more systematic and frequent monitoring by teachers, probably in consequence of the perception of their learning difficulties. This requires, at least, a drastic reduction in the number of students in classroom.

The cases in which the disabilities, themselves or associated with other health problems, manifest themselves more severely, reveal the institutional fragility of regular schools when dealing with such cases. It is necessary to establish a consistent educational work aiming to work on a significant school learning, as well as to deal with issues regarding indiscipline and with physical or symbolic violence against persons with intellectual disabilities.

The participation of families in the research showed that the care and monitoring of children remain a predominantly female social role. Only one father systematically accompanied his child and three fathers participated at one time or another.

Final Remarks

Self-representations show that students with intellectual disabilities have a positive image of themselves as students in regular schools. Although they face prejudice and discrimination individually, when it is necessary they generally resort mainly to the school coordinator and to their families.

Even those who have more severe levels of disabilities or association with other health problems showed consistent and relevant thoughts. They showed that the challenge to society in general is to learn how to listen to them, letting aside prejudices that prevent people from understanding the coherence of what they say and think.

Contrary to what commonly occurs, taking into account only the inconsistencies perceived, considered and used to justify social invalidation of disabled people's discourses or to maintain them "under suspicion", a new way of dealing with persons with intellectual disabilities is essential. In other words, it concerns a change of perspective in relation to such subjects.

The authorship expressed in their discourses validates Foucault's perspective, in which the person who is in position of being an author expresses through language "their units, their knots of coherence, their presence into real" (Foucault, 1996, p. 28).

Students revealed that their attitudes are not always spontaneous. They are usually adapted to the environment, context, expectations, intentions and interactions. Therefore, they are regulated, regulatory and reflective behaviors.

Self-representations corroborate Moscovici's assertion (2011) and the theoretical ideas presented, showing that the representations are sociocentric. The representations shape the ideas and concepts located in their imagination, taking them into the physical world. They are drawn from situations of social and collective experiences, never detached from the social reality in which they are formed.

Eventually, this study refutes the idea that intellectual disabled people are unable to make meaningful representations of themselves, to formulate critical analyses and that they are always sweet and infantilized. Rather, they are people who have characteristics of peculiar personality and temperament, with self-determination and fully able to participate in debates promoted socially in several institutions about their rights, needs, desires and possibilities.

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