

Living and Learning with Down Syndrome

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Abstract: *Inclusion, an intensively studied descriptor, is still a very sensitive subject. Nonetheless, including a child with Down syndrome in the classroom is not impossible. Children with such a syndrome present rapid adaptation to the classroom as long as the infrastructure and pedagogical resources are adequate to their needs; therefore, this work aims at the classroom observation of a student's cognitive development, regarding the Portuguese and Mathematics syllabuses, after the application of pedagogical activities. The classroom observed was a 6th Grade in a public school, Middle School, State of São Paulo (Brazil). The methodology used was a single case study and the research has a bibliographic and exploratory approach. The results were sorted according to Piaget's stages of cognitive development. The data collected showed that a child with Down syndrome, properly inserted and stimulated in the classroom, can develop his/her intellectual capacity more quickly.*

Keywords: Behavior. Classroom, Teaching. Down

1. Introduction

Although inclusion has been widely discussed, it is still a sensitive subject. The very discovery that the family will have a child with Down syndrome has a great impact. However, the family support can, and will, help the child to overcome discrimination and prejudice, which unfortunately are still quite present in our society [19]. Furthermore, in the teaching-learning process, the family has a fundamental role; thus, this work aims at the classroom observation of a student's cognitive development after the application of pedagogical activities. A 6th Grade, Middle School classroom was observed.

2. Literature Review

2.1 The Down syndrome

In 1866, for the first time, the British physician John Langdon Down described the phenotype of children with Down Syndrome (DS), at that time using the term "Mongolian" or "Mongols" [19] due to the physical similarities with the people of Mongolia. He noted these similarities among children with some mental disability [11].

In 1958, the French geneticist Jérôme Jean Louis Marie Lejeune verified that the people studied by Md. John Down had, in addition to physical similarities, syndromes in their genotype. The changes observed in the genetic structure were due to an error in the chromosomes distribution. All humans have 46 chromosomes whereas people affected by Down syndrome present 47 chromosomes, whose extra chromosome makes connection with the 21 chromosome

pair, which leads to the name Trisomy 21. The excess of genetic material linked to chromosome 21 causes characteristic changes, such as learning difficulties, decrease in the involuntary state of natural contraction of body muscles, intellectual or cognitive impairment, difficulties in motor coordination, language delay, phonation, in some cases even congenital heart disease, oblique eyes, rounded face, small hands with short fingers, single palm fold and small ears [11]. Then, in 1961, a group of genetic experts suggested to that the Lancet Journal changed the name and the editor adopted Down Syndrome; the name was a tribute to its first academic researcher, Md. John Langdon Haydon Down [18]. According to the Down Movement (Síndrome de Down, 2012), for the Brazilian population, it is estimated that for every 700 births, at least 1 birth will be a child with Down syndrome. In the United States, according to the National Down Syndrome Society (2012), for every 691 births, at least 1 child is observed to be affected by the Down syndrome. In Portugal, according to the Pais 21 association (2012), for every 800 births, at least 1 birth involves a baby with Down syndrome. [14].

2.2 The child and the school

School beginning is a milestone in the life of any child. It is a time for socialization, integration, discovery, challenges. It is a mixture of freedom and cooperation. The school must be prepared to welcome children, both those with Down syndrome or not. A well developed educational plan should be created to assist children with Down syndrome. This action will give greater peace of mind and security to children, parents, and even teachers. The interaction of children in the classroom must be harmonious.

The coexistence of the students and the children with Down syndrome helps the development of respect, condescension, tolerance, willingness to help each other.

For children with Down syndrome, the experience of living with children whose development is considered normal is of great relevance, since the classmates become behavioral examples, thus contributing to emotional, social and intellectual development. Teachers should propose interactive activities among children, always respecting differences, in order to encourage the development of them all.

2.3 Legal support

The term diversity has currently been used intensively at school; however, when mentioned, it encompasses any type of student, with or without disabilities. Thus, to ensure that children with disabilities are accepted into any school, some laws have been created. Yet the creation of one law does not guarantee that the children will be treated respectfully and/or will receive the conditions they deserve [3].

Inclusion is not a straightforward event. In Brazil, since the Brazilian Empire, there have been institutions to support blind children, such as the Imperial Instituto dos Meninos Cegos (Imperial Institute for Blind Boys). In 1926, the Instituto Pestalozzi [15] was founded to assist people with mental disabilities. The Associação de Pais e Amigos dos Excepcionais (Association of Parents and Friends of Exceptional People, APAE) was created aiming at specialized educational assistance to people with giftedness in the Pestalozzi Society in 1954 [13]. Currently, Instituto Pestalozzi Institute and APAE also serve people with Down syndrome [15].

To support and to ensure the rights of people with disabilities, Brazil, as well as the world, has several laws and decrees. According to Dezotti [3], from 1990 to 2003, seven international documents, accompanied in the same period by fourteen statements from other world organizations, dealt with guaranteed rights for all. Some of these Brazilian laws and decrees will be described as follows.

In Brazil, the Federal Constitution states that any child in need has a constitutional right to specialized educational assistance. The Federal Constitution, Chapter III, Education, Culture and Sport, Section I, Education, Item 208, III - specialized educational assistance to people with disabilities, preferably in the regular school system [2]. Legislative power issued a decree that describes the rights of people with disabilities. This decree states that children with disabilities are entitled to equal opportunities. Decreto legislativo (Legislative Decree) n. 186, 2008:

[...] Convention on the rights of people with disabilities. Preamble. The Federative States to the present Convention [...] r) Recognizing that children with disabilities must fully enjoy all human rights and fundamental freedoms on an equal basis (emphasis added) with other children and stressing the obligations assumed to that end by the Federative States to the Convention on the Rights of the Child [...] [9].

Article 3 of the aforementioned decree shows that the development of children with disabilities must be respected.

[...] Article 3. General principles. [...] h) Respect for the development of the abilities of children with disabilities (emphasis added) and for the right of children with disabilities to preserve their identity [...] [9].

In Article 7, there is the description of the right to freedom, equal opportunities and the guarantee of adequate attendance to their disability.

[...] Article 7, Children with disabilities, 1. The Federative States shall take all the necessary measures to ensure that children with disabilities fully exercise all human rights and fundamental freedoms, on an equal basis (emphasis added) with other children. 2. In all the actions regarding children with disabilities, the child's best interests will receive primary consideration. 3. The Federative States shall ensure that children with disabilities have the right to freely express their opinion on all matters that concern them, have their opinion duly valued according to their age and maturity, on an equal basis (emphasis added) with the other children, and receive appropriate care for their disability (emphasis added) and age, so that they can exercise this right [...] [9].

Article 24, Item 1, of the same decree, recognizes the right to education for people with disabilities, guaranteeing an inclusive educational system, enabling the development of physical and intellectual skills.

[...] Article 24, Education, 1. The Federative States recognize the right of persons with disabilities to education (emphasis added). To enforce this right without discrimination and based on equal opportunities, the Federative States shall ensure an inclusive educational system (emphasis added) at all levels, as well as lifelong learning, with the following objectives: a) Full development of human potential and a sense of dignity and self-esteem, in addition to the strengthening of respect to human rights, fundamental freedoms and human diversity; b) The maximum possible development of the personality, talents and creativity of people with disabilities, as well as their physical and intellectual abilities (emphasis added); c) The effective participation of people with disabilities in a free society [...] [9].

Item 2 shows the assured right to free and of good quality education, at elementary and high school, as well as the necessary adaptations.

[...] 2. For exercising this right, the Federative States shall ensure that: a) Persons with disabilities are not excluded from the general education system on the grounds of disability and that children with disabilities are not excluded from free and compulsory elementary or from high school education, on the grounds of disability; b) People with disabilities

may have access to inclusive, good quality and free elementary education (emphasis added), and to high school education, under equal conditions with other people (emphasis added) in the community in which they live; c) Reasonable adaptations according to individual needs (emphasis added) may be provided; d) Persons with disabilities should receive the necessary support, within the scope of the general educational system, aiming facilitating their effective education; e) Individualized and effective support measures may be adopted in environments that maximize academic and social development, in accordance with the goal of full inclusion [...] [9].

In item 3 there is a description of different pedagogical practices, with the use of Braille writing, augmentative and alternative communication and sign language.

[...] 3. The Federative States shall ensure that persons with disabilities are able to acquire the practical and social skills necessary to facilitate their full and equal participation in the education system and in the community life. To that end, the Federative States will take appropriate measures, including: a) Facilitating Braille learning, alternative writing, modes, means and formats for augmentative and alternative communication besides orientation and mobility skills, as well as facilitating peer support and counseling; b) Facilitating the learning of sign language and promoting the linguistic identity of the deaf community; c) Ensuring that the education of people, in particular the blind, deaf/blind and deaf children, is provided in languages and in the modes and means of communication most suited to the individual (emphasis added) and in environments that favor their academic and social development to the most [...] [9].

Item 4 shows that the State will be responsible for hiring specialized professionals to work with people with disabilities.

[...] 4. In order to contribute to the exercise of this right, the Federative States shall take appropriate measures to employ teachers, including teachers with disabilities, qualified to teach sign language and / or Braille, and to train professionals and teams working at all levels of education (emphasis added). This training will incorporate awareness of the disability and the use of appropriate modes, means and formats of augmentative and alternative communication, and pedagogical techniques and materials, as a support to people with disabilities (emphasis added) [...] [9].

Item 5 describes access to higher education.

[...] 5. The Federative States shall ensure that persons with disabilities have a broad access to higher education (emphasis added), to professional training in accordance to their vocation, adult education and continuing training, without discrimination and on equal conditions. To this end, The Federative

States shall ensure the provision of reasonable accommodation for persons with disabilities [...] [9].

Law n. 8,069, created in 1990 and named Statute of Children and Adolescents, specifies the rights of children and adolescents, and in Article 3, single paragraph, describes the right to mental development and learning.

[...] Title I. Preliminary Provisions. Art. 3 - The child and the adolescent shall enjoy all the fundamental rights inherent to the human person, without prejudice to the full protection referred to in this Law, assuring them, by law or by other means, all opportunities and facilities, in order to provide them with physical, mental, moral, spiritual and social development, under conditions of freedom and dignity (emphasis added) [7].

Single paragraph. The rights set out in this Law apply to all children and adolescents, without discrimination of birth, family status, age, sex, race, ethnicity or color, religion or beliefs, disability, personal condition on development and learning (emphasis added), economic condition, social environment, region and place of residence or other condition that differentiates the people, families or community in which they live (text included by Law n. 13,257, in 2016) [...] [7].

Chapter IV assures that disabled people are entitled to specialized educational assistance.

[...] Chapter IV. From the Right to Education, Culture, Sport and Leisure. Article 54 - It is the State duty ensure to children and adolescents: III - specialized educational assistance (emphasis added) to the disabled, preferably in the regular school system [...] [7].

Chapter VII, Article 208, points out actions regarding responsibility for offenses against the guaranteed rights of people with disabilities.

[...] Chapter VII. Judicial Protection of Individual, Diffuse and Collective Interests. Art. 208 – Responsibility actions for offending the guaranteed rights (emphasis added) of children and adolescents, regarding non-offer or irregular offer, as stated by this Law: II – on the specialized educational assistance for the people with disabilities [...] [7].

In Brazil, Law n. 9,394 (acronym LDB), created in 1996, establishes bases and guidelines for national education. This law describes the right to specialized and free assistance for people with disabilities.

[...] TITLE III. From the Right to Education and the Duty of Educating. Art. 4 - The State duty regarding public school education will be carried out guaranteeing: III - free specialized educational assistance to students with disabilities, global developmental disorders and high skills or giftedness, across all levels, stages and modalities, preferably in the regular school system

(emphasis added) [...] (This final form is present in Law n. 12,796, passed in 2013) [8].

Chapter V, article 58, describes special education, specialized support service, and the offering of special education.

[...] CHAPTER V. SPECIAL EDUCATION. Art. 58 - Special education means, for the purposes of this Law, the type of school education offered preferably in the regular school system, for students with disabilities, global developmental disorders and high skills or giftedness (emphasis added). (Final form in Law n. 12,796, created in 2013). § 1° There will be, if necessary, specialized support services in the regular school (emphasis added), in order to satisfy the peculiarities of the special education clientele. § 2° Educational service will be rendered in classes, schools or specialized services, as long as, due to the specific conditions of the students, it is not possible to integrate them in the regular classes of regular education. § 3° Special education offering, in accordance with this item, begins at early childhood education and extends throughout life (emphasis added), as observed in Item III, Art. 4 and single paragraph, Art. 60 of this Law. (Final form presented in Law n° 13.632, passed in 2018) [8].

Article 59 describes curricula, methods, techniques, educational resources and specific organization for people with disabilities. It also mentions that teachers with specialization will be made available along with equal access to the benefits of social programs available for regular education.

[...] Art. 59. The education systems will ensure students with disabilities, global developmental disorders and high skills or giftedness: (As stated in Law n. 12,796, of 2013) . I – specific curricula, methods, techniques, educational resources and organization (emphasis added), to meet their needs; II - specific terminality for those who cannot reach the level required for completing basic education, due to their deficiencies, and acceleration to complete the school program for the gifted in a shorter time; III - teachers with adequate specialization (emphasis added) at a secondary or higher level, for specialized assistance, as well as teachers of regular education trained to integrate these students in common classes; IV - special education for work, aiming at their effective integration in life in society, including adequate conditions for those who do not reveal their ability to enter competitive work, through the articulation with official agencies, as well as for those who have a superior skill in the artistic, intellectual or psychomotor areas; V - equal access to the benefits of supplementary social programs available for the respective level of regular education (emphasis added) [...] [8].

Article 60 deals with the characterization of private, specialized institutions, with an exclusive role in special education to support the government in assisting people with disabilities.

[...] Art. 60. The normative agencies of the education systems will establish criteria for the characterization of private, non-profit institutions, specialized and ex-

clusively acting in special education, for the purposes of technical and financial support by the Public Power. Single paragraph. The public authorities will adopt, as a preferable alternative, the expansion of the service to students with disabilities, global development disorders and high skills or giftedness in the regular public school system, regardless of support for the institutions provided for in this article. (Wording of Law n. 12,796, of 2013) [...] [8].

In Brazil, there is also a National Education Plan (PNE), Law n. 13,005, of 2014, whose goals are:

[...] Art. 2 The PNE guidelines are: I - eradicating illiteracy; II - universal school attendance; III - overcoming educational inequalities, with an emphasis on promoting citizenship and eradicating all forms of discrimination; IV - improving the quality of education; V - training for work and citizenship, with an emphasis on the moral and ethical values on which society is founded; VI - promoting the principle of democratic management of public education; VII - humanistic, scientific, cultural and technological promotion in the country; VIII - establishment of a target for applying public resources in education as a proportion of the Gross Domestic Product - GDP, which ensures meeting the expansion needs, with a standard of quality and equity; IX - valuing education professionals; X - promoting the principles of respect for human rights, diversity and socio-environmental sustainability [...] [5].

PNE promotes research to detail the profiles of the educational population from 4 to 17 years of age. The aim is to help the government to verify that the aforementioned goals are met.

People with disabilities in general are supported by Law n. 13,146, 2015, Brazilian Law for the Inclusion of Persons with Disabilities (LBI). This law deals with the right to equal opportunities for people with disabilities and points out that they will not suffer any kind of discrimination [6].

2.4 Pedagogic Practices and the Down syndrome

In order to deal with pedagogical practices aimed at children with Down syndrome, it is necessary to consider that the inclusion of these children in the school environment is a process that goes far beyond “just placing” the child in the classroom. For the child to remain at school, it is essential that the school has the necessary infrastructural adaptations and technical and pedagogical support for developing the teaching-learning process. For the success of the teaching-learning process to be achieved, the school and the family must work together.

The inclusive system emerged for generating integration in detriment of the segregation of people with disabilities. At school, teachers play a highly relevant role within the classroom. They have to see beyond appearances, seeking professional improvement and believing in the potential of children with Down syndrome.

Children with Down syndrome can be integrated into the school environment and can be socially adapted to other children. The entire integration process of the child with Down syndrome depends on the psychological factors related to the student's behavior. They also depend on their degree of psychomotor development, their cognitive development stage. Swiss psychologist Jean Piaget divided cognitive development into four stages: Sensorimotor, Preoperational, Concrete operational and Formal operational [17].

The first stage defined by Piaget, the Sensorimotor, explains the complexity of sensory and motor capabilities in the first months of life.

[...] This stage involves increments in the number and complexity of sensory (input) and motor (output) capacities during childhood - from approximately birth to about 18-24 months of age [...] babies gain conscious control and intention on their motor actions [...] their thoughts are concentrated only on sensory perceptions and motor behaviors [...] Piaget believed that the pattern of progressive capacity to form internal mental representations continues throughout childhood [17].

Children with Down syndrome in this age group do not have this stage well developed, so they have some motor difficulties. The second stage defined by Piaget, Preoperational, shows the child beginning to actively develop internal mental representations, reaching verbal communication.

[...] In the preoperational stage, from the age of approximately 1 1/2 or 2 years to about 6 or 7 years, the child begins to actively develop the internal mental representations, which began at the end of the sensorimotor stage. [...] According to Piaget, the appearance of representative thought, during the preoperative stage, opens the way for the subsequent development of logical thinking, during the stage of concrete operations. With representative thought, verbal communication arrives. [...] Many changes in development occur during this stage. The intentional and active experimentation of children with language and with objects in their environments results in huge additions, in conceptual and linguistic development.[...] [17].

In this age group, children with Down syndrome have some language difficulties. The third stage, Concrete operational, considers that children not only have ideas and memories of objects, but can also perform mental operations.

[...] approximately from 7 or 8 years old to 11 or 12 years old, children become able to mentally manipulate the internal representations they formed, during the preoperational period. In other words, they now not only have ideas and memories of objects, but can also perform mental operations on those ideas and memories. However, they can do so only with concrete objects (for example, ideas and memories of cars, food, toys, and other tangible things) - hence the name "concrete operations". [...]. The final stage of cognitive development, according to Piaget, involves

overcoming such concrete operations and applying the same principles to abstract concepts. [...] [17].

Low intellectual and behavioral development is observed in this age group for children with Down syndrome. In the fourth and stage, Formal Operational, children are able to create mental operations and symbols that may not have concrete or physical forms; in addition, they begin to understand some things that they themselves had not experienced directly, and begin to be able to see the perspective of others.

[...] approximately from 11 or 12 years of age onwards, it involves mental operations with abstractions and symbols that may not have concrete or physical forms. Furthermore, children begin to understand some things that they themselves have not experienced directly. During the stage of concrete operations, they begin to be able to see the others' perspective, if the alternative perspective can be manipulated concretely. [...] In addition, at the stage of formal operations, people intentionally seek to create a systematic mental representation of the situations they face. [...] [17].

Due to their lower intellectual development, in this age group, children with Down syndrome do not have this stage well developed.

Several authors deal with the teacher's pedagogical practices in the classroom, Werneck [19], Stratford [16], Brazil [1] among others. Nonetheless, all of them state that pedagogical practices should be aimed at integrating students, encouraging group work, stimulating cooperation practices, developing empathy.

In Brazil, the Ministry of Education has a program called Continued Education for Teachers in Special Education (Formação Continuada de Professores na Educação Especial). This program promotes teacher training to deal with students who have the syndrome. Activities can be performed in person or remotely and, among the various stages of the program, teachers should learn new classroom practices and choose teaching materials to help the child's cognitive development [20].

3. Methodology

Scientific research methodology refers to the approach to the study carried out, as well as to the systematic procedures chosen to obtain the description and explanation of phenomena. According to Gil [4], the choice of a method will depend on the characteristic of the research object; available material resources; the level of comprehensiveness of the study; and the researcher's interest. Thus, the focus of this work was the observation in the classroom of the cognitive development of a student with Down syndrome after the application of pedagogical activities directed to him.

The chosen subjects were Mathematics and Portuguese and the period, the 6th year of elementary school II. The student was part of regular students of a public school, based in the State São Paulo, Brazil. For ethical reasons, the name of the

school and the name of the student participating in the research will be omitted. The method was classified as a case study. In this type of method, specific cases or small groups are studied, aiming to understand how certain facts occur. It is based on the principle that the study of a case in depth can be representative of several others or of all similar cases. To this end, a bibliographic research was initially carried out to find out about the different scientific contributions available on the given topic [10]. For observing the Down syndrome child's intellectual development, an exploratory research was carried out. This is used with a little-known problem, the hypotheses of which are not yet clear, which requires greater involvement of the researcher with the research object, with the purpose of seeking information about it and, thus, being able to delineate it better and make it clearer. Not only was the teaching/learning performance evaluated but also the classroom behavior of the child with Down syndrome. The research was conducted with the aid of filming, i.e., for not interfering with the students' behavior and for not hindering the interpretation of written activities. For observation, the development was classified based on the stages of cognitive development defined by Piaget. The data collected through exploratory research was tabulated and allowed observing some trends.

4. Results

Assistance in early childhood education must comply with municipal, state and federal laws and regulations, such as the Child and Adolescent Statute (Estatuto da Criança e do Adolescente, ECA), the National Curriculum Guidelines for Early Childhood Education (Diretrizes Curriculares Nacionais para Educação Infantil), the Municipal Law (Lei Orgânica Municipal), besides the requirements related to Civil Construction and the Health Code. In this work, the cognitive development of a child with Down syndrome was

studied based on the pedagogical practices developed with Portuguese and Mathematics subjects.

The pedagogical proposal for this study was elaborated taking into account the context and culture in which the child was already inserted, that is, according to his level of cognitive development. The child was 15 years old and was in the 6th year of elementary school II. The pedagogical proposal was developed on the basis of National Curriculum for Early Childhood Education (Ministry of Education, 2010), which aimed to ensure to the child full pedagogical conditions. That means to provide conditions and resources for the child to make use of his civil human and social rights, to enable not only coexistence between children and adults but also the expansion of knowledge, which should be of different natures. Furthermore, it should promote equal educational opportunities among children, build new forms of sociability and subjectivity, committed to playfulness, democracy, the sustainability of the planet. It should eventually break the bias in relationships regarding age, socioeconomic, ethnic, racial or gender condition, besides regional, linguistic and religious issues.

The case study school supplies elementary school II, in face-to-face form and daily period. Classes are divided into: physical education, arts, Portuguese, science, geography, history, Mathematics. The teaching methodology applied to this case involved daily playful and pedagogical activities, which contribute to the integral development and training of the student. In addition to the material offered by the State, a handout was made considering the relationship between daily facts experienced by the student and the content to be addressed. Figure 1 shows some parts of the workbook used in the Portuguese discipline.



Figure 1: Part of the material for the Portuguese discipline

Source: the author

In the material developed, there was a series of exercises in which the child had to correlate columns with terms placed on one side and figures on the other, i.e., always stimulating the child's memory. Other forms of activities were also employed, such as exercises completing sentences, crosswords, completing pictures, coloring activities, cutting and pasting activities, among others. Figure 2 shows some parts of the handout used in the Mathematics discipline.

According to the criteria presented by Piaget, the child in question had already gone through the sensorimotor stage, a

period in which the children begin to have conscious and intentional control over their motor actions, and was in the preoperational stage, a period in which the children develop their mental representations, logical thinking, conceptual and linguistic development. Thus, the activities developed were intended to help the child relate the content of the syllabus to facts, events experienced in his daily life. One of the activities most used by the child was to buy items in the canteen. The child started by adding up the money bills to foresee what he would be able to buy in the canteen. Sharing fruit and candies with colleagues was also a milestone in the

child's daily life. The development of children's stories and onomatopoeia in comic books also marked the child's

linguistic and written abilities.

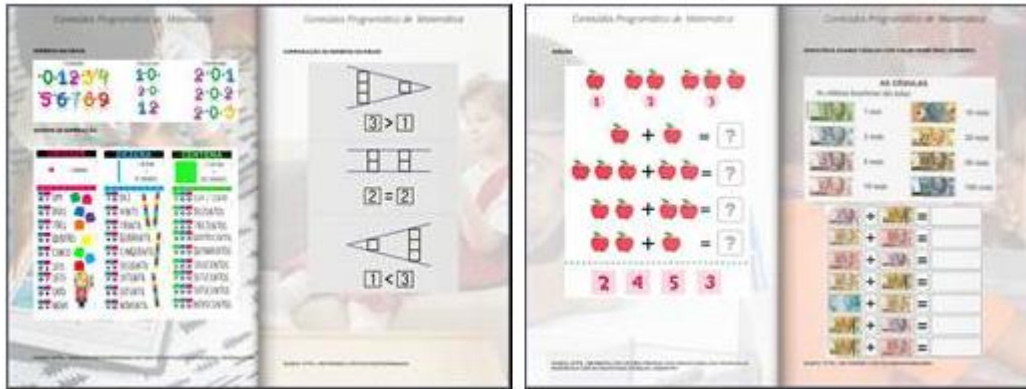


Figure 2: Part of the material for the Mathematics discipline

Source: the author

5. Final Considerations

We studied the cognitive development of a 15-year old child with Down syndrome attending the 6th grade of elementary school II, in a public state school in the State of São Paulo (Brazil). A study case was used, based on bibliographical and exploratory research, using pedagogical practices focused on the Portuguese and Mathematics disciplines.

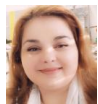
Based on Piaget's studies, it was observed that pedagogical practices supported by inclusion should be a continuous and constant, interactive and integrative process. In the present case study, the integration and interaction among children in the classroom helped the cognitive and motor development of the child with Down syndrome. This also served as an incentive for the child to remain at school.

Considering the cognitive stages defined by Piaget, although the child with Down syndrome was already 15 years old and had already gone through the sensor motor stage, he was still in the preoperational stage, i.e., he was developing his mental representations, his logical thinking and, due to the activities developed, was showing enormous improvements in his conceptual and linguistic development. The activities helped the child to relate the disciplines content to his daily practices. Both the parents and the child felt part of the educational process due to the focus of these pedagogical practices.

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