(RE)SIGNIFICATION IN THE ASSESSMENT PROCESS OF YOUNG AND ADULT SUBJECTS WITH INTELLECTUAL DISABILITY¹

(Re) Significações no Processo de Avaliação do Sujeito Jovem e Adulto COM DEFICIÊNCIA ÎNTELECTUAL²

> Elisiane Perufo ALLES³ Sabrina Fernandes de CASTRO⁴ Eliana da Costa Pereira MENEZES⁵ Cláudia Adriane Graeff DICKEL6

ABSTRACT: This paper aims at problematizing the assessment process of subjects with Intellectual Disabilities (ID), and its effects in terms of definition, classification and diagnoses produced on ID. The proposed discussions stem from an analysis of the different approaches presented in the manuals of the American Association for Intellectual and Developmental Disability (AAIDD, 2010 and AAMR, 2006) and their (re)significations. We seek to put under tension the discourses used to define who the subjects with ID are; what characteristics constitute them; what behaviors characterize them; what learning potential they have and what supports they need in the educational context. In articulation with these analyzes, we present data produced in the project "The contributions of Rio Grande do Sul for the validation of the Support Intensity Scale - SIS, in Brazil". Based theoretically on the socio-anthropological discussions proposed by Lev S. Vygotsky, we consider the data as elements for the construction of an analysis that indicates the possibility (and necessity) to look at the ID from a perspective other than one that derives from IQ indicators, which are historically responsible for the delimitation of ID in levels of severity, whose development possibilities were previously indicated by clinical diagnoses.

KEYWORDS: Special Education. Intellectual Disability. Development. Support systems. Cultural practices.

RESUMO: Este artigo objetiva problematizar o processo de avaliação do sujeito com Deficiência Intelectual (DI) e seus efeitos em termos de definição, de classificação e de diagnósticos produzidos sobre a DI. As discussões propostas partem de uma análise referente às diferentes abordagens presentes nos manuais da Associação Americana de Deficiência Intelectual e de Desenvolvimento (AAIDD, 2010 e AAMR, 2006) e suas (re)significações. Procuramos colocar sob tensionamento discursos utilizados para delimitar quem são os sujeitos com DI; que características os constituem; que comportamentos os caracterizam; que potencialidades em termos de aprendizagens eles possuem e que apoios necessitam no contexto educacional. Em articulação com tais análises, apresentamos os dados produzidos no projeto "As contribuições do Rio Grande do Sul para a validação da Escala de Intensidade de Suporte - SIS no Brasil". Amparadas teoricamente nas discussões socioantropológicas propostas por Lev S. Vigotski, tomamos tais dados como elementos para a construção de uma análise que nos possibilite indicar que faz-se possível (e necessário) um olhar para a DI que não parta dos indicadores de QI, historicamente responsável pela delimitação da DI em níveis de severidade, cujas possibilidades de desenvolvimento passaram a ser antecipadamente indicadas pelos diagnósticos clínicos. Nesse sentido, entendemos que, ao deslocarmos a ênfase do diagnóstico do QI para os sistemas de apoio, passamos a perceber um sujeito produzido nas práticas culturais, cujas possibilidades de desenvolvimento e aprendizagem não são exclusivamente determinadas pelos seus aspectos biológicos, mas, sim e principalmente, pelas interações sociais que ele estabelece ao longo de seu desenvolvimento.

PALAVRAS-CHAVE: Educação Especial. Deficiência Intelectual. Desenvolvimento. Sistemas de Apoio. Práticas Culturais.

¹ http://dx.doi.org/10.1590/s1413-65382519000300002

² Project funded with scholarships by the Fundo de Incentivo à Pesquisa (FIPE) and the Programa de Licenciaturas (PROLICEN) of the Federal University of Santa Maria (UFSM).

³ Master's Degree student in Education from the Federal University of Paraná. Graduated in Pedagogy and Special Education from the Federal University of Santa Maria, Rio Grande do Sul, Brazil. alles.elisiane@gmail.com. Santa Maria/Rio Grande do Sul/Brazil. ORCID: https://orcid.org/0000-0003-0178-7442

⁴ Adjunct Professor, Department of Special Education, Education Center, Federal University of Santa Maria. sabrinafcastro@ gmail.com. Santa Maria/Rio Grande do Sul/Brazil. ORCID: https://orcid.org/0000-0002-2204-6136

⁵ Adjunct Professor, Department of Special Education, Education Center, Federal University of Santa Maria. elianacpm@hotmail. com. Santa Maria/Rio Grande do Sul/Brazil. ORCID: https://orcid.org/0000-0002-5908-0039

⁶ Teacher of the private school network, graduated in Pedagogy and Special Education from the Federal University of Santa Maria. kaudickel@gmail.com. Santa Maria/Rio Grande do Sul/Brazil. ORCID: https://orcid.org/0000-0002-7200-3927

1 Initial locations on theoretical-methodological choices

This work is the result of a research that has been developed in Rio Grande do Sul / Brazil since May 2014, based on a partnership between researchers from the Federal University of Santa Maria (UFSM) and the Federal University of Sao Carlos (UFSCar). The project "Adaptation and Validation of the Support Intensity Scale - SIS for Brazil" is coordinated by PhD Professor Maria Amélia Almeida, linked to UFSCar. At the regional level, the project "The Contributions of Rio Grande do Sul for the validation of the Support Intensity Scale - SIS in Brazil" is being developed with UFSM.

The Supports Intensity Scale (SIS) has the purpose of measuring the intensity of the need for support that a person with intellectual disability needs to relate, live and coexist in accordance with the demands of today's society (Almeida, 2013). Thus, Scale is an evaluation tool that focuses on the level of support that the subject needs, contributing to the development of individualized educational plans focused on the areas that the subject with intellectual disability (ID) needs more support.

The definition of support was proposed by the American Association for Intellectual and Developmental Disability [AAIDD] (2010, p. 109) as the set of "resources and strategies that aim to promote the development, education, interests and personal well-being of a person and enhance individual functioning". The need for support refers to "the pattern and intensity of the supports necessary for a person to participate in activities linked with normative human functioning". Thus, four levels of support are presented: **Intermittent**, provided according to the need of the subject and for short periods of time throughout life; *Limited*, characterized by consistency over time in a specific environment for a limited time; *Broad*, it refers to regular support in some environments and not characterized by limited time; and, lastly, *Permanent*, offered with high intensity, long duration or throughout life and often involves several professionals and different care environments (AAIDD, 2010; Almeida, 2004; Zutião, 2016).

SIS consists of three sections (Thompson et al., 2004): Section 1 - Support Need Scale, consisting of 49 activities that are grouped into six support subscales; Section 2 - supplementary subscale, consists of eight items related to the Protection and Defense activity; and Section 3 - Exceptional Medical and Behavioral Support Needs, which includes 15 medical conditions and 13 behavioral problems that typically require higher levels of support regardless of support needs relative to other areas of life activities.

It should be noted that Section 1 totals are the result of the frequency, daily time and type of support that the subject needs to perform the activities presented in each subscale item. This section is divided into six subscales: Daily Life (Part A); Community Life (Part B); Lifelong Learning (Part C); Employment (Part D); Health and Safety (Part E); and Social (Part F).

Thus, this instrument aims to assess the levels of support needed in the day-to-day activities of youth and adults with intellectual disabilities, covering the following areas: activities of daily living; community life activities; lifelong learning activities; employment activities; health and safety activities; social activities; and protection and defense activities.

A total of 66 young people and/or adults with intellectual disabilities and/or their legal guardians or working professionals, who assisted them for more than three months⁷, participated in the Rio Grande do Sul survey. In order to participate in the research, one of the selection criteria is the subject to have clinical diagnosis. The scale was applied with the following percentages of participants according to the intellectual level: 42.4% of the scales were applied with youth and adults with mild intellectual disabilities; 36.4% with moderate intellectual disability; 7.6% with severe intellectual disability; and 13.6% for young people and adults with profound intellectual disabilities.

The project consisted of six stages: For data collection, three were followed, namely: Stage 1. Initial contact with the entities; Stage 2. Schedule of visits in the participating entities; Stage 3. Application of the Support Intensity Scale (SIS - Brazil).

The analysis of the data followed two more stages: Stage 4. Typing the collected data and sending the data to the national project team; and Stage 5. Procedure for the analysis of local data according to the instructions of the SIS Scale; in this way, the data were inserted into the SPSS Statistical Software and statistical tests (such as Pearson's correlation) were performed to show the validity of the scale.

After collecting and analyzing the data, an extra stage was added to the project: Stage 6. Producing the individual report of each participant with the SIS result and some suggestions for elaborating the Individualized Educational Planning - IEP (this report was delivered to the participant institutions).

Fragments of this analysis produced on the data collected in the project, specifically those collected by UFSM researchers, constitute the continuity of this text, whose objective is to problematize the evaluation process of the subject with ID and its effects in terms of definition, classification and diagnosis. In order to make this problematization feasible, we focused the analysis on the questions related to item C of the Scale - Lifelong Learning Activities. Item C is composed of nine sub-items, which are: C1 - Interacting with others in learning activities; C2 - Participating in decisions about his/her own education and training; C3 - Learning and using strategies for problem solving; C4 - Using technology to learn; C5 - Accessing educational and training contexts; C6 - Learning functional academic skills (reading signs, counting change, etc.); C7 - Learning health skills and physical activities; C8 - Learning self-determination skills; and C9 - Learning self-management strategies.

The choice of item C specifically occurred because we understand that the evaluation proposal presented by SIS, centered on the current definition of ID proposed by AAIDD (2010), by shifting the focus of the evaluation process and diagnosis of severity levels and reallocating it in support levels, produces other forms of ID classification and can produce significant effects on the developmental and learning processes of the subjects, as we will discuss next in this text.

⁷We point out that the national project was approved by the Research Ethics Committee of the Federal University of São Carlos (approved by Opinion No. 462.550, of December 10, 2013). In addition, prior to the start of data collection, the participants signed the Forms according to the level of participation (namely, the forms used in the research are: Institutional Free Informed Consent Forms, Informed Consent Forms to Participants, Informed Consent to the legal Responsibility of the youth and adults with intellectual disability and the Form of Assent for the person with a disability).

2 Intellectual disability: from the first definitions and classifications to the current diagnosis process

In the current educational context, guided by inclusive principles, the presence of students with disabilities in regular schools is a frequent reality. Produced historically from the alliance of medical knowledge and pedagogical knowledge, subjects with intellectual disability still carry limiting stigmas regarding their possibilities and potential for learning and development. The meaning of intellectual disability, today legitimized by health in alliance with the school, results from a long historical process operated on (scholarized) childhood in search of identification and definition of the abnormality. These issues were discussed here from the interlocution between the current conceptual proposition of intellectual disability and the theoretical underpinnings of the vygotskian perspective. It seems to us that the effects of interlocution between these instances can be significantly productive for the (re)signification of the schooling processes offered to the students in question and especially potent for overcoming practices developed even today under a clinical bias, historically produced in a limiting way, which undoubtedly needs to be overcome.

When we begin the analyzes proposed here with the discussion of concepts such as norm/normality/normalization and school/schooling, we want to problematize the alliance between medical knowledge and school practices, established in a privileged way from the beginning of the 20th century, trying to discuss its effects in the constitution of the abnormal child. This discussion is especially prevalent because it is precisely the identification of the abnormal child, which occurs by the production of psychiatry knowledge about behaviors initially classified as imbecility, dementia, alienation, stupidity, that we saw in the 19th century to emerge pedagogical theories aimed at the schooling of those considered "idiots", today "people with intellectual disability".

As Silva et al. (2007) point out, in order to better understand the historical emergence of the abnormal child, it is necessary to dismantle the past in order to seek, in idiocy, the lines of construction that gave birth to it. In this sense, the 19th century is taken as a milestone in the identification of the abnormal child, from the differentiation of what would constitute certain mental diseases, present in the subjects with preserved intellectual development, and what would constitute an incapacity for intellectual development. According to the aforementioned authors, prior to this definition, imbecility, stupidity, and dementia were pictures of madness, which, in turn, was defined from the concept of delusion. Imbecility would be characterized by a state of maximum delirium, producing a subject incapable of conceiving the truth. In this context, idiocy was described as a total and absolute form of madness.

In opposition to this definition, in the 19th century, we saw the production of the separation between the subjects who belonged to the condition of the sick, and, therefore, they were subject to treatment and cure, and those classified as general monstrosities, identification, the status of incurability and incapacity that result to the present day in stigmatizing and limiting representations on the subject with intellectual disability.

Idiocy is not a disease, but a condition in which the intellectual faculties are never manifested; or have never been developed sufficiently to enable the idiot to acquire such an amount of knowledge, as persons of his own age, and placed in similar circumstances with himself, are capable of receiving. Idiocy commences with life, or at that age which precedes the development of the intellectual and

affective faculties; which are, from the first, what they are doomed to be, during the whole period of existence. Everything about the idiot betrays an organization imperfect, or arrested in progress of development. We can conceive of no possibility of changing this state. (Esquirol, 1845, p. 446).

This notion of idiocy coined by Esquirol indicates as an important element for the diagnosis, the concept of development. "Idiocy would be an absence of development, in which the intellectual faculties would never manifest or could not develop, being characterized by a stable form and without possibilities of evolution" (Silva, Pires, Scisleski, & Hartmann, 2010, p. 404). We then have the concept of development delimiting what would characterize madness, a mental illness - understood as a developmental problem - and what would characterize idiocy (nowadays intellectual disability) - understood by the absence of development.

A man in a state of dementia is deprived of advantages which he formerly enjoyed; he was a rich man, who has become poor. The idiot, on the contrary, has always been in a state of want and misery. The condition of a man in a state of dementia may change; that of the idiot is ever the same. The latter retains many of the features of infancy; while the former preserves much of the physiognomy of the adult man. In the case of both, the sensations are null, or nearly so. The man who is in a state of dementia, however, indicates in his organization, and even in his intelligence, something of his past perfection; while the idiot is, what he always was; and is all that he can be, so long as his organizations remains unchanged. (Esquirol, 1845, p. 447).

Thus, Esquirol points to the first clear differentiation between idiocy and dementia (and its derivatives), from which madness can be diagnosed as the loss of reason and idiocy as absence from childhood as a result of problems in childhood or of prenatal or perinatal conditions (Pessotti, 2012). Here it is possible to perceive signs of the concept of intellectual disability that persist until the present day: the idea of organic origin, its incurability and its appearance even in childhood.

From Silva et al. (2010), we can point to Édouard Séguin, from the 19th century, as responsible for producing a new understanding of the idiocy concept, taking the concept of development, coined by Esquirol, as the central element for this definition. According to Séguin, the idiot is not someone whose development does not manifest, but someone whose development has been interrupted. The development in Séguin is an achievement of every individual, it is like a rule of chronological succession with an ideal arrival moment, following a temporal linearity (Silva et al., 2010). In this understanding of development, we can also find the emergence of normality patterns and their correlated meanings of abnormality. If there is a previous development path, delimited by a temporal linearity, whose ideal destination of arrival (which would occur in adulthood) is defined for all subjects, and if there are subjects who do not achieve this ideal of development, precisely because their linearity is interrupted, then we have the indication of those that do not fit an established normative pattern. In this case, the understanding (and production) of idiocy emerges as a deviant state of a norm (Silva et al., 2010). And so it goes on to define that the idiot is, in fact, an abnormal.

Once their incurability has been decreed, it remains for specialists to indicate ways of maintaining these subjects in conditions of life in a social collectivity. At this point, the alliance with the school, as we have already announced, points to one of the most (if not more) potent strategy of normalization. Then, the talk about the possibilities of educability of the idiot starts.

Since, to the medical instruments there was nothing left to do to improve the conditions of the idiots, their discussions about the possibility of improving them through education had started (SILVA et al., 2007).

Silva et al. (2010), when analyzed discourses produced by psychiatry in the country in the middle of the 20th century, indicated that, in that context, it was possible to perceive the necessary alliance instituted by the knowledge of psychiatry (responsible for identifying the abnormal via clinical diagnoses) and school practices (responsible for the indication of possible abnormalities, referred for evaluation and clinical identification). According to Silva et al. (2010), the issue of education becomes crucial, because school can function as the first prophylactic instance before a formal referral to mental health services. It is perceived, then, as stated by the authors, a strategy of the psychiatric power to expand beyond the walls of the hospital. Thus, the psychiatrist requires help from the educator to detect which students are potentially capable of having an abnormality, and it is up to the professional to perform the tests that will reveal the truth about the student (Silva et al., 2010).

Thus we have the alliance between medical knowledge and pedagogical knowledge, producing and legitimizing those who need specialized care, in order to achieve rehabilitation and standardization. Although we have evolved much in conceptual terms in function of the scientific knowledge produced, we understand that it is in the first classifications of the childhood abnormalities at the end of the 19th century that the conditions of possibility for the invention, throughout the 20th century, of conceptions diagnosis of intellectual disability. Such conceptions have determined what is offered to these subjects in terms of schooling up to the present day.

According to Alles (2016), works and research with pedagogical focus made possible the resignification of intellectual disability, from the attempt to abandon approaches centered on purely physiological and pathological aspects. To the author, it was the 20th century marked by research whose objective was to search for a conceptualization of the definition and functional characterization of intellectual disability.

In this search for definition and conceptualization, Alles (2016) highlights the manuals published by the American Association of Mental Retardation (AAMR), founded in 1876, having as its first president Séguin, and currently denominated American Association of Intellectual and Developmental Disability (AAIDD). The amendment of the term "mental disability" to "intellectual disability" occurred after the "International Conference on Intellectual Disability" held in 2001 in Canada, on the recommendation of the International Association for the Scientific Study of Intellectual Disabilities (IASSID). Such terminology - intellectual disability - is now officially used, including in Brazil, to refer to the previously classified subject as mentally disabled. It should be pointed out that this is a terminological change that does not alter the conceptual understanding of such a disability. However, as pointed out by Pletsch and Glat (2012), it is not simply the exchange of an expression by a less stigmatizing synonym. This change in terminology - the result of a broad debate in international scientific circles - represents a new paradigm in terms of defining the construct of intellectual disability, in process since the definition and classification presented by the AAMR in 2002.

According to Alles (2016), the manuals and their revisions were published in the years 1908, 1937, 1941, 1959, 1961, 1973, 1983, 1992, 2002, being the current definition of 2010. It is considered that the manuals produced by the Association have occupied central place, as much in the diagnostic definition of the intellectual disability as in the proposal of public policies destined to the schooling and professionalization of the subjects. The theoretical model presented in the tenth edition and used in the eleventh edition, presented in 2010, has an ecological focus in which the individual functioning is the result of the interaction of supports with the dimensions of Intellectual Skills; Adaptive Behavior; Participation; Health and Context. It should be noted that the difference found in the theoretical models of 2002 and 2010 is the inversion of the dimensions of health and participation, as well as in the tenth edition, the participation dimension (third dimension) also referred to interactions and social roles.

We understand that it is possible to visualize here the proposition of a theoretical model whose focus falls on a conception of subject that is in interaction with the social environment in its most diverse dimensions, which brings the concepts of the Association closer to Vygotskian theorization. By indicating that it is necessary to analyze the subject with ID not only for their intellectual factors, but also for their possibilities of participation in social life through evaluation of the supports received in their development process, AAIDD points to a less clinical conceptualization of ID, focused not exclusively in the subject, but mainly in a context that needs to be analyzed, evaluated and (re)organized when necessary.

In this context, we can verify in the 2010 edition that the proposed evaluation structure is composed of three functions: diagnosis, classification and planning of the supports, which present the appropriate instruments to be used in order to reach the evaluation objectives. Therefore, it is necessary to respect three criteria in the evaluation structure: (a) the evaluation instruments and process must correspond to the objective of the evaluation; (b) the results of the evaluation should be as valid as possible, and (c) the results should be both useful and purposefully applied (AAIDD, 2010).

Thus, with regard to diagnosis, it needs to be presented as a specific purpose the presence or absence of intellectual disability and establish eligibility for services, benefits and legal protections. In this way, the AAIDD presents as examples of instruments and methods for evaluating the diagnosis: Intelligence tests; Scales of adaptive behavior; Documented age of onset; Development measures; Social History and Educational Records (AAIDD, 2010).

Considering the inexistence of adaptive assessment instruments validated in Brazil, we can infer that the diagnosis of ID has been centered on clinical judgment, based on international guidelines for classification of diseases such as Diagnostic and Statistical Manual of Mental Disorders - DSM-5 (American Psychiatric Association [APA], 2014) and the *ICD-10 Classification of Mental and Behavioural Disorders* (World Health Organization [WHO], 1992).

In the DSM-5 it is presented a terminology of intellectual disability (intellectual development disorder) based on the concept proposed by AAIDD (2010), based on three criteria: deficits in intellectual functions, in adaptive functions and originating in the phase of development. The difference between the two guidelines is that the concept presented by AAIDD focuses on a multidimensional model focused on the support of the different areas of the subject's development (intellectual abilities, adaptive behavior, health, participation and

context), which are defined from the adaptive functioning of the subject, while DSM-5 still places the emphasis on intelligence quotient (IQ).

In this sense, we understand that the current conceptualization of ID proposed by the AAIDD represents an advance in diagnosis for the subject, since it suggests that the diagnosis of intellectual deficiency as well as the severity levels should be defined based on the adaptive functioning and not on IQ scores, since it is the adaptive functioning that determines the level of support that the subject with ID needs. What we want to point out here is that the (re) significations proposed by the AAIDD indicate that it is possible to look at the ID that does not depart from factors historically responsible for the delimitation of ID in levels of severity, whose development possibilities were previously indicated by the clinical diagnoses. In this respect, we understand that by moving the emphasis from the diagnosis of IQ to the support systems, we come to perceive a subject with ID produced in social practices, whose developmental and learning possibilities are not exclusively determined by their biological aspects, but rather, and primarily, by the interactions that it establishes throughout its development.

According to Vygotsky (2011), the psychology of the abnormal child was constructed, in general, by the method of subtraction of the functions lost in relation to the psychology of the normal child. In substitution for this limiting understanding, the author advocates considering not only the difficulties of development due to the disability, but also the need to search for alternative ways of development presented to the body by the disability itself. The author's thesis then takes the disability as a stimulus for the search of other forms of interaction of the subject with the cultural environment that could compensate the disability and lead the whole system of broken equilibrium to a new order.

Here we have culture⁸ as the center of the process of the constitution of man (whether or not he has a disability) and of his more complex and superior forms of thinking. As stated by Vygotsky (2011), the development of higher psychic functions is possible only through the paths of cultural development, be it through the domain of the external means of culture (speech, writing, arithmetic), or through the internal improvement of one's own psychic functions (elaboration of voluntary attention, logical memory, abstract thinking, the formation of concepts, the development of volition, and so on). Research shows that the abnormal child, in general, has delays in precisely this respect. Such development does not depend on organic deficiency. That is why the history of the child's cultural development makes it possible to propose the following thesis, according to the author: "Cultural development is the main area in which for compensation of deficiency when further organic development is impossible; in this respect, the path of cultural development is unlimited" (Vygotsky, 1993, p. 169, emphasis added).

As teachers who work in the education of Special Education teachers who will work with students who have ID, we understand that such a conception (centered in the social environment) seems to give us more possibilities of pedagogical activity, while it requires the school to exercise permanently the attention to the relations that this student establishes with classmates, teachers, family and other subjects with whom he coexists. In this sense, it is

⁸ According to Vygotsky (2011), there is a relation of interdependence between social and cultural life. To the author, everything that is cultural is social. Culture, which consists of signs and tools, is a product of the social activity of men, so that men, insofar as they develop in a social environment, produce culture (modifying it) and are a product of it.

important that the practices developed in the context of the inclusive school are not limited to the actions of Special Education via the student's assistance in the space of the multifunctional resource room. If the subject is constituted by the results of the interactions that establishes, it is determinant that such relations are the focus of pedagogical planning, which, in turn, presupposes the production of other forms of understanding of ID in the context of the school.

3 THE PRODUCTION OF OTHER FORMS OF UNDERSTANDING THE INTELLECTUAL DISABILITY AND ITS POSSIBLE EFFECTS IN THE PROCESSES OF LEARNING OF THE INDIVIDUALS

As already indicated, from the use of the AAIDD proposition (2010), ID becomes understood by personal and environmental factors present in the life of the subjects. Thus, it is possible to analyze that there is an intentionality to blur the diagnosis of the subject with ID of his/her intellectual capacity, changing it to the level of support that he/she will need when performing social activities. In this context, the SIS Scale (Thompson et al., 2004) is proposed as an evaluation tool whose objective, as already announced, is to measure the intensity of support that a person with intellectual disability needs to live, coexist and relate to society.

Thus, when looking at the project data, which indicate issues related to item C of the Scale - Lifelong learning activities, comprised of tasks necessary to achieve success in lifelong learning situations, including in this item vocational training, we find the means presented in Figure 1 below.

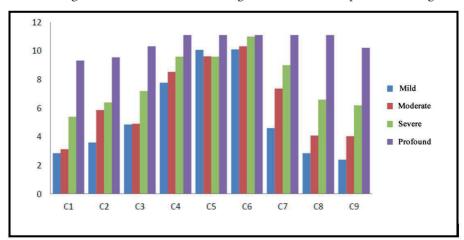


Figure 1. Averages by questions and level. Source: Data obtained from the project "Contributions from Rio Grande do Sul to the Validation of the Support Intensity Scale - SIS in Brazil", 2014.

The results related to lifelong learning⁹ activities point, as can be seen in the graph of Figure 1, to a certain leveling of the need for support for all subjects in items C5 (Access

⁹ For didactical purposes, we remind here the detail of item C of the Scale - Lifelong Learning Activities, already presented at the beginning of this text: C1 - Interacting with other people in learning activities; C2 - Participating in decisions about his/her own education and training; C3 - Learning and using strategies for problem solving; C4 - Using technology to learn; C5 - Accessing educational and training contexts; C6 - Accessing educational and training contexts; C7 - Learning health skills and physical activities; C8 - Learning self-determination skills; and C9 - Learning self-management strategies.

educational and training contexts) and C6 (Learning academic and functional competencies). These are the items in which subjects need more support, both those classified in the mild and moderate level of ID, and those with severe and profound level. Also, we can see that, in item C5, there is a slight inversion between the mild and moderate levels and a leveling between the moderate and the severe. These factors lead us to question the support given to these subjects, since the graph indicates that in relation to learning, more specifically access to educational and training contexts, and learning functional academic competences (such as reading signs, counting change, reading the time), the subjects surveyed did not present great differences in the need for support, even though they had different clinical diagnoses of ID according to severity levels.

According to the data collected, we can consider that 16 of the subjects who are aged between 31 and 41 years old, and also 30 subjects with ages between 20 and 30, started their schooling process in a period in which Special Education in Brazil began to organize its practices in the perspective of inclusive education, seeking to promote the development of the subject with disability through schooling in the common system of education. However, although they witnessed the beginning of this process in the country, these subjects ended up having educational experiences for a significant period of time in specialized institutions. This factor may have interfered in their development processes and thus have caused this greater need for support in activities such as learning functional academic skills and also access to educational contexts. In this sense, Figure 2 shows the subjects' schooling.

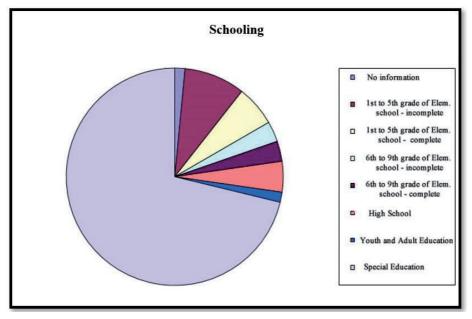


Figure 2. Schooling.
Source: Data obtained from the project "Contributions from Rio Grande do Sul to the Validation of the Support Intensity Scale - SIS in Brazil", 2014.

As Figure 2 shows, of the 66 subjects who participated in the study, 47 had only Special Education as a means of schooling. If we consider, as Vygotsky points out, that it is

because of experiences in formal schooling processes that subjects construct scientific concepts that, in turn, enable the development of increasingly complex psychological functions, we may infer that the schooling practices offered the subjects of the study in specific spaces of Special Education for long periods may have produced restricted possibilities of interaction of these subjects and the world that surrounds them. These interactions, by not allowing the development of scientific concepts, produce stagnation of the processes of meaning of the world from concepts that the author calls "everyday concepts". In this context, it is produced a subject with ID that operates in the world with limited autonomy in the development of academic and functional competencies and difficulty to enter and remain in educational and training spaces and, later, in the world of work.

To Beyer (2013), the history of Special Education shows us that special schools sought to develop activities using concrete and manual methodological resources, based on an overly therapeutic understanding of disability, focusing on the lack and impossibility of development, resulting in a stagnation in more elementary thinking processes. According to the author, the factor that deserves more attention regarding the exclusive process of schooling of people with disabilities in specific spaces of Special Education concerns the damage in interpsychological exchanges. Drawing from Vygotsky, the author stresses that schooling of children with disabilities in groups of "special" children, with a similar individual condition, would provoke a process of social limitation, since the interpsychological changes would be restricted to those made in the group of "equals" (Beyer, 2005, p. 2).

By taking culture and social interactions as sources of the development process, we assume the importance of coexistence between subjects who are at different stages of learning. It is through exchanges established in the social environment that subjects are presented to the challenges that serve as propellers for the construction of more complex forms of thinking. In this sense, it seems to us important to reflect on the forms of coexistence that the subjects who participated in the study could establish in their life histories.

As we advocate the importance of this reflection, it is that we visualize, in the conceptual proposition of ID of the AAIDD (2010), another possibility of constitution of the subjects. As we have seen, this proposition removes the focus of the subject and moves it to the context, from the indication of the possibility of identifying the necessary supports for each one in specific, that is, centered on the subject him/herself.

Once the necessary supports have been identified, the objective of the educational work is to offer such support so that the subjects can gradually stop needing them. We highlight, again, the potent interlocution between this understanding of ID and Vygotsky's theoretical perspective. According to Vygotsky (1997), development occurs through the relation and correlation between elemental structures (reflexes, automatic reactions, simple associations, among others) conditioned by biological determinants, and the structures that arise through interaction in culture, which are designated as higher psychological processes, from which the ability to form concepts is found (Pletsch, 2013). Thus, the process of conceptual formation is closely linked to the historical-cultural constitution of the human being and, in this logic, the author affirms that learning of concepts occurs even before the subject has contact with the school environment, since it occurs through interactions that are established with the world.

Considering this need to establish qualitative exchanges between the subjects, it may be possible to affirm that the space of the inclusive school, when effective such exchanges, can constitute as an important space for the development of subjects with disabilities. In this sense, the project of school inclusion would be effective starting from the expansion of the coexistence between interpersonal differences, in an area without prior established capacities, that would allow the psychosocial exchanges indispensable for the development of all the students (Beyer, 2005). According to the author, the major problem or major obstacle when thinking about children with disabilities is their frequent isolation, whether in the family, in school life, or in life in society. Isolation, in the Vygotskian view, is not only a social or ethical problem, but it has a very delicate psychosocial (more correctly to say, as stated by the author, psychological) facet. This vulnerability is due to the central Vygotskian premise of the need for socio-gene dynamics for healthy child development. The more intense and positive they are to psychosocial exchanges, the stronger the child development will be, being the reciprocal true, that is, the more debilitated these exchanges are, the more lacking the development will be (Beyer, 2005).

Thus, thinking about environments that provide the development of subjects with disabilities is to consider in an environment that not only provides the development of affective aspects but also cognitive and social aspects. When we look at the school from these principles, we begin to understand the teacher as a mediator who, when relating to the student in the process of school inclusion, takes into account the personal characteristics of each student, the specific forms of learning they present and the cultural and intellectual baggage they bring.

In this conception, the life histories of each are understood as necessary elements for the construction of individualized plans, proposed from the supports identified as necessary for these students to interact independently or with the least support possible in the society. Thus, in order to enable the student's learning and development, it is necessary to leave aside the pre-established diagnoses and start to think about the subject and the relationships established throughout life.

4 Final considerations: important aspects for discussion continuity

When we proposed this discussion, we aimed to problematize the evaluation process of the subject with ID and the effects in terms of definition, classification and diagnosis of the subject. From fragments of the analytical exercise developed in the context of the project "The contributions of Rio Grande do Sul for the validation of the Support Intensity Scale - SIS in Brazil", more specifically from the analysis carried out on the data collected about lifelong learning activities (part C of SIS), we tried to indicate how much the gaze destined to the subject, when based on an understanding of disability as lack or impossibility, can limit their conditions of learning and development.

From this perspective, we understand the limitations and significant need for support presented by the subjects of the study related to the issues of access to educational and training contexts and the achievement of academic and functional learning and skills. When we consider that 69.7% of the subjects in the study are older than 20 years, we point out that their schooling histories coincide with the emergence of policies of school inclusion in the country. However, the data indicate that even though they have experienced this context

of inclusive education policies, most have integrated their schooling processes exclusively into special teaching spaces.

Considering Vygotsky's studies, we look at the history of Special Education practices developed since its origin, based on a clinical conception of disability, as practices that can produce as effect subjects with limited autonomous living conditions. When assuming such a position, we do not intend to develop a simple defense of the inclusive school or devaluation of the Special Education spaces. What seems to us imperative is the possibility of highlighting the cultural character present in the development of the subjects that places the social interactions instead of being prominent in the processes of their learning and their development. From this point of view, we understand that, before we concern ourselves with indicating more adequate spaces for the processes of schooling, it is necessary to emphasize the possibility of evaluation and pedagogical planning based on the individual stories and the support systems that were or are necessary for the subjects.

By establishing an articulation between the concept of ID proposed by AAIDD (2010), whose focus is on the levels of support necessary for the conquest of an autonomous life and the Vygotskian theoretical perspective, we aim to highlight the power of this conceptualization for the production of other possibilities of interaction between the subject with ID, the school and society. Such interactions would not be predetermined (and limited) by clinical diagnoses and prognoses, determined by the level of IQ, but rather by the potential for development and learning that each subject makes and which determines a unique and peculiar way of being in the world. In this sense, we may perceive a subject produced in cultural practices, whose possibilities of development and learning are not exclusively determined by their biological aspects, but rather and mainly by the social interactions that he/she establishes throughout his/her development.

To conclude, we understand that by highlighting new possibilities for understanding ID, we can bring about modifications in the practices carried out by Special Education in the contexts of schooling of subjects with disabilities. Practices that (re)signify the action of the teacher of Special Education as an action directed to the interactions that are established between the students with ID and the other subjects in the school context. Such forms of signification may also bring about changes in the teacher's formative processes, since the proposition of forms of evaluation, diagnosis and conceptualization of ID focused on levels of support presupposes a teacher who understands the subject as a product of the complex inseparability between the organic aspects and social processes in learning and development, and that they effectively take these aspects into account when constructing their planning.

REFERENCES

Association of Intellectual and Developmental Disability. (2010). *Intellectual disability: definition, classification, and systems of supports* (11th ed.). The AAIDD Ad Hoc Committee on Terminology and Classification.

American Association on Mental Retardation. (2006). *Retardo mental: definição, classificação e sistema de apoio* (10th ed.). Porto Alegre: Artmed.

Alles, E. P. (2016). Escala de intensidade de apoio (SIS) como ferramenta de compreensão da definição de deficiência intelectual (Undergraduate thesis). Universidade Federal de Santa Maria, Santa Maria, Rio Grande do Sul, Brazil.

- Almeida, M. A. (2004). Apresentação e análise das definições de deficiência mental propostas pela AAMR Associação Americana de Retardo Mental de 1908 a 2002. *Revista de Educação*, Campinas, *16*, 33-48.
- Almeida, M. A. (2013). Adaptação e validação da Escala de Intensidade de Suporte SIS para o Brasil: uma contribuição para avaliação funcional de jovens e adultos com deficiência intelectual. Projeto submetido ao edital: MCTI/CNPq/MEC/CAPES Nº 43/2013. São Carlos.
- American Psychiatric Association. (2014). *DSM-5: manual diagnóstico e estatístico de transtornos mentais* (5th ed.). Porto Alegre: Artmed.
- Beyer, H. O. (2005). Por que Lev Vygotski quando se propõe uma educação inclusiva? *Revista Educação Especial*, 26, 1-4.
- Beyer, H. O. (2013). *Inclusão e avaliação na escola: de alunos com necessidades educacionais especiais*. Porto Alegre: Mediação.
- Pessotti, I. (2012). Deficiência Mental da superstição à ciência. Marília: ABPEE.
- Pletsch, M. D. (2013). A escolarização do aluno com deficiência intelectual... apesar do diagnóstico. In S. M. F. Meletti, & M. C. M. Kássar (Orgs.), *Escolarização de alunos com deficiência: desafios e possibilidades* (pp. 243-269). Campinas, SP: Mercado das Letras.
- Pletsch, M. D., & Glat, R. (2012). A escolarização de alunos com deficiência intelectual: uma análise da aplicação do Plano de Desenvolvimento Educacional Individualizado. *Linhas Críticas*, 18(35), 193-208.
- Silva, R. N. da, Pires, M. L., Scisleski, A. C. C., & Hartmann, S. (2010). Anormais escolares: a psiquiatria para além dos hospitais psiquiátricos. *Interface*, 14(33), 401-410. DOI: http://dx.doi.org/10.1590/S1414-32832010000200013.
- Silva, I. M. da, Cruz, A. M., Lobo, L. F., Moraes, L. A. de, Santos, L. L. M. dos, Cavalcante, S. de S. et al. (2007). *A aliança médico-pedagógica:uma genealogia do processo de exclusão/demanda.* Paper presented at the 14th 'Encontro Nacional da ABRAPSO', Rio de Janeiro, Brazil.
- Thompson, J. R., Bryant, B. R., Schalock, R. L., Shogren, K. A., Tassé, M. J. ... Wehmeyer, M. L. (2004). *Supports Intensity Scale user's manual*. Washington, DC: American Association on Mental Retardation. Version for adaptation and validation in Brazil. Responsible: PhD Professor Maria Amélia Almeida/UFSCAR.
- Vygotsky, L. S. (2011). A defectologia e o estudo do desenvolvimento e da educação da criança anormal. *Educação e Pesquisa*, *37*(4), 863-869.
- Vygotsky, L. S. (1993). *The collected works of L. S. Vygotsky*. Vol. 2: The fundamentals of defectology (abnormal psychology and learning disabilities). New York: Plenum.
- Vygotsky, L. S. (1997). Obras escogidas V. Madrid: Visor.
- World Health Organization. (1992). ICD-10 Classification of Mental and Behavioural Disorders: clinical description and diagnostic guidelines. Geneva: WHO.
- Zutião, P. (2016). *Programa "Vida na Comunidade" para familiares de jovens com deficiência intelectual* (Master's thesis). Universidade Federal de São Carlos, São Carlos, São Paulo, Brazil.¹⁰

Submitted on 25/02/2019 Reformulated on 30/05/2019 Accepted on 31/05/2019