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ARTICLE

Mismatch between diagnostic reports and special educational needs classification in a public educational system

Descompasso entre os registros diagnósticos e a classificação de necessidade educacional especial em uma rede municipal de educação

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ABSTRACT

Objective: To assess the diagnostic status, the sociodemographic and health profiles for students with special educational needs (SEN) in a public educational system, and to map their use of educational/social services. **Methods:** The sample comprised 1,202 SEN students from a total of 59,344 students. **Results:** Only 792 students of the 1,202 had an established diagnosis. The most prevalent SEN condition was intellectual disability. There was a low percentage (29.4%) of use of specialized educational services or support. It was found that, for some neurodevelopmental disorders, prevalence data suggest an under-reporting in the school system. **Conclusion:** Results suggest that there is a mismatch between the diagnostic reports and the SEN condition legally recognized according to Brazilian law, in addition to the under-reporting and under specialized service use of students with disabilities.

Keywords: diagnosis; child; school; disability.

RESUMO

Objetivo: Avaliar a situação diagnóstica, o perfil sociodemográfico e de saúde dos alunos com necessidades educacionais especiais (NEE) de uma rede municipal de educação, assim como mapear o uso de serviços educacionais e sociais. **Métodos:** A amostra foi composta por 1202 alunos com NEE de um total de 59344 alunos. **Resultados:** Dos 1202 alunos somente 792 tinha diagnóstico estabelecido. A condição de NEE mais prevalente foi a deficiência intelectual. Verificou-se um baixo percentual (29,4%) de uso de serviços educacionais especializados ou de apoio. Foi constatado que, para alguns transtornos do neurodesenvolvimento, os dados de prevalência parecem indicar uma subnotificação. **Conclusão:** Os resultados sugerem um descompasso entre os registros diagnósticos e a condição de necessidade educacional especial segundo a legislação brasileira, além disso verificou-se uma subnotificação diagnóstica e baixo uso de serviços especializados entre estudantes com deficiências.

Palavras-chave: diagnóstico; criança; escola; deficiência.

In developed countries, the identification of neurodevelopmental disorders for health interventions, education and psychosocial management is usually done with periodic population screening[1,2,3]. This not only allows the prevalence rates of these disorders to be established, but also helps to clarify genetic and environmental risk factors and, consequently, influence the development of public health and education policies.

In Brazil, the National Policy for Inclusive Education began to be outlined at the beginning of 2000. A government decree, 6571/2008, was issued giving legal support to the policy. The decree has been amended over time, with changes being made to regulations, technical notes and resolutions. The latest document outlining all the policy details is called, "Guidelines for the Implementation of Special Education Policy in Relation to Inclusive Education" published by the Ministry of Education. Currently, there are seven conditions supported by this policy: intellectual, visual, hearing, physical, multiple disabilities/impairment and autism spectrum disorders, and high skills[4]. To be entitled to an education plan specifically structured to their needs, students with

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special educational needs (SEN) have to be given a diagnosis. However, there are few studies that verify the reliability of the diagnoses of SEN students in Brazil. In addition, Brazilian studies that map the diagnosis, and characterize and describe the educational and health service usage profiles of SEN students are even scarcer.

In any area of health, reliable diagnostics are essential to guide treatment recommendations, identify prevalence rates, and plan educational and mental health service provision[5]. In the specific case of special educational support services, a reliable diagnosis has several advantages for the child or adolescent affected, their families and for the broader society. For example, for an educator it would allow them to develop educational and pedagogical action plans tailored to the typical characteristics of the disorder and to the specificities of the students' to cognitive functioning, behavioral patterns, learning skills and social and adaptive functioning[6]. With regard to the law, a correct and trustworthy diagnosis allows the family and the community to guarantee the rights protected by the current legislation[5,7].

Diagnostic evaluation of a given population should be done through periodic monitoring, helping to identify vulnerable cases and thus increasing the chances of individuals receiving appropriate treatment according to their needs[8]. Neurodevelopment disorders during childhood need to be monitored from an early age to deliver interventions in line with development indicators.

Taking into account the importance and scarcity of population data on Brazilian students with SEN, this study aimed to examine their diagnostic status, and socio-demographic and health profiles in a public school system.

METHODS

Participants

The study sample was based on secondary data from a database produced by the Municipal Secretariat for the Rights of People with Disabilities from a public educational system. This database was designed to record and characterize all SEN students in the city's public schools, including kindergarten, elementary schools (stages I and II) and special education schools. The database contains the following indicators for SEN students: diagnostic reports, sociodemographic and socioeconomic indicators, school unit and use of educational, social and health services.

The study sample comprised the 1,202 SEN students recorded in the database who attended public schools, from a total of 59,344 students. However, only 792 of the 1,202 students had an established diagnosis. The average age of these 792 SEN students was 13 years old (SD = 6.59), 500 were male (63.1%).

Table 1 shows the sample data according to sex, age range, distribution by educational levels and indicators of medication profile and use of educational support services and social indicators.

RESULTS

In order to present up-to-date data, the diagnostic reports of the 792 students were grouped according with the SEN categories as defined by Brazilian law[9]. We verified that 13.3% of the disorders were not part of this SEN categories but were classified as specific learning disorders and psychiatric disorders according to 5th edition of the Diagnostic and Statistical Manual of Mental Disorders. Two specialists in developmental disorders made this grouping jointly.

From the diagnostic reports, it was possible to create six qualifying groups: (1) intellectual disability, comprising genetic syndromes and other conditions associated with intellectual disability; (2) sensory impairment, comprising visual impairment, hearing impairment, multiple sensory disabilities without intellectual disability or autism spectrum disorder; (3) physical disability, comprising cerebral paralysis, localized paralysis, non-progressive chronic encephalopathy without intellectual disability, isolated physical defects not related to the central nervous system or intellectual disability; (4) autism spectrum disorder, comprising global disorder/pervasive developmental disorder and Asperger's; (5) specific learning disorders, comprising dyslexia, dyscalculia or learning disorders; (6) other psychiatric disorders, comprising depression, anxiety, schizophrenia, disruptive behavior, impulse control and conduct disorders, and attention deficit/hyperactivity (Table 2).

DISCUSSION

It is notable, in Table 1 that a large proportion of SEN students show school delay, since 29.4% should have completed elementary school by 14 years of age. Benefits offered by the government can be used as indicators of poverty. In this study, 36% of families received food aid and 19.6% received a family allowance. Currently, approximately 25% of all Brazilian families receive a family allowance, with the highest concentration in the north-east[10]. As only those with per capita incomes of less than R$70 receive a family allowance, one can conclude that almost one in five students in this research are below the poverty line. Recent studies have pointed to the significant benefits of the family allowance program with regard to various aspects of child health, such as more frequent attendance of children at primary health care units to monitor development and for vaccination, as well as decreased mortality of children under five years of age as a result of poverty[11,12]. There are no specific data on the benefits of a family allowance for people with SEN, but a plausible hypothesis is that these children and adolescents are benefiting equally or even more than typical ones, as poverty adds to the particular challenges of disability or chronic health problems.

Our data shows in Table 2 that intellectual disability is the most frequent SEN condition in the studied public schools, followed by sensory disabilities, physical disability,

Table 1. Characteristics of special educational needs students in a public educational system: sociodemographic profile, schooling, diagnosis and use of services (N = 792).

Characteristics		Total Sample N (%)
Sex	Female	292 (36.9)
	Male	500 (63.1)
Age range	0 - 3 years	14 (1.2)
	4 - 5 years	63 (5.2)
	6 - 10 years	379 (31.5)
	11 - 14 years	393 (32.7)
	≥15 years	353 (29.4)
Use of medication	Yes	347 (43.8)
	No	383 (48.4)
	No information	62 (7.8)
School type	Day-care nursery	12 (1.5)
	Kindergarten	58 (7.3)
	Elementary school	563 (71.1)
	Special education school	159 (20.1)
Specialized education support service	Yes	233 (29.4)
	No	526 (66.4)
	No information	33 (4.2)
Family allowance	Yes	155 (19.6)
	No	584 (73.7)
	No information	53 (6.7)
Food aid	Yes	285 (36.0)
	No	457 (57.7)
	No information	50 (6.3)
Wheelchair user	Yes	50 (6.3)
	No	711 (89.8)
	No information	31 (3.9)
Adapted transport	Yes	24 (3.0)
	No	713 (90.0)
	No information	55 (6.9)
Use of diaper	Yes	100 (12.6)
	No	670 (84.6)
	No information	22 (2.8)

Table 2. Regrouped diagnosis of records of students with special education needs (N = 792).

Diagnosis	n (%)
Intellectual Disability	410 (51.8)
Sensory Impairment (Visual/Hearing/Multi)	125 (15.8)
Physical Disability	124 (15.7)
Autism Spectrum Disorder	28 (3.5)
Specific Learning Disability	14 (1.8)
Other Psychiatric Disorder	91 (11.5)

psychiatric disorders, autism spectrum disorder and, finally, specific learning disorders. Considering the proportion of students with SEN in relation to the total number of students enrolled in the schools, it is possible to conclude that there is underdiagnosis of SEN cases, and consequently under-reporting of these cases to the education department. Taking autism spectrum disorder as an example, where the estimated prevalence is between 0.6 and 1%[13,14], in this study only 0.05% of students were classified with this diagnosis.

The under-reporting of autism spectrum disorder found in our study (Table 2) makes us reflect on two problems: firstly, the probable negative effects arising from a lack of a diagnosis on development and behavior, as evidence-based practice recommends early intervention in autism spectrum disorder[15,16,17] and secondly, that undiagnosed children are not receiving any specialized educational support. This creates a mismatch between the actual situation and the records of diagnostic reports that have been used in studies in Brazil, with examples of flawed or incomplete records or, in some cases, missing records[18]. Furthermore, when a child is enrolled in a regular school, the educational team may develop teaching methods that are not focussed on the needs of these students, accentuating learning difficulties and prejudicing social adaptation in general[6]. Curricular adaptations and appropriate management strategies are essential to support learning in autism spectrum disorder students. Evidence shows that most of them cannot learn by traditional methods because of the difficulty of responding to complex instructions and maintaining attention on several simultaneous stimuli presented during classes, due to multiple deficits in social cognition indicators, behavioral changes, cognitive deficits, such as in inhibitory control functions, and the presence of intellectual disability in approximately 70% of cases[19,20,21].

Diagnostic reports also shows that 105 students (13.3% of those with SEN) are grouped as having a learning disability or other psychiatric disorder that is not legally recognized as SEN according to Brazilian law. The fact that there is such a high proportion of SEN students recorded as having learning/psychiatric disorders further strengthens the need to take steps to produce accurate diagnoses. This outcome raises the following considerations: a) it is probable that these learning/psychiatric diagnoses do not reflect the real primary condition, and it is the responsibility of the health services to provide a reliable diagnosis so that these students are included as SEN students; b) if this actually is the primary diagnosis of the student, we note an inappropriate use of SEN services in these cases.

This study also mapped aspects related to the use of social inclusion services and medication. The identified data show that, from a functional point of view, about 10% use a wheelchair, adapted transport or diapers. One interesting development is the registration and classification of various functional domains using the criteria of the International Classification of Functioning[22]. There have been some successful experiences in the Brazilian educational context[23,24,25]. As well, almost 50% of SEN students use medications regularly.

One noteworthy item in Table 1 is the low percentage of SEN students who have access to specialized educational services or support. Approximately 67% do not use this type of service. An analysis comparing the diagnostic condition with the use of these services indicated that only 32% of students with intellectual disability, and 25% with autism spectrum disorder were using them. To provide comprehensive care to this population, pedagogical and educational measures, and adaptations to the curriculum (multilevel or overlapping curricula), as recommended in studies from other countries, should be made in the classroom[6].

Although the present study brings contributions for the field, it has some limitations typical of studies based on secondary data, such as the reduced number of collected variables and absence of some relevant information, such as the diagnostic status of some of the sample.

In conclusion, these data suggest that there is a mismatch between the diagnostic records and the SEN condition legally recognized according to Brazilian law, in addition to the under-reporting and under specialized service use of students with disabilities.

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