frontiers | Frontiers in Education

TYPE Original Research
PUBLISHED 10 February 2026
DOI 10.3389/feduc.2026.1716827

Check for updates

OPEN ACCESS

EDITED BY
Brahm Norwich,
University of Exeter, United Kingdom

REVIEWED BY
İsmail Seçer,
Atatürk University, Türkiye
Grazielle Rodrigues Pereira,
Instituto Federal de Educação, Ciência e Tecnologia do Rio de Janeiro, Brazil

*CORRESPONDENCE
Maria de Fátima Joaquim Minetto
✉ fa.minetto@gmail.com

RECEIVED 30 September 2025
REVISED 19 December 2025
ACCEPTED 05 January 2026
PUBLISHED 10 February 2026

CITATION
Minetto MFJ, Kruszielski L, Matos EMBB and Choinski AM (2026) Barriers to inclusive education and support services for children with autism and developmental delays in Brazil.
Front. Educ. 11:1716827.
doi: 10.3389/feduc.2026.1716827

COPYRIGHT
© 2026 Minetto, Kruszielski, Matos and Choinski. This is an open-access article distributed under the terms of the Creative Commons Attribution License (CC BY). The use, distribution or reproduction in other forums is permitted, provided the original author(s) and the copyright owner(s) are credited and that the original publication in this journal is cited, in accordance with accepted academic practice. No use, distribution or reproduction is permitted which does not comply with these terms.

Barriers to inclusive education and support services for children with autism and developmental delays in Brazil

Maria de Fátima Joaquim Minetto*, Leandro Kruszielski, Elyse Michaele Bacila Batista de Matos and André Marques Choinski

Graduate Program in Education, Federal University of Paraná, Curitiba, Brazil

Background: Brazil, the largest South American nation, lacks comprehensive data on services for children with autism spectrum disorder (ASD) and other neurodevelopmental delays (NDD), such as cerebral palsy, speech impairments, and ADHD. While outdated regional studies estimate ASD prevalence at 27.2 per 10,000 children, global trends suggest rising rates. Limited research highlights barriers like delayed diagnosis, family stress, and access to health and social services, despite an increase in legal rights since 2012 (ASD Statute). This study uses a large community sample to characterize caregiver needs, acknowledging socioeconomic biases in the cohort.

Methods: We adapted and translated the Autism Speaks Family Needs Assessment (FNA) survey to Brazilian Portuguese following WHO guidelines. The Ico Project Foundation disseminated the online survey via social media networks (September–October 2020, amid the COVID-19 peak). No proof of diagnosis was required; 5,220 responses were collected, with 4,940 selected for analysis (descriptive statistics and logistic regression controlling for demographics).

Results: The research revealed that 68.5% of children were diagnosed with Autism Spectrum Disorder (ASD) or developmental delays before the age of 3, with higher-income families and those from more developed regions of Brazil accessing diagnoses earlier. Furthermore, medical and educational attention were identified as the biggest challenges, and caregivers' education level and family income were significantly associated with various difficulties and care priorities.

Discussion: Despite the privileged socioeconomic profile of the sample, systemic gaps and unmet needs persist, with notable disparities in access to services based on income and geographical location, reinforcing the urgency of policies for equitable diagnoses, clinical interventions, and inclusive education in Brazil.

KEYWORDS

autism, developmental delays, diagnostic, education, family needs, inclusion

1 Introduction

Many parents realize in the first years of life that there is a difference in their child's development and constantly seek to understand what is happening. Arriving at a diagnosis can be difficult and time-consuming. The processes from identifying symptoms to accessing services usually involve logistical, financial, and social challenges for parents to navigate (Lappé et al., 2018). This uncertainty impacts the development of the child and the family. Minetto et al. (2013) and Minetto et al. (2012), as well as Ribeiro et al. (2017), identified that delays in diagnosis increase stress, influence educational practices, and affect family functioning.

For Alonso Soriano et al. (2015), the literature has not yet sufficiently focused on parents' experiences of having a child diagnosed with developmental disorders. The authors conducted a study of 228 parents in the UK regarding their experiences in obtaining a diagnosis for their children. The results showed that, on average, the diagnosis was confirmed two and a half years after the parents initially sought professional help. Additionally, 45% of the parents expressed dissatisfaction for various reasons, such as delays in obtaining the diagnosis, the stress caused by this delay, the manner in which the report was communicated to the parents, and the lack of post-diagnosis support, which was considered the primary source of dissatisfaction. The researchers noted that 43% of the reports the parents received offered no practical help or support during the diagnostic process and very little after the diagnosis was received.

With the recent evolution in the diagnostic criteria established by the Statistical and Diagnostic Manual of the American Psychiatric Association (2013), there is greater clarity and more resources available for diagnoses. Various authors, including Zwaigenbaum et al. (2015), Van Cong et al. (2015), Gomes et al. (2015), and Ribeiro et al. (2017), point out that clearer criteria have led to an increase in diagnoses of autism spectrum disorder (ASD) at an earlier age, even though the heterogeneity of its manifestation remains a challenge (Lappé et al., 2018).

In the case of children with ASD, their parents are confronted with atypical development in social communication and interaction, as well as repetitive behaviors before 24 months of age, which drives the search for diagnoses and resources (Zwaigenbaum et al., 2015). In Brazil, a study conducted by Gomes et al. (2015) concluded that the diagnosis of ASD significantly influences family dynamics, resulting in caregiver burden, particularly for mothers. The author suggests that the Brazilian Unified Health System needs to provide comprehensive and continuous care. Additionally, the author highlighted the need for initiatives that strengthen the bond between families and their children, as well as promote the development and social inclusion of children with ASD.

The improvement of diagnostic criteria for ASD, increased awareness among parents about developmental delays, and the importance of early intervention have resulted in demands for quality resources in various areas, such as health, education, and policy (Sousa, 2021). Brazil's Constitution and legislation are significantly aligned with the Universal Declaration of Human Rights, signed in 1948. Thus, there is a legal and theoretical commitment from the government to promote respect for differences and the specific needs of each citizen (Brasil, 2024). According to the Ministry of Women, Family and Human Rights (Brasil, 2024), laws and norms in Brazil aimed at providing accessibility and quality of life for people with disabilities have been established since 1962, with the officialization of Braille for use in writing and reading texts, as well as the Code of Contractions and Braille Abbreviations. Today, there are 40 laws and 29 decrees addressing the diverse needs of people with disabilities. However, various authors (Minetto, 2021; Gomes et al., 2015) highlight the gap between the laws and their practical effectiveness, which impacts families with children with disabilities.

Major changes have occurred since 2009, when Brazil became a signatory to the International Convention on the Rights of Persons with Disabilities. The National Plan for the Rights of Persons with Disabilities, called Living Without Limits, was introduced through Decree No. 7612 on November 17, 2011, and has been revised over the years (Decree 11.793 of 23 November 2023). Since its launch, there have been investments in various areas of education, including the National Reference Center in Assistive Technology and the Money Direct at School Program (PDDE), which allocated 235 million reais to 26,000 schools across the country for architectural adaptations for people with disabilities, adapted buses for school transport, among others (Ministry of Women, Family and Human Rights, Brazil, 2021). The new edition of the Brasil (2023) indicates a budget of 6 billion reais to be executed until 2026 and establishes improved criteria for monitoring and evaluating its actions at the state level.

In line with the United Nations (2006), the National Policy on the Rights of Persons with Autism Spectrum Disorder was approved in 2012 (Law No. 12764, of 27 December 2012). A key highlight is that autism spectrum disorder is no longer viewed as a mental disorder but rather as a neurodevelopmental disorder; therefore, individuals with autism are considered "persons with disabilities."

> Art. 1 The person with autism spectrum disorder is considered a person with a disability, for all legal purposes.
> Single paragraph. The rights and obligations provided for in the International Convention on the Rights of Persons with Disabilities and its Optional Protocol, enacted by Decree No. disability (Brasil, 2012).

The Law covers social, health, and education rights. Regarding education, it is stated that the right of the person with autism spectrum disorder to education must be ensured within an inclusive educational system, guaranteeing the integration of special education from early childhood education to higher education. The law also stipulates the collection of a fine in case an educational institution denies enrollment, which is a new provision. There is an emphasis on the right to a specialized companion in the school context whenever necessary. Despite the legislative progress, the rights of autistic individuals have yet to be fully implemented in the education and health systems. Most guiding documents regarding public health policies are not unified, exhibiting different pathways for Mental Health and Rehabilitation.

Concerning the age of diagnosis, a pilot study conducted in São Paulo in 2018 indicated that the mean age for ASD diagnosis was approximately 4 years and 11 months. However, given the significant variability observed across regions and services, further studies are necessary, and Brazil still lacks a comprehensive national database to inform public policies (Paula et al., 2011). The most recent national census (Instituto Brasileiro de Geografia e Estatística (IBGE), 2023) included ASD data for the first time and reported that 2.6% of children had received an ASD diagnosis, with no substantial regional differences.

Although this represents an important advancement in national surveillance, the census does not yet provide detailed information on diagnostic pathways, age at diagnosis, or access to intervention.

Despite the importance of the topic, scientific publications addressing the care of children with developmental disorders in Brazil remain scarce, particularly those evaluating the availability and adequacy of services across public and private sectors. Given this context, the present study aims to identify the most significant challenges faced by families of children with developmental delays and disabilities in the country. A secondary goal is to inform policymakers about priority areas requiring investment to reduce disparities and improve service provision. The data collected here contribute to broader international efforts and are part of the Global Report on developmental disabilities coordinated by the World Health Organization and United Nations Children's Fund (UNICEF).

2 Materials and methods

Quantitative, descriptive survey research. Approved by the Ethics Committee of the Universidade Federal do Paraná (CEP/UFPR), CAAE No. 29706720.4.0000.0102, on August 17, 2021.

2.1 Instruments

The research used a model for data collection based on "caregiver needs" authored by the American foundation Autism Speaks Global Public Health Initiative (2016), aimed at families of autistic children, known as the Family's Needs Assessment (FNA). The FNA is divided into three parts: demographic data; information about the child; and caregiver concerns regarding access to services and education.

The adaptation process of the instrument followed internationally recommended procedures for cross-cultural research. The original Family Needs Assessment (FNA), developed by Autism Speaks, was translated into Brazilian Portuguese by a bilingual specialist, back-translated by a certified translator, and reviewed by the authors in accordance with guidelines from the WHO and the International Test Commission, which emphasize translation, back-translation, and expert review as essential steps (Beaton et al., 2000; World Health Organization, 2014; International Test Commission, 2017; Organização Mundial da Saúde, 2023). Nevertheless, we acknowledge that more extensive assessments of semantic and cultural equivalence, involving multiple independent reviewers, were not feasible at the time. The pilot study involved only five participants due to COVID-19 restrictions, which prevented broader in-person testing. Although this pilot confirmed the general clarity and intelligibility of the instrument, the small sample size limited our ability to evaluate cultural adequacy or response stability across sociodemographic subgroups.

Psychometric analyses, including internal consistency, were not feasible, both because the FNA is a multidimensional needs-assessment tool not originally designed as a psychometric scale and because its use has been internationally recommended by WHO and UNICEF to support cross-country comparability rather than scale validation (Autism Speaks Global Public Health Initiative, 2016; World Health Organization and United Nations Children's Fund (UNICEF), 2023). Given its large number of nominal and ordinal indicators and the absence of continuous quantitative scores, the instrument does not allow for conventional psychometric procedures, including factor analysis or reliability estimation. Even so, retaining the original structure of the FNA remains consistent with its widespread use in low- and middle-income countries as a descriptive tool for identifying service gaps and ensuring comparability across contexts (Montiel-Nava et al., 2020; Smith et al., 2010).

2.2 Procedure

The Brazilian FNA was hosted on the SurveyMonkey platform. To access the questionnaire, families needed to follow a link that was made available in various ways: through sponsored posts on Meta's social networks for the NGO Ico Project Foundation; contact with activists and influencers linked to the movement for people with autism and disabilities in several states; public online lectures conducted by the authors; and videos released by parents and individuals with Down syndrome requesting participation in the survey.

The first page of the questionnaire was an informed research consent; only participants who voluntarily accepted participation were included in the sample. Participants were not required to answer all the questions, resulting in a variation in sample size for each question. Additionally, they were not required to provide proof of their child's condition, which is a limitation of this sample. Data collection took around 40 days between September and October of 2020. After that, the data were analyzed using descriptive and inferential statistical analysis with the software *Jamovi* version 2.6.44. For inferential statistics, Welch's *t*-test (used due to unequal variances), One-way ANOVA, and Chi-Square tests were conducted at a significance level of 5%. A logistic regression model was developed to describe the unmet needs of children in the areas of health care, mental health, and education while controlling for parental socioeconomic characteristics. Missing data were handled using Multiple Imputation by Chained Equations (FCS), with five imputations, using the mice package in R (version 4.5.2). Ordinal variables were imputed using ordinal logistic regression (polr), while dichotomous variables were imputed using binary logistic regression (logreg).

3 Results

The sample, described in Table 1, was composed of 4,940 respondents, primarily women (91.6%) and mothers (81.9%), with ages varying between 26 and 55 years old (86.9%), peaking between 36 and 45 years old (45.5%). The participants were the primary caregivers (87.2%). The ethnicity was predominantly white (56.6%) or multiracial (33.3%). Most of them were married or in a stable relationship (72.7%).

Regarding educational levels, the highest attainments were postgraduate degrees (34.9%), elementary school (20.1%), and college degrees (19.8%). Participants engaged in household tasks (30.7%), were employed at least 40 h/week (25.7%) or less (15%), or were unemployed (11.6%). Among the participants who were not employed, almost all had worked previously (83.7%), and more than half of these (55.1%) left work because of the child's condition. Participants' partners were mostly employed for 40 h/week (51.7%) and completed elementary school (21.5%), college degrees (19.4%), or postgraduate degrees (18.2%).

TABLE 1 Sociodemographic characteristics of the sample.

Variable	Category	Frequency	Percentage
Gender	Male	3,817	91.4%
	Female	349	8.4%
	Others	9	0.2%
Relationship to the child	Mother	3,393	81.9%
	Stepmother	5	0.10%
	Father	223	5.4%
	Stepfather	8	0.2%
	Grandmother	70	1.7%
	Grandfather	11	0.3%
	Others	435	10.5%
Ethnicity	White	2,338	56.2%
	Multiracial	1,404	33.7%
	Black	303	7.3%
	Asian	85	2.0%
	Indigenous	9	0.2%
	Others	24	0.6%

Families' incomes were one to three minimum wages (55.9%) and four to six minimum wages (20.9%) (the Brazilian minimum wage is estimated at $190 per month). Participants lived in the South (32.1%), Southeast (30%), Northeast (16.2%), North (11.9%), and Midwest (9.7%) Brazilian geographic regions. The vast majority (95.5%) lived in urban locations. In most households, only one person (79.3%) with disabilities lived there, while two (9.6%) and three or more (1.8%) were present. Adults diagnosed with mental disorders lived in 38.7% of the households.

Regarding the developmental delays with which the child has been diagnosed, there was a high prevalence of ASD (51.3%), followed by ADHD (11.7%), genetic syndromes (11.0%), and intellectual disability (9.7%). This may be explained by the fact that data collection had the support of many parents of children with ASD in disseminating the research.

The other conditions with which the child had been diagnosed included the highest rates of allergies (9.2%), sleep disorders (8.1%), and motor problems (8.1%), while 30.0% of the sample reported that they had not received any additional diagnoses.

Most participants believed that the disability was due to genetic or hereditary factors (57.2%), unknown causes (20.8%), the influence of a supreme being (11.2%), or traumatic experiences very early in life or in the womb (9.1%). Less than 2% attributed the causes to vaccinations (1.1%), cold or rejecting parents (0.6%), or bad luck or a curse from a past life (0.1%).

When asked who was the first to notice characteristics of developmental delays in the child, caregivers were the most frequent responders (56.7%), followed by health professionals (14.4%). These characteristics were first noticed before 18 months by 40% of the 2,541 parents who answered this question.

Almost half of the sample (49.0%) had been diagnosed between 1 and 3 years of age, 22.2% between 4 and 8 years old, and 19.5% before the age of 1. It is noteworthy that 68.5% of the sample was diagnosed before the child was 3 years old, in this relatively advantaged group. A similar pattern of diagnoses before 3 years of age was observed when considering caregiver education level (Primary Education: 66.7%, Secondary Education: 66.8%, Higher Education: 69.5%, Postgraduate: 69.6%) and geographic area (Urban: 68.7%, Rural: 65.7%). However, greater variations were observed when considering monthly family income (1–3 minimum wages: 67.8%, 4–6 minimum wages: 67.9%, 7–9 minimum wages: 66.1%, above 10 minimum wages: 74.4%) and different regions of the country (South: 73.2%, Northeast: 69.6%, Southeast: 68.2%, North: 60.3%, Midwest: 51.0%).

The results reveal a high rate of early diagnosis of autism spectrum disorder (ASD) and developmental delays before 3 years of age (68.5% of the sample), with similar patterns observed in relation to caregivers' education level (primary education: 66.7%; secondary education: 66.8%; higher education: 69.5%; postgraduate: 69.6%) and geographic location (urban: 68.7%; rural: 65.7%). This suggests that these sociodemographic factors do not significantly influence the age at diagnosis in this sample. However, more pronounced variations emerge when considering monthly family income (1–3 minimum wages: 67.8%; 4–6: 67.9%; 7–9: 66.1%; above 10: 74.4%) and regions of the country (South: 73.2%; Northeast: 69.6%; Southeast: 68.2%; North: 60.3%; Midwest: 51.0%). This indicates that families with higher purchasing power and those residing in more developed regions, such as the South and Southeast, access earlier diagnoses, possibly due to greater availability of specialized services and awareness (Paula et al., 2020; Ribeiro et al., 2017). This disparity reinforces evidence of structural barriers in Brazil, where access to diagnostic assessments is unequal, with average delays reported at around 3 years between the initial perception of symptoms and formal diagnosis (Ribeiro et al., 2017), and without substantial regional differences noted in the recent national census (Instituto Brasileiro de Geografia e Estatística (IBGE), 2023). Furthermore, the observed pattern of early diagnoses may be influenced by sampling bias, as recruitment via social networks overrepresents caregivers with greater digital connectivity and socioeconomic resources, limiting generalizability to more vulnerable populations in rural or low-income areas (Biernat et al., 2020; Montiel-Nava et al., 2020). These findings highlight the need for public policies that expand equitable access to early screening services, aligning with global recommendations for reducing inequalities in ASD (Wallace et al., 2012).

Concerning travel distance and time to receive support, just over half of the participants (58.2%) found support in their own city, while 677 participants (26.9%) needed to go to other cities to access it. The majority experienced a short wait time to receive support: 30% waited less than a month, 26.9% waited between 1 and 3 months, and a total of 82.8% of the sample received support in less than a year.

From 2,865 responses, 27.5% of the respondents reported no difficulties or delays in receiving medical attention. Among those who did experience issues, high costs (16.2%), long waiting times (15.5%), and a lack of services in the area (13.9%) were the most frequently cited difficulties.

Regarding the type of school the child attends, it is noteworthy that 35.3% of the children were enrolled in regular public schools and 31.5% in regular private schools, meaning that 66.8% of the sample attended regular schools. Additionally, 13.5% attended a special school for children with disabilities, and 10.4% were not enrolled in school.

When questioned about academic support, a little more than half of the participants (50.9%) said that the schools offer additional

support, while 36.7% stated that there is no support. A small group of participants (12.4%) indicated that they do not know this information. Additionally, 93.6% of participants reported that schools were aware of their child's diagnosis. Most participants (80.9%) responded that they do not believe the child would be prohibited from attending school if the school knew about the diagnosis.

Regarding difficulties with the child's education, almost half of the sample (44.9%) did not report any difficulties. The most frequent challenges identified were lack of services (13.6%), lack of services in the area (11.7%), and high costs (10.6%).

Figure 1A represents the parents' concerns about the child ranked from one to six. The highest concern is communication difficulties, while the least concern is behavioral difficulties. Concerning the challenges in obtaining help for caring for a child with developmental delay, Figure 1B shows that education is the greatest challenge, followed by civil rights and medical help.

In Figure 2A, communication difficulties are identified as the greatest challenge in caring for a child with developmental delay, followed by social interactions and daily living skills. Participants also indicated that health problems and safety concerns are the least challenging. Participants were asked what they believed were the greatest challenges faced by families with individuals with developmental delays. The data generated by this question are shown in Figure 2B. The greatest challenges were medical and educational attention, with similar results, while the least priorities were safety, counseling, and household support.

3.1 Inferential analysis

Starting with the greatest challenges identified by parents, a significant association was found between the education of the primary caregiver and health ($\chi^2 = 15.4$, $p = 0.031$), diet ($\chi^2 = 23.8$, $p = 0.001$), social relationships ($\chi^2 = 82.5$, $p < 0.001$), repetitive behavior ($\chi^2 = 25.8$, $p < 0.001$), communication ($\chi^2 = 86.8$, $p < 0.001$), and sensory issues ($\chi^2 = 22.6$, $p = 0.002$).

Regarding the priorities of Brazilian families with children who have developmental delays, it is evident that the parents' income is significantly associated with medical care ($\chi^2 = 15.4$, $p = 0.031$), counseling ($\chi^2 = 83.2$, $p < 0.001$), the pursuit of rights ($\chi^2 = 7.73$, $p = 0.049$), social awareness ($\chi^2 = 22.3$, $p < 0.001$), and finances ($\chi^2 = 20.6$, $p < 0.001$). Among the families' priorities, the child's education was significantly associated with several investigated variables: parental education ($\chi^2 = 17.0$, $p = 0.018$), employment ($\chi^2 = 12.7$, $p = 0.048$), the number of individuals with delays in the household ($\chi^2 = 146.0$, $p < 0.001$), and the relationship status of the primary caregiver ($\chi^2 = 131.0$, $p < 0.001$). Additionally, "Medical Assistance" showed an association with the number of individuals with delays at home ($\chi^2 = 26.9$, $p < 0.001$) and employment.

When asked about the delays or difficulties in accessing medical assistance, the variable "lack of service in the area" showed a significant association with parents' education ($\chi^2 = 67.2$, $p < 0.001$), family income ($\chi^2 = 88.2$, $p < 0.001$), and the number of individuals with delays in the household ($\chi^2 = 44.0$, $p < 0.001$). In contrast, the variable "lack of information" only correlated with the employment status of the caregiver ($\chi^2 = 16.6$, $p = 0.011$) and the number of individuals with delays in the household ($\chi^2 = 55.1$, $p < 0.001$). The variable "waiting time" showed significant correlations with race/ethnicity ($\chi^2 = 69.6$, $p < 0.001$), parental education ($\chi^2 = 89.1$, $p < 0.001$), the number of individuals with delays in the household, and family income ($\chi^2 = 39.4$, $p < 0.001$). Long waiting times for therapies have a significant association ($p < 0.01$) with the variables race/ethnicity ($\chi^2 = 69.6$, $p < 0.001$), parental education ($\chi^2 = 89.1$, $p < 0.001$), income ($\chi^2 = 168.0$, $p < 0.001$), employment ($\chi^2 = 57.3$, $p = 0.002$), and the number of individuals in the household ($\chi^2 = 49.4$, $p < 0.001$).

Education delay showed a statistically significant association with the variables family income ($\chi^2 = 31.8$, $p < 0.001$) and the number of individuals with developmental delays at home ($\chi^2 = 42.9$, $p < 0.001$). Parents' education showed a statistically significant association with the prioritization of medical care ($\chi^2 = 20.7$, $p = 0.004$) and the pursuit of information ($\chi^2 = 34.2$, $p < 0.001$). A highlight that can be observed is related to the participants' employment status; this variable was statistically related to the search for medical care

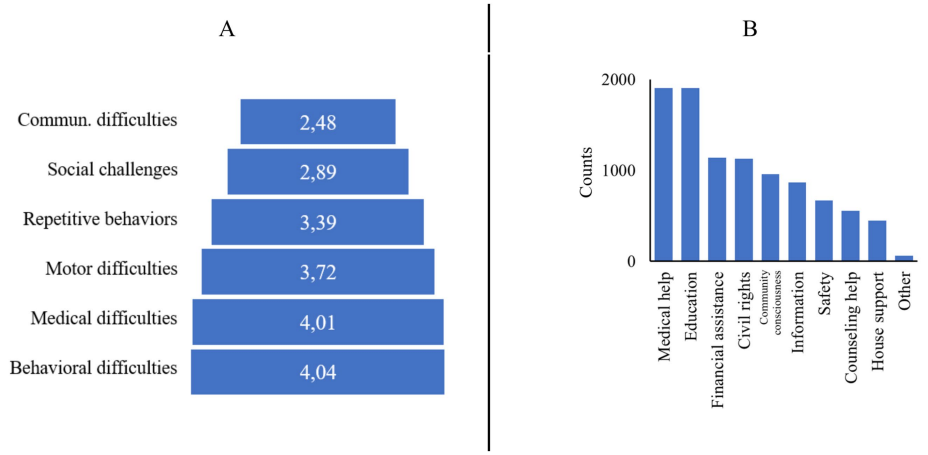

FIGURE 1
(A) Ranking of reasons for parents' concerns about their child's development (the lower the value, the higher the priority). **(B)** Greatest challenges in obtaining help for a child with developmental delay.

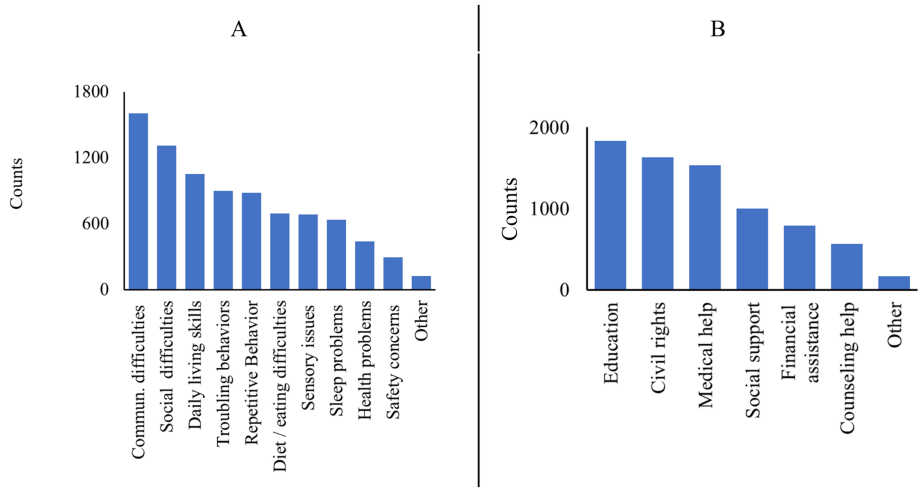

FIGURE 2
(A) Greatest challenges in caring for a child with developmental delay. **(B)** Greatest challenges faced by families with individuals with developmental delays in Brazil.

($\chi^2 = 25.9$, $p < 0.011$), education for children ($\chi^2 = 12.7$, $p = 0.048$), seeking advice ($\chi^2 = 48.6$, $p < 0.001$), knowledge regarding their rights ($\chi^2 = 14.9$, $p = 0.021$), and financial relations ($\chi^2 = 27.7$, $p < 0.001$).

Regarding the main challenges of caring for children with developmental delays, the number of individuals with developmental delays in the home showed significant associations with health issues, worrying behaviors ($\chi^2 = 34.0$, p < 0.001), sleep ($\chi^2 = 25.1$, $p < 0.001$), diet ($\chi^2 = 28.0$, $p = 0.005$), daily life activities ($\chi^2 = 15.4$, $p = 0.001$), social issues ($\chi^2 = 60.8$, $p < 0.001$), security concerns ($\chi^2 = 39.6$, $p < 0.001$), and sensory issues ($\chi^2 = 35.0$, $p < 0.001$), while the race/ethnicity variable showed no association with these challenges.

For the following analyses, the sample was divided into two groups, comparing participants with autism spectrum disorder (ASD) with those having other neurodevelopmental disorders (NDD). The groups were formed based on the child's diagnosis: participants in the ASD group ($n = 1{,}130$) were respondents with children diagnosed with ASD, while participants in the NDD group ($n = 1{,}419$) were respondents with children diagnosed with ADHD, genetic syndromes, ID, epilepsy, and other diagnoses.

As presented in Table 2, comparing the results between the groups reveals a significant association in the challenges of caring for a child in terms of health problems, social interaction, repetitive behavior, and communication difficulties, as well as in family priorities regarding access to civil rights and information. This suggests a difference between the groups concerning these priorities and challenges in caring for children. The challenges of social interaction, repetitive behavior, and communication difficulties were greater for the ASD group, which can be explained by the prevalence of symptoms related to these areas in this disorder. The challenge of health problems was greater for the NDD group, which may be related to the fact that children in this group could present conditions that directly affect their physical health. Regarding the priority of information, it was higher for the ASD group and may be associated with difficulties in diagnosis or prejudice due to the absence of specific phenotypic characteristics.

TABLE 2 Group differences (ASD vs. NDD) in caregiving challenges and family priorities: Chi-square test results.

Caregiving challenges and family priorities	ASD	NDD	χ^2	*p*-value
Health problems	6.5%	25.9%	6.59	0.010
Social interaction	59.9%	45.1%	55.2	<0.001
Repetitive behavior	41.4%	29.7%	37.7	<0.001
Communication difficulties	68.8%	57.4%	35.0	<0.001
Access to civil rights	38.3%	49.4%	31.3	<0.001
Access to information	27.9%	27.9%	55.8	<0.001

Using the independent samples Student *t*-test, statistically significant differences were found between the NDD and ASD groups regarding the reasons parents may be worried about their child's development in the areas of social challenges ($t = -4.63$, $p < 0.001$, $d = -0.20$), repetitive behaviors ($t = -3.76$, $p < 0.001$, $d = -0.16$), motor difficulties ($t = 7.72$, $p < 0.001$, $d = 0.33$), and medical difficulties ($t = 6.19$, $p < 0.001$, $d = 0.27$). The one-way ANOVA analysis showed statistically significant differences among different family income levels and the reasons parents may be worried about their child's development in repetitive behaviors ($F = 5.71$, $p < 0.001$) and medical difficulties ($F = 3.38$, $p = 0.018$).

4 Discussion

This is a descriptive survey with a convenience sample, which is inherently biased. The collected sample is relevant, but due to its recognized limitations, it cannot support generalization. The participants were individuals engaged in associative movements who use social networks, which does not reflect the general profile of the Brazilian population.

However, the number of participants is substantial and presents a significant profile of this population, which has a higher level of

education than the national average. This nonetheless reveals interesting data about this population, mostly composed of women/mothers, white, married, and just over half having children diagnosed with ASD. Thus, despite the large size, the sociodemographic profile of the sample reveals important limitations for the generalizability of the findings, and their implications warrant careful consideration. The high proportion of participants with postgraduate education (34.9%, substantially above the national average of 7.9%), combined with the predominance of respondents living in urban areas (95.5%) and identifying as white (56.6%), indicates a selection bias shaped by both online recruitment strategies and the greater likelihood of participation among individuals with higher educational attainment and digital access. Recent studies emphasize that research relying exclusively on social media and online dissemination tends to overrepresent individuals with greater socioeconomic resources, digital literacy, and connections to advocacy networks—factors that reduce external validity and constrain the applicability of findings to more marginalized populations (Topolovec-Vranic and Natarajan, 2016; Whitaker et al., 2017). Thus, despite the large sample size, it reflects a specific segment of Brazilian caregivers that does not adequately capture the country's socioeconomic, racial, and geographic diversity.

The geographic distribution further reinforces these limitations, as the majority of respondents were concentrated in the South and Southeast regions of Brazil-areas characterized by greater economic development and broader availability of healthcare, educational services, and support networks. This regional imbalance may have produced comparatively optimistic estimates regarding access to diagnostic services, therapies, and school inclusion. National population surveys and health equity studies consistently demonstrate significant disparities across Brazilian regions, with the North and Northeast facing more severe challenges related to income, infrastructure, and the implementation of public policies (Instituto Brasileiro de Geografia e Estatística (IBGE), 2019; Matta et al., 2021). Given that children with disabilities and their families rely heavily on consistent and comprehensive care networks, it is likely that the barriers documented in this study are substantially more pronounced in under-resourced regions. Therefore, the findings presented here should be interpreted as a conservative depiction of the structural challenges affecting families of children with ASD and NDD in the country.

More than half of the respondents in our sample resided in the South and Southeast regions of Brazil, which, as confirmed by the 2022 Brazilian Census, continue to display the country's highest socioeconomic indicators, including higher average income, more extensive healthcare and educational infrastructure, and the highest levels of educational attainment (Instituto Brasileiro de Geografia e Estatística (IBGE), 2023). This regional concentration likely contributed to the above-average educational levels observed among participants (postgraduate: 34.9%; higher education: 19.8%; elementary school: 20.1%). These sociodemographic characteristics may also help explain other findings in this study, such as the higher proportion of caregivers who attributed their child's disability to genetic or hereditary factors (57.2%), a pattern more commonly associated with families possessing higher health literacy. Another finding consistent with this sociodemographic profile is the relatively short delay between diagnosis and the initiation of interventions: 27.5% of caregivers reported no difficulties or delays in obtaining medical attention. This contrasts with prior national studies such as Paula et al. (2020), which identified long waiting lists for interventions as a major challenge for Brazilian families (56.5%). In contrast, only 15.5% of respondents in our sample reported long delays, suggesting that the advantages associated with their regional and socioeconomic profile may have facilitated earlier access to services.

Paradoxically, even within a socioeconomically advantaged sample characterized by higher education levels, greater digital access, and increased awareness of available services, caregivers reported substantial unmet needs, particularly regarding timely diagnosis, educational supports, and mental health services. This aligns with international evidence indicating that families of children with neurodevelopmental conditions face systemic barriers even in comparatively favorable contexts, including delays in diagnosis, fragmented service pathways, and insufficient specialized support (Christensen et al., 2016; Bölte, 2023). It is reasonable to infer that families living in rural areas, those with lower socioeconomic status, and racialized populations underrepresented in this study experience even greater challenges. These findings underscore that inequalities in access to services and opportunities for child development are deeply rooted in broader structural inequities within Brazilian society.

The collection of data through social media, although efficient for reaching a large number of participants (n = 5,220) in a short period, introduces inherent biases due to self-selection, with more engaged caregivers and those with higher digital literacy being overrepresented. This may inflate perceptions of needs and barriers compared to less accessible populations (Biernat et al., 2020, in similar studies on ASD). This methodological limitation is particularly relevant in the Brazilian context, where digital inequalities exacerbate disparities in neurodevelopmental research (Brazilian Network for Inclusive Education Assessment, 2022). To mitigate these biases in future studies, hybrid recruitment strategies are recommended, such as partnerships with community associations in peripheral and rural areas, or the use of probabilistic sampling in public schools, aiming for more equitable representation. Such approaches would not only enhance the generalizability of the findings but also enrich the understanding of the intersections between educational inclusion, social equity, and family support for children with ASD and NDD in Brazil, aligning with the goals of the Convention on the Rights of Persons with Disabilities (Organização das Nações Unidas, 2006).

Additionally, probabilistic sampling approaches, when feasible, or post-stratification weighting strategies may improve external validity. Given the scarcity of national data on the needs of children with ASD and NDD, developing more robust research designs is essential for generating evidence capable of informing equitable public policies that adequately respond to Brazil's regional and social disparities.

Regarding educational inclusion, most children (66.8%) were enrolled in regular schools, a finding aligned with Brazil's National Policy on Special Education (Brasil, 2008), which mandates inclusive practices throughout the educational system. These results are also consistent with previous data from Latin America indicating similar regional trends in school enrollment for children with developmental disabilities (Montiel-Nava et al., 2020). When examining caregivers' educational attainment within the sample—34% with postgraduate degrees, 19% with higher education, and 20% with elementary schooling—these values remain significantly higher than national estimates. Although educational attainment in Brazil has improved substantially over

the past decades, as reflected in census data showing reductions in the proportion of individuals with minimal schooling and increases in those holding higher degrees ((Instituto Brasileiro de Geografia e Estatística (IBGE), 2023), considerable regional disparities persist. Studies conducted in the Northeast, for example, demonstrate lower levels of maternal education among families of children with disabilities (Sá et al., 2020), underscoring the heterogeneity of the Brazilian population and suggesting that our sample represents a more socioeconomically advantaged subset.

Most respondents were from families with children with ASD, followed by those with ADHD and Genetic Syndromes. This may relate to factors such as the support for dissemination coming from family groups of people with autism and the fact that many syndromes, such as Down syndrome, Fragile X, and some rare syndromes, are associated with ASD.

Data were comprised mostly of women and mothers, with ages varying between 26 and 55 years old, which is consistent with other national and international studies. In most cases, mothers assume the care of the child in the case of a disability, which reinforces the discourse that women are socially charged with caring for their children (Barokova et al., 2022; Sá et al., 2020). Another noteworthy data point is the high rate of married parents, in line with other studies, such as those carried out in Bulgaria, where 84.1% are married. In Brazil, a study conducted in 2020 portrays a peculiar situation: an increase in the number of cases of microcephaly detected in children born in the second half of 2015, from 162 occurrences to more than 1,608 in less than a year (Sá et al., 2020). This condition is associated with several impairments in bodily functions, leading to limitations in child development as a result of the congenital syndrome associated with the Zika virus (SCZV). Severe developmental risk conditions, such as motor impairment, autism, and visual loss, impact the organization of families. The researchers point out that more than half of the sample remained married and that the presence of a child with a disability was not a determining factor in the marital crisis for this sample. However, they emphasize that the individual characteristics of the couple are more evident in the crisis of perceiving a child with significant developmental delays. The authors note that the arrival of a child with serious developmental sequelae revealed a controversy in the mothers' discourse when investigating the marital relationship, with some pointing to marital distance and others feeling closer to the couple (Sá et al., 2020).

A surprising finding was that most of the participants worked before the diagnosis, and a little more than half of these left work because of their child's condition. In this sample, most had higher education, yet they felt the need to leave their jobs to care for the child. Sá et al. (2020) highlight that the caregiver's burden impacts their personal and work lives and, consequently, the family's financial situation, as there is inevitably an increase in expenses related to doctors, therapies, transport, and medicines, among others. In Brazil, higher education is not a guarantee of good salaries, as the data reveal that families' incomes are low. Oliveira (2021) corroborate this finding, highlighting that the burden for the caregiver, in this case the mothers, is greatly increased when there is little social and marital support and limited access to health services, especially when the child's developmental characteristics are more challenging. According to the authors, the combination of these factors prevents them from reviewing the strategies for coping with the situation and forces them to abandon their professional lives, negatively impacting the mother's wellbeing.

Other research in Brazil corroborates the findings that in most cases it is the parents who perceive the delay or difference in development. Ribeiro et al. (2017) state that mothers are concerned about the delay in child development before the age of 2; however, the authors note that in most cases, the confirmation of a diagnosis occurs around 5 years of age in families with low schooling. The authors point out that a little over half of the responding mothers report negative experiences with medical services, feeling discouraged from pointing out delays, as a diagnosis was dismissed by pediatricians in the identification of signs of ASD or NDD (Gomes et al., 2015). These results do not differ from studies in other countries, according to WHO (2017) and Van Cong et al. (2015). Yet, some data indicate that families receive little information regarding developmental delays, and 46% feel frustrated when searching for interventions (Paula et al., 2020).

A notable fact that contradicts the literature is that approximately 68% of the sample reported being diagnosed before the age of 3. This may be influenced by biases in the sample, as further explained. International studies indicate that the overall mean age at diagnosis of ASD was 51 months, regardless of sex and racial and ethnic groups, when not associated with cognitive impairment (Maenner et al., 2020). A minority of children are diagnosed early, especially those with mild symptoms (Sheldrick et al., 2017). In Brazil, the average delay between the onset of symptoms perceived by parents and the reported diagnosis was 3 years (Ribeiro et al., 2017), which, according to the authors, indicates a lack of preparation in the health network to carry out this diagnosis. A factor that may be contributing to early diagnosis, according to Wallace et al. (2012), is the increasing awareness of the topic fostered by studies, parent-led organizations, and NGOs, in addition to scientific meetings, conferences, and research.

More than half of the children of the sample participants attended regular schools; only a small percentage attended special schools for children with disabilities or were in alternative educational settings. According to Minetto (2021), despite the difficulties in practice, inclusion is a fact supported by legislation in Brazil. However, the author points out the many challenges in meeting diversity with quality, which is confirmed by the data found here. When asked about academic support, only half of the participants indicated that schools offer additional support, while a third stated that there is no support, and a smaller group of participants did not know if any differentiated support was available. Faria et al. (2018), in a study with more than 100 teachers, identified that they possess good theoretical knowledge and training regarding the needs for accommodations and/or curricular adaptations in inclusive cases. Research data also indicate that teachers recognize the need for differentiated pedagogical practices so that all students can learn, but only 56% of teachers managed to implement changes in their practices.

The results of the differences between families of children with NDD and those with ASD indicate that families with children with ASD face slightly more difficulties in accessing medical, counseling, and educational services. This can be explained by the longer wait

times to receive a diagnosis; unfortunately, this has not been previously evaluated in the region.

The parents' employment situation was emphasized in relation to seeking medical care, education for their children, counseling, knowledge of their rights, and social and financial relationships. Regarding the challenges faced and the priorities of the participants, the education of the children and medical care are highlighted, both showing statistical associations.

Finally, this study offers contributions to the development of public policies in Brazil that must focus on ensuring adequate education and medical access, aimed at reducing behavioral, motor difficulties, repetitive behaviors, and increasing opportunities for social interaction and communication, as well as supporting caregivers in maintaining employment.

In light of the challenges posed by the COVID-19 pandemic, it was not possible to conduct an active public search or facilitate in-person filling in the health and educational systems of Brazil. Thus, all contact with caregivers was made through the researcher's social networks. This may reflect a bias in socioeconomic and educational aspects and may not fully represent the Brazilian social reality. Still, the sample size is quite significant.

In conclusion, this study offers one of the largest national datasets on families of children with ASD and NDD in Brazil; however, its findings must be interpreted in light of the sample's socioeconomic and regional biases. Nevertheless, the unmet needs identified here mirror global evidence showing persistent inequities in diagnosis, service access, and family support. The *Lancet Commission on the Future of Care and Clinical Research in Autism* highlights that such gaps are widespread and reflect structural shortcomings in care systems worldwide. Recent CDC surveillance data similarly document rising ASD prevalence and ongoing disparities across communities (Centers for Disease Control and Prevention, 2025). These international benchmarks reinforce the urgency for Brazil to expand equitable diagnostic pathways, strengthen educational and therapeutic services, and develop coordinated public policies that meet the diverse needs of children with developmental disabilities and their families.

5 Final considerations

Although this study is shaped by a socioeconomically advantaged and digitally connected sample, its large size (n = 4,940) provides robust insights into the experiences of a substantial segment of Brazilian caregivers. The unmet needs and barriers reported here echo global evidence of persistent inequities in diagnostic access, service coordination, and family support for neurodevelopmental conditions. Even in comparatively favorable contexts, families continue to face systemic obstacles, a pattern highlighted by both the Lancet Commission on the Future of Care and Clinical Research in Autism and recent CDC surveillance documenting rising ASD prevalence and ongoing disparities in care (CDC, 2025). These converging findings reinforce the urgency for Brazil to strengthen early diagnostic pathways, expand specialized health and counseling services, and ensure the effective implementation of inclusive educational policies. Investing in these areas is essential to advance equity, reduce regional and socioeconomic gaps, and support the developmental trajectories of children with ASD and other NDDs as well as the wellbeing and socioeconomic stability of their caregivers. Future studies should prioritize diverse recruitment to validate these findings across Brazil's socioeconomic spectrum.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the Ethics Committee of the Universidade Federal do Paraná (CEP/UFPR), CAAE No. 29706720.4.0000.0102, on August 17, 2021. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent from the participants was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

MF: Supervision, Writing – original draft, Writing – review & editing. LK: Formal analysis, Methodology, Software, Writing – original draft, Data curation, Investigation, Supervision. EM: Funding acquisition, Project administration, Resources, Visualization, Writing – review & editing. AC: Formal analysis, Investigation, Methodology, Software, Writing – original draft.

Funding

The author(s) declared that financial support was not received for this work and/or its publication.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declared that Generative AI was not used in the creation of this manuscript.

Any alternative text (alt text) provided alongside figures in this article has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

References

Alonso Soriano, C., Hill, E. L., and Crane, L. (2015). Surveying parental experiences of receiving a diagnosis of developmental coordination disorder (DCD). *Res. Dev. Disabil.* 43–44, 11–20. doi: 10.1016/j.ridd.2015.06.001

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders. 5th Edn. Washington, DC: American Psychiatric Publishing doi: 10.1176/appi.books.9780890425596.

Autism Speaks Global Public Health Initiative (2016) Available online at: https://www.autismspeaks.org/global-autism-public-health-initiative-gaph (Accessed January 20, 2026).

Barokova, M. D., Andreeva-Sapundzhieva, A., Andonova, E., Markova-Derelieva, G., and Karpur, A. (2022). Diagnostic paths and service needs of children with autism spectrum disorder and with other neurodevelopmental disorders in Bulgaria. *Front. Psych.* 13:937516. doi: 10.3389/fpsyt.2022.937516

Bölte, S. (2023). A more holistic approach to autism using the international classification of functioning: the why, what, and how of functioning. Autism 27, 3–6. doi: 10.1177/13623613221136444

Brasil (2008). Ministério da Educação. Política Nacional de Educação Especial na Perspectiva da Educação Inclusiva. Secretaria de Educação Especial. Available at: https://pnee.mec.gov.br/integra (Accessed January 15, 2026).

Brasil (2012). "Lei n° 12.764, de 27 de dezembro de 2012" in Institui a Política Nacional de Proteção dos Direitos da Pessoa com Transtorno do Espectro Autista. Available online at: https://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/l12764.htm

Brasil (2023). "Ministério dos Direitos Humanos e da Cidadania" in Novo Viver Sem Limite – Plano Nacional dos Direitos da Pessoa com Deficiência (Brasília, DF: MDHC. Available online at: https://novoviversemlimite.mdh.gov.br/

Brasil (2024). "Lei n° 15.069, de 23 de dezembro de 2024" in Institui a Política Nacional de Cuidados (Brasília, DF: Presidência da República. Available online at: https://www.planalto.gov.br/ccivil_03/_ato2023-2026/2024/lei/L15069.htm

Brazilian Network for Inclusive Education Assessment. (2022). Relatório anual. Available online at: https://ampid.org.br

Beaton, D. E., Bombardier, C., Guillemin, F., and Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine* 25, 3186–3191. doi: 10.1097/00007632-200012150-00014

Biernat, E., Gregerson, R., and Johnson, A. (2020). Online recruitment for autism spectrum disorder research: challenges and opportunities in diverse populations. *J. Autism Dev. Disord.* 50, 2854–2865. doi: 10.1007/s10803-020-04445-2

Centers for Disease Control and Prevention (2025). 2025 Community report on autism: Findings from the Autism and Developmental Disabilities Monitoring Network. U.S. Department of Health and Human Services. Available online at: https://www.cdc.gov/autism/media/pdfs/2025/04/ADDM-Community-Report-SY2022.pdf (Accessed January 16, 2026).

Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., et al. (2021). Centers for Disease Control and Prevention (CDC). (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, 65, 1–23. doi: 10.15585/mmwr.ss6503a1

Faria, K. T., Teixeira, M. C. T. V., Carreiro, L. R. R., Amoroso, V., and de Paula, C. S. (2018). Atitudes e práticas pedagógicas de inclusão para o aluno com autismo. *Rev. Educ. Espec.* 31, 339–352. doi: 10.5902/1984686X28701

Gomes, P. T. M., Lima, L. H. L., Bueno, M. K. G., Araújo, L. A., and Souza, N. M. (2015). Autism in Brazil: a systematic review of family challenges and coping strategies. *J. Pediatr.* 91, 111–121. doi: 10.1016/j.jped.2014.08.009

Instituto Brasileiro de Geografia e Estatística (IBGE). (2019). Pesquisa Nacional por Amostra de Domicílios Contínua (PNAD Contínua) 2019. Rio de Janeiro: IBGE. Available online at: https://www.ibge.gov.br

Instituto Brasileiro de Geografia e Estatística (IBGE). (2023). Censo Demográfico 2022: População e domicílios: Primeiros resultados. Available online at: https://biblioteca.ibge.gov.br/

International Test Commission (2017). The ITC guidelines for translating and adapting tests. 2nd. Edn. Available online at: https://www.intestcom.org/files/guideline_test_adaptation_2ed.pdf (Accessed November 29, 2025).

Lappé, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., and Kuo, A. A. (2018). The diagnostic odyssey of autism spectrum disorder. *Pediatrics* 141, S272–S279. doi: 10.1542/peds.2016-4300C

Maenner, M. J., Shaw, K. A., Baio, J., EdS1Washington, A., Patrick, M., et al. (2020). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveill. Summ.* 69, 1–12. doi: 10.15585/mmwr.ss6904a1

Matta G. C., S. Rego, E. P. Souto and J. Segata (Eds.) (2021). "A Covid-19 no Brasil e as várias faces da pandemia: Apresentação" in Os impactos sociais da Covid-19 no Brasil: Populações vulnerabilizadas e respostas à pandemia (Rio de Janeiro: Editora FIOCRUZ), 15–24.

Minetto, M. F. (2021). O currículo na educação inclusiva: Entendendo esse desafio. Curitiba: Editora Intersaberes.

Minetto, M. F., Crepaidi, M. A., Bigras, M., and Moreira, L. C. (2012). Práticas educativas e estresse parental de pais de crianças pequenas com desenvolvimento típico e atípico. *Educar em Revista* 43, 117–132.

Minetto, M. F., Crepaldi, M. A., and Martins, M. (2013). Particularidades de famílias que têm filhos com deficiência intelectual. *International Journal of Developmental and Educational Psychology* 1, 75–83.

Montiel-Nava, C., Cukier, S., Garrido, G., Valdez, D., Paula, C., García, R., et al. (2020). Service encounters across the lifespan in individuals with autism spectrum disorders: results from a multisite study in Latin America. *Res. Autism Spectr. Disord.* 79:101671. doi: 10.1016/j.rasd.2020.101670

Oliveira, C. M. (2021). Cuidar do outro e de si: Análise da sobrecarga do cuidador informal de crianças com deficiência [Master's thesis, Universidade Federal do Ceará, Campus Sobral]. Programa de Pós-Graduação em Saúde da Família.

Organização das Nações Unidas. (2006). *Convenção sobre os Direitos das Pessoas com Deficiência.* Available online at: https://www.un.org/development/desa/disabilities/

Organização Mundial da Saúde (2023) World report on disability 2023: Regional disparities in neurodevelopmental services WHO. Available online at: https://www.who.int/publications/i/item/9789240075050

Paula, C. S., Ribeiro, S. H., Fombonne, E., and Mercadante, M. T. (2011). Brief report: prevalence of pervasive developmental disorder in Brazil: a pilot study. *J. Autism Dev. Disord.* 41, 1738–1742. doi: 10.1007/s10803-011-1200-6

Paula, C. S., Fombonne, E., Gadia, C., Tuchman, R., and Rosanoff, M. (2020). Challenges, priorities and stigma for autism in Latin America. *Autism Res.* 13, 328–336. doi: 10.1177/1362361320940073

Ribeiro, S. H. B., Paula, C. S., Bordini, D., Mari, J. J., and Caetano, S. C. (2017). Barriers to early identification of autism in Brazil. *Rev. Bras. Psiquiatr.* 39, 352–354. doi: 10.1590/1516-4446-2016-2141

Sá, S. A. A. G., Galindo, C. C., Dantas, R. S., and Moura, J. C. (2020). Dinâmica familiar de criança com a síndrome congênita do Zika vírus no município de Petrolina, Pernambuco, Brasil. *Cad. Saúde Pública* 36:e00246518. doi: 10.1590/0102-311X00246518

Sheldrick, R. C., Maye, M. P., and Carter, A. S. (2017). Age at first identification of autism spectrum disorder: an analysis of two US surveys. *J. Am. Acad. Child Adolesc. Psychiatry* 56, 313–320. doi: 10.1016/j.jaac.2017.01.012

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., and Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders* 40, 167–178. doi: 10.1007/s10803-009-0844-y

Sousa, M. M. de (Org.). (2021). Autismo: legislação, jurisprudência e políticas públicas. 1ª Edn. Brasília, DF: OAB Editora.

Topolovec-Vranic, J., and Natarajan, K. (2016). The use of social media in recruitment for medical research studies: a scoping review. *J. Med. Internet Res.* 18:e286. doi: 10.2196/jmir.5698

United Nations (2006). Convention on the rights of persons with disabilities: UN General Assembly, A/RES/61/106, December 12, 2006. Available online at: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

Van Cong, T., Weiss, B., Toan, K. N., Le Thu, T. T., Trang, N. T., and Hoa, N. T. (2015). Early identification and intervention services for children with autism in Vietnam. *Health Psychol. Rep.* 3, 191–200. doi: 10.5114/hpr.2015.53125

Wallace, S., Fein, D., Rosanoff, M., Dawson, G., Hossain, S., Brennan, L., et al. (2012). A global public health strategy for autism spectrum disorders. *Autism Res.* 5, 211–217. doi: 10.1002/aur.1236

Whitaker, C., Stevelink, S., and Fear, N. (2017). The use of Facebook in recruiting participants for health research purposes: a systematic review. *J. Med. Internet Res.* 19:e290. doi: 10.2196/jmir.7071

World Health Organization (2014). Comprehensive and coordinated efforts for the management of autism spectrum disorders (WHA resolution 67.8). World Health Assembly, 67th session. Available online at: https://www.who.int/substance_abuse/research_tools/translation/en/ (Accessed May 3, 2020).

World Health Organization and United Nations Children's Fund (UNICEF) (2023). Global report on children with developmental disabilities: From the margins to the mainstream. Executive summary. Geneva: World Health Organization and United Nations Children's Fund (UNICEF). Licence: CC BY-NC-SA 3.0 IGO. Available online at: https://www.who.int/publications/i/item/9789240080539

Zwaigenbaum, L., Bauman, M. L., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L., et al. (2015). Early identification of autism spectrum disorder: recommendations for practice and research. *Pediatrics* 136, S10–S40. doi: 10.1016/j.bbr.2013.04.004