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ARTICLES

The cost of inclusion: race, gender, and the burden of family care for people with disabilities

O custo da inclusão: raça, gênero e sobrecarga no cuidado familiar de pessoas com deficiência

El costo de la inclusión: raza, género y sobrecarga en el cuidado familiar de personas con discapacidad

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Abstract
People with disabilities and their caregivers face a range of challenges. This study aimed to analyze the resources and challenges involved in the educational and social inclusion of people with disabilities, focusing on their relationship with care work and the realization of rights from the perspective of family members. A qualitative research design was used. Participants were 16 caregivers and one person with a disability. Semistructured interviews were conducted, processed using IRaMuTeQ, and interpreted through thematic analysis. The findings indicated multiple barriers to school inclusion, prejudice, and ableism. Care work, performed primarily by Black women, entails excessive demands. Full inclusion requires intersectoral policies, stronger schools, support for families, and a commitment to social justice.
Keywords: people with disabilities, inclusive education, family, special education, social exclusion

Resumo
As vivências de pessoas com deficiência (PcD) e de cuidadoras/es são marcadas por dificuldades. Objetivou-se analisar os recursos e dificuldades presentes nos processos de inclusão educacional e social de PcD, com foco na articulação entre o trabalho de cuidado e a efetivação de direitos, a partir da percepção de familiares. Trata-se de uma pesquisa qualitativa. Participaram 16 cuidadoras/es e uma PcD. Entrevistas semiestruturadas foram aplicadas, sistematizadas pelo software IRaMuTeQ e interpretadas via análise temática. Os resultados indicaram múltiplas barreiras na inclusão escolar, preconceitos e capacitismo. O cuidado, exercido majoritariamente por mulheres negras, é sobrecarregado. A inclusão plena exige políticas intersetoriais, escolas fortalecidas, apoio às famílias e compromisso com justiça social.
Palavras-chave*: pessoa com deficiência, educação inclusiva, família, educação especial, exclusão social.*

Resumen
Las vivencias de personas con discapacidad (PcD) y de personas cuidadoras están marcadas por dificultades. Se buscó analizar los recursos y dificultades de la inclusión educativa y social de las PcD, con énfasis en su articulación con el trabajo de cuidados, desde la perspectiva de sus familiares. En esta investigación cualitativa participaron 16 personas cuidadoras y una PcD. Las entrevistas semiestructuradas, procesadas en IRaMuTeQ, se interpretaron mediante análisis temático. Se identificaron múltiples barreras para la inclusión escolar, prejuicios y capacitismo. El cuidado, realizado mayoritariamente por mujeres negras, está marcado por la sobrecarga. La inclusión plena exige políticas intersectoriales, escuelas fortalecidas, apoyo a las familias y compromiso con la justicia social.
Palabras clave: *persona con discapacidad, educación inclusiva, familia, educación especial, exclusión social.*

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Introduction

Special education in Brazil historically developed within a segregationist framework. From the nineteenth century onward, with the establishment of the Imperial Instituto dos Meninos Cegos (Imperial Institute for Blind Boys; 1854) and the Instituto Nacional de Educação de Surdos (National Institute of Deaf Education; 1857), people with disabilities received services in settings separate from mainstream education, within a charity-based and clinical perspective that framed disability as an individual problem to be corrected or managed (Mazzotta, 2005). Throughout the twentieth century, this model was reinforced by the establishment and expansion of specialized institutions. Prominent among these is the Associação de Pais e Amigos dos Excepcionais (Association of Parents and Friends of Exceptional People, APAE), founded in 1954, which became one of Brazil's leading providers of services for people with intellectual disabilities. Although APAE played an important role in ensuring access to services where the state was absent, it also operated within a segregationist framework by keeping people with disabilities in settings separate from mainstream education, reinforcing the notion that these individuals do not belong in mainstream schools (Bueno, 1993; Jannuzzi, 2004). The fact that this study was conducted at an APAE makes this critical contextualization necessary.

Understandings of disability have changed over recent decades. The medical model, which predominated until the mid-twentieth century, located disability within the individual as a pathology to be cured or rehabilitated (Diniz, 2007; Oliver, 2013). In contrast, the social model, developed by British researchers from the 1960s onward, shifted the problem to the social, physical, and attitudinal barriers imposed on disabled bodies (Diniz, 2007; Oliver, 2013). The biopsychosocial model, incorporated into the United Nations Convention on the Rights of Persons with Disabilities (Organização das Nações Unidas [ONU], 2006) and the International Classification of Functioning, Disability and Health (ICF), proposes an approach that integrates biological, psychological, and social dimensions, recognizing that disability arises from the interaction between bodily characteristics and environmental barriers (Diniz et al., 2009; Organização Mundial da Saúde [World Health Organization, OMS], 2012). In Brazil, this debate has been advanced by researchers[1] who connect the biopsychosocial model with struggles for

[1] Note on language: In keeping with the principles of inclusion and diversity that underpin this study, gender-inclusive language is used to move beyond the androcentric conventions associated with the generic masculine.

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rights, questioning the persistence of paternalistic and ableist practices in public policy (Gesser et al., 2020, 2024; Marques et al., 2025; Mello, 2016).

In terms of access to rights, the adoption of the Brazilian Inclusion Law (LBI, Law No. 13.146/2015) represented a key legal milestone, consolidating a paradigm of autonomy and full participation in place of the charity-based and paternalistic framework that had historically guided policies for this population. However, recent research shows that the effective implementation of these rights remains uneven and shaped by social markers such as race, gender, territory, and social class (Gesser et al., 2024; Lage et al., 2023). However, effective educational inclusion requires not only legislation but also material conditions, intersectoral policies, and adequate training for teachers and other professionals involved in education (Abrahão et al., 2025; Silva et al., 2026).

Until the twentieth century, the education of people with disabilities was characterized by segregation, justified through religious, medical, and pedagogical discourses. Services were provided in specialized philanthropic institutions, with separate curricula that reinforced this population's exclusion from mainstream education. Although professionals and institutions serving blind people, deaf people, and other groups emerged, these services remained far removed from the idea of education as a universal right (Guimarães et al., 2021). From the 1990s onward, influenced by international frameworks such as the Salamanca Statement (1994), Brazil began to reorient its policies toward inclusive education. The Law of Guidelines and Bases of National Education (LDB, Law No. 9.394/1996) stipulated that special education is a form of education to be provided preferably within the mainstream school system. In 2008, the National Policy on Special Education from the Perspective of Inclusive Education (PNEEPEI) consolidated this paradigm, advocating access, participation, and learning in mainstream schools for students with disabilities, pervasive developmental disorders, and high abilities/giftedness (Brasil, 2008, 2012).

The recent trajectory of Brazilian special education has been marked by tensions between segregationist and inclusive perspectives. Decree No. 10.502/2020 was criticized for legitimizing segregated settings as the preferred option, constituting a setback for inclusive education (Gallert & Pertile, 2022). Following its repeal by the Supremo Tribunal Federal (Federal Supreme Court, STF) in 2023 (Decree No. 11.370/2023; Brasil, 2023), Decree No. 12.686/2025 established the National Policy on Inclusive Special Education and the National

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Network of Inclusive Special Education, reaffirming the right to schooling in mainstream schools (Brasil, 2025). Advances include continuing teacher education, the strengthening of specialized educational support (Atendimento Educacional Especializado, AEE) as a complementary rather than substitute service, the expansion of assistive technology, and recognition of intersectionality in educational inequalities, in line with recommendations for multilevel support and shared intersectoral responsibility (Ainscow, 2020; Brasil, 2025; UNESCO, 2020). In this context, APAEs, recognized as private nonprofit organizations eligible for public support (Brasil, 1996, art. 60), were called upon by CNE/CEB Resolution No. 4/2009 to transition from operating as special schools that replace mainstream schooling to serving as AEE centers that complement mainstream schools.

Inclusion extends beyond access, requiring continued participation and quality through curriculum adaptations, accessibility, assistive technology, a welcoming environment, and recognition of individual progress (Abrahão et al., 2025; Piccolo, 2023). However, challenges such as increasingly precarious conditions for teachers, underfunding, regional inequalities, and attitudinal barriers threaten the continuity of inclusive policies (Castro & Vilela-Ribeiro, 2020). Intersectoral practices, flexible curricula, and formative assessment are essential to sustaining these policies. Inclusion, care, and social participation are understood as inseparable dimensions: There is no learning without care, and no educational inclusion without social inclusion. This historical trajectory and the struggles against prejudice and ableism reinforce the contemporary understanding of disability as a social construct and a human rights issue. Although disability is a human condition, whether congenital or acquired over the life course, it is mediated by the social, cultural, and material context. It is not disability itself that constitutes an expression of the social question, but rather the conditions of exclusion and impoverishment, together with the social, attitudinal, architectural, and communication barriers produced in the relationships between capital, labor, and society (Conselho Federal de Serviço Social [Federal Council of Social Work, CFESS], 2019; Iamamoto, 2001; Oliver, 2013; ONU, 2006).

Sociodemographic data also reflect these tensions. In 2022, the Instituto Brasileiro de Geografia e Estatística (Brazilian Institute of Geography and Statistics, IBGE) definitively adopted this international standard, identifying 14.4 million people with disabilities, corresponding to 7.3% of the population. Regional inequalities, population aging, and the impact of socioeconomic vulnerabilities are clearly evident in these data, demonstrating that disability cannot be understood without examining social conditions. In education, the data

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reveal stark inequalities: While more than 63% of adults with disabilities had not completed primary and lower secondary education, only 7.4% had reached higher education, and illiteracy remained significantly higher than among people without disabilities (IBGE, 2025). These data underscore that disability is profoundly shaped by structural inequalities and that exclusion from schooling remains one expression of institutional ableism.

Ableism is associated with the idea of normative embodiment and the exclusion of bodies and minds that differ from the standard considered normal (Gesser et al., 2020, 2024; Mello, 2016; Mello et al., 2024). It is a structural system that ranks people according to functionality, productivity, and bodily normality, placing people with disabilities in a position of ontological and social inferiority (Tarvainen, 2019; von der Weid, 2025). The social response to this condition takes the form of devaluation, discriminatory practices, and violence (Diniz, 2007; Diniz et al., 2009; Gesser et al., 2024), manifested not only interpersonally but also institutionally and symbolically – embedded in public policies, pedagogical practices, inaccessible spaces, and narratives that represent disability as a personal tragedy or deviation from the norm (Oliver, 2013; Shakespeare, 2006; Tarvainen, 2019).

In this context, the struggle for rights comes to require not only legal recognition but also a fundamental cultural transformation. Marchesan and Carpenedo (2021) argue that ableism is rooted in the productivist logic of capitalism, which links social value to economic utility and relegates nonnormative bodies to subordinate roles. Confronting ableism therefore requires a critique of the logic that measures people's value by their productivity and reinforces class, racial, and gender inequalities. The international slogan "Nothing about us without us" encapsulates this demand for agency, affirming that policies and decisions cannot be made without the active participation of people with disabilities themselves.

The inequalities experienced by people with disabilities cannot be analyzed in isolation. An intersectional perspective demonstrates that multiple social markers operate simultaneously, shaping opportunities, rights, and forms of social participation (Crenshaw, 1991). Feminist disability studies constitute a fundamental theoretical field for this critical analysis, particularly by bringing together feminism, opposition to ableism, and intersectionality (Diniz, 2007; Diniz et al., 2009). In Brazil, women researchers show that women with disabilities experience specific forms of oppression arising from the combination of sexism, ableism, and other forms of discrimination, arguing that care, education, and health policies must be designed around these

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intersections or risk reproducing invisibility (Gesser et al., 2020, 2024; Mello, 2016). Crip feminism proposes an epistemology centered on the experiences of people with disabilities as the starting point for knowledge production and the transformation of public policy (Mello et al., 2024).

In special education, this intersection becomes relevant when examining who has historically been excluded from mainstream schools and how care and AEE practices reproduce or address these inequalities. In this respect, Decree No. 11.956/2024, which establishes the National Care Policy, represents an advance by defining care as a social right and a state responsibility, with a commitment to combating inequalities related to gender, race, disability, and income (Brasil, 2024). This policy breaks with the familistic logic that has historically assigned responsibility for caring for people with disabilities to women, particularly Black and low-income women, without social, economic, or institutional recognition (Carloto & Mariano, 2010; Tartuce, 2013).

Care work is an essential social practice involving material, emotional, and technical activities directed toward the well-being of others. Although indispensable to life and social cohesion, it continues to be rendered invisible and devalued, profoundly shaped by gender, racial, and class inequalities. This erasure deepens when care is provided to people with disabilities, a historically marginalized group facing social, symbolic, and structural barriers that make care practices even more complex. This brings into focus the social devaluation of care, its intersectional dimensions, and its specific character in the context of disability (Hirata, 2022).

Care has roots in the earliest human societies, in which cooperation and mutual assistance were essential to survival, with women assuming a central role in this activity. In the pre-Christian period, illness and disability were viewed as divine punishment, and care was provided by priests and women healers through rituals and medicinal plants. With Christianity, care acquired a moral and charitable character, becoming associated with religious practices and the first hospitals. In the nineteenth century, Florence Nightingale revolutionized care by introducing hygiene, organization, and nutrition during the Crimean War and recognizing the influence of physical, psychological, and social factors on healing – a perspective that subsequently inspired the Brazilian public health model (Silveira-Alves et al., 2020; Tartuce, 2013).

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Hirata (2020) emphasizes that care has always been associated with women's labor and the working classes, and is now shaped by migration flows that constitute what she calls a "global chain of affection and assistance," marked by inequalities between countries and a racialized international division of reproductive labor. In Brazil, this division takes specific forms: Care is provided predominantly by Black and mixed-race women, many from the North and Northeast regions, who occupy precarious positions in large urban centers.

The feminization and racialization of care are rooted in Brazil's legacy of slavery, which associated Black women's bodies with servitude. Following abolition, Black women were channeled into domestic work in White households, perpetuating the racial division of reproductive labor from the colonial-era enslaved domestic servant to the modern domestic worker (Passos, 2017). This legacy persists, with Black and poor women forming the foundation of the care workforce and facing low wages, a lack of rights, and emotional overload, while middle- and upper-class White women transfer these responsibilities to them.

The Brazilian state has historically failed to establish care policies, transferring this responsibility to families and, above all, to women, thereby making care privatized and familistic. Capitalism consolidated this logic by separating productive labor, associated with the market and men, from reproductive labor, naturalized as women's work and performed "out of love," allowing its exploitation without recognition (Leite, 2023).

From the 1970s onward, population aging, the retrenchment of social policies, and women's entry into the labor market generated the so-called "care crisis," a structural contradiction in which capitalism depends on the reproduction of life but does not provide the conditions to sustain it. Social reproduction theory demonstrates that care is central to maintaining the labor force and to capital accumulation, although it continues to be rendered invisible. In contexts involving disability, this contradiction intensifies because the physical, emotional, and financial costs of care are much greater, while institutional recognition remains minimal (Leite, 2023).

This precarity also extends to paid care work. In Brazil, as Hirata (2020) argues, growing demand for women caregivers has led to the sector's expansion, but through informal arrangements characterized by inadequate training, precarious employment, low wages, and a lack of social protection. The Brazilian Classification of Occupations recognized caregiving as an occupation only in 2002, and comprehensive professional regulation is still lacking. In

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disability-related care, this precarity is even more pronounced: Long working hours, complex responsibilities, and insecure employment combine to produce extremely demanding working conditions. Batista and Bandeira (2015) observe that affection, although an essential element of care, is frequently instrumentalized to justify the economic devaluation of this work, reinforcing the idea that care is a moral obligation rather than skilled work. However, as Leite (2023) notes, implementation faces challenges such as a lack of funding, institutional fragmentation, and gender conservatism, which continues to assign primary responsibility for care to women.

Valuing care requires policies structured around three dimensions (Fraser, 2016): redistribution (expanding public services so that care does not fall exclusively on low-income women); recognition (assigning social and economic value to care, challenging its perception as secondary work); and representation (ensuring the active participation of women caregivers and people with disabilities in shaping these policies). As Hirata (2022) and Leite (2023) emphasize, discussing care means questioning the structural foundations of contemporary capitalism, which relies on the exploitation of reproductive labor, racial inequality, and the sexual division of labor. In the field of disability, rethinking care is essential to ensuring autonomy, dignity, social participation, and the realization of rights. Making visible this work, which has historically been concealed by discourses of love, vocation, and sacrifice, is an essential step toward building a more just and inclusive society committed to sustaining life.

The National Care Policy directly connects with debates on disability and special education by recognizing that people with disabilities are subjects of care with specific needs and that caregivers, often family members, predominantly women, and socially vulnerable, need support, training, and social protection to perform this role with dignity (Brasil, 2024). This perspective moves beyond the residual and fragmented approach that characterized earlier policies, proposing an integrated, intersectoral, and intersectional understanding of care as a foundational public policy.

Given the complexity surrounding the inclusion of people with disabilities in contemporary society, this study aimed to analyze the resources and difficulties involved in their educational and social inclusion, focusing on the relationship between care work and the realization of rights, from the perspectives of family members and the participant with a disability.

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Method

This qualitative, descriptive, cross-sectional field study forms part of a larger multimethod project.

Participants

Participants were selected through convenience sampling, an approach widely used in exploratory qualitative research (Creswell & Creswell, 2021). This sampling strategy is considered appropriate when the aim is to examine individual experiences rather than to achieve statistical generalizability (Minayo et al., 2015).

The study included 17 participants, of whom 16 were caregivers, predominantly women (n = 13, 76.7%): 12 mothers, 1 sister, 1 father, and 2 people with other relationships to individuals with disabilities served by an APAE in a medium-sized municipality in the state of São Paulo. The students with disabilities whose families participated in the study ranged in age from 17 to 55 years. Intellectual disability was predominant (n = 7); multiple disabilities (n = 1) and Down syndrome (n = 9) were also reported. Regarding schooling, 10 students had attended APAE exclusively for educational provision, while 4 attended both a mainstream public school and APAE for complementary AEE services; 2 3, had attended mainstream education. Participant 17 is a person with a disability who completed the interview independently, without mediation by a family member or caregiver. This is significant because it demonstrates the capacity for self-determination and direct expression of experiences, perspectives, and needs, in line with the principle "Nothing about us without us," which guides the disability rights movement and disability studies (Diniz, 2007).

Regarding race/ethnicity, 47.1% of caregivers were White, while 52.9% self-identified as Black/mixed-race. In terms of socioeconomic status, 47% of participants received income from work. The mean income of the participants interviewed was 2 times the minimum wage (then set at BRL 1,412.00), with the main sources of income being cash transfer programs and government benefits such as the Continuous Cash Benefit (BPC), retirement pensions, survivors' pensions, and sickness benefits.

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Setting

The APAE where the study took place is a philanthropic organization founded in 1967 and affiliated with the Federação Nacional das APAEs (National Federation of APAEs, FENAPAES), a network comprising 2,275 units across all Brazilian states and constituting the largest social movement of people with disabilities in Latin America (FENAPAES, 2023).

The unit studied offers the following services in line with education, health, and social assistance policies. The organization serves more than 1,400 service users each month. simultaneously in a mainstream school within the municipal or state public school system.

Instruments

Semistructured interview: The interview included questions designed to characterize the resources and challenges of caregivers and people with disabilities in relation to social and educational inclusion and to collect sociodemographic data. The interview guide comprised 36 questions organized around the following thematic areas: 1. Socioeconomic and family profile: caregiver characteristics (age, educational attainment, family income, household composition, and relationship to the person with a disability); 2. Caregiving trajectory: onset of caregiving responsibilities, daily care routines, division of tasks within the family, and effects on the caregiver's professional and social life; 3. Access to education and specialized services: the educational trajectory of the student with a disability, experiences with APAE and mainstream schools, perceptions of AEE, and barriers and facilitators to accessing education; 4. Ableism and discrimination: experiences of prejudice, exclusion, and violence affecting the person with a disability and the family in school, social, and institutional settings; 5. Public policies and access to rights: knowledge of and access to benefits, social programs, and policies protecting people with disabilities and caregiving families.

Procedures

Following authorization and approval from the municipal APAE's management and the Ethics Committee (CAAE: 3 78707824.6.0000.5408), legal guardians were contacted. A meeting was scheduled with the individuals who comprised the sample and agreed to participate. Interviews were conducted individually at APAE by two female researchers who were undergraduate social work students, with an average duration of 90 minutes. Participants signed an informed consent form (TCLE).

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Data analysis

Sociodemographic data were analyzed using frequencies in Excel, and interview responses were transcribed and entered into a Word document in accordance with the software's guidelines for preparing the textual corpus. Responses were analyzed quantitatively and qualitatively using IRaMuTeQ. IRaMuTeQ (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) was developed in 2009 by Pierre Ratinaud. It is free, open-source software licensed under the GNU GPL (v2) and runs in the R statistical environment. It uses the same algorithm as Alceste to perform statistical analyses of texts, with additional features such as descending hierarchical classification (DHC) and other lexical analyses that support text analysis and interpretation. The dendrogram generated by IRaMuTeQ provides a visual representation of how the program organized the text into thematic groups. The percentages indicate the proportion of the analyzed material represented by each class. Examining the dendrogram helps identify which themes are most distinct and which are more closely related. Each class is interpreted by examining its most frequent words and the excerpts that best represent the group. The dendrogram thus organizes the text visually and provides a clear basis for understanding the main themes in the statements analyzed. IRaMuTeQ processes text to identify vocabulary, enabling inferences about the ideas conveyed by the textual corpus. Textual corpora are considered suitable for analysis in IRaMuTeQ when retention rates are 75% or higher (Salviati, 2017), a criterion met in this study. The resulting classes were then interpreted through thematic analysis. This flexible, interpretive approach allows patterns of meaning (themes) in the data to be identified, analyzed, and reported (Braun & Clarke, 2006).

Results and discussion

The textual corpus, comprising 17 interviews, was analyzed and classified, yielding a retention rate of 82.61%, which was therefore deemed meaningful. DHC yielded seven lexical classes, which were interpreted and named through thematic analysis.

Figure 1 shows the connection between Classes 1 and 7, which IRaMuTeQ grouped together based on similar themes. These classes represent the resources and challenges involved in the educational and social inclusion of people with disabilities, with a focus on the interconnections involving care work from family members' perspectives. The classes will be presented and discussed according to the relationships between their themes.

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Figure 1

Dendrogram of the distribution of classes



Class 4 (13.2%)	Class 5 (11.8%)	Class 7 (13.2%)	Class 1 (18.4%)	Class 2 (11.8%)	Class 3 (14.5%)	Class 6 (17.1%)
Academic skills and achievements attained	Lack of access to and poor quality of educational services	Expectations regarding the development of new skills and/or autonomy among people with disabilities	Difficulties in access to and continued participation in education for students with disabilities	Architectural, urban, and attitudinal barriers in the lives of people with disabilities	Effects of exclusion on mothers' lived experiences	Effects of social stigma and care on caregivers' lives
TO WRITE *escrever*	OWN *próprio*	NEVER *nunca*	TEACHER *professor*	PERSON *pessoa*	MOTHER *mãe*	EMPATHY *empatia*
TO COMMUNICATE *comunicar*	TO ATTEND *frequentar*	EXPECTATION *expectativa*	BEFORE *antes*	TO WALK *andar*	PREJUDICE *preconceito*	TO GIVE *dar*
TO READ *ler*	EDUCATION *ensino*	RELATIONSHIP *relação*	TO STUDY *estudar*	DAY *dia*	TO GO THROUGH *passar*	ATTENTIVE *atenta*
HERE *aqui*	TO LEARN *aprender*	TO ATTEND *frequentar*	SUPPORT *apoio*	WHEELCHAIR *cadeira*	A LOT *muito*	LACK *falta*
ALREADY *já*	TO MANAGE TO *conseguir*	TO WANT *querer*	FINE/CALM *tranquilo*	TO SPEAK *falar*	YES *sim*	TO CARE FOR *cuidar*
TO DRAW *desenhar*	TO NOTICE *perceber*	SCHOOL *escola*	CLASSROOM *sala*	GREATER *maior*	SHOULD/MUST *dever*	DIFFICULT *difícil*
TO HOPE/WAIT *esperar*	MAINSTREAM *regular*	TO HAVE *possuir*	SPACE *espaço*	TO THINK *achar*	CAREGIVER *cuidador*	TOGETHER *junto*
TO HELP/AIDE *auxiliar*	SPECIAL *especial*	INDEPENDENT *independente*	TO PUT/PLACE *colocar*	TO CHANGE *mudar*	TO DIE *morrer*	CARE *cuidado*
TIME (OCCASION) *vez*	LESS *menos*	ONLY *apenas*	TO NEED *precisar*	LIFE *vida*	TO LIVE (RESIDE) *morar*	INCLUSION *inclusão*
WELL *bem*	TO HOPE/WAIT *esperar*	ALREADY *já*	ONLY *só*	WHEN *quando*	NOW *agora*	STILL *ainda*
EDUCATION *ensino*	TO WALK *andar*	APAE *APAE*	FRIEND *amigo*	SPACE *espaço*	PLACE *lugar*	HELP *ajuda*
A LOT *muito*	TO READ *ler*	CURRENTLY *atualmente*	ALWAYS *sempre*	TO ADAPT *adaptar*	TO THINK *achar*	THING *coisa*
ALWAYS *sempre*	PREJUDICE *preconceito*	ALWAYS *sempre*	UNTIL/EVEN *até*	CRAZY *doido*	DISABILITY *deficiência*	TO LIKE *gostar*
TO PUT/PLACE *colocar*	DIFFICULTY *dificuldade*	DIFFICULTY *dificuldade*	TO WANT *querer*	FIGHT *briga*	GOOD *bom*	FATHER *pai*
YOUTH/ADULT ED. *EJA*	EQUAL/SAME *igual*	MAINSTREAM *regular*	DIFFICULTY *dificuldade*	FATHER *pai*	WELL *bem*	TO CHANGE *mudar*

Source: prepared using Iramuteq software and adapted by the authors.

Caption: Dendrogram of lexical analysis with seven thematic classes on inclusion, disability, and education, generated using textual analysis software.

Description: The figure consists of a dendrogram at the top and a table of words organized by classes at the bottom, presented against a white background. The dendrogram, located in the upper section of the figure, is composed of horizontal and vertical lines representing the hierarchical division of the textual corpus into groups. The tree structure indicates that the corpus was divided, at the first level, into two major branches. The left branch is subdivided into two subbranches: the first groups Classes 4, 5, and 7; the second groups Classes 1 and 2. The right branch is subdivided into Classes 3 and 6. The dendrogram lines connect the successive groupings from top to bottom until reaching the seven individual classes. Below the dendrogram, the table is organized into seven colored columns, each corresponding to a class. Each column presents, in the first row, the class name and percentage; in the second row, the central theme of the class; and, in the following rows, the most characteristic words of that class, listed vertically. The word cells alternate between the class background color and yellow, possibly indicating different levels of chi-square values or statistical relevance. A detailed description of each column follows: Column 1 – Class 4 (13.2%), yellow background: theme: "Developed School-Related Skills/Achievements." Listed words: write, communicate, read, here, already, draw, wait, assist, turn, well, education, very, always, place, EJA. Column 2 – Class 5 (11.8%), orange background: theme: "Lack of Access to and Low Quality of Educational Services." Listed words: own, attend, education, learn, manage, perceive, regular, special, less, wait, walk, read, prejudice,

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difficulty, equal. Column 3 – Class 7 (13.2%), purple/magenta background: theme: "Expectations Regarding the Development of New Skills and/or Autonomy among Persons with Disabilities." Listed words: never, expectation, relationship, attend, want, school, possess, independent, only, already, APAE, currently, always, difficulty, regular. Column 4 – Class 1 (18.4%), blue background: theme: "Difficulties in Access to and Retention of Students with Disabilities in Education." Listed words: teacher, before, study, support, calm, classroom, space, place, need, only, friend, always, even, want, difficulty. Column 5 – Class 2 (11.8%), green background: theme: "Architectural/Urban and Attitudinal Barriers Present in the Lives of Persons with Disabilities." Listed words: person, walk, day, wheelchair, speak, greater, think, change, life, when, space, adapt, crazy, argument, father. Column 6 – Class 3 (14.5%), lilac/light purple background: theme: "Impacts of Exclusion on Mothers' Experiences." Listed words: mother, prejudice, go through, very, yes, duty, caregiver, die, live, now, place, think, disability, good, well. Column 7 – Class 6 (17.1%), red background: theme: "Impacts of Social Stigma and Caregiving on the Lives of Caregivers." Listed words: empathy, give, attentive, lack, care, difficult, together, caregiving, inclusion, still, help, thing, like, father, change.

Class 1 – Difficulties in access to and continued participation in education for students with disabilities (accounting for 18.4% of the text) – is characterized by the central word "professor" [teacher], followed by "antes" [before] and "estudar" [to study]. It illustrates the barriers students with disabilities encounter in accessing education, including inadequate urban infrastructure and architectural design, insufficient preparation of institutional staff, and prejudice. The statements – "He wasn't adjusting, and the students and teachers abused him" (participant 1) and "He had difficulties when he switched to a teacher who came here from the school system; that was a long time ago." (participant 15) – suggest that mainstream education presents more barriers. However, both mainstream and special education present difficulties, as illustrated by the statement: "He had difficulties. Before, there was an uncovered ceiling, and I fought to get them to put a roof on it. Before, students who used feeding tubes couldn't study here. My son was the first because he was already studying here before he needed a feeding tube. Before, there also wasn't a dedicated space to feed the children. Before, students with feeding tubes didn't take part in physical education either, and now they do." (participant 13). In this respect, the class reveals the persistence of structural, pedagogical, and attitudinal barriers that undermine the effectiveness of inclusive policies, confirming the gap between advanced legal frameworks, such as the LBI (Brasil, 2015) and the PNEEPEI (Brasil, 2008), and the realities experienced in schools, as discussed in the literature (Castro & Vilela-Ribeiro, 2020; Kassar et al., 2019). The absence of adequate architectural and material conditions illustrates the gap between inclusive discourse and practice. These challenges confirm that inclusion extends beyond enrolling students with disabilities: It requires changes in school culture, collective commitment, and public policies that ensure both access and continued participation in quality education (Abrahão et al., 2025; Kassar et al., 2019). Thus, the gap between legal provisions and

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school practice, already documented by Castro and Vilela-Ribeiro (2020) and Kassar et al. (2019), cannot be understood without considering the social hierarchies that determine which families have a voice, resources, and time to fight for better schooling conditions.

Class 7 – Expectations regarding the development of new skills and/or autonomy among people with disabilities (accounting for 13.2% of the text) – has "nunca" [never] as its central word, followed by "expectativa" [expectation] and "relação" [relationship]. It illustrates the difficulties caregivers face regarding the lack of independence of people with disabilities, framed by a perception of regression and limited expectations, with negative social consequences for those providing care. These difficulties are expressed in the statements – "Right now, I don't have many expectations because they're already quite old." (participant 8), "I feel that my relationships are affected because of people's contempt for my disability." (participant 17), and "My expectations are for him to be more independent. I will never give up on him, and I will always be available to help him." (participant 2).

Class 7 highlights the tension between hope and discouragement that shapes families' and caregivers' expectations regarding the development of people with disabilities. This contrast reveals the influence of social representations of disability, which remain characterized by a charity-based perspective and assumptions of dependency. As Guimarães et al. (2021) note, the development of people with disabilities is conditioned by the social and educational opportunities available to them, rather than by individual factors alone. Moving beyond this regressive view requires policies that recognize people with disabilities as rights holders with capacities for development (Dainez, 2017). An intersectional analysis reveals that the limited expectations expressed by caregivers are not merely an individual psychological phenomenon, but a response to structural conditions of deprivation. Low-income Black women caregivers without adequate institutional support face the dual invisibility of their own life aspirations and the capacities of the people with disabilities in their care. This invisibility is a direct product of ableism intertwined with racism and sexism (Gesser et al., 2024; Mello et al., 2024). Accordingly, the lowered expectations recorded in the narratives should not be read as a lack of affection or commitment, but as a concrete expression of the care crisis (Leite, 2023): When the state fails to act and the family, particularly women, is left to face the complexities of caring for a person with a disability alone, emotional exhaustion and material scarcity converge to narrow the horizon of possibilities. Broadening these expectations therefore requires not only pedagogical

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interventions, but also intersectoral policies that ease the burden on women caregivers and strengthen social support networks (Brasil, 2024; Hirata, 2022).

Class 4 – Academic skills and achievements attained (accounting for 13.2% of the text) – is characterized by the central word "escrever" [to write], followed by "ler" [to read] and "comunicar" [to communicate]. It shows that developing academic skills such as those expressed by these salient words constitutes a major achievement in the autonomy of people with disabilities. Caregivers thus describe these gains as a "victory," using words such as dreams and goals. This is illustrated by the statements – "Reading and writing – he has already achieved the dream" (participant 1) and "He can read a little, writes, draws, signs his name, and communicates a lot" (participant 16).

Families' accounts indicate positive perceptions of the development of students with disabilities after they began receiving AEE, consistent with literature identifying this service as an important source of support throughout students' educational trajectories (Mendes, 2006). However, these reported advances constitute subjective data and do not establish a direct causal relationship with AEE or conclusively demonstrate the success of inclusive practices more broadly (Ainscow, 2020). Family perceptions are socially relevant data in their own right, as they reveal how families make sense of institutional practices and develop expectations regarding their children's schooling (Polônia & Dessen, 2005).

The enthusiastic celebration of skills such as reading, writing, and communicating indicates that these students entered school amid social expectations that they would learn little – an expectation that is itself a barrier. From an intersectional perspective, it can be inferred from the data that, it is important to recognize that the paths to these achievements differ. Students from more socioeconomically vulnerable families, whose women caregivers combine paid and unpaid work, have less time available for support with learning at home, increasing their exclusive reliance on the school environment to develop functional skills. This reinforces the need to consider AEE in conjunction with care policies and social protection policies for families (Brasil, 2024; Hirata, 2022). Given the predominance of participants whose schooling took place exclusively in special education (APAE, n = 10), this indicates that, despite regulatory advances toward school inclusion, recent research shows that many families of people with intellectual disabilities still choose, or are prompted, to keep their children exclusively in specialized institutions such as APAEs, either because mainstream schools lack adequate

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support or because attitudinal and structural barriers persist in education systems (Kassar et al., 2019). This tension between inclusion and institutionalization constitutes one of the central analytical contexts of this study.

Class 5 – Lack of access to and poor quality of educational services (accounting for 11.8% of the text) – is characterized by the central word "próprio" [own], followed by "frequentar" [to attend] and "ensino" [education]. It shows that access to and continued participation in mainstream/special education are indispensable resources for promoting the independence of people with disabilities. However, the right to education is often denied, and when access is permitted, it is hindered by various barriers, including attitudinal and professional barriers. This is illustrated by the statements – ":When I realized that my son had achieved his own independence, like taking the bus on his own"; when asked about difficulties in mainstream education, "Bullying and teaching"; and when asked about difficulties in special education, "He didn't attend" (participant 11).

Class 5 highlights families' frustration with the precariousness of educational services and the explicit or implicit denial of the right to education. Poor-quality teaching and difficulties accessing both mainstream and special education reveal the gap between statutory guarantees and the daily experiences of people with disabilities. Castro and Vilela-Ribeiro (2020) further argue that the advancement of inclusive policies within a neoliberal framework has prioritized indicators and outcomes while neglecting the concrete conditions of learning. Thus, the lack of access to, and quality in, education constitutes both a structural failure and a violation of rights. In this respect, Law No. 13.935/2019, grounded in social work and psychological practice in school settings, brings together the democratization of access, continued participation, social justice, and the promotion of citizenship (CFESS & Conselho Federal de Psicologia [Federal Council of Psychology], 2020). This context indicates that, despite advances in inclusive education, persistent challenges require interdisciplinary and multidisciplinary work, community participation, and a move beyond the biologizing model (Abrahão et al., 2025).

The thematic analysis identified four lexical classes, accounting for 56.6% of the narratives (located on the left), that were associated with difficulties in education and revealed multiple dimensions of exclusion that run through the schooling experiences of people with disabilities. The classes reveal structural, pedagogical, and symbolic barriers that undermine access, continued participation, and the quality of the educational process (Ainscow, 2020).

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Class 2 – Architectural, urban, and attitudinal barriers in the lives of people with disabilities (accounting for 11.8% of the text) – features the word "pessoa" [person], followed by "andar" [to walk] and "dia" [day]. It illustrates families' perceptions of the insufficient dissemination of information on topics such as accessibility, inclusion, policies, and rights. These perceptions are expressed in the statements – "I think there is prejudice. I've experienced a lot of it in the street. Many people don't see people with disabilities as special, but as 'crazy.' I think it would be good for people to visit APAE more to learn about them, because the people close to me changed their minds when they met him." (participant 17), "Extremely poor. To get around downtown, for example, either two people have to help or the wheelchair tips over. There are no adaptations at all. Even the city council didn't have an accessible bathroom. The public employees' club doesn't even have a ramp. My son's wheelchair doesn't even fit onto the São José buses." (participant 13), and "Yes, I was ignorant, and I learned how to live. I came here with him when he was 6 days old. I changed completely. I learned that APAE isn't a place for crazy people, as people used to say, and I realized that everyone at APAE is very polite. I learned how to live; before, I didn't know how to share anything" (participant 15).

Class 2 highlights the lack of accessibility in public spaces and insufficient information about rights and inclusion, which reproduce segregation and everyday prejudice. The findings point to the interaction between people with disabilities and persistent environmental barriers that prevent their full and effective participation on an equal basis with others (Brasil, 2015). Although the LBI (Brasil, 2015) is the principal legal framework guiding legislators and public policymakers in guaranteeing the right of access and eliminating accessibility barriers, these requirements are not fully met.

Families' perceptions of prejudice and the inaccessibility of public spaces find empirical and theoretical support in the literature on structural ableism. As von der Weid (2025) and Tarvainen (2019) argue, barriers are not accidental but constitutive of a social order that ranks bodies according to functionality and productivity. An intersectional perspective further shows that urban and informational inaccessibility affects families differently. For women caregivers who depend on public transportation, live in peripheral neighborhoods, and have lower levels of education that affect their access to information about rights and policies, architectural and communication barriers compound socioeconomic barriers, producing a regime of multiple exclusion that renders both the person with a disability and their caregiver invisible (CFESS, 2019; Crenshaw, 1991; Mello, 2016).

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Whereas the other participants describe prejudice and barriers from a position of observation and care, participant 17 describes them through their own body, their everyday mobility, and their encounters with the gaze of others. This distinction is epistemologically significant and politically relevant. Theoretically, this particularity relates directly to the principle "Nothing about us without us," which guides the international disability rights movement and grounds its critique of the historically dominant charity-based and paternalistic model (ONU, 2006). Their narrative also reveals a central mechanism in the reproduction of ableism by highlighting social ignorance about disability as a driver of exclusion. This is supported by Tarvainen's (2019) analysis, which holds that ableism feeds on social representations that reduce people with disabilities to a homogeneous category of incapacity or deviance. The change in opinion among people close to them following direct contact

Class 3 – Effects of exclusion on mothers' lived experiences (accounting for 14.5% of the text) – is characterized by the central word "mãe" [mother], followed by "preconceito" [prejudice] and "passar" [to go through]. It shows that society is crucial to the meaningful inclusion of people with disabilities while also playing a central role in their exclusion, resulting in the distancing of people with disabilities and their families from social life. The class also presents the "mother" as the primary symbol of care, as reflected in the statements – "I think everyone should be treated equally, but there is still a lot of prejudice, even from mothers toward their children. I wish there wasn't prejudice in places like work, and so on. I wish people had more empathy." (participant 16), "Very poorly regarded; there's no inclusion in practice. Not everyone is prejudiced, but most people are. Unfortunately, many mothers of people with disabilities would have to live forever because there are so many challenges. I don't think people see the mentally disabled as disabled. When I go to the grocery store, the doctor, or anywhere else, I have to show his ID card." (participant 15), and "I started avoiding many places I used to go to" (participant 3).

Class 3, in turn, exposes the effects of exclusion on mothers and women caregivers, who assume the central role in care amid invisibility and social prejudice. This burden reflects gender inequalities and the absence of public support policies. As Iamamoto (2001) indicates, social inequalities generated under capitalism arise from the contradiction between collective production and the private appropriation of its fruits. This logic determines how people are perceived and treated socially according to their productive capacity, rendering invisible those

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who fall outside the norm of the productive worker, such as people with disabilities and their women caregivers (CFESS, 2019).

The centrality of the maternal figure in the narratives, expressed both in participants' statements and in the class's keyword itself, is a structural finding that calls for analysis. The "mother" as the universal subject of care is not a natural reality, but the historical product of the sexual division of labor, deepened in Brazil by the legacy of slavery, which assigned Black and poor women the care of bodies deemed dependent or unproductive (Hirata, 2020; Passos, 2017). Mothers who report avoiding public settings, facing prejudice in grocery stores and health services, or feeling that they "should live forever" describe an experience of exclusion shared by them and their children: The inclusion of people with disabilities is blocked by social prejudice and by the lack of support for women caregivers, who must withdraw from public life to ensure the survival and minimal participation of those in their care. This mechanism constitutes what Fraser (2016) calls the contradiction between the demands of labor market participation and the responsibilities of social reproduction. This contradiction falls disproportionately on low-income Black women caring for people with disabilities – precisely, also reflecting the profile of this sample.. In this respect, the National Care Policy (Brasil, 2024) represents an effort to break with this logic by proposing that care be recognized as a social right and a state responsibility. Its effectiveness, however, will depend on overcoming gender conservatism that continues to naturalize women's sacrifice as an expression of love (Leite, 2023).

Class 6 – Effects of social stigma and care on caregivers' lives (accounting for 17.1% of the text) – is characterized by the central word "empatia" [empathy], followed by "dar" [to give] and "atenção" [attention]. It shows how people's lack of understanding of disability affects the lives of people with disabilities and their families, while also expressing the need for care arising from a lack of independence. This is reflected in the statements – "Difficult. I wish people had more empathy for others." (participant 8), "No, what changed was the lack of money. Of course, I gave him a lot of attention; I had to devote myself to caring for him. The main difficulty was getting money to buy what was needed." (participant 16), and "Yes, things changed with work, since he needs more attention at APAE and to go to the doctors." (participant 2).

Class 6 highlights the emotional and material consequences of a lack of empathy and social recognition, revealing that care, although imbued with affection, is also marked by

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sacrifice, precarity, and isolation. This reality results from a society that delegates responsibility for inclusion to families without ensuring adequate state support. Mothers' accounts of caregiver burden and isolation reveal the care crisis (Leite, 2023) and the feminization of reproductive labor analyzed by Hirata (2022), demonstrating how the absence of support policies turns care into a source of social exclusion for women caregivers themselves. An intersectional analysis reveals that this source of exclusion has an uneven impact: Low-income Black women caregivers without formal employment face a threefold deprivation of income, recognition, and time. This deprivation is self-reinforcing, as full-time dedication to care reduces opportunities for labor market participation, deepening dependence on social benefits and reinforcing economic subordination (Germine & Peres, 2021; Hirata, 2022).

Taken together, the three classes (on the right) indicate that the effective inclusion of people with disabilities requires not only the removal of physical barriers, but also an ethical and political transformation of social relations guided by justice, empathy, and the valuing of diversity. Accounting for 43.4% of the narratives, they concern difficulties in social relations marked by exclusion arising from insufficient dissemination of information on accessibility, inclusion, policies, and rights, which negatively affects the experiences of caregivers and people with disabilities. These findings empirically confirm the central theoretical premise of this investigation: Sustainable educational inclusion requires the social inclusion of women caregivers. The care crisis (Leite, 2023), the feminization and racialization of reproductive labor (Hirata, 2020, 2022), and structural ableism (Gesser et al., 2024; von der Weid, 2025) are not parallel phenomena but interconnected dimensions of the same social order, which subordinates bodies that fall outside the norm, whether those of people with disabilities or those of the Black and poor women who care for them. Intersectionality as an analytical tool (Crenshaw, 1991) makes it possible to capture precisely these overlaps: The narratives collected describe not only individual difficulties, but also the materialization of structures of oppression that operate simultaneously through gender, race, class, and disability.

The vulnerability of this population is further intensified by the finding that, for 53% of the sample, the main sources of income are cash-transfer programs and government benefits. In this regard, Germine and Peres (2021) analyze how Bolsa Família, by preferentially designating women as benefit recipients, ultimately produces ambiguous effects. On the one hand, the policy contributes to family well-being, greater food security, and women's financial autonomy; on the other, it reinforces traditional gender roles because women assume

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responsibility both for managing the benefit and for meeting the program's conditions. The starting hypothesis is that the devaluation of care work and its excessive demands, borne predominantly by women, act as central barriers to effective inclusion, reproducing inequalities to be investigated through family caregivers' own perceptions (Hirata, 2022; Leite, 2023). The analysis presented here connects the theoretical frameworks discussed – the social model of disability, the sexual and racial division of care work, and inclusive education policies – with empirical data collected from family caregivers. It demonstrates how categories such as ableism, the care crisis, and institutional barriers materialize in the everyday experiences reported, validating and adding complexity to the premise that care and inclusion are inseparable (Guimarães et al., 2021).

Analyzing the seven classes through the theoretical framework confirms that care work mediates the educational and social inclusion of people with disabilities. Barriers in schools (Classes 1, 4, and 5) increase the demand for family care, while the social devaluation of this care (Classes 2, 3, and 6) and limited expectations (Class 7) restrict opportunities for the social participation of people with disabilities. This circular dynamic, captured in the narratives, illustrates the relationship between the social question (Iamamoto, 2001), gender and racial inequalities, and the realization of the right to education. In this context, the recent National Care Policy (Law No. 15.069/2024; Brasil, 2024) represents a significant institutional advance, but its effective implementation will depend on adequate funding and overcoming the fragmentation of sectoral policies.

Concluding remarks

This study showed that the educational and social inclusion of people with disabilities in the sample studied is limited by a gap between normative progress and material reality. The findings indicate that structural, attitudinal, and institutional barriers in schools, together with societal ableism and insufficient state support, undermine access, continued participation, and learning. The study also revealed that care work, performed predominantly by working-class Black women under conditions of invisibility and excessive burden, constitutes an indispensable yet precarious pillar that sustains, and is simultaneously strained by, these systemic failures.

The study's main contribution is to articulate, through the perceptions of family caregivers and the participant with a disability, the inseparability of the care crisis and the limits

of school inclusion. The analysis demonstrates that inclusion is a political and relational process, rather than a technical one, mediated by intersecting inequalities of gender, race, and class. This study makes it possible to methodologically validate the complexity of the narratives from the perspective of those who experience this reality and its contradictions.

One limitation is that the study focused on caregivers' perspectives without directly including other voices of people with disabilities or school professionals. Within this framework, the study adds to scholarship advocating a society that recognizes and values diversity as a foundation of life. It underscores that full inclusion requires intersectoral policies, strengthened schools, support for families, and a commitment to social justice.

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