

# DIFFERENTIAL COST OF LIVING FOR BRAZILIAN FAMILIES WITH A CHILD OR YOUNG PERSON WITH AUTISM SPECTRUM DISORDER

Custo diferencial de vida para famílias brasileiras com criança ou jovem com transtorno do espectro autista

## AUTORES

Antonio Carlos Coelho Campino<sup>1</sup>

Denise Cavallini Cyrillo<sup>1</sup>

Hélio Nogueira da Cruz<sup>1</sup>

Sérgio Augusto Jábali Barretto<sup>2</sup>

Regina Tomie Ivata Bernal<sup>3</sup>

Isadora Bousquat Árabe<sup>4</sup>

Denise Eugenia Pereira Coelho<sup>5</sup>

Fátima Rodrigues Fernandes<sup>6</sup>

João Tenorio Cavalcante<sup>6</sup>

Luciana Silva Risi<sup>6</sup>

1 Departamento de Economia, Faculdade de Economia, Administração, Contabilidade e Atuária, Universidade de São Paulo e FIPE Fundação Instituto de Pesquisas Econômicas.

2 Ministério do Desenvolvimento e Assistência Social, Família e Combate à Fome, MDS.

3 Programa de Pós-Graduação da Escola de Enfermagem da Universidade Federal de Minas Gerais.

4 PhD Student in Economics, London School of Economics and Political Science.

5 Instituto Nacional de Ciência e Tecnologia - INCT Combate à Fome - Instituto de Estudos Avançados/Universidade de São Paulo.

6 Instituto Pensi, São Paulo-SP, Brasil.

## CONTATO

Antonio Carlos Coelho Campino

[accampino@gmail.com](mailto:accampino@gmail.com)

**Obs:** este artigo reflete exclusivamente a opinião do(s) autor(es), não representando a posição do IESS.

## ABSTRACT

Caring for people with Autism Spectrum Disorder (ASD), especially in the most severe cases, involves specialized healthcare, special nutrition and education, as well as support in daily activities. This study analyzed the additional living costs that families face in raising and caring for a child or young person with severe ASD in the state of São Paulo, Brazil. A quantitative analysis was carried out, based on primary data collected from 115 families, through an online questionnaire. The results, in 2022 values, indicated higher expenses in families where there is a member with severe ASD, to the order of R\$ 712.54 (US\$ PPP 304.50) per capita per month, when compared to families without ASD. Health expenses were those that caused the biggest difference between the budgets of Typical (no ASD) families and those with severe ASD. When considering the income lost by the caregiver, when abandoning or reducing their professional activities to meet the special needs of the child or young person with severe ASD, the difference reaches approximately R\$ 2,067.00 (US\$ PPP 883.33) per capita per month. The data suggests that the costs for families with a member with severe ASD can be considered catastrophic. These findings highlight the high economic burden associated with caring for individuals with severe ASD and underscore the need for public policies providing financial support and assistance to affected families.

**Keywords:** autism spectrum disorder; catastrophic health expenditure; family economic burden; Brazil

## RESUMO

O cuidado de pessoas com Transtorno do Espectro Autista (TEA), especialmente nos casos mais graves, envolve a necessidade de atenção especializada em saúde, educação diferenciada, alimentação específica e suporte contínuo nas atividades da vida diária. Este estudo analisou os custos adicionais enfrentados por famílias ao cuidar de uma criança ou jovem com TEA nível 3 (grave) no estado de São Paulo, Brasil. Foi realizada uma análise quantitativa baseada em dados primários coletados de 115 famílias por meio de questionário online. Os resultados, em valores de 2022, indicaram que famílias com um membro com TEA grave apresentam despesas adicionais médias de R\$ 712,54 (US\$ PPP 304,50) per capita por mês em comparação a famílias sem TEA. As despesas com saúde foram responsáveis pela maior parte dessa diferença no orçamento familiar. Quando considerada também a renda perdida por cuidadores que precisaram reduzir ou abandonar suas atividades profissionais para atender às necessidades da criança ou jovem com TEA grave, a diferença de custo mensal alcança aproximadamente R\$ 2.067,33 (US\$ PPP 883,47) per capita. Os resultados também mostram que os gastos em saúde representam parcela substancial da capacidade de pagamento dessas famílias, caracterizando custos potencialmente catastróficos. Esses achados evidenciam o elevado ônus econômico associado ao cuidado de indivíduos com TEA grave e destacam a necessidade de políticas públicas de apoio financeiro e assistência direcionadas às famílias afetadas.

**Palavras-chave:** transtorno do espectro autista; custos familiares; gasto catastrófico em saúde; economia da saúde; políticas públicas; Brasil

## INTRODUCTION

Autism Spectrum Disorder (ASD) appears in childhood and tends to persist into adolescence and adulthood. In most cases, the conditions become noticeable during the first four or five years of life. People diagnosed with ASD present atypical neurodevelopment, varying levels of deficits in communication and social interaction, repetitive and stereotyped patterns, and may also exhibit a restricted repertoire of interests and activities (Pan American Health Organization [PAHO], 2008).

Specialized literature considers Autism Spectrum Disorder to be a public health problem, due to its high prevalence throughout the world (which has increased by diagnostic improvements) and its important implications for the lives of individuals in society (Li et al . 2022; Solmi et al., 2022).

At Level 1 – Mild, the individual requires minimal support for social life. At Level 2 – Moderate, there is a greater demand for support, with more significant interpersonal communication challenges (Katz et al., 2020). On the other hand, when a person is diagnosed with ASD Level 3 – Severe, it is essential that they receive intensive family support and, whenever possible, assistance from specialized professionals, in addition to the need to live in adapted accommodation and residences during adulthood. This is due to great difficulty in communication, cognitive impairment and, often, the absence of social interaction (Waizbard-Bartov et al., 2023).

Consequently, both society and families end up bearing important additional costs throughout the lives of these individuals, mainly due to their demand for health goods and services, special food and education, and support activities (Buescher et al. al., 2014; Rogge & Janssen, 2019). It is important to highlight that there is a clear relationship between the greater severity of ASD and increased family expenses (Rogge & Janssen, 2019; Lavelle et al., 2014).

The costs involved with ASD were classified into explicit direct costs, medical and non-medical, and implicit direct costs. The first category includes, for example, the acquisition of medications, outpatient consultations and therapies, among others. Special education expenditures are a typical non-medical explicit direct cost, while employment disruptions and income losses for parents and caregivers are implicit direct costs (Liao & Li, 2020; Marsack-Topolewski & Church, 2019). In other words, caring for and maintaining the quality of life for a family member diagnosed with ASD imposes additional expenses that represent a high share of the family's expenditure, thus jeopardizing other necessary expenses or preventing adequate access to health services

for family members without ASD and can even lead the family to impoverishment (Ghazy et al., 2022; Wagstaf et al., 2018).

The objective of this research is to analyze the additional cost of living that a family faces in raising and caring for a child or young person with ASD Level 3 – Severe in the state of São Paulo, Brazil. Additionally, we seek to: a) estimate the difference in cost of living between families with a child or young person with ASD Level 3 – Severe and families without a child or young person with ASD; b) identify the components of expenses that most burden families with a member who presents ASD Level 3 – Severe; and c) assess the degree of household budget commitment associated with the presence of a family member with ASD Level 3 – Severe. The hypothesis of the work is that the cost of living of families that have a member diagnosed with ASD Level 3 – Severe is higher than that of Typical families, where a Typical family is defined as one in which no member has ASD.

## **METHODS**

### **Empirical Strategy**

This is a quantitative study based on primary data collected from two samples of families: a) those with a child or young adult diagnosed with ASD Level 3 – Severe (ASD 3 families); b) those with no members with ASD (Typical families).

The research was conducted in the state of São Paulo, located in the Southeast of Brazil. São Paulo is the most developed state in the federation, housing approximately 22% of the Brazilian population (IBGE). It has the highest per capita income of the country, though it also exhibits high levels of economic inequality, with a portion of the population in social vulnerability.

### **Study Design for Family Cost of Living**

The reported expenses on non-durable consumer goods of ASD 3 families were compared with the respective expenditures of Typical families to estimate the difference in per capita cost of living between the two groups.

To achieve the goals of this study, a cost categorization adapted from Drumond et al. (1997), widely used in literature, was adopted. Expenses are presented in Brazilian Reais and converted into PPP US Dollars, at 2022 values, with US\$ PPP 1 equivalent to R\$ 2.34, according to the International Monetary Fund (2022).

## The Questionnaire

These expenditures were collected through an online questionnaire made available to the participating families via REDCap platform.

The household budget survey regarding the consumption of non-durable goods allowed for the estimation of direct non-medical and direct medical costs. The explicit direct non-medical costs included the following aggregated items: food at home and away from home, housing expenses, transportation, education, communication, hygiene, cleaning, telephone and internet, culture, leisure, and services. The explicit direct medical costs – healthcare expenses – involved payments for health insurance, medical consultations, pharmacy expenses, laboratory and imaging tests, physiotherapy, psychological therapy, speech therapy, other therapies, and hospitalizations. These major consumption aggregates allowed for the estimation of total explicit family expenditures and per capita expenditures (Brazilian Institute of Geography and Statistics, 2022; PAHO, 2008).

The questionnaire also included questions about the socioeconomic and demographic conditions of the families, as well as whether the caregiver of the child or young adult with ASD Level 3 – Severe had left the labor market and the estimated monthly income lost in 2022 presented in brazilian reals. This specific situation of income loss represented the implicit direct cost associated with the ASD 3 family condition, as mentioned previously.

Before answering the questionnaire, participants needed to provide written consent for researchers to access the data, adhering to the Informed Consent Form (ICF). The field research, including questionnaire completion by participants, took place from February 23, 2023, to July 31, 2023.

## Sampling

The inclusion criteria for the samples were: having at least one member aged 4 to 21 years with ASD Level 3 – Severe (ASD 3 Family) or without ASD (Typical family); belonging to the month per capita expenditure class equal to or greater than R\$ 800.00 (US\$ PPP 341.88) and residing in the state of São Paulo.

Due to the lack of a registry of ASD 3 families to facilitate their location it was not possible to compose a probabilistic sample. In this context, the "Snowball" method (Kennedy-Shaffer et al., 2021) was adopted for recruiting participants, which led to the constitution of a convenience sample. To obtain the sample size, the statistical calculator

OpenEpi.com (Sullivan et al., 2009) was used to identify the difference between means, with a confidence level of 95% and a test power of 80%. The samples were obtained using expressions 1 and 2 (Rosner, 2020).

The required sample size for the two groups was calculated using the following expressions (Rosner, 2000):

(1)

$$n_1 = \frac{(\sigma_1^2 + K\sigma_2^2)(z_{1-\alpha/2} + z_{1-\beta})^2}{\Delta^2}$$

(2)

$$n_2 = K \cdot n_1$$

where:

- $n_1$  and  $n_2$  represent the sample sizes of groups 1 and 2;
- $\sigma_1$  is the standard deviation of the group of families with children or youth with ASD Level 3;
- $\sigma_2$  is the standard deviation of the group of families without ASD;
- $\Delta$  represents the difference between the means of the two groups;
- $K = \frac{n_2}{n_1}$  is the ratio between sample sizes, assumed as 1;
- $z_{1-\alpha/2} = 1.96$ , corresponding to a 95% confidence level;
- $z_{1-\beta} = 0.84$ , corresponding to a statistical power of 80%.

## Analysis

A descriptive analysis of costs and their compositions was performed, calculating the means of the variables. The homogeneity of the age structure of the children and youth in the two groups of families was assessed using the chi-square test. The difference in cost distributions between ASD 3 families and Typical families was analyzed using the Wilcoxon statistical test, a non-parametric alternative to the t-test, suitable for situations where the data are not normally distributed, as is the case with the final sample of this research. The significance level adopted was 5%.

The possibility of expenditures on ASD family members being catastrophic for their families was also evaluated (Ghazy et al., 2022; Diaz et al., 2012). To accomplish this, the share of specific expenditures on ASD family members was estimated by adapting the methodology presented by Xu (2005) to calculate the capacity to pay for the

specific case of the families in this study. The family's capacity to pay was determined by deducting subsistence food expenses from the total expenses. For this purpose, per capita food expenses were calculated as the average per capita food expenses of the families, net of out-of-home food expenses, considering for this average, the families in the 45th to 55th percentiles selected based on the share of food expenses in the total expenditure. The family's subsistence expenditure was then calculated (computing the product of the per capita subsistence expenditure by the family size) and this value was compared to the food expenses net of out-of-home food expenses. If the food expense net of out-of-home food expenses declared was less than the estimated subsistence expenditure for the family, the declared expenditure by the family was adopted; otherwise, the estimated subsistence expenditure was adopted to determine the capacity to pay. Once the capacity to pay was determined, the share of healthcare expenses in relation to it was calculated in four versions: total healthcare expenses including health plan premiums; excluding health plan premiums; only specific healthcare expenses for the ASD 3 member; and a final version including other specific expenses for the person diagnosed with ASD 3.

### **Community participation**

It should be noted that the collaboration of parents and those responsible for families, especially those with a family member with ASD 3, in filling out the questionnaire that provided the data for the analysis carried out was of fundamental importance in this study.

The study (CAAE: 58990722.0.0000.5567) was submitted to the Research Ethics Committee on Human Beings of the José Luiz Egydio Setubal Foundation and was approved on 06/27/2022, under number 5,492,845.

## **RESULTS**

### **Sociodemographic aspects**

Initially, the sample for this research comprised 119 questionnaires answered by participants. The distribution included 79 families without Autism Spectrum Disorder – Typical – and 40 families with at least one member diagnosed with ASD Level 3 – Severe. It is important to highlight that, to analyze the results, we chose to exclude outliers from the distribution of per capita income in each group. After removing the first and 99th percentiles from this distribution, a sample of 115 families resulted, 77 of which were Typical and 38 ASD 3.

Examination of the sample, regarding the number of individuals aged 4 to 21 years, indicated the presence of 156 children and young people, 25.6% of whom have ASD 3. A difference was observed in the frequency of gender between the two groups: 82.5% of children with ASD 3 are male, while in Typical families this percentage is 62.9%. It is worth noting that the chi-square test indicated that the age distribution between the two groups was homogeneous (p-value of 0.25).

Furthermore, it was found that 78% of families with a child or young person with ASD 3 were headed by women, compared to 70% in the group without ASD. Although there are no significant differences in the distribution regarding ethnicity and level of education of the heads of the family, it is noteworthy that approximately 35% of the heads of households in ASD 3 families are single or divorced, all of whom are female, compared to 21% in Typical families. In relation to the number of individuals in the household, the data reveal that 18% of ASD 3 families are made up of just two people (the mother and the member with ASD 3), while in the group without ASD this percentage is 13%.

When analyzing the occupation declared by the heads of households, it appears that the majority (53.2%) of the heads of Typical families are salaried; but this percentage is only 31.6% in ASD 3 families. It is remarkable that 31.6% of heads of ASD 3 families are unemployed, a portion substantially higher than the 7.8% observed in Typical families.

### **Direct Costs – Explicit Non-Medical Direct Costs**

The average total direct non-medical cost per capita, along with its subcomponents, was calculated and is presented in Table 1. When comparing expenses across different family groups, no statistically significant difference was observed between the total direct non-medical expenses of families in the ASD 3 group and those of typical families. Specifically, the average total direct non-medical cost per capita for ASD 3 families was estimated at R\$ 2,429.28 per month (US\$ PPP 1,038.16). This value does not differ statistically from the corresponding cost for the group without ASD.

Among the subcomponents, the only one that shows a statistically significant difference between the two groups of families is domestic support (professional caregiver). On the other hand, Typical families spend more on recreation and leisure, education and transportation than ASD 3 families, although these differences are not statistically significant.

The specific non-medical expenses of individuals with ASD 3 (food, domestic support and education) were also compared to the corresponding per capita expenses of their families. For a member with ASD 3, these subcomponents of expenses total R\$ 775.00 monthly (US\$ PPP 331.20), more than double the per capita family expenditure on such items – R\$ 318.13 (US\$ PPP 135.95).

**Table 1:** Comparison of direct monthly non-medical costs per family per capita, according to family condition – State of São Paulo/Brazil (at 2022 prices).

| Type of Expense        | Average Cost R\$ (US\$ PPP) |           | p-value |
|------------------------|-----------------------------|-----------|---------|
|                        | Typical                     | ASD 3     |         |
|                        |                             |           |         |
| Food                   | 769,46                      | 832,82    | 0.157   |
|                        | (328.33)                    | (355.90)  |         |
| Housing                | 570,93                      | 582,92    | 0.544   |
|                        | (243.39)                    | (249.11)  |         |
| Education              | 435,80                      | 270,93    | 0.950   |
|                        | (186.24)                    | (115.78)  |         |
| Domestic Support       | 109,46                      | 258,13    | 0.001*  |
|                        | (46.78)                     | (110.31)  |         |
| Transport              | 156,18                      | 114,45    | 0.857   |
|                        | (66.74)                     | (48.91)   |         |
| Clothing               | 94,65                       | 128,96    | 0.560   |
|                        | (40.45)                     | (55.11)   |         |
| Recreation and Leisure | 155,06                      | 90,26     | 0.940   |
|                        | (66.26)                     | (38.57)   |         |
| Domestic Animals       | 45,02                       | 47,42     | 0.833   |
|                        | (19.24)                     | (20.26)   |         |
| Others                 | 179,79                      | 103,39    | 0.984   |
|                        | (76.83)                     | (44.18)   |         |
| <b>Total</b>           | 2.516,34                    | 2.429,28  | 0.481   |
|                        | (1075.36)                   | (1038.16) |         |
|                        |                             |           |         |
| Number of Families     | 77                          | 38        |         |

**Notes:** US\$ PPP = US Dollar Purchasing Power Parity (Purchasing Power Parity with the United States Dollar),

US\$ PPP 1.00 to R\$ 2.34. \* = Difference in Means with Statistical Significance at 5%.

### Explicit Medical Direct Costs

Table 2 displays the average per capita monthly health expenditures for the two groups of families. It is important to highlight that ASD 3 families have considerably high health expenses, amounting to R\$ 1,115.92 per capita per month (US\$ PPP 476.89). This value is much higher than that declared by Typical families – R\$ 316.33 (US\$ PPP 135.18).

The means test showed that there is a significant difference for all components of health expenditure in ASD 3 families in relation to Typical ones. It can be highlighted, for example, that the monthly per capita expenses of ASD 3 families with speech therapy (R\$ 78.55 / US\$ PPP 33.57), physiotherapy (R\$ 45.31 / US\$ PPP 19.36), consultations (R\$ 295.83 / US\$ PPP 126.42) and pharmacy (R\$ 223.63 / US\$ PPP 95.57) are, respectively, around 180, 15, 10 and 3 times those of Typical families.

**Table 2:** Comparison of the monthly direct medical cost per capita and its components, according to the family condition – State of São Paulo/Brazil (at 2022 prices)

| Type of Health Expense. | Average Cost R\$ (US\$ PPP) |          | p-value |
|-------------------------|-----------------------------|----------|---------|
|                         | Typical                     | ASD 3    |         |
|                         |                             |          |         |
| Health Plan             | 140,75                      | 260,86   | 0,016*  |
|                         | (60.15)                     | (111.48) |         |
| Pharmacy                | 73,28                       | 223,63   | 0,000*  |
|                         | (31.32)                     | (95.57)  |         |
| Consultations           | 28,45                       | 295,83   | 0,000*  |
|                         | (12.16)                     | (126.42) |         |
| Exams                   | 4,42                        | 46,65    | 0,000*  |
|                         | (1.89)                      | (19.93)  |         |
| Physioterapy            | 2,98                        | 45,31    | 0,000*  |
|                         | (1.27)                      | (19.36)  |         |
| Psychology              | 61,73                       | 99,57    | 0,008*  |
|                         | (26.38)                     | (42.55)  |         |
| Speech Therapy          | 0,43                        | 78,55    | 0,000*  |
|                         | (0.19)                      | (33.57)  |         |
| Other Therapies         | 3,43                        | 55,79    | 0,000*  |
|                         | (1.47)                      | (23.84)  |         |
| Hospitalization         | 0,87                        | 9,74     | 0,089   |
|                         | (0.37)                      | (4.16)   |         |
| <b>Total</b>            | 316,33                      | 1.115,92 | 0,000*  |
|                         | (135.18)                    | (476.89) |         |
|                         |                             |          |         |
| Number of Families      | 77                          | 38       |         |

**Note:** US\$ PPP = US Dollar Purchasing Power Parity, US\$ PPP 1.00 to R\$ 2.34.

\* = Difference in Means with Statistical Significance at 5%.

**Table 3:** Components of the monthly direct medical cost per family per capita and specific with the ASD 3 member – State of São Paulo/Brazil (at 2022 prices)

| Type of Expense           | Average Cost R\$ (US\$ PPP) | Standard Deviation R\$ (US\$ PPP) | Range R\$ (US\$ PPP)   |
|---------------------------|-----------------------------|-----------------------------------|------------------------|
| <b>Health Plan</b>        |                             |                                   |                        |
| Family Expense Per Capita | 260,86<br>(111.48)          | 355,69<br>(152.00)                | 0 – 1500<br>(0 - 641)  |
| <b>Pharmacy</b>           |                             |                                   |                        |
| Family Expense Per Capita | 223,63<br>(95.57)           | 259,14<br>(110.74)                | 0 – 1230<br>(0 - 526)  |
| ASD 3 Expense Per Capita  | 449,34<br>(192.03)          | 477,43<br>(204.03)                | 0 – 2000<br>(0 - 855)  |
| <b>Consultations</b>      |                             |                                   |                        |
| Family Expense Per Capita | 295,83<br>(126.42)          | 406,17<br>(173.58)                | 0 - 1667<br>(0 - 712)  |
| ASD 3 Expense Per Capita  | 585,00<br>(250.00)          | 944,99<br>(403.84)                | 0 – 5000<br>(0 - 2137) |
| <b>Exams</b>              |                             |                                   |                        |
| Family Expense Per Capita | 46,65<br>(19.93)            | 86,26<br>(36.86)                  | 0 – 333<br>(0 - 142)   |
| ASD 3 Expense Per Capita  | 98,68<br>(42.17)            | 196,07<br>(83.79)                 | 0 – 1000<br>(0 - 427)  |
| <b>Physiotherapy</b>      |                             |                                   |                        |
| Family Expense Per Capita | (19.36)                     | (35.79)                           | (0 - 142)              |
| ASD 3 Expense Per Capita  | 100,26<br>(42.85)           | 237,33<br>(101.42)                | 0 – 1200<br>(0 - 513)  |
| <b>Psychology</b>         |                             |                                   |                        |
| Family Expense Per Capita | 99,57<br>(42.55)            | 175,98<br>(75.20)                 | 0 – 800<br>(0 - 342)   |
| ASD 3 Expense Per Capita  | 202,11<br>(86.37)           | 405,66<br>(173.36)                | 0 – 1600<br>(0 - 684)  |
| <b>Speech Therapy</b>     |                             |                                   |                        |
| Family Expense Per Capita | 78,55<br>(33.57)            | 187,96<br>(80.32)                 | 0 – 1000<br>(0 - 427)  |
| ASD 3 Expense Per Capita  | 188,03<br>(80.35)           | 428,45<br>(183.10)                | 0 – 2000<br>(0 - 855)  |
| <b>Other Therapies</b>    |                             |                                   |                        |
| Family Expense Per Capita | 55,79<br>(23.84)            | 95,06<br>(40.63)                  | 0 – 400<br>(0 - 171)   |
| ASD 3 Expense Per Capita  | 149,21<br>(63.77)           | 266,84<br>(111.04)                | 0 – 900<br>(0 - 385)   |
| <b>Hospitalization</b>    |                             |                                   |                        |
| Family Expense Per Capita | 9,74<br>(4.16)              | 33,77<br>(14.43)                  | 0 – 133<br>(0 - 57)    |
| ASD 3 Expense Per Capita  | 17,63<br>(7.53)             | 66,80<br>(28.55)                  | 0 – 350<br>(0 - 150)   |
| <b>Total</b>              |                             |                                   |                        |
| Family Expense Per Capita | 1.115,92<br>(476.89)        | 960,63<br>(410.53)                | 0 – 4660<br>(0 - 1991) |
| ASD 3 Expense Per Capita  | 2.051,12<br>(876.55)        | 1.819,19<br>(777.43)              | 0 – 7580<br>(0 - 3239) |

**Notes:** Health Plan expenses do not distinguish between family expenses and specific expenses ASD 3.  
US\$ PPP

= US Dollar Purchasing Power Parity (Purchasing Power Parity with the United States Dollar), US\$ PPP 1.00 to R\$ 2,34. N = 38 families.

Complementing these analyzes and seeking to offer subsidies for the development of public policies, Table 3 presents the specific medical expenses for the member with ASD 3, compared with the corresponding per capita family expenses.

It is observed that the total direct medical cost specific to the care of the member with ASD 3 (R\$ 2,051.12 / US\$ PPP 876.55) is almost double (1.9 times higher) the corresponding per capita family cost (R\$ 1,115.92 / US\$ PPP 476.89). And almost all spending components show this same relationship, in which the per capita family value is practically half of the specific expenses for the member with ASD 3, with the difference being even greater for costs with “other therapies”.

### **Implicit direct costs**

The questionnaire used in this study also assessed whether any members of the ASD 3 families ceased working, either fully or partially, to become the primary caregiver for the individual with severe autism. Additionally, it evaluated the lost income of these caregivers, updated to 2022 values. The estimated amount was R\$ 1,386.76 (US\$ PPP 592.63) per month.

In 26 families in the ASD 3 group, at least one member chose to give up, totally or partially, her occupation to dedicate herself to the role of main caregiver for the family member with severe autism. In these families, the age of the child or young person with severe autism was: 4 to 10 years old in 19 of them; 11 to 15 years old in 3 of them; and 16 to 21 years old in 4 of them.

### **Explicit and implicit direct costs**

The total value of the cost of living incurred by families that have among their members a child or young person diagnosed with ASD 3 was calculated based on the sum of explicit direct costs (non-medical and medical) and implicit costs (loss of income). Table 4 allows us to compare the cost of living according to family conditions.

As can be seen, the difference in the average direct cost of living, per capita, between ASD 3 and Typical families is R\$ 712.54 (US\$ PPP 304.50) per month. This difference is statistically significant. When the income lost due to the departure of a family member from the job market to care for a member with severe autism is included, the average difference between ASD 3 and Typical families widens considerably and reaches R\$ 2,067.33 (US\$ PPP 883.47) monthly per capita.

**Table 4:** Comparison of monthly per capita cost of living, according to type of cost and family condition – State of São Paulo/Brazil (at 2022 prices).

| Type of Cost                       | Average Cost R\$ (US\$ PPP) |            | p-value | Cost Dfference (ASD 3 - Typical) |
|------------------------------------|-----------------------------|------------|---------|----------------------------------|
|                                    | Typical                     | ASD 3      |         |                                  |
| Explicit Non-Medical Direct Costs  | 2.516,34                    | 2.429,28   | 0.481   | NS                               |
|                                    | (1,075.36)                  | (1,038.16) |         | NS                               |
| Explicit Medical Direct Costs      | 316,33                      | 1.115,92   | 0.000*  | 799,59                           |
|                                    | (135.18)                    | (476.89)   |         | (341.71)                         |
| <b>Explicit Direct Costs (EDC)</b> | 2.832,67                    | 3.545,21   | 0.009*  | 712,54                           |
|                                    | (1,210.54)                  | (1,515.05) |         | (304.50)                         |
| <b>Implicit Direct Costs (IDC)</b> | 0,00                        | 1.386,76   |         | 1.386,76                         |
|                                    | (0,00)                      | (592.63)   |         | (592.63)                         |
| <b>EDC + IDC</b>                   | 2.832,67                    | 4.900,00   |         | 2.067,33                         |
|                                    | (1,210.54)                  | (2,094.02) |         | (883.47)                         |
| Number of Families                 | 77                          | 38         |         |                                  |

**Notes:** US\$ PPP = US Dollar Purchasing Power Parity (Purchasing Power Parity with the United States Dollar), US\$ PPP 1.00 to R\$ 2.34. \* = Difference in Means with Statistical Significance at 5%. NS = Not Significant.

### Catastrophic costs: share of health spending

The proportion of family health expenditures – direct medical costs – was estimated in relation to total spending net of living expenses, to examine the impact of the presence of a family member with ASD 3 on the household budget. In this context, different versions of the proportion of expenses in relation to the ability to pay were estimated. Table 5 presents these estimates, comparing the two groups of families.

Firstly, it is observed that, on average, the proportion of total health expenditure, including monthly health plan fees, is 36.16% for ASD 3 families and much lower for Typical families (12.48 %).

When payments relating to health plans are discounted, the proportion for the ASD 3 group (28.58%) is also much higher than the group without ASD (6.89%).

The estimated proportion of specific health expenditures for the member diagnosed with ASD 3 was 20.4%. This portion of expenses increases to 33.34% when other specific expenses are added, including expenses with food, education and special care for the child or young person with ASD 3. These high percentages highlight the catastrophic nature of the cost of living for families who face the challenge of caring for and maintaining a member diagnosed with ASD 3.

**Table 5:** Proportion of health and specific expenditures according to family condition – State of São Paulo/Brazil.

| Type of Expenditure               | Indicators         | Typical Families % | ASD 3 %      |
|-----------------------------------|--------------------|--------------------|--------------|
| <b>Health</b>                     | Average            | 12,48              | 36,16        |
|                                   | Standard Deviation | 11,75              | 21,04        |
|                                   | Range              | 0 - 62,18          | 0 - 79,96    |
| <b>Health without health plan</b> | Average            | 6,89               | 28,58        |
|                                   | Standard Deviation | 8,75               | 20,50        |
|                                   | Range              | 0 - 62,18          | 0 - 71,87    |
| <b>Health with ASD 3</b>          | Average            |                    | 20,04        |
|                                   | Standard Deviation |                    | 16,87        |
|                                   | Range              |                    | 0 - 57,67    |
| <b>Specifics with ASD 3</b>       | Average            |                    | 33,34        |
|                                   | Standard Deviation |                    | 16,93        |
|                                   | Range              |                    | 3,03 - 77,26 |
|                                   |                    |                    |              |
| Number of Families                |                    | 77                 | 38           |

## DISCUSSION

This research, using primary data obtained from an online questionnaire, found that families with a child or young person with ASD Level 3 – Severe, in the state of São Paulo/Brazil, actually face a significant burden of costs and expenses, when compared to Typical families.

It was initially found that around 82.5% of children or young people in families with ASD are male. This result is in line with what is observed in the literature, regarding the higher prevalence of boys diagnosed with autism (Benevides et al., 2019; Gomes et al., 2015).

In both groups of families (ASD 3 and Typical), the formal or stable union prevails for the marital status of the head of the household. However, as also observed in other studies (Roddy & O'Neill, 2019; Lima et al., 2022), a significant proportion of ASD 3 families are made up of just two members, a woman and her child. For Gomes et al. (2015), there is indeed a great feeling of helplessness on the part of many mothers of children or young people with autism, when they are abandoned by their spouse and must take care of their child with this disorder alone.

The vulnerability of ASD 3 families appears to be even greater as the percentage of unemployed heads of household in this group is the most significant (31.6%).

In turn, the main data described here demonstrate, unequivocally, that mainly medical or health expenses heavily burden the household budgets of families with a child

or young person with ASD 3. The explicit direct cost differential, monthly per capita, among ASD 3 and Typical families is on average R\$ 712.54 per capita per month (US\$ PPP 304.50), around R\$ 8,500.00 (US\$ PPP 3,600.00) per capita per year. This value more than doubles when considering the sacrificed income (implicit direct cost), reaching approximately R\$ 24,800.00 (US\$ PPP 10,600.00) per capita per year. It can be seen from these data that an ASD 3 family likely spent, in 2022, around 19 minimum wages (in the state of São Paulo) more than a Typical family.

It is well known that the greater the severity of the disorder, the more intense the monitoring and assistance for people with autism must be. When there are severe difficulties in social interaction and carrying out usual activities, not only is there an increase in expenses, but the constant presence of an adult at the side of the child or young person with ASD 3 also becomes essential, which generally implies the abandonment of work by one of the parents. This research points in this direction and corroborates the trends described in other works, such as those by Rogge and Janssen (2019), Roddy et al. (2019), Esteban-Figuerola et al. (2019), Horlin et al. (2014).

Once the hypothesis of the present study was confirmed, we then sought to evaluate the degree of commitment of the household budget associated with the presence of a family member with ASD 3. In other words, to check whether the expenses of these families can be considered catastrophic.

Catastrophic health costs occur when a high percentage of the adjusted family budget is spent on health services and goods, compromising other necessary expenses; the family budget is adjusted, excluding from the total family budget, expenses necessary to maintain the family alive, like nutrition. Thresholds in the literature typically range from above 20% to above 40% of household budget (Ghazy et al., 2022; Diaz et al., 2012; Xu, 2005; Knaul et al., 2011).

The results indicated that, even excluding expenses with health plans intended for everyone in the household, ASD 3 families are exposed to catastrophic health costs (28.58%), which increase (33.34%) when other expenses specific to the individual with ASD 3 are added, such as those related to professional caregivers, extra educational activities and special food. It is noteworthy that Typical families have health expenses in a proportion of less than 13% of their household budget (even when Health Plans are included).

As already mentioned, the existence of an overload of costs, of the most diverse nature, on families in which there is a member with autism is very well established in the

literature. Some examples are the extensive reviews by Rogge and Janssen (2019) and Martin et al. (2022) and specific studies such as that by Ou et al. (2015) and Zuveskas et al. (2021) and even in the qualitative study by Fletcher et al. (2012), which also includes intangible costs (loss of friends, absence from social events, constraints) in the analysis. However, no references or evidence were found regarding the existence of catastrophic health costs for these families with at least one member with ASD 3, which adds to the novelty of this study, especially in the Brazilian context.

It is worth mentioning that the set of data presented here can contribute, in an important way, to support the discussion of assistance and income transfer policies in the country, aimed at families with children or young people with Autism Spectrum Disorder, especially those who are in situation of greater socioeconomic vulnerability.

## **Public Policy Implications**

### **Who Should Bear the Cost?**

As shown in Table 4, families raising a child with ASD Level 3 face an average monthly cost differential of R\$2,067.33 (USD PPP 883.47) compared to families without an autistic child. A critical policy question follows: who should bear this additional burden?

International experience points to two broad approaches: direct financial support to families, and integration of ASD children into public education systems. On the financial support side, Australia's National Disability Insurance Scheme (NDIS) is one of the most comprehensive examples, providing individualized funding packages that, as of early 2019, averaged AUD\$32,800 per year for autistic adults and AUD\$16,700 for children under seven, guided by principles of self-determination and personalized care (<https://www.ndis.gov.au/news/1276-ndis-plans>).

On the school inclusion side, a systematic review by Nuske et al. (2019) synthesized findings from 27 studies across four continents—North America, Europe, Africa, and Australia—covering data from 443 students with ASD, 453 parents, and 546 teachers highlights the main challenges faced. The review found that children with ASD consistently struggled with anxiety and heightened social pressure during school transitions; parents felt overwhelmed by complex placement decisions and worried about their children's well-being; and teachers worked hard to provide appropriate support, often with inadequate resources. When effective strategies were identified, they centered on helping students adjust to new school settings, individualizing transition support,

clarifying the process for parents, and strengthening communication between schools and families.

Even in countries with more developed educational infrastructure, integrating ASD children into school systems remains a significant challenge. In Brazil, where the public education system is still focused on improving basic quality of instruction for the general population, this challenge is considerably greater. This path, therefore, does not appear to be a feasible alternative for countries facing structural educational challenges like Brazil, making targeted financial support from the State to families caring for individuals with ASD the most promising way forward.

### **Caregiver income support**

Regarding financial support, there are two complementary channels through which the Brazilian government could act to fulfill its constitutional mandate of guaranteeing universal and comprehensive healthcare to the population with ASD Level 3.

In most cases, it is the mother who steps away from paid employment to provide full-time care for a child with ASD Level 3. Brazil's existing unemployment insurance framework already accommodates non-standard cases—artisanal fishers, for instance, receive benefits during the *defeso* (closed fishing season) even without a formal layoff. By analogy, a legislative amendment could extend similar protections to parents who leave employment to care for a child with severe ASD. Under current law, unemployment benefits consist of three to five monthly payments, each no less than one minimum wage (R\$1,284.00 = US\$ PPP 548.72 in São Paulo in 2022). It seems reasonable, similarly, that eligible caregivers receive five transfers at the minimum wage value. Importantly, however, this transfer does not address the long-term nature of the caregiving burden—caregivers do not return to the labour market after five months.

### **Disability income transfer**

Brazil's *Benefício de Prestação Continuada* (BPC-PCD) already provides one minimum wage per month to persons with disabilities in families with per capita income below one-quarter of the minimum wage. Extending or adapting this instrument to reach ASD-affected families with higher income thresholds could substantially improve coverage and increase welfare. Given that our calculations show the cost differential for ASD Level 3 families is approximately 1.61 times the minimum wage (see Table 4), it

seems reasonable that the State compensate eligible families with 1.6 minimum wages per month. Critically, this benefit should not be time-limited to childhood: autism is a lifelong condition, and adults with ASD continue to require support regardless of age. It is worth noting, however, that for adults with ASD who are not in the most severe cases, a complementary policy avenue would be to facilitate employment opportunities via disability quotas for this group — thereby also reducing the overall fiscal burden on the government.

### **Fiscal Feasibility**

According to the 2022 Brazilian Census (IBGE), approximately 2.4 million Brazilians—or 1.2% of the total population—are autistic, with higher prevalence among males (1.5%) than females (0.9%). In the state of São Paulo alone, 548,000 individuals were diagnosed with ASD (1.19% of the state's population).

If the federal government were to provide one minimum wage per month to every family with an autistic member, the annual fiscal cost would be approximately R\$36.98 billion (US\$ PPP 15.80 billion). Brazil's GDP in 2022 was R\$10.1 trillion (US\$ PPP 4.316 trillion), meaning this expenditure would represent roughly 0.37% of GDP. For context, Brazil's total health expenditure stood at approximately 9.14% of GDP in 2022. Such a transfer program for ASD would thus represent less than one-twentieth of current health expenditure, a manageable fiscal commitment by any standard. If the more appropriate transfer value of 1.61 minimum wages were used instead, the annual cost would rise to approximately 0.59% of GDP — still less than one-fifteenth of current public health expenditure, and a modest figure relative to the scale of the need.

However, it cannot be forgotten that the number of individuals diagnosed with ASD is increasing year over year. The U.S. Centers for Disease Control and Prevention (CDC), for instance, has estimated that approximately 36 in every 1,000 births involve ASD. Therefore, projections of future cost should account for both ASD birth rates and the mortality profile of the autistic population.

These projections, while incomplete, point clearly in one direction: targeted financial support for families caring for individuals with ASD is fiscally achievable. What is required is political will and appropriate legislative reform.

### **Caveats**

Several qualifications apply to these estimates. One of them is convenience

sampling, which was used due to the great difficulty of locating the study population; it should be noted, however, that this is a resource used in several other studies. Another limitation refers to the application of an online questionnaire whose answers depended on the respondents' memory and were consequently subject to possible recall errors.

In addition to these, it is important to consider that our calculations use the cost differential observed for ASD Level 3 families, which represents the most severe manifestation of the disorder; the appropriate transfer for Level 1 or Level 2 families would be lower. Since the IBGE does not disaggregate ASD prevalence by severity level, the fiscal projections above should be interpreted as indicative upper bounds.

However, despite the methodological difficulties, the results were consistent and corroborated other studies on the topic.

#### **Declaration of conflict of interests**

The authors declare that there are no potential conflicts of interest with respect to the research, authorship, or publication of this article.

## References

1. Benevides T W, Lee J, Nwosu N A O and Franks J (2019) Understanding the Family Impact of Autism Spectrum Disorder in a Racially and Ethnically Diverse Sample: Findings from the National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal* 23(7): 951–960.
2. Buescher A V, Cidav Z, Knapp M, and Mandell D S (2014) Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics* 168(8): 721–728.
3. Diaz M D M, Sartri F M, Campino A C C and Iunes R (2012) Catastrophic Health Expenditure in Brazil. Regional Differences, Budget Constraints and Private Health Insurance. Published by Harvard Global Equity Initiative, Mexican Health Foundation International Development Research Center, Harvard University Press.
4. Drummond M F, O'Brien B J, Stoddart G L and Torrance G W (1997) *Methods for the economic evaluation of health care programmes*. Oxford University Press.
5. Esteban-Figuerola P, Canals J, Fernández-Cao J C and Val V A (2019) Differences in food consumption and nutritional intake between children with autism spectrum disorders and typically developing children: A meta-analysis. *Autism* 23(5): 1079–1095.
6. Faculty of Medicine of the University of São Paulo (2023) REDCap Platform. Available at: <https://redcap.hc.fm.usp.br/surveys/?s=P8JFHT8MYL9H7JXF> (accessed 13 January 2022).
7. Fletcher P C, Markoulakis R and Bryden P J (2012) The Costs of Caring for a Child with an Autism Spectrum Disorder. *Comprehensive Pediatric Nursing* 35: 45–69.
8. José Luiz Egydio Setúbal Foundation (2021) Ethics Committee. Available at: [https://institutopensi.org.br/cep\\_fjles/](https://institutopensi.org.br/cep_fjles/) (accessed 03 April 2021).
9. International Monetary Fund (2022) Purchasing Power Parity. Available at: <https://www.imf.org/external/datamapper/PPPSH@WEO/OEMDC/ADVEC/WEOWORLD/BRA> (accessed 13 June 2023).
10. Ghazy R M, El Saeh H M, Abdulaziz S, Esraa A H, Amira M E, Heba K, Nardine Z, Ehab E and Samar A E (2022) A systematic review and meta-analysis of the catastrophic costs incurred by tuberculosis patients. *Scientific Reports* 12: 558. Available at: <https://doi.org/10.1038/s41598-021-04345-x> (accessed 06 June 2022).
11. Gomes P T, Lima L H, Bueno M K, Araújo L A and Souza N M (2015) Autism in Brazil: a systematic review of family challenges and coping strategies. *Jornal de Pediatria (Rio J)* 91: 111–121.
12. Horlin C, Falkmer M, Parsons R, Albrecht M A and Falkmer T (2014) The Cost of Autism Spectrum Disorders. *PLoS One* 9(9): e106552. Available at: <https://doi.org/10.1371/journal.pone.0106552> (accessed 30 March 2022).
13. Brazilian Institute of Geography and Statistics (IBGE) (2020) Family Budget Survey 2017-2018 – Expenditure profile in Brazil – Selected indicators, Rio de Janeiro. Available at: <https://biblioteca.ibge.gov.br/visualizacao/livros/liv101761.pdf> (accessed 26 March 2022).
14. Katz L, Nayar K, Garagozzo A, Schieszler-Ockrassa C and Paxton J (2020). Changes in Autism Nosology: The Social Impact of the Removal of Asperger's

- Disorder from the Diagnostic and Statistical Manual for Mental Disorders, Fifth Edition (DSM-5). *Journal of Autism and Developmental Disorders* 50(9): 3358–3366.
15. Kennedy-Shaffer L, Qiu X and Hanage W P (2021) Snowball Sampling Study Design for Serosurveys Early in Disease Outbreaks. *American Journal of Epidemiology* 190(9): 1918–1927.
  16. Knaul F M, Wong R, Arreola-Ornelas H and Méndez O (2011) Household catastrophic health expenditures: A comparative analysis of twelve Latin American and Caribbean Countries. *Salud Pública de México* 53 Supplement 2.
  17. Lavelle T A, Weinstein M C, Newhouse J P, Munir K, Kuhlthau K A and Prosser L A (2014) Economic burden of childhood autism spectrum disorders. *Pediatrics* 133(3): e520–e529.
  18. Li Z, Yang L, Chen H, Fang Y, Zhang T, Yin X, Man J, Yang X and Lu M (2022) Global, regional and national burden of autism spectrum disorder from 1990 to 2019: results from the Global Burden of Disease Study 2019. *Epidemiology and Psychiatric Sciences* 31: e33.
  19. Liao X and Li Y (2020) Economic burdens on parents of children with autism: a literature review. *CNS Spectrums* 25(4): 468–474.
  20. Lima A P, Pessoa C C, Silva M P, Oliveira P A and Bezerra M M M (2022) The family of the child with Autism Spectrum Disorder (ASD). *Id On Line Revista de Psicologia* 16(60): 15–27. Available at: <https://idonline.emnuvens.com.br/id/article/download/3421/5320/13512> (accessed 13 June 2023).
  21. Marsack-Topolewski C N and Church H L (2019) Impact of caregiver burden on quality of life for parents of adult children with Autism Spectrum Disorder. *American Journal on Intellectual and Developmental Disabilities* 124(2): 145–156.
  22. Matin B K, Byford S, Soltani S, Kazemi-Karyani A, Atafar Z, Zeresghi E, Soofi M, Rezaei S, Rakhshan S T and Jahangiri P (2022) Contributing factors to healthcare costs in individuals with autism spectrum disorder: a systematic review. *BMC Health Services Research* 22: 604.
  23. Pan American Health Organization (PAHO) (2008). Basic indicators for health in Brazil: concepts and applications, 2nd Edition. Available at: <http://tabnet.datasus.gov.br/tabdata/livroidb/2ed/indicadores.pdf> (accessed 26 March 2022).
  24. Ou J, Xun G, Chen C, Wu R, Luo X, Zhang R and Zhao J (2015) Employment and financial burdens of families with preschool children diagnosed with Autism Spectrum Disorders in urban China: Results from a descriptive study. *BMC Psychiatry* 15:3.
  25. Roddy A and O'Neill C (2019) The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed? *Autism: The International Journal of Research and Practice* 23(5): 1106–1118.
  26. Rogge N and Janssen J (2019) The Economic Costs of Autism Spectrum Disorder: A Literature Review. *Journal of Autism and Developmental Disorders* 49(7): 2873–2900.
  27. Rosner B (2000) *Fundamentals of Biostatistics* (5th Edition). Duxbury Press, Belmont.
  28. Solmi M, Song M, Yon D K, Lee S W, Fombonne E, Kim M S, Park S, Lee M H, Hwang J, Keller R, Koyanagi A, Jacob L, Dragioti E, Smith L, Correll C U, Fusar-Poli P, Croatto G, Carvalho A F, Oh J W, Lee S and Cortese S (2022)

- Incidence, prevalence, and global burden of autism spectrum disorder from 1990 to 2019 across 204 countries. *Molecular Psychiatry* 27(10): 4172–4180.
29. Sullivan K M, Dean A and Soe M M (2009) OpenEpi: a web-based epidemiological and statistical calculator for public health. *Public Health Reports* 124(3): 471–474.
30. Wagstaf A, Flores G, Hsu J, Smitz M F, Chepynoga K, Buisman L R, Wilgenburg K and Eozenou P Progress on catastrophic health spending in 133 countries: a retrospective observational study. *Lancet Global Health* 6(2): e169–e179.
31. Waizbard-Bartov E, Fein D, Lord C, Amaral D (2023) Autism severity and its relationship to disability. *Autism Research* 16(4): 685–696.
32. Xu K (2005) Distribution of Health Payments and Catastrophic Expenditures Methodology. World Health Organization. Available at: <https://www.who.int/publications/i/item/EIP-FER-DP.05.2> (accessed 30 June 2022).
33. Zuveskas S H, Grosse S D, Lavelle T A, Maenner M J, Dietz P, Ji X (2021) Healthcare costs of pediatric Autism Spectrum Disorder in the United States, 2003–2015. *Journal of Autism and Developmental Disorders* 51(8): 2950–2958.
34. Nuske H J, Hassrick E M G, Bronstein B, Hauptman L, Aponte C, Levato L, Stahmer A and Smith T (2019) Broken bridges—new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success. *Autism* 23(2). <https://doi.org/10.1177/1362361318754529>