

THE ROLE OF WOMEN IN THE SEARCH FOR HEALTH OF CHILDREN AND ADOLESCENTS: AN ANALYSIS OF THE JUDICIALIZATION OF PUBLIC HEALTH IN PERNAMBUCO, BRAZIL

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ABSTRACT

The Constitution of the Federative Republic of Brazil of 1988 points out that health is a fundamental social right, composing the right to life itself in its broadest form, being an integral part of the right to a dignified life. It is even more protective when it deals with the right to health of children and adolescents, who have absolute priority in health policies. One of the reasons for the increase in the judicialization of public health, according to recent studies, is the growing awareness and search for the realization of fundamental rights and guarantees, therefore, it is not necessarily a negative phenomenon for a Democratic State of Law. In view of the need for adequate protection and more specialized processing, the Court of Justice of the State of Pernambuco created the Center for Justice 4.0 - Child and Youth Health of Pernambuco, with absolute competence for the processing and judgment of health-related claims that have a child or adolescent as the active pole of the procedural legal relationship and as a passive pole a legal entity of public law, this nucleus having territorial jurisdiction throughout the State, with the exception of the single court and general jurisdiction districts. However, children and adolescents, according to Brazilian procedural legislation, have the capacity to be a party, but they do not have the capacity to be in court on their own, needing, for that, the figure of the procedural representative. These representatives are of paramount importance to initiate and succeed in lawsuits, because, in practice, they are the ones who perform the material acts in favor of the parties, which is why this research analyzed data regarding the plaintiffs and their

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procedural representatives in a quantitative and retrospective cross-sectional descriptive study that analyzed the 749 lawsuits judicialized by the Electronic Judicial Proceedings System, of the 4.0 Center for Childhood and Youth Health of the Court of Justice of Pernambuco, Brazil, incorporated in 2023. As a result, it was noticed that the majority of the applicants were male (61.9%; n= 464), being significantly higher than those of the female (37.4%; n=280), in addition to 5 (0.7%) cases in which the applicants presented both sexes. The prevalence of mothers as the only procedural representative was 76.4% (n=572) of the cases, followed by only 14.9% (n=112) of the cases in which the representatives were exclusively the father. In relation to the cause of action, Autism Spectrum Disorder – ASD was more frequent, with 301 requests, which means that in 40.1% of the cases analyzed, at least one of the causes of action was this. This was followed by Attention Deficit Hyperactivity Disorder (ADHD) (10.1%; n=76), epilepsy in all its forms (8.9%; n=67;) and severe acute respiratory syndrome (8.1%; n=61). The findings of the research allowed us to verify the important and arduous role played by women in the search for health of their children or family members, and the knowledge of these data contributes to the understanding and prevention of judicialization.

Keywords: Effective Access to Health Services. Judicialization of Health. Defense of Children and Adolescents. Gender Studies.



INTRODUCTION

In Brazil, the phenomenon of judicialization of public health emerged in the mid-1990s, with requests for drugs aimed at the treatment of Acquired Immunodeficiency Syndrome – AIDS. However, what began as a one-off request for health has shown steady growth year by year, with no trend of deceleration. (VERBICARO; SANTOS, 2017) (INSPER, 2019)

The judicialization of health is not necessarily a negative fact for a country recognized as a Democratic State of Law, as it may arise from the tendency of the population to be more aware of their rights, and consequently seek a more receptive judiciary in relation to the social rights of the most vulnerable. Thus, "judicialization emerges as a mechanism to plead for the enforcement of fundamental guarantees, while evidencing the failure of traditional systems to obtain medicines and treatments". On the other hand, there is much discussion about the loss of democratic representativeness and harmony between powers as a result of judicial activism, given that the judiciary has a direct impact on the creation and implementation of public policies (GUEDES (FERRAZ, 2019) (DE OLIVEIRA; DE ALMEIDA; RAMOS, 2024) et al., 2025).

Research shows that health as an unlimited right "is sustainable only at the expense of the principles of equity and universality established in the Constitution of the Federative Republic of Brazil of 1988 - CF/88. In other words, in order to give unlimited care to some, the services and actions that benefit others are necessarily reduced." (FERRAZ; VIEIRA, 2009)

In normative terms, article 6 of the FC/88 establishes that health is a fundamental social right, it is part of the right to life itself in its broadest form, being an integral part of the right to a dignified life. In another passage, in its article 196, it adds details to the right to health in Brazil, adducing that "Health is everyone's right and the duty of the State", in addition to being guaranteed through policies "aimed at reducing the risk of disease and other health problems and universal and equal access to actions and services for its promotion, protection and recovery". (BRAZIL, 1988) The Constitution is even more protective when it deals specifically with the right to health of children and adolescents, given that this segment of society is guaranteed absolute priority in the implementation of rights, and it is the duty of the family, society and the State to ensure such protection (art. 227), and the State is obliged to promote comprehensive health care programs, through specific public policies. (BRAZIL, 1988)



It should be noted that for children and adolescents with physical, sensory or mental disabilities, the creation of specialized prevention and care programs are also guaranteed, as well as their social integration, through, among other points, the facilitation of access to collective goods and services (art. 227, § 1, II). This context includes children and adolescents with Autism Spectrum Disorder – ASD, a disorder that tends to be one of the main causes of action in health-related lawsuits, largely due to the alarming increase in diagnosed cases and the inability, at least temporarily, of the government to adapt its health systems to meet the growing demand. (BRAZIL, 1988) (MAENNER *et al.*, 2023) (BEZERRA; ASSISI; MOTA, 2023)

In view of the need for adequate protection of the right to health of children and adolescents in the State of Pernambuco, the Court of Justice of that State created the Justice Center 4.0 - for Child and Youth Health of Pernambuco, with absolute competence for the processing and judgment of health-related claims that have a child or adolescent as an active pole of the procedural legal relationship and a legal entity governed by public law as a passive pole, this nucleus has territorial jurisdiction throughout the State of Pernambuco, with the exception of the single court districts and courts of general jurisdiction (art. 1, §§ 1 and 2). The Joint Act of creation of the Nucleus expressly registers the recency of the model of judicial unit acting as Nucleus 4.0, which is why it does not yet have historical data, which highlights the need for studies and periodic review of its structure to assess the fulfillment of its objectives of seeking efficiency, the reasonable duration of the process, greater agility and effectiveness of justice, as well as the optimization of the services provided from the identification of problems, the improvement of efficiency in the provision of jurisdiction and judicial management. (TJPE, 2022)

For this reason, this research focused on the data of the processes of the aforementioned Center in the search for information regarding the profile of the plaintiffs and their procedural representatives. Such data are complementary, considering that children and adolescents, according to Brazilian procedural legislation, have the capacity to be a party, but do not have the capacity to be on their own in court, thus requiring the figure of the procedural representative.

These representatives are of paramount importance to initiate and succeed in lawsuits, because, in practice, they are the ones who perform the material acts in favor of the parties (children and adolescents) and who seek the appropriate services, treatments and health medicines for their represented. These acts are not limited to the procedural



phase, as there is also an intense and extremely exhausting performance in the preprocedural phase.

It is important to highlight that the representatives go through several difficulties in the path from the initial care to the diagnosis, receive denials in the administrative sphere of public entities and seek to reverse them; suffer from several barriers and queues for care, with the disorganization of some services and, sometimes, the lack of training of professionals; they seek the necessary documentation to judicialize, resorting to private lawyers, the Public Defender's Office or the Public Prosecutor's Office to sponsor the causes. In this scenario, the search for health of children and adolescents is usually extremely exhausting for their representatives, bringing unequal negative consequences to family members, which affects several other aspects of their lives (ALMEIDA et al., 2024; CONCEIÇÃO DOS SANTOS et al., 2023; LUNA et al., 2023; MELO et al., 2023).

METHODOLOGY

This is a descriptive, cross-sectional, quantitative and retrospective study, which analyzed the profile of judicial proceedings under the jurisdiction of the Child and Youth Health Center 4.0 of the Court of Justice of Pernambuco - TJPE, Brazil, in 2023, based on the Electronic Judicial Proceedings System - PJe, a digital platform developed by the National Council of Justice - CNJ.

A total of 782 cases were identified distributed to the Child and Youth Health Center 4.0 of the Pernambuco Court of Justice, of which 749 were analyzed and 33 were discarded, according to the exclusion criteria of the research. Thus, the processes analyzed represent 95.8% of the total number of cases distributed to the Center that year.

For inclusion criteria, all the processes under the competence of the TJPE Child and Youth Health Center 4.0 incorporated into the system in the period from January 2023 to December 2023 were considered. Excluded from the study were cases that were extinguished without resolution of the merits due to lis pendens, res judicata, extinguished without having previously had any manifestation from the magistrate, those sent to another court due to a declaration of incompetence of the Child and Youth Health Center 4.0 of the TJPE and, to avoid duplicate analysis of data, procedural incidents that, even obtaining a new Unique Procedural Numbering (NPU), they were attached to main proceedings, having data already analyzed.



To delimit and collect data regarding the Unique Procedural Number - NPU generated for each lawsuit filed in 2023, whose Judging Body was the Justice 4.0 Center - for Child and Youth Health, the Datajud Public API (a tool that grants public access to the metadata of legal proceedings) was consulted. The information contained in the procedural covers and movements related to the lawsuits of interest were accessed through the *Postman tool*.

The authentication of Datajud's Public API was done through a Public Key, provided by the CNJ's Department of Judicial Research available in https://datajud-wiki.cnj.jus.br/api-publica/acesso. Afterwards, a file in JSON format was returned, which was converted to tabular format, with xls extension, extracting NPU and the date of filing of each lawsuit, which originated the raw data table, which was complemented with the other data collected. The data consultations, according to the objectives of the study, were carried out from the TJPE's PJe System, with an access profile granted by the Court's Information and Communication Technology Service SETIC.

The data were statistically analyzed using the Excel version 2308 program, a descriptive analysis was performed to expose the results obtained and the presentation of the distribution of the measured variables was carried out through tables and figures.

RESULTS

The prevalence of mothers as the only procedural representative was 76.4% (n=572) of the cases, followed by only 14.9% (n=112) of the cases in which the representatives were exclusively the father (Table No. 1 and Figure No. 1).

It should be noted that in cases in which the Public Prosecutor's Office was the plaintiff, he was as an extraordinary representative (procedural substitution), pleading in his own name the rights of others, which is why in such cases there is no procedural representative of the plaintiff, and these cases are therefore classified as "not applicable", according to the data shown in Table No. 1 and represented in Figure No. 1.

Table 1 - Kinship of the procedural representative

Representative's relationship procedural	Count	Proportion	Percentage
mother	572	0.76368	76,4%
father	112	0.14953	14,9%
Both parents	23	0.03071	3,0%
grandmother	19	0.02537	2,5%
Not applicable	17	0.02270	2,3%
sister	2	0.00267	0,3%



Legal guardian	2	0.00267	0,3%
aunt	2	0.00267	0,3%
Total	749	1	100%

Source: Prepared by the authors.

Figure 1 - Kinship of the procedural representative 800 600 572 400 200 19 17 2 2 2 23 112 0 genitora genitor genitores Não irmã guardiã tia avó aplicável legal

Source: Prepared by the authors.

Entering the profile of applicants who seek health through the 4.0 Center for Childhood and Youth Health of the Court of Justice of Pernambuco, of the total number of cases analyzed, the prevalence of applicants was of male children and adolescents (61.9%; n= 464), being significantly higher than that of females (37.4%; n=280). In 5 (0.7%) cases, the applicants presented both sexes, demands generally related to groups of siblings, who join jointly. The results presented are shown in the table below (Table No. 2).

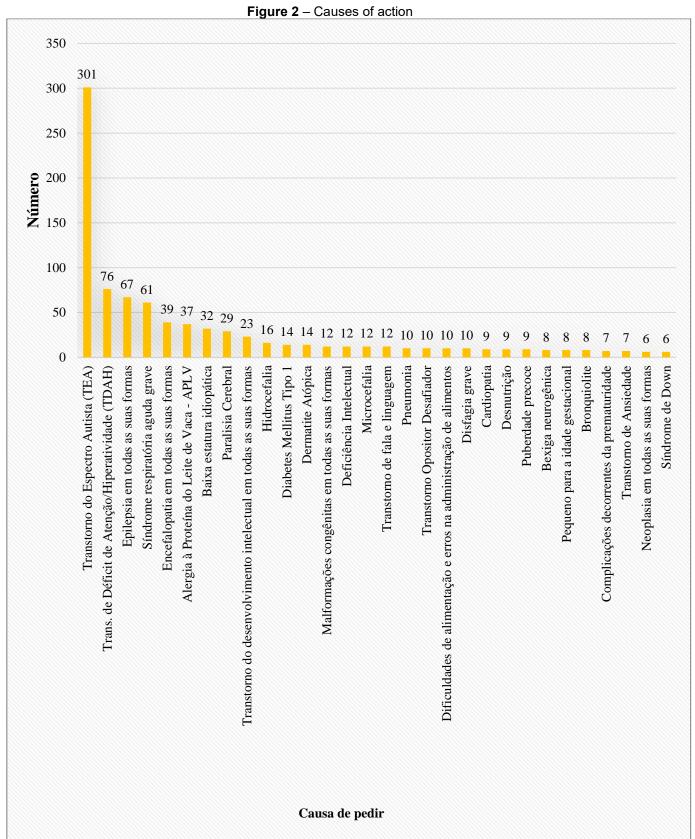
Table 2 - Gender of the applicant

Gender of the applicant	Count	Proportion	Percentage
Male	464	0.61949	61,9%
Female	280	0.37383	37,4%
Both sexes	5	0.00668	0,7%
Total	749	1	100%

Source: Prepared by the authors.

The most prevalent cause of action was related to Autism Spectrum Disorder – ASD, with 301 requests, which means that in 40.1% of the cases analyzed at least one of the causes of action was this. This was followed by Attention Deficit Hyperactivity Disorder (ADHD) (10.1%; n=76), epilepsy in all its forms (8.9%; n=67;) and severe acute respiratory syndrome (8.1%; n=61), as shown in Figure 2.





Source: Prepared by the authors.



DISCUSSION

In this study, in the analysis of the profile of the plaintiffs, it was found that there is a marked difference in the kinship of their procedural representatives. The ratio is 5.1 to 1.0 in favor of representation by mothers only. The search for judicialization of the health of children and adolescents, mostly males, presented the most prevalent cause of action as Autism Spectrum Disorder (ASD), followed by Attention Deficit/Hyperactivity Disorder (ADHD), Epilepsy in all its forms and severe acute respiratory syndrome (n=61), in addition to other less demanded causes of request. Such numbers reinforce the idea that mothers have a more active role in claiming rights related to their children's health and provide a scientific basis for the continuity and expansion of public and legislative policies aimed specifically at them, especially mothers of neuroatypicals.

Previous studies have revealed that gender inequality is latent when it comes to raising children in Brazilian families, with mothers having an almost full role in caring for basic activities, food, education, leisure and health of their children. In 89% of families, the mother is responsible for raising children in very early childhood (children up to 3 years old), with parents being responsible for this responsibility in only 5% of cases and other caregivers in another 5%. (MARTINS, 2017)

Mothers of children and adolescents with Autism Spectrum Disorder – ASD also suffer from exhaustion in the search for public health for the benefit of their children. A study developed with an exploratory method and a qualitative approach on the care of children with autism in primary care, focusing on the mothers' perception, found that the feeling of these women is that the trajectory of seeking care was marked by great difficulties until diagnosis, with the absence of specific protocols or confirmatory tests, several pre-diagnoses and frequent search for several professionals. There was also a perception that there are barriers to care for children in primary care, generating in these mothers a greater exposure to causes that lead to psychological illness due to exhaustion due to overload, depression and anxiety. (ALMEIDA et al., 2024)

Research has findings that reinforce the same idea and conclude that the impact on all aspects of mothers' lives is a common characteristic, affecting fathers and other family members unequally. Among them, the research carried out by Conceição dos Santos *et al.*, with 105 caregivers (mothers) of children with congenital Zika virus syndrome, identified that 85.7% of them were unemployed, 90.5% were part of class D or E, and 81% depended on the Continuous Cash Benefit (BPC). Concluding, among other points, that



most mothers had severe or intense overload, inversely correlated with the quality of life of these women. (CONCEIÇÃO DOS SANTOS et al ., 2023)

Souza *et al* explain, based on the comparative analysis between the data obtained in their research and data from IBGE gender studies, that "the participation rate of women in the labor force is lower than that recorded for men" even though they have a higher adjusted rate of net school attendance in higher education in the age group of 18 to 24 years. These data demonstrate that in many cases it is not the lack of qualification of women that imposes the lowest rate of employability. Furthermore, the condition of being a mother of children and/or adolescents with some type of need for special health care creates another barrier in the search for a job. (DE SOUZA *et al* ., 2023)

The findings of the research carried out by Mello *et al* also identified the primary role of mothers in the care of children with some type of special need. The researchers found, through an integrative review on the family impacts of Congenital Zika Virus Syndrome - CZS, that the occurrence of the syndrome within the family has a direct impact on their routines, especially affecting women, who assume greater responsibility in the role of care, generating their isolation, cessation of personal projects, renunciation of self-care, chronic illness, loss of sociability, among other negative effects. Such implications, when mitigated, are due to the support network formed by the generations of women in the family, such as grandmothers, aunts and sisters. On the other hand, for fathers the impact is smaller, as they are more likely to be less involved in domestic and care work. Regarding the financial impacts, the loss of paid work, with the consequent decrease in family income, was also the most preponderant consequence associated with the CZS. (MELO *et al* ., 2023)

It should be noted that microcephaly also appeared in the findings of this research, in Nucleus 4.0, being at least one of the causes of action registered in 12 lawsuits. Our findings pointed to the active role not only of mothers, but also of other women in the family in the search for the health of children and adolescents who need special care. Because, excluding the parents themselves (14.5%; n=112), there is not even one male family member who represented children and adolescents in the cases analyzed. In addition to mothers and fathers, only grandmothers (2.5%; n=19), sisters (0.26%; n=2), legal guardians (0.26%; n=2) and aunts (0.26%; n=2) were representatives.

It is important to highlight that previous research has already identified initiatives by the government to mitigate the harmful effects on mothers' health. We list among them the qualitative-descriptive research conducted by semi-structured interviews with mothers of



children diagnosed with ASD, in the municipality of Natal, State of Rio Grande do Norte, which demonstrates initiatives that place mothers as subjects who need specific care. There are reports of training offered through lectures and meetings, although some failures in communication and invitations were pointed out, as well as difficulties due to lack of time or distance from the mothers' homes. Well-being practices provided by the institutions were also reported, focusing on the mental health of mothers and promoting meetings to meet other mothers in the same situations. Other initiatives that were reported were leisure activities, dance, water aerobics. However, it should be noted that apparently the perception of each mother is very individual, as other mothers report not having access to the same benefits and when they do, they are unable to benefit, because they lack time, routines are exhausting, their socioeconomic situation does not allow them, among others. (LUNA et al ., 2023)

Another factor that tends to significantly improve the quality of life of these mothers of children with special health needs, especially neuroatypical children and adolescents, would be the integration between health and education resources, providing care and a holistic view of the subject. However, integrating aspects related to health with those of education is also a challenge, as it depends on several factors, most of which have not yet been implemented in the public school system, such as continuous investment in teacher training, increase in pedagogical resources and greater investments in infrastructure, in addition to greater integration between the school, the family and specialized professionals. (MAZZEI et al., 2025)

In this way, our research supports government policies that create or strengthen more protective legislation for women and mothers. These are the cases, for example, of assistance programs that offer preferences for women, such as the implementation of a pension for children with CZS⁶, of some benefits in labor legislation, with longer periods of leave and provisional stability (BRAZIL, 1943) 8 or of the benefit in the criminal law,

⁶ PL 6,064/2023, which guaranteed compensation and a monthly pension for life for CZS holders, was completely vetoed by the presidency of the republic, which issued provisional measure 1,287/2025 providing only for compensation.

⁷ More information at: https://www12.senado.leg.br/noticias/materias/2025/01/09/governo-veta-projeto-do-congresso-e-decide-pagar-r-60-mil-para-vitimas-da-zika#:~:text=Prote%C3%A7%C3%A3o%20de%20Dados-,Governo%20veta%20projeto%20do%20Congresso%20e%20decide%20pagar%20R,mil%20para%20v%C3%ADtimas%20da%20zika&text=A%20Presid%C3%AAncia%20da%20Rep%C3%BAblica%20editou,(MP%201.287%2F2025

⁸ Article 391-A. The confirmation of the state of pregnancy arising during the course of the employment contract, even if during the period of prior notice worked or indemnified, guarantees the pregnant employee the provisional stability provided for in subparagraph b of item II of article 10 of the Transitional Constitutional



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which establishes special rules of provisional release for pregnant women or mothers of children (BRAZIL, 1941) 9, so that children are not deprived of maternal care.

CONCLUSION

The analysis of the judicialization of the public health of children and adolescents in Pernambuco, in 2023, allowed us to verify the important and arduous role played by women in the search for health for their children or family members. It was also possible to identify ASD as the most frequent cause of action and that most of the applicants are male. Such data provide subsidies for public and judicial policies to be developed based on the knowledge of the profile of procedural actors and their main needs, which also contributes to the better performance of a Justice Center 4.0, which seeks efficiency, optimization of services, agility and effectiveness of justice.

Provisions Act. [...] Article 392. The pregnant employee is entitled to maternity leave of 120 (one hundred and twenty) days, without prejudice to employment and salary.

⁹ Article 318. The judge may replace preventive detention with home detention when the agent is: [...] IV pregnant woman; V - woman with a child up to 12 (twelve) years of age; [...]. Article 318-A. Preventive detention imposed on pregnant women or those who are mothers or guardians of children or people with disabilities will be replaced by house arrest, provided that: I - they have not committed a crime with violence or serious threat to the person; II - has not committed the crime against his child or dependent.



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