

Autistic Children: And Who Takes Care of the Parents? Proposals and Improvements for Public Policies in Support of Families with Children with ASD

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Abstract

This technological article presents both an analysis and a proposal. The analysis examined preventive and interventionist public policies for families with children diagnosed with Autism Spectrum Disorder (ASD). It aimed to investigate how the diagnosis of a child with ASD changed the lives of the parents, what events occurred when seeking healthcare for their children, and how the necessary adaptations to this new reality took place. As a technological outcome, a guide titled “Aldeia Project” was developed to be presented to public authorities. It proposes improvements to public policies in support of families with children with ASD, with actions to expand support for parents, offering them a dedicated moment to care for their mental and physical health while also providing a space for their child’s specific care during the same period. The “Aldeia Project” aims to complement the public policy initiative for the construction of the first Reference Center for Autism Care in Teresina, Piauí. The study results indicate that parents of children with ASD need continuous support through public policies related to mental health and social well-being.

Keywords

Autism, Parents, Support, Public Policies

1. Introduction

1.1. What Is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a heterogeneous group of neurodevelopmental

tal phenotypes that involves subjective clinical concepts with three levels of impairment, a chronic and non-degenerative course, which help guide the evaluation and diagnosis of children with ASD. It is also understood as “a complex behavioral syndrome with multiple etiologies, combining genetic and environmental factors” [1].

According to the American Psychiatric Association (APA), “ASD shares core symptoms involving impairments in three specific areas of development: deficits in social skills, deficits in communicative abilities (both verbal and non-verbal), and the presence of repetitive, restricted, and stereotyped behaviors” [2]. The syndrome is categorized into three distinct levels of support—1, 2, and 3—according to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders [3]. Cohen [4] emphasizes that “clinical manifestations of ASD occur before 36 months of age and become more noticeable, especially when the child is placed in a social context.”

Barbaro [5] and Daley [6] explain that this disorder has biological bases that are only partially understood and that diagnoses should be based on both the individual’s history and behavior. Furthermore, as the term “spectrum” suggests, it is scientifically proven that intellectual capacity varies among individuals with ASD. That is, it can range from profound impairment to above-average intelligence, according to the Pan American Health Organization [7]. These complexities justify the need for support in behavioral, educational, familial, health, leisure, and other areas [2].

Studies on ASD have been conducted in several countries since 1942, when it began with the term “affective contact disorder,” coined by Kanner [8]. Since then, it has gone through a long timeline of concepts until reaching the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders), with the concept of three levels of support. The trend is that, with technological advances and new studies, new findings and new terminologies will emerge, allowing the observation of the past to serve as a basis for understanding the future. According to Silva and Mulick [9], “ASD is a disorder that affects people all over the world, in families of every racial, ethnic, and social configuration.”

Regarding public policies, according to Cavalcante [10], government initiatives related to ASD were late, a fact that ended up creating two different groups that historically developed actions simultaneously in favor of individuals with autism. The first group consisted of those involved in actions linked to public mental health policies within the SUS (Unified Health System). The second group was made up of associations of families and parents of children with autism, who began to take action for the benefit of their children.

From the actions developed by these two social groups, as well as from the actions related to mental health, public services began to have a greater role in the care pathway for children with ASD. According to Cabral [11], in social assistance policy, it is necessary to implement and carry out public actions in the health sectors, training these bodies for the inclusion of People with Disabilities from the

perspective of intersectorality.

Given the above, the relevance of programs that support the parents of these children emerges, especially in the implementation of actions that both prevent and intervene in the process of adaptation and family support, aiming to strengthen self-esteem, hope, and the desire for change [12]. Therefore, the focus of this technological study is on preventive and interventional public policies for families with children with ASD. It is about observing how the diagnosis of a child with ASD changed the lives of the parents, what events occurred when seeking health assistance for their children, and how the adaptations to this new reality took place.

The reasons for studying this technological article include, in addition to the few studies related to the topic, the near absence of public policies aimed at families of children with ASD. The public authorities must consider that today's children with ASD will be tomorrow's adults with ASD. Thus, a project is proposed to welcome the parents of children with ASD, as a complement to the actions of the public policy project related to the construction of the first Reference Center for Care of People with Autism Spectrum Disorder, in Teresina, in the state of Piauí.

1.2. Consequences of an ASD Diagnosis for the Family

First and foremost, it is important to highlight that other studies support the findings of this technological article, albeit from different perspectives. These studies emphasize that mothers of children with ASD experience significantly higher levels of stress and lower levels of psychological well-being compared to mothers of children without ASD [13]-[15]. Smith *et al.* [16] even compare the stress experienced by parents of children with ASD to that of soldiers in combat. Therefore, it is clear that addressing this issue is a matter of public health. However, little is known about the interventions provided by public authorities to support these parents.

In this context, it is important to recognize that the first shock for parents is the diagnosis itself. Christofari and Baptista [17] emphasizes that children with ASD should not be labeled, as they are not defined solely by autism. In reality, they present a combination of symptoms, conditions, and behavioral patterns. He also notes that some symptoms involve issues that people are already familiar with, while others involve stigma and social exclusion, which make life even more difficult for parents.

An unexpected ASD diagnosis is the most difficult phase for parents, as it represents an emotional loss [18] [19]. According to Sá and Rabinovich [20], "the birth of a child with special needs can interrupt the dream with reality, causing a shock for the mother, as the imagined child is replaced by a real being, different from what was expected." After discovering their child has ASD, "this moment becomes one of pain, tears, frustration, anguish, fear, insecurity, and many other emotions" [21]. Sadness, according to Brunhara and Petean [22], "reveals feelings of disappointment, frustration, hurt, and distress in the presence of a child who

was not the one dreamed of.”

Raines [23] reports that parents go through five stages after an ASD diagnosis. First is the initial stage of grief, marked by shock, crying, feelings of helplessness, and a desire to escape. The second stage involves denial of the diagnosis; the third brings anxiety, more crying, and the emergence of anger. In the fourth stage, there is a sense of balance, and in the fifth, parents undergo a process of reorganization, reintegrating and recognizing the child within the family. In this final stage, “parents enter a process of adaptation, marked by emotional instability, as moments still fluctuate between acceptance and rejection” [20]. Some families report ongoing grief after the diagnosis, as the impact of this discovery brings constant concerns about how to navigate this new reality [9].

According to Nogueira and Rio [24], parents’ questions are constant, permeating their daily thoughts and causing anxiety. For example: “Who will take care of my autistic child when I die? Who will take my place as a caregiver when I am gone? What will their life be like without me?” Most parents wish to die after their children so they won’t be left alone [25].

It is perceived that in this new family context, “the birth of a child with ASD is an unexpected event that strongly affects its structure. If this family is not able to positively accept the event, adapting to the new patterns of this relationship,” seeking to find balance, there is a great possibility that it will become dysfunctional and may even separate [26].

Families of children with ASD begin to experience in their daily lives a vulnerability caused by the fear of the new situation and the prejudice that society demonstrates [27]. Even within the family itself, there is veiled prejudice that, at any moment, erupts when it comes into contact with the new family and social reality. Bosa [28] reports that “mothers of children with autism show significantly higher levels of stress and depression, as well as lower marital intimacy than mothers of children with typical development and mothers of children with Down syndrome.”

Miller [29] understands, on the one hand, that the sadness felt by parents is chronic and is never fully experienced or overcome. On the other hand, it becomes stronger on important dates in the lives of children with ASD, and he gives examples such as birthdays or when they go to school.

Hastings *et al.* [30] highlight as a result the stress and coping that fathers and mothers of children with autism have to face continuously, especially when the children are young. Benson and Karlof [31] emphasize that the more symptoms the child with ASD has, the greater the parents’ stress. Gomes *et al.* [32] argue that coping with this situation depends on some factors: “the severity and type of the child’s impairment, the meaning that each family attributes to the disability, the family’s sociocultural level, and each person’s capacity for adaptation.”

1.3. Current Public Policies for Children with ASD

In Brazil, public policies for individuals with Autism Spectrum Disorder (ASD) were implemented quite late. Until 1988, there were no actions in place to benefit

individuals with ASD. It was only in 2002, after the creation of the Unified Health System (SUS), that an administrative ordinance was published, including procedures related to patients with mental health issues and ASD in the SUS Outpatient Information System (SIA/SUS). Only 24 years after the creation of SUS, Law No. 12.764/2012 was enacted, establishing the “National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder” [33]. This marked the first public initiative specifically aimed at individuals with ASD.

With the publication of Ordinance No. 324 on March 31, 2016, the “Clinical Protocol and Therapeutic Guidelines for Aggressive Behavior in Autism Spectrum Disorder” was approved [34]. According to this ordinance, the diagnosis of ASD should be clinical and differential, and the diagnostic information should include: “the level of verbal and non-verbal communication, intellectual level, range of interests, family and educational context, and the individual’s capacity for autonomous living” [34]. In 2020, Law No. 13.997/2020 created the Autism Spectrum Disorder Identification Card (CIPTEA), which “ensures comprehensive care, prompt service, and priority access to public and private services, especially in the areas of health, education, and social assistance.” This was a milestone in advancing the inclusion of individuals with ASD in society [35].

At the state level, Piauí has stood out in developing public policies for individuals with ASD. In 2022, the state government enacted Law No. 7.761, guaranteeing individuals with ASD “the right to engage in work activities compatible with their skills, education, experience, and preferences, and prohibiting discrimination” [36]. On February 13, 2023, Law No. 7.963 was enacted [37], originating from Bill No. 40 (2022), establishing “administrative penalties for individuals or public agents who discriminate against people with autism in the state of Piauí.” Law No. 7.960 [38] was also enacted, originating from Bill No. 175 (2022), amending Law No. 7.468 (2021) to include adult individuals with autism and their companions in adapted cinema sessions.

For the coming years, there is a project to build the first “Reference Center for Autism Spectrum Disorder Care,” scheduled for completion in 2024, in Teresina. This center will include consultation rooms, observation rooms, a nursing station, sensory rooms, parental support areas, training rooms for families, a family kitchen, social assistance rooms, therapy rooms, a pool with accessible changing rooms, landscaped outdoor areas, reception areas, a playroom, a 114-seat auditorium, accessible restrooms throughout the facility, and administrative and operational areas.

2. Methodological Approach

This research is qualitative, exploratory, and descriptive. Qualitative research allows for the observation of facts as they occur naturally, aiming to understand the phenomenon under investigation from the perspective of those experiencing it. In this context, a questionnaire was applied to parents of children with ASD to build a theoretical framework supporting the technological proposal of the “Aldeia Pro-

ject” guide.

Exploratory research enables the researcher to understand a subject that is still little known or explored, while descriptive research goes beyond merely identifying the existence of relationships between subjects. It also explores the qualitative aspects of these relationships, with a focus on the broader social group [39] [40].

The target population of this study consisted of parents of children with ASD, encompassing 70 families assisted by three specialized autism clinics located in São Paulo, Rio de Janeiro, and Curitiba. Of these, two families chose not to participate, resulting in a final sample of 68 families with children diagnosed with ASD.

For data collection, a standardized questionnaire was made available to parents via Google Forms. It included six sociodemographic questions (age, gender, marital status, number of children), 20 closed-ended questions, and 17 open-ended questions. For the closed-ended questions, a questionnaire adapted from Balestro [41] was used, employing a five-point Likert scale ranging from 1 [Strongly Disagree] to 5 [Strongly Agree]. The open-ended questions were developed based on the theoretical framework discussed in this article, which helped strengthen the ideas, justifications, and arguments that formed the basis of the proposed project.

This research also adhered to Resolution No. 510/2016, which regulates “research involving human beings in the human and social sciences” [42]. The clinic administrators who collaborated with the study signed an “Institutional Authorization Term,” while the participating family members signed a “Free and Informed Consent Form,” which guaranteed their privacy rights and the freedom to withdraw from the study at any time, as an independent document. Please do not revise any of the current designations.

3. Study Results

The sociodemographic profile of the study participants is detailed in **Table 1**, based on data collected through the administered research instrument. The findings indicate a predominance of female respondents (56.8%), with male participants comprising 43.2% of the sample. In terms of age distribution, the majority of individuals fall within the 31 - 45 age range (66%), followed by those over 45 years of age (22%) and a smaller proportion aged between 17 and 30 years (12%).

Regarding marital status, a significant portion of the sample reported being in a common-law relationship (37%) or legally married (32%), accounting for 69% of the total. Conversely, 31% of respondents identified as single, separated, or divorced. Notably, a considerable number within this group are single mothers or fathers, suggesting the presence of diverse family structures within the population under study.

The responses to the question “When you found out your child had ASD, what did you feel?” were collected from 68 participants. These responses revealed a range of emotions, including concern, confusion, loneliness, fear, and helplessness. The

diagnosis clearly has a significant emotional impact on parents. The letter (E) refers to the interviewee (**Figure 1**).

Table 1. Sample profile.

Dados demográficos		n	%
Gender	Male	29	43.2
	Femele	38	56.8
Age	Between 17 and 30 years	8	12
	Between 31 and 45 years	44	66
	Over 45 years	15	22
Marital Status	Married	21	32
	Single	8	12
	In a stable union	25	37
	Separated	6	8.9
	Divorced	7	10.1
Numeber of children with Autism in the family	One chind	42	63
	More than one child	25	37
Do the Parents Live Together?	Yes	46	69.1
	No (single mothers)	15	22
	No (single fathers)	6	8.9
Total Sample Size		68	100

(E) My family denied it at first, then came fear and concern, and finally support. I felt sad and guilty for having a child with a disability.

(E) My family did not accept the diagnosis, and to this day some pretend it doesn't exist. I felt very lonely and lost.

(E) They were supportive, but never very close. I feel indifferent toward them.

(E) They went into denial about the diagnosis, and I confronted them.

(E) My family reacted well (...), but at the same time, their reaction was one of concern because we didn't know anything about autism or how to handle certain situations.

(E) To this day, there is still prejudice. Some still believe in the idea of incapacity, that it's a disease. I suffer a lot from family prejudice, which in my view is the worst kind.

Figure 1. What was felt upon the ASD diagnosis.

In **Figure 2**, the researcher highlighted responses from single mothers and fathers. The responses reflect the emotional toll on mothers as primary caregivers, with narratives differing slightly from those of fathers, but both echo Nunes [43], who notes that the loss of the imagined future creates a sense of mourning and uncertainty. This emotional burden affects the quality of life of these families due to frequent stress [32].

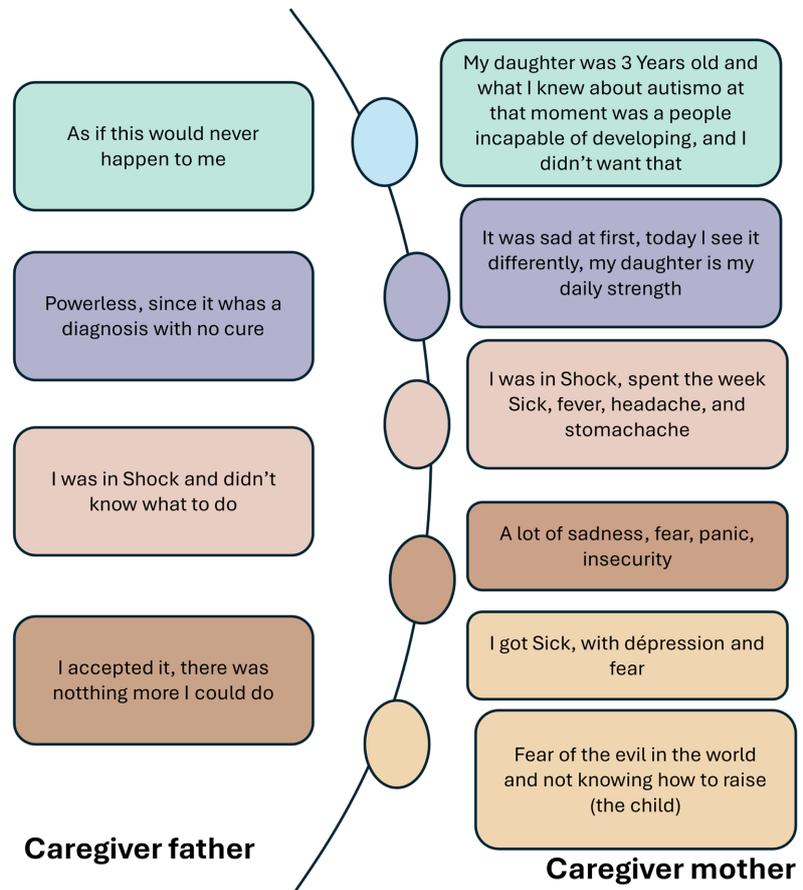


Figure 2. What was felt upon the ASD diagnosis (single mothers and fathers)”.

Fathers and mothers faced with an ASD diagnosis, having to care for their children alone, first experiencing shock, followed by fear and insecurity. According to Pinto *et al.* [44], “the experiences lived by family members at the time of diagnosis are intensified due to a lack of knowledge about ASD.” And as Takeda [45] points out, all social rejections directed at people with disabilities—especially those on the autism spectrum—are rooted in prejudice and discrimination. Another aspect observed in the study was the impact on parents’ professional lives.

For mothers, the diagnosis often led to greater sacrifices. Many reported leaving their jobs to dedicate themselves entirely to their children. This is supported by Pinto *et al.* [44], who found that such sacrifices are more common among mothers. Smeha and Cezar [46] also emphasize that the responsibility of caring for an autistic child typically falls on the mother, who often gives up her career to focus exclusively on her child. This is illustrated in **Figure 3**.

In light of the sacrifices made by the parents of children with ASD, as observed above, Walsh [47] emphasizes that “the ability to overcome adversity in times of crisis is called resilience”. It is at this moment that support must also be provided to these parents through public policies that promote the strengthening and growth of inclusion, as well as educational programs for society regarding all types of disabilities.

- (E) Yes. At first, I was calm, but then I became very anxious about needing more income to help with the treatments.
- (E) Yes, I had to give up my career to be able to take my daughter to therapy sessions. It's very frustrating to have to give up everything you spent half your life building.
- (E) I changed everything — from job to schedule. I spent years without working, just studying and dedicating myself to understanding ASD.
- (E) Yes, actually I haven't been able to work yet because I live alone with him and his brother. The entire routine depends on me.
- (E) I don't work; I can't balance a job with occupational therapy, speech therapy, psychiatrist appointments, and extra activities.
- (E) I quit my job and ended up changing careers to work with ABA. The child's father left the household to dedicate himself exclusively to his own work.
- (E) I chose to study in order to treat my son.
- (E) For two years I was doing well, and the guilt I felt started to fade. After two years without working, I began to really miss having a bit of my life back, and since I haven't been able to find a job, I now feel sad.

Figure 3. Parenting and work balance.

Public authorities play a crucial role in equipping society to address the challenges faced by families of children with disabilities. This includes fostering inclusive values and offering educational programs that promote understanding and acceptance. As Walsh [47] emphasizes, “It is not enough to encourage the resilience of children and families at risk so that they can ‘overcome obstacles’; we must also fight to change the obstacles that are placed in their way.”

In this context, participants were asked: What do you think could be done to change or improve your life? A summary of 68 responses is presented in **Figure 4**.

What do you think could be done to change or improve your life?

Mothers

- (E) Only public or financial support to afford caregivers would make a difference.
- (E) I wish I could invest more in my professional career.
- (E) To have more motivation/time to take care of myself.
- (E) A job with working hours that would also allow me to attend therapy sessions.
- (E) To be certain that my child's treatment will continue.
- (E) I would like to have more time for myself, but I don't see that as a possibility.
- (E) More support from the healthcare system, more help for mothers.
- (E) A job and more time.
- (E) I would like to have more time for myself, but I don't see that as possible due to the demands.
- (E) I just want to die, I feel like giving up on everything.
- (E) My life is just the way I always wanted. We are all well and healthy. My son is developing very well, and I'm happy about that.
- (E) I want to take better care of myself, but I don't yet have the energy for it.
- (E) Just a job that allows me to have time for my child too.
- (E) More support from the healthcare system.

Fathers

- (E) Everything now revolves around my son.
- (E) I believe a support network would help a lot. I could have time for myself, to breathe a little.
- (E) Nothing. I'm quite happy. Sadness hits sometimes, but I have to be strong. I do everything possible and impossible for him.
- (E) Seeing my son well on his path would also be a great relief. Although he's in therapy, I still don't see enough progress to give me peace of mind.
- (E) Financially, if the health plan complied with the court order, my life would get back on track.
- (E) A larger support network.
- (E) If the government provided proper support, like financial assistance for healthcare and general expenses.
- (E) To have peace.
- (E) A real support network, opportunities to meet with peers, true inclusion.
- (E) To have a better country that would help my son.
- (E) To have a health insurance plan.
- (E) To earn a little more, because the government doesn't help.
- (E) That the health plan would comply with the court order.
- (E) More support from the healthcare system, more rights in companies for parents of autistic children.

Figure 4. What could be done to improve the lives of fathers.

It is noticeable that the fathers' responses revolve around concerns related to work, health insurance, inclusion, support networks, depression, public healthcare,

and financial independence. These fathers play a unique role in their children's development but lack support when it comes to taking care of themselves. They would like to feel more secure in their professional lives. Mothers wish to feel useful to society. A sense of insecurity permeates their daily lives, and public authorities could be more involved in this regard.

Negative Reactions

They thought he had nothing, that he would get better with time. I felt sad.
Some denied it, which left me very disappointed, and others supported me.
They cried, and I felt guilty.
They doubted it, and I felt helpless.
In denial. They didn't want to accept it.
They went into denial about the diagnosis, and I confronted them.
Feelings of pity, you know?
Yes. They said there was nothing wrong, that he was just too spoiled.
I suffer a lot from family prejudice, which in my view is the worst kind.
Sad, in mourning. I always joked and treated this diagnosis as an irrelevant detail compared to the love we should have for my daughter. I showed that there is light—we just have to fight for the right treatment.
The family denied it at first, then came fear and worry, and finally, support. I felt sad and guilty for having had a child with a disability.

Figure 5. Negative reactions from Family members upon receiving the ASD diagnosis.

Positive Reactions

They acknowledged the situation and offered me support. Even though there was still some denial, I felt okay.
They were welcoming, although they were never very close. I feel indifferent toward them
Thankfully, everyone accepted the diagnosis with ease.
I felt supported. The family embraced the cause.
My family provided support and viewed—and still views—therapy as a form of salvation.
My family already suspected something; they encouraged me to consult a psychiatrist, as I was in denial.
My family did not accept the diagnosis, and to this day, some pretend it does not exist. I felt very lonely and lost.
My family reacted well, as we have other relatives with special needs, and everyone had already noticed that, for his age, he was not developing like the others.
Everyone reacted well.
Everyone was and continues to be very involved and loving. They all supported me through the changes needed to help her.
Everyone supported me, and together we sought help. I felt encouraged.
We were all supported, and I felt that my son received even more love than before.
They were surprised, but I felt more encouraged to talk about the issue.
I felt secure.

Figure 6. Positive reactions from family members upon receiving the ASD diagnosis.

When asked how family members reacted upon learning of the child's autism diagnosis, the reports show reactions of denial (**Figure 5**), positive responses such as acceptance from the beginning, and even a certain neutrality (**Figure 6**). It is

evident that family members expressed how difficult it was to receive the child's autism diagnosis. Most of them responded with denial, in a mix of fear and insecurity.

Receiving a diagnosis of a chronic illness or syndrome, such as ASD, is often a deeply challenging moment for families. It brings a mix of emotions—fear, insecurity, shock, and frustration. As Ebert *et al.* [48] note, “the birth of a child marks the beginning of a new life cycle, one that is idealized by parents and the entire family. However, when this plan is disrupted, all family members are affected.”

Despite this rupture, some families respond with acceptance, offering support and care to the parents. Maughan *et al.* [49] highlight that Acceptance and Commitment Therapy (ACT) can be a valuable approach for caregivers facing symptoms of depression and stress. Rooted in the third wave of behavioral and cognitive therapies, ACT does not aim to eliminate negative thoughts and emotions but rather to help individuals accept their internal experiences and commit to actions aligned with their values [50].

Regarding the question about the need to revise working hours to stay at home more to take care of the child, the responses shown in **Figure 7** range from total resignation to a reduction or maintenance of the workload. There are also cases of mothers who chose to study, not to mention those who do not work.

Decisions	Some Responses
Pursuit of Education	I gave up everything and feel frustrated, upset, sad, and useless. I left everything behind and now only take care of my child.
	I was unable to return to the job market because the demands of caring for him are always very intense. I felt frustrated for a long time, as I had completed a degree with the intention of pursuing a career, but I could not.
	I quit my job and now dedicate myself solely to my child.
Not Working	I chose to study in order to better care for my child. For two years, I felt well, and the guilt I had been feeling gradually faded. After two years without working, I began to miss having a part of my life back, and since I have not been able to find a job, I now feel sadness.
	I changed everything—from my job to my schedule. I spent years without working, solely studying and dedicating myself to understanding Autism Spectrum Disorder (ASD).
Reduction or Maintenance of Workload	I do not work; I cannot balance a job with occupational therapy, speech therapy, psychiatric appointments, and extracurricular activities.
	I have never worked. There are many therapies, and I am the one who takes my child to all of them. The father works, and I stay home taking care of the children. I managed to reduce my working hours. I reduced my working hours to meet my child's needs.
	I had to give up my career in order to take my daughter to therapy sessions. I changed my work schedule, and everything has been going well. I continue to work. I work full-time, both morning and afternoon. I do not have support from my husband, so I have to do everything on my own—take my son to therapy, psychologist, educational therapist, psychiatrist, speech therapist, school, manage his crises, teach him daily living skills to foster independence, clean the house, and organize myself for work.

Figure 7. Decisions made by mothers after receiving an ASD diagnosis.

It is very difficult for parents—especially mothers—to experience the differences that society often imposes: men work while women stay at home. Soares and

Carvalho [51] state that “when women do not conform to the expectations of patriarchal representation, the processes of blaming them are extended,” because when a family breaks its marital bond, it is expected that the woman will take on the entire burden, giving up everything—physically, culturally, and professionally.

According to Sprovieri and Assunção [52], mothers often end up leaving their jobs because they cannot find anyone to care for their children. As a result, they are forced to miss work, which almost always leads to quitting or being dismissed from their jobs. In light of this, it becomes clear that these mothers, “even while living in a sea of uncertainty about the future and what life will be like for their children, experience the birth of an unconditional love at that moment—one capable of facing any and all obstacles that life may still impose” [53].

It is believed that once the Provisional Measure (MP) that initiated the ratification process of ILO Convention No. 156 [54], titled “Equal Opportunities and Equal Treatment for Men and Women”, is enacted, workplace and family responsibility-related discrimination will be reduced. This convention provides an additional tool in the fight for the rights of families who wish to maintain their jobs while also caring for their children with disabilities.

Regarding health insurance, parents were asked whether or not they had coverage. Only 10% of respondents reported not having health insurance. However, among those who do have a plan, there is an ongoing struggle with court orders imposed on health insurance providers that are not being followed. These are distressing accounts that deserve public support.

Another aspect addressed in the study concerns the social and psychological well-being of the parents—whether they take prescription medication, go to the movies, what kind of leisure activities they engage in, how they take care of themselves, and how much time they dedicate to being with friends. According to **Figure 8**, it is evident how much they lack quality of life, not enjoying leisure moments, and may even rely on prescription medication. In other words, there is no time for either personal or mental self-care.

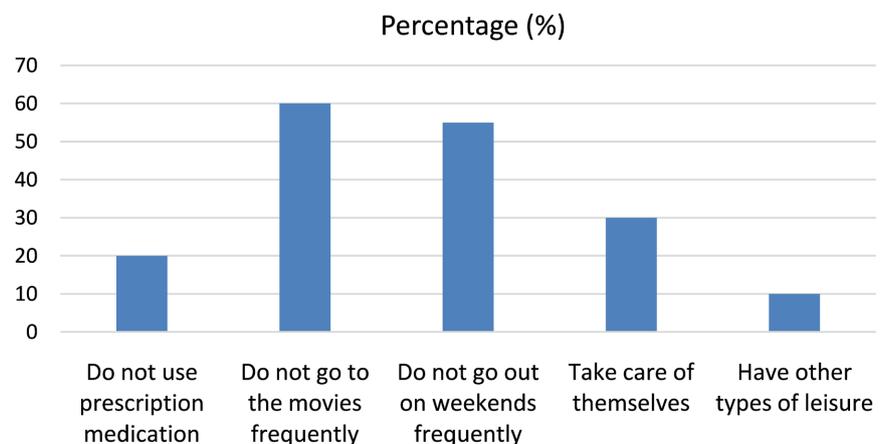


Figure 8. Leisure activities of parents.

It is important to highlight that the intense dedication of mothers—focusing on caring for their child, husband, household tasks, and other children, if any—can lead to physical and mental health issues. According to Barbosa and Fernandes [55], leisure is one of the essential resources for maintaining quality of life, especially for parents who live directly with children diagnosed with ASD.

In the question related to parents' greatest fear regarding raising a child with ASD, the answers encompass concerns about the future, lack of financial and emotional support, discrimination, lack of social support, and insufficient development for a more functional life, as shown in **Figure 9**.

The responses highlight parents' worries about the future of their children, who are extremely dependent. They also express frustration upon witnessing discrimination and realizing that people feel uncomfortable with the presence of an autistic child—an act of prejudice. Furthermore, any offense directed at the child is perceived as if it were directed at the parents themselves. Due to prejudice and discrimination, parents tend to become even more overprotective, viewing their children as fragile and defenseless. This perception further shapes their concern for their children's future.

Concerns	Some Responses
Fear of the Future	<p>My greatest fear is that one day I will pass away, and my son will not be able to live independently, because no one will care for him the way I do.</p> <p>That I might die and there will be no one to care for my daughter. And that she may not be able to care for herself and/or be happy.</p> <p>Not having good health and not having my partner to support me through this process—and unfortunately, that is my current reality.</p> <p>Not having time to be with him during critical moments, although I try to teach him to be strong.</p> <p>My greatest fear is thinking about the future—when I am no longer here, what will happen to him? Will he have someone to support him? Will he be able to manage on his own?</p> <p>That something might happen to both me and his father, leaving our son without support. He will grow up, and we will no longer be able to care for him alone.</p> <p>The future... knowing that my son will achieve independence.</p> <p>I am afraid of what his future will be like as an adult.</p> <p>I have not yet thought about this topic—I am still living one day at a time.</p> <p>Not being able to provide the best therapy for my daughter to fully develop.</p>
Concerns Regarding Lack of Financial and Emotional Support	<p>Not being able to offer all the support my son needs, especially financially, as therapies, leisure, and activities all come at a cost.</p> <p>That the health insurance will stop covering the treatment and my son will regress.</p> <p>That I may not be able to fully guide him through life.</p> <p>That my daughter may lose access to therapy and regress. I am afraid of regression.</p> <p>I fear he will be excluded, face prejudice from the world, suffer during adolescence... and that I may die and he will have no one to fight for him.</p>
Concerns About Discrimination and Lack of Social Support	<p>That he will face prejudice and difficulties if he does not fit into society.</p> <p>That he will be discriminated against because of his condition.</p> <p>Prejudice from society and the lack of rights for my son.</p> <p>My greatest fear is the prejudice my son may face.</p> <p>That he will not be able to live in a community, will not know how to express himself, or will be misunderstood.</p> <p>That he will not be happy.</p>
Concerns About Insufficient Development for a Functional Life	<p>That he will not achieve autonomy.</p> <p>That he will not speak or have the autonomy to live without third-party assistance.</p> <p>That he will not develop the autonomy needed for adult life.</p> <p>That he will not be able to manage on his own when I am no longer here.</p> <p>My greatest fear is adulthood.</p> <p>They are very dependent, and I do not know how they would live without me.</p>

Figure 9. Main concerns of parents.

In light of these responses, it is evident that the social issue is much broader. These children will grow into adults who will not have their parents forever, which is a distressing reality for all respondents. Gomes *et al.* [32] “support the idea that social support and care programs for parents and/or guardians are important tools for overcoming family vulnerabilities in the presence of a member with ASD.” All respondents express concern about their children’s future.

However, mothers tend to take on this responsibility more heavily, which is consistent with the studies by Cardoso and Françoso [56] and Gomes *et al.* [32]. These studies highlight the relationship between mother and autistic child, emphasizing the mother’s concern with care, inclusion, and health. They also point out that the greatest concern is what will happen to the child when the mother is no longer present.

3.1. Study Results—Closed-Ended Questions

For the closed-ended questions, a questionnaire adapted from Balestro [41] was used, applying a five-point Likert scale ranging from 1 [Strongly Disagree] to 5 [Strongly Agree]. Descriptive statistics were calculated for each question, as shown in **Table 2**.

Table 2. Descriptive statistics.

Question	Mean	Standard Deviation	Minimum	Maximum
I am concerned about my child’s future.	4.882	0.561	1	5
I feel that public authorities are neglectful regarding the situation of individuals with Autism Spectrum Disorder (ASD).	4.544	0.679	2	5
I truly need time for myself.	4.544	0.836	1	5
I would like to have time to take better care of myself.	4.485	0.889	1	5
I miss having a social environment in my life.	4.147	0.981	1	5
I have the impression that people do not understand what my child is trying to communicate.	4.088	1.129	1	5
I feel alone.	3.985	1.275	1	5
I have difficulty understanding what my child feels.	3.471	1.227	1	5
I do not know how to respond to some of my child’s behaviors.	3.441	1.297	1	5
I do not know how to act when my child does not understand me or when I do not understand them.	3.279	1.280	1	5
I have difficulty communicating with my child.	2.779	1.359	1	5
I have difficulty playing with my child.	2.691	1.538	1	5
I have made plans for my child in case something happens to me.	2.632	1.515	1	5
I do not feel comfortable in public places with my child.	2.618	1.476	1	5
I have difficulty communicating with my child when other people are present.				5
I have the impression that people mock my child when they try to communicate something.	2.382	1.282	1	5

Continued

I have the impression that my child does not understand what I say.	2.368	1.434	1	5
I have been sleeping more.	2.029	1.360	1	5
I have difficulty communicating with my child when it is just the two of us.	1.941	1.157	1	4
If I could leave everything behind and walk away, I would.	1.941	1.465	1	5

Source: Research data (2024).

The data indicate that parents agree that they are concerned about their child's future; they feel that the government is neglectful regarding the situation of people with ASD; they need time for themselves; they would like to have more time for self-care; they miss having a social environment in their lives; and they feel that people do not understand what their child is trying to communicate. The data also suggest a tendency to agree with the perception of feeling alone.

The data also show disagreement regarding difficulties in communicating with their children, having contingency plans, not feeling comfortable in public with their child; having difficulty communicating with their child when other people are around; and having the impression that people mock their child when they try to communicate something, or that the child does not understand what the parents are saying. In other words, parents do not face these challenges in their daily lives. However, they are no longer sleeping.

Parents remain neutral regarding having difficulty understanding what their child feels; not knowing how to act in response to certain behaviors; or when neither party understands the other. The low standard deviation indicates little variability in responses among participants.

The World Health Organization (WHO) and the Federal Constitution of Brazil (CFB) guarantee the same rights for individuals with ASD as for other citizens, along with other laws and regulations in this regard. The issue lies in the organization of more inclusive public policies directed toward individuals with ASD and their families. This can be observed through the increase in the number of beneficiaries covered by private health insurance plans. On August 7, 2023, the National Supplementary Health Agency (ANS) reported that 50.8 million Brazilians are currently covered [57].

According to Gaiato [58], "it can be said that around 600,000 children and adolescents show some symptoms of ASD, just in public schools." "It is estimated that most of these children and adolescents do not receive the necessary treatment for their development in Brazil," which is concerning [32]. Suppo and Floyd [59] also point out that, When properly guided, parents can become facilitators of positive changes in their children's development, as they are considered essential partners in the treatment.

3.2. Proposals for Improving Public Policies in Support of Families with Children with ASD

Given the above, it is believed that public authorities could play a stronger role in

supporting the parents of children with Autism Spectrum Disorder (ASD). This is a matter of public health. In this regard, Resende [60] argues that “[...] the rule of isonomy is the structural beam of society. Its existence also implies respect for individual differences and the obligation to provide services that meet the needs of all, regardless of citizens’ conditions.” According to Nogueira and Rio [24], “family concerns are mostly related to what can be done by public and/or private entities to defend the rights of the child and ensure the continuity of their care.”

Therefore, a support project for parents of children with ASD is proposed, as a complement to the actions of the public policy initiative related to the construction of the first Reference Center for the Care of People with Autism Spectrum Disorder in Teresina, in the state of Piauí. In other words, this proposal to improve public policies in favor of families with children with ASD is called the “Aldeia Project,” a parental support initiative. The choice of this name was inspired by an African proverb: “It takes a village to raise a child.” It is a proposal for a supportive village for the parents of children with autism.

The structure of the Aldeia Project, which outlines the proposal, the interventions with parents and children with ASD, how parents can access the Project, and the organizational chart of the Project, can be found in Appendix A. In other words, it includes some guidelines, foundations, and the applicability of a differentiated methodology to facilitate public administrators’ understanding. **Figure 10** presents the proposed organizational chart for the Aldeia Project.

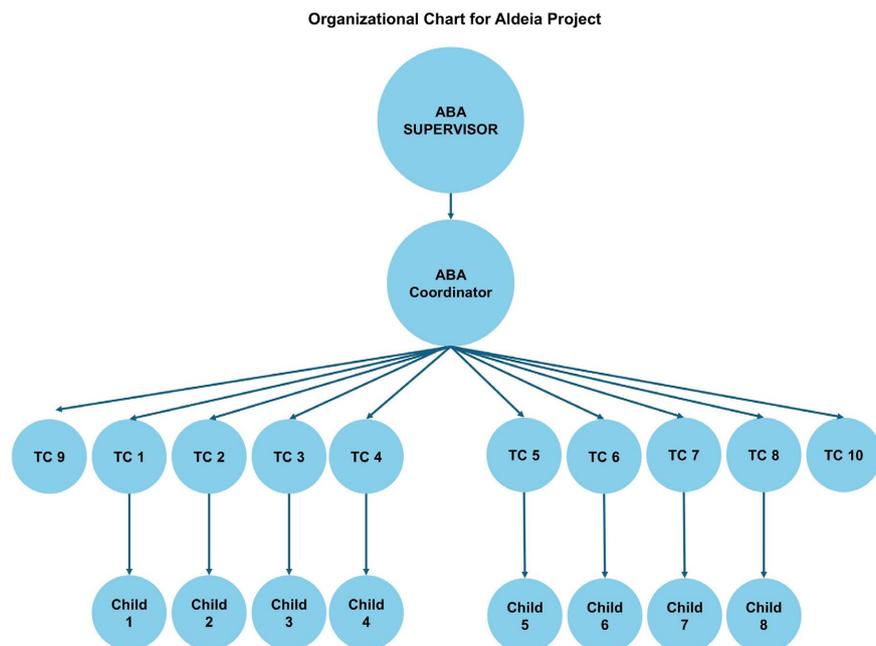


Figure 10. Proposed organizational chart for the Aldeia Project. **Source:** Research data (2024).

4. Final Considerations

The rights guaranteed to individuals with ASD range from the right to health and

social assistance, education, employment and social security, tax exemption, accessibility, sports, culture, and leisure, among others. It is not enough to focus solely on the individuals with ASD without including their families in public policies, as these families need to be supported and assisted through inclusive and welcoming actions.

In this technological article, it was possible to observe the suffering and anguish experienced by parents and family members upon receiving an ASD diagnosis—a moment that triggers many conflicting emotions. Most families manage to adapt to the limitations, but often find it difficult to cope with the challenges that arise in daily life. O'Brien [61] highlights that parents of children with ASD are aware that this condition is lifelong, that it is stressful, and at the same time a daily struggle. Even so, these parents demonstrate a remarkable degree of resilience.

Finally, it is hoped that this study can contribute to the development of strategies to support and welcome families of children with ASD, starting from an understanding of the vulnerabilities they face, the recognition they need, and the support required to share the practical responsibilities of daily care for their children. Further studies in this area are necessary, with a larger and more diverse sample, including autistic adolescents and adults, to highlight the ongoing needs of parents throughout their children's development. This would allow for more specific contributions that address the concerns of these parents and the implications of public policy related to social security.

It is important to understand that autism brings about changes within the family. The parents who participated in this study likely find renewal and comfort in the new meanings they begin to assign to their lives and daily activities—emerging stronger, reorganizing commitments and responsibilities, and giving life a sense of continuity, as if it were a mission. Adapting to change and continuing to grow is generally a process built over time, not a sudden achievement, and it is perhaps this process that allows them to preserve their mental health.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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