

# AUTISM, MATERNAL NARRATIVES AND ACTIVISM FROM 1970 TO 2008<sup>1</sup>

## AUTISMO, NARRATIVAS MATERNAS E ATIVISMO DOS ANOS 1970 A 2008

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**ABSTRACT:** This paper aims to reflect on historical aspects related to autism in Brazil from the 1970s to 2008. We analyzed two autobiographies written by mothers whose children were diagnosed with autism between the 1970s and the 1980s. The writings of these women were produced in distinct moments (one in 1988 and the other in 2008), and they are understood here as pertinent sources for producing stories that illuminate issues related to maternal activism in the period in focus from the female perspective. We concluded that the two analyzed documents demonstrate that the family, in the case of the autistic spectrum, was a fundamental subject in the development of an incipient protection network for autistic people, in a moment of democratic transition in the country. Despite the temporal distance of the narratives, it is possible to verify elements in common, such as the motivations to write about the subject, the role of associations of mothers and fathers of autistic people and the difficulties in finding adequate services for the needs of their children. Differences are also found, especially in terms of maternal activism.

**KEYWORDS:** Autism. Motherhood. Activism.

**RESUMO:** Este artigo tem como objetivo refletir sobre aspectos históricos relacionados ao autismo no Brasil ao longo das décadas de 1970 a 2008. Analisamos duas autobiografias elaboradas por mães cujos filhos receberam o diagnóstico de autismo entre os anos 1970 e 1980. Os escritos dessas mulheres foram produzidos em momentos distintos (uma em 1988 e outra em 2008) e são aqui compreendidos como fontes pertinentes para se produzir histórias que iluminam questões relativas ao ativismo materno no período em foco a partir da perspectiva feminina. Concluímos que os dois documentos analisados demonstram que a família, no caso do espectro autista, foi um sujeito fundamental no desenvolvimento de uma incipiente rede de proteção aos autistas, em um momento de transição democrática no país. Apesar da distância temporal das narrativas, é possível verificar elementos em comum entre elas, como as motivações para escrever sobre o assunto, o papel das associações de mães e pais de autistas e as dificuldades em encontrar serviços adequados para as necessidades de seus filhos. Também se encontram nelas diferenças, principalmente no olhar acerca do ativismo materno.

**PALAVRAS-CHAVE:** Autismo. Maternidade. Ativismo.

## 1 INTRODUCTION

The first description of autism as a differentiated diagnostic entity occurred in 1943, through the publication of the article entitled *Autistic disturbances of affective contact*, written by child psychiatrist Leo Kanner (1943). In this study, the researcher presented results of the analysis of eleven children who, as defended by Kanner, had characteristics that, until then, were not studied by the academic community, namely: deficits in sociability and communication, in addition to the presence of repetitive behaviors and restricted interests (Joseph, Soorya, & Thurm, 2016).

Family members, especially mothers, were fundamental subjects in the history of autism, both for its construction as an object of academic study - as, since Leo Kanner, family reports have been used by researchers to build, analyze and propose forms of intervention/treatment for the phenomenon - and for its transformation from a disorder that was barely recognized, in the most talked about and controversial diagnosis of our time (Donvan &

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Zucker, 2017, p. 13). This transformation occurred through the encouragement of research on the theme and activism and political struggle, aiming to build and guarantee basic rights and public policies aimed at autistic people.

There is, in the field of studies on autism in Brazil, a gap about the history of the political mobilization of families in the realization of citizenship of autistic people in the country (Leandro & Lopes, 2018) and the role of mothers in the construction of this process<sup>3</sup>. Thus, this paper proposes to collaborate in filling this gap, addressing the history of activism in autism in Brazil from the 1970s to 2008, based on the analysis of two autobiographies: *Autismo: depoimentos e informações* (Autism: testimonials and information), written by Cleusa Barbosa Szabo, published by Edicon in 1988; and *Um autista muito especial* (A very special autistic), elaborated by Deusina Lopes da Cruz, in 2008, published by Mediação. Such writings are taken as relevant sources to produce stories from the perspective of the subjects who experienced them, in addition to enabling an understanding of the relationship between autism and maternal activism in the period in focus. We adopted a feminist perspective - as a theoretical-epistemological reference -, guiding the analysis from authors such as Silverman (2005), Darré (2013), Douglas (2014) and Jack (2014), as well as problematizing the historical construction of the mothers' image of autism in the classic bibliography on the subject, activism and empowerment of these women through autobiographical writing.

## 2 BLAME AND MATERNAL RESPONSE THROUGH ACTIVISM

In the first decades of the study of autism - more specifically in the period marked between the 1940s and 1960s -, theories of psychoanalytic basis predominated<sup>4</sup> in the explanation of the phenomenon (Castela, 2013; Joseph, Soorya, & Thurm, 2016). Except for the singularities expressed by the authors, in general, autism was defined as an affective disorder, whose triggering agent was the bad mother-child relationship (Castela, 2013). Such a way of understanding the phenomenon helped to put mothers at the center of the debate on the topic, characterizing them as “bad”, “cold” and “not very loving”, or simply as “refrigerator mother” (Donvan & Zucker, 2017; Grinker, 2010; Lima, 2014; Silverman & Brosco, 2007).

The term “refrigerator mother” emerged in 1949, inspired by an article written by Leo Kanner in which he devoted more emphasis on the family relationships of his patients - relationships he understood as not very affectionate - to explain the emergence of the phenomenon. When referring to children, Kanner said that they were kept in a “refrigerator which did not defrost” (Lima, 2014, p. 111). In other words, they were little loved.

Kanner raised the hypothesis of a relationship between autism and “maternal guilt”, but it was up to Bruno Bettelheim to intensify and propagate such discussion (Donvan & Zucker, 2017). Although he wrote on the subject since the 1950s, it was with the publication

<sup>3</sup> Regarding the works that address the relationship between autism and activism in Brazil, from a historical perspective, we highlight: Cavalcante (2003), who discusses the history of the creation of the *Associação de Amigos do Autista* (AMA) – Association of Autistic Friends, the first association of autistic mothers and fathers in Brazil; Leandro and Lopes (2018), who presented the claims of family members of autistic people, by sending letters to the *Jornal do Brasil* in the 1980s; and Lopes (2019), who analyzes the history of maternal activism in Brazil.

<sup>4</sup> In general, these theories can be divided as follows: psychoanalytic theories, psychological theories, neurological theories and social, cognitive and neuropsychological theories (Castela, 2013; Joseph, Soorya, & Thurm, 2016).

of the book *The empty fortress* in 1967 that Bettelheim obtained recognition inside and outside the academic space, with his book selling more than 15,000 copies at the end of 1969 (Pollak, 2003).

Based on three case studies (Laurie, Marcia and Joy), the psychoanalyst defended the thesis that autism would be an emotional pathology, in which the child - for not feeling supported and welcomed by those who lived with him - would choose to inhabit an “empty fortress” and surrender to a state of non-existence. In his words: “Throughout this book I state my belief that the precipitating factor in infantile autism is the parent’s wish that their child should not exist” (Bettelheim, 1987, p. 137).

Although psychoanalyst Bruno Bettelheim was not the pioneer (nor the only one) to blame mothers, *The empty fortress* catalyzed several thoughts that had been present since the 1940s: concern for the infantile psyche; psychoanalysis as a theory capable of explaining phenomena related to the mind and offering advice on caring for children; and the association between mental disorders and pathologies with the exercise of “bad” maternity (Darré, 2013; Douglas, 2014; Grinker, 2010).

Throughout the history of autism, there was an overexposure of family members, especially mothers. Each piece of information, response and behavior was used as an argument in favor of understanding that family relationships were the cause of the phenomenon. Despite this offensive that articulated autism, motherhood and guilt<sup>5</sup>, the response did not take long. Whether preparing academic papers or contributing through the provision of data for research - or even its funding - and dissemination of therapies, the basis of which was the empirical knowledge of the family members, mothers and fathers of autistic people were fundamental to the questioning of psychogenic explanations about autism (Silverman & Brosco, 2007). The main example of this family response was Bernard Rimland - a psychologist, father of an autistic child and who, through the book entitled *Infantile autism: the syndrome and its implication for a neural theory of behavior* (published in 1964), stated that the basis of autism was organic and not emotional (Lopes, 2019).

The work had the support of Leo Kanner and was fundamental for the creation of the *National Society for Autistic Children* (NSAC), since it collaborated to unite parents of children diagnosed with autism and, from this union, form an association composed of family members, professionals, therapists and researchers (Eyal & Hart, 2010). Thus, if in the beginning the knowledge of mothers and fathers of autistic people was considered with suspicion, with NSAC the path was opened to raise family status, recognizing them as subjects with expertise.

In terms of advocacy<sup>6</sup>, and its expression through autobiography, it is worth highlighting Clara Claiborne’s book, *The Siege*, which was published in 1967, the same year as Bruno Bettelheim’s book. In *The Siege*, Claiborne reported the experience of being the mother of Jessica - a girl diagnosed with autism -, this being one of the first works developed in the

<sup>5</sup> Roy Richard Grinker (2010) points out that this association between autism, motherhood and guilt had a greater influence, especially in countries whose influence of psychoanalysis is greater, as was (and still is) the case of France and Argentina.

<sup>6</sup> Advocacy are practices developed by and for groups that have no space in the formal political arena. These are actions that encompass a communicative, technical-competent dimension and the occupation of political, media and social spaces (Mafrá, 2014).

United States based exclusively on the maternal view of the phenomenon (Pollak, 2003; Wing, 2010). Through the book, Claiborne publicly questioned the association between autism and maternal guilt, and “[...] led the way for a strong tradition of parent campaigners and began to tackle myths and misconceptions. Her work encouraged other parents to reject such theories, and the associated blame and guilt” (Wing, 2010).

Even though it is an important historical landmark, since it represents one of the first attempts by mothers of autistic people to express themselves - criticizing the theories of the “refrigerator mother” - without the mediation of professionals, at the time of its publication, little emphasis was given to the work, especially when compared to the reception of Bruno Bettelheim’s work (Pollack, 2003).

With regard to Brazil, it is worth noting that, although there have been some publications - mainly in print media - on the subject since the 1950s (Lopes, 2019), autism as an object of political mobilization emerged in the 1980s, dating of this period the emergence of the first associations of mothers and fathers of autistic people in defense of the cause (Cavalcante, 2003; Leandro & Lopes, 2018; Lopes, 2019). Some examples are: the *Associação de Amigos do Autista* (AMA) - Association of Autistic Friends, created on August 8, 1983, in São Paulo; the *Associação de Pais de Autistas do Rio de Janeiro* (APARJ) - Association of Parents of Autistics of Rio de Janeiro, officially founded on July 17, 1985; and the *Associação Terapêutica e Educacional para Crianças Autistas* (ASTECA) - Therapeutic and Educational Association for Autistic Children, opened by family members of autistic children in the Federal District, in 1986 (Cavalcante, 2003; Leandro & Lopes, 2018; Lopes, 2019). Inspired by similar associations from other countries, these devices were intended to help family members, disseminate, share and produce information on the subject, in addition to demanding effective actions from the State.

It is at this moment that mothers and fathers of autistic people - either individually or through associations - used the media, mainly the printed one, to publicize their experiences and perceptions about autism and demand from the State public policies aimed at this public, being the main elements of their claims: the training of professionals, especially doctors, on the subject - since there were very few who knew the topic; and the criticism of the absence of qualified institutions to meet the demands of this public and the prejudice experienced by autistic people and their families (Leandro & Lopes, 2018; Lopes, 2019).

### 3 RESEARCH SOURCES AND THE METHODOLOGICAL PATH

Jack (2014) observed that, from the first writings produced by Leo Kanner to the current productions and speeches about neurodiversity, the speeches produced about autism favor the male voices - of doctors or autistic males, for example -, which makes the historical narrative on such a gendered subject, essentially masculine, erasing and excluding female experiences from it.

In view of these issues, we will use autobiographies as a source of study as they enable the observation of the phenomenon from the maternal perspective. It is worth remembering that these writings have the clear purpose of making their potential reader feel through the narrator/author empathy for the characters and stories narrated (Pereira, 2000). The statements

present in these works present both gender and memory issues. If autobiographies are written pieces in which the individual him/herself decides what to narrate and how to narrate his/her life trajectory, gender becomes an important marker for the analysis of these documents, since it influences not only the individual experience, but also the view of the reader about the narrated facts. Thus, it is worth noting that the autobiographies do not convey exactly “what happened”, but rather the interpretation of those who experienced the events.

With regard to methodological procedures, the author also highlights that one of the elements that draws the researchers’ attention to the analysis of autobiographical texts is related to the fact that they enable an understanding of the subject’s vision/expression. However, the analysis of such documents needs to consider both the context of the production of the text and the interlocutor imagined for reading the autobiographical writing, since, although centered on the subject, such writings have a political and social dimension that must be observed in the analysis of such sources.

Considering the issues mentioned above, we analyzed two autobiographies written by mothers of autistic children at different times. The first is *Autismo: depoimentos e informações* (Autism: testimonials and information), a book written by Cleusa Barbosa Szabo and published by Edicon in 1988. The author, at the time of writing, was the mother of Alexandre, a young autistic whose diagnosis was made in the 1970s. The second work studied here is *Um autista muito especial* (A very special autistic), written by Deusina Lopes da Cruz and published in 2008 by Mediação Publisher. Deusina is the mother of Carlos Felipe, an autistic adult, diagnosed in the 1980s.

The autobiographies presented were selected based on the following criteria: they are productions that address the theme of autism in a poorly studied period – from the 1970s to the 1990s<sup>7</sup> - and present the point of view of women and the paths they follow in the search for the guarantee of their children’s rights. The authors lived in states that have historical importance in family activism - Cleusa in São Paulo and Deusina in Brasília -, in addition to having contact with associations of mothers and fathers of autistic people that emerged in the 1980s and that play an important role in the struggle for the rights of autistic people in Brazil, namely: AMA and ASTECA, respectively.

The first book analyzed, *Autismo: depoimentos e informações* (Autism: testimonials and information), although it addresses issues related to the 1970s, is a product of the following decade, 1980’s, marked by political and social changes characterized mainly by the rise of different social movements and the desire to building a democratic country. Thus, the experience of Cleusa Barbosa Szabo (1988) is published in a context in which several subjects, including mothers and fathers of autistic children, entered the public sphere, initiating the process of politicizing motherhood/paternity in autism.

<sup>7</sup> Among the works that deal with the history of autism in Brazil, we mention: the article *Cartas de mães e pais de autistas ao Jornal do Brasil na década de 1980* (Letters from mothers and fathers of autistic people to *Jornal do Brasil* in the 1980s), written by Leandro and Lopes (2018); the book *Pessoas muito especiais: a construção social do portador de deficiência e a reinvenção da família* (Very special people: the social construction of the disabled and the reinvention of the family), written by Cavalcante (2003); and Lopes’s (2019) doctoral dissertation, entitled *Não existe mãe-geladeira: uma análise feminista da construção do ativismo de mães de autistas no Brasil* (There is no refrigerator mother: a feminist analysis of the construction of activism by mothers of autistic children in Brazil (1940-2019)).

The work *Um autista muito especial* (A very special autistic), even though it has a retrospective look for the 1980s until the early 2000s, was elaborated in a context of changes in the status of people with disabilities in Brazil, having, in the legal field, some documents that formally ensured values such as democracy, freedom and dignity in the treatment of such groups. As an example, considering the field of Special Education, there are the following documents: the Constitution of the Federative Republic of Brazil (1988); the Statute of the Child and Adolescent (Law no. 8,069, of July 13, 1990); the Decennial Education for All Plan (Ministry of Education and Sport [MEC], 1993); and the National Policy of Special Education (MEC, 1994). With regard to activism in autism, the associations of mothers and fathers accumulated experiences that helped, in turn, in a reflection on the advances achieved through collective action and on the issues that deserved (and still deserve) a closer look.

In view of the adopted bibliography (Darré, 2013; Douglas, 2014; Grinker, 2010; Jack, 2014; Lopes, 2019) and the research context, autism, motherhood and activism arose as categories of analysis for, based on them, we problematize the sources and discuss issues related to the perception of the diagnosis of autism, the demands expressed by these mothers and the activism of these women in the search for their rights, being the act of writing an autobiography an act of political dimension.

#### 4 REASONS TO WRITE

When Cleusa published her book<sup>8</sup>, autism was considered a comparatively rare state (Serrajordia & Silva, 1988, p. 82). According to international data produced at the time, 5 out of every 10,000 born were autistic (Gauderer, 1987). Currently, in the United States, that number is 11.3 out of 1,000 children (Joseph, Soorya, & Thurm, 2016).

Books that discussed the theme published in Brazil were rare. Cleusa Barbosa Szabo (1988) mentions two works with which she had contact: *Autism and childhood psychosis*, by Francis Tustin, published in Brazil in 1975; and *Autismo – década de 80: uma atualização para os que atuam na área – do especialista aos pais* (Autism - 1980s: an update for those working in the field - from specialist to parents), written by E. Christian Gauderer (1987) and published for the first time in 1985<sup>9</sup>. Thus, autism was not just a “rare syndrome”, since it was also characterized as an unknown phenomenon, even by child health specialists.

Such issues may have influenced the reception of *Autismo: depoimentos e informações* (Autism: testimonials and information), in which Cleusa Barbosa Szabo (1988) narrates her story as the mother of an autistic boy diagnosed in 1976. The first edition of the book, which had a circulation of 3,000 copies, was a success, which enabled the author to discuss the topic in several places, such as universities, schools, television and radio programs and newspapers.

At the time of the third edition of the book, the newspaper *Jornal do Brasil* published, on May 1, 1989, a short article entitled “*Mãe de autista vai publicar livro*” (Mother of autistic will publish book). On the occasion, the journal highlighted that,

<sup>8</sup> The first edition dates from April 1987. The second, used in this work, was published in 1988.

<sup>9</sup> The edition used in this paper dates from 1987.

[...] although she only completed her first degree, Cleusa can, through her account, help even pediatricians who know little about autism. She is not a specialist, but she tried to describe in detail the symptoms that, since the first days of his life, Alexandre had manifested. (Nestlehner, 1989, p. 14).

Cleusa's autobiography can be presented as one of the first productions of its kind in the field of autism in Brazil. When analyzing the work, it is visible, on the part of the author, the recognition of the social place she occupies and, at the same time, the awareness of the importance of her act of narrating herself. In her words: "I am not a technician to bring up a subject like a professional, but as a mother I want to bring to all a testimony of struggles and victories" (Szabo, 1988, p. 7).

Writing, in Cleusa's perspective, meant, in the first place, "bringing hope" (Nestlehner, 1989; Szabo, 1988) for family members of autistic people or children who had similar experiences. It was also a way of sharing knowledge, which is noticeable from the lists she makes and shares, at the end of the work, referring to the books and articles she read on the subject, as well as in relation to the institutions - mainly schools - that attended her son.

Developing and publishing an autobiography on autism in the 1980s meant much more than an "outburst", it was the possibility of inserting into the public sphere - even more in a context of building a democratic society - the theme of autism and its demands in health and education. Thus, writing as an advocacy action was an important instrument, as it enabled Cleusa Barbosa Szabo spaces to "advocate" not only in relation to her son, but to speak on behalf of other mothers who went through similar situations and did not find professionals and institutions specialized in autism and that, at the same time, were accessible to the population.

Deusina Lopes da Cruz, in turn, published her account in 2008, 20 years after Cleusa's book. This temporal distance in relation to the first autobiography affected both the content - there was a greater emphasis on associations and the historical achievements they achieved - as well as on the objectives themselves regarding what it meant to write about autism from the mother's point of view.

The two autobiographies have in common the desire to understand/give meaning to their personal trajectory, the recognition that they write from the place of mother and the use of writing as an instrument to thank those who were important in their lives and those of their children - family members, doctors, teachers, friends, among others. However, although in both cases writing can be understood as an advocacy practice, in Deusina's book, political action is exercised with greater clarity and awareness. This is noticeable not only in the introduction, when she talks about "complaining about situations of injustice", but throughout the book, when the State's responsibility towards the autistic is made explicit and how the absence of certain public policies affected not only her son Felipe's life and development, but also her own life.

It is important to note that in *Um autista muito especial* (A very special autistic) the demand for assistance and care is broadened: not only for the autistic person, but for the whole family, especially for the main caregiver - usually the mother. Deusina's account draws attention to the current debate, in the political and social sciences, about the relationship between gender, disability and inequalities, and how such an intersection affects the full exercise of

citizenship. Biroli (2018), for example, highlights the little attention given by researchers in the areas mentioned to the care category, especially in debates about democracy and citizenship. In the author's perspective, this marginality leads to the invisibility of gender inequalities - and here the disability category is also inserted - perpetrated in family relationships and which are mainly observed in the inequality in relation to accountability for those in need of care - children, the elderly, sick or disabled people who make it impossible to fully exercise autonomy - and the political consequences of this unequal allocation: lack of representation in the public sphere and lack of visibility of the precariousness of some services for the provision of care - mainly in the fields of health and education.

In the two autobiographies, it is possible to observe the notes made by Biroli (2018): when the State abstains from providing basic services for the care of the population, even violating formally acquired rights, it is women who end up taking on tasks, usually alone, tasks that should be shared, whether in micro relationships with other members of the family nucleus, or at the macro level, with the State, through public policies.

The absence of free and quality services was also an issue present in both books. Cleusa and Deusina mention, for example, the financial difficulties to carry out medical consultations and how in many cases the help of third parties was essential for them to have access to the necessary services:

When I called the clinic and found out about the price of the appointment, I decided to wait until my husband received the allowance. A few days later a pleasant surprise. That lady called me and asked me to come to the watch shop with Alexandre. [...] then she gave me an envelope containing a check. "This is my complement to my Christmas present. Arrange an appointment [...]". (Szabo, 1988, p. 38).

In this report, Cleusa narrated that she only had access to the appointment due to the help of a watch shop owner who, when observing Alexandre and listening to his story, decided to help him. However, the absence of specialized and free services in the aforementioned period would have made access to the service unfeasible, or postponed, had it not been for the solidarity of an unknown person. Deusina also told a story that reminds us of the absence of free services and the high costs of multidisciplinary care for autistic people. When Felipe was about 14 years old (this was in 1995), he started showing signs of worsening of his condition. In view of her difficulties and needs, the mother opted for home care that changed the routine and family expenses:

During this period, considering the need for support from a professional caregiver during the day, at night and on weekends, and the wear and tear of the job, it was necessary to change professionals several times. The educational part of this educational service was public, but other professionals - the psychologist, the speech therapist and the caregiver - were private. Other expenses were added to this: renting the new house and paying the auxiliaries. This service alternative was, therefore, very financially costly for me. Even so, we kept it for about five years in the hope that Felipe would improve and we could return to live as before. (Cruz, 2008, p. 78).

These reports refer, once again, to the reflections made by Biroli (2018), when observing that, when care is outsourced/commercialized, issues involving class and income are indispensable for the analysis, since they define access to the necessary services, as well as

representing important social markers that help us to understand the arrangements established by the subjects/individuals so that women exercise the role of caregivers.

In the case in question, Cleusa did not - at the time she wrote and published her book - formal and paid work. Deusina has worked at the *Companhia Brasileira de Alimentos* (COBAL) - National Food Company, since 1978 - later transformed into *Companhia Nacional de Abastecimento* (CONAB) *National Supply Company* - and, in the 1990s, she was invited to coordinate the Coordination for the Integration of Persons with Disabilities (CORDE) at the Ministry Social Welfare; thus, she carried out a double workday: the formal one and the one related to the care of her two children, one of them autistic.

The 20 years that distance the publication of the two autobiographies bring distinctions about what it means for the authors to be a mother of the autistic and, from this view of themselves, to elaborate a book. Cleusa, when writing in the 1980s, a period in which the first associations and activism for autistic people were born, did so by calling herself a “victorious mother” for having managed, despite the difficulties, to achieve significant advances in the development of her son. Deusina, when reporting in 2008, in a context in which associations obtained a status related to the political struggle, wrote politicizing identity: she was a mother who was “part of social movements that fought for the right to social integration of autistic people and for offering specialized services for it” (Cruz, 2008, p. 11). Thus, although both were activists in the 1980s, the appropriation of this image is observable only in Deusina’s book.

## 5 ASSOCIATIONS

In both books, there is a space dedicated to associations of family members of autistic people. In *Autismo: depoimentos e informações* (Autism: testimonials and information), reference is made to the Association of Autistic Friends (AMA) from São Paulo, Brazil. In *Um autista muito especial* (A very special autistic), the association mentioned is the Therapeutic and Educational Association for Autistic Children (ASTECA) from the Federal District, Brazil. Although the associations are present in the two works, their meanings in the individual trajectories are different.

As previously mentioned, Alexandre was diagnosed with autism in the 1970s, before the first associations. Thus, in the process of searching for knowledge about autism and improving her son’s development, Cleusa had the support of friends, family, the evangelical community in which she participated and some professionals (doctors and teachers). Although she had a support and solidarity network, she was unaware of other cases similar to her son’s. As she reported: “13 years ago, that is, in 1973, autism was little known in Brazil. As much as I tried to inform myself about other children, I only knew about my son’s case” (Szabo, 1988, p. 56).

Alexandre was born on March 27, 1970. The first association of mothers and fathers of autistic people in Brazil, AMA of São Paulo, was founded on August 1, 1983, which demonstrates a solitary trajectory, without sharing experiences with other mothers who experienced similar situations. Even so, Cleusa mentions AMA and opens space for the Association - through an article entitled *Subsídios sobre o autismo* (Subsidies on autism), written by Ana Maria Serrajordia and Marisa Furia Silva (1988) - to talk about autism and present the

work carried out by the Association, which, at the time, had five years of existence. In addition, she left the address of the Association at the end of the book, in case any family member of the autistic person wanted more information. The solitary walk may have helped Cleusa to visualize the importance of associationism, not only to remove the feeling of being the only mother of a child diagnosed with autism, but also in the development of a support and care network for the autistic person.

In Deusina's book, associations are presented with greater emphasis and defended as an important mechanism of mutual aid, as well as for the elaboration and dissemination of knowledge about the theme, including an important element in the composition of her identity as a mother and activist in cause of autism. The special highlight goes to ASTECA - Association created in 1986, in Brasília, on the initiative of family members and professionals linked to autism -, of which the author was part.

On the insertion process in activism via the association of family members and the importance of these devices, Deusina reported the important role played by the neuropediatrician who took care of her son and who advised her to get in touch with other family members of autistic people who, at the time, were interested in creating an association. It was then that she met other mothers and fathers with stories similar to hers and who together built ASTECA. When talking about the experience, she mentions:

Creating a parent association was a good start. It became easier to identify other parents whose children had behaviors similar to those presented by my son, as well as other professionals in Brazil and abroad who had experience in the area. [...]. Our association participated in several government initiatives to discuss and adapt public health, education and social assistance policies and related areas, aimed at assisting autistic people and their families in order to guarantee their social rights. (Cruz, 2008, p. 41).

It is possible to observe not only the influence/inspiration coming from associations elaborated in other countries - the experience of Spain is mentioned in the work -, but also the importance attributed to collective activism in the 1980s. This awareness of the importance of collective struggle led, as observed in the two sources analyzed, the creation, in 1986, of the Brazilian Association of Autism (ABRA), which represented an attempt to unify the regional associations that arose across the country at that time.

## **6 FROM DIAGNOSIS TO THE ABSENCE OF ADULT SERVICES**

The theme of the diagnosis appears with great emphasis on maternal reports, highlighting the difficulties encountered by mothers to obtain, in the 1970s and 1980s, the diagnosis of autism in a context in which few professionals knew the subject. The few who knew often shared the perspectives that associated autism with bad motherhood (Lopes, 2019), making this theme a common subject in both works.

Cleusa started her autobiography with a quote taken from the book *Autismo – década de 80: uma atualização para os que atuam na área – do especialista aos pais* (Autism - 1980s: an update for those working in the field - from the specialist to the parents), written by E.

Christian Gauderer (1987) and prepared by the National Society for Autistic Children, in 1978. Here is the complete quote:

Autism is a developmental inadequacy that manifests itself severely throughout life. It is disabling, and typically appears in the first three years of life. It affects about five out of every ten thousand born and is four times more common among boys than girls.

It is a disease found worldwide and in families of all racial, ethnic and social configurations. It was not possible to prove any psychological cause in the environment of these children that could cause autism (National Society for Autistic Children, 1978 as cited in Gauderer, 1987, p. 1).

Deusina, in turn, presented the theme in detail, interspersing historical discussions - pointing out how autism was presented by names like Kanner and Bettelheim - with her experience as a mother. At a certain moment, she made the following description:

The only public institution in Brasilia that served children with developmental delay was the Psychopedagogical Medical Orientation Center [Centro de Orientação Médico Psicopedagógico – COMPP] of the Hospital Foundation of the Federal District. The waiting list was so long that I signed up at the age of three and he was only called for evaluation when he was five. The result of the long-awaited evaluation said that: “Felipe did not recognize and did not interact with his mother, he suffered from maternal deprivation (deprived of living with his mother)”. It was the first time that I heard of these things. In addition to not knowing what he had and how to deal with the situation, I would still be to blame for my dear son’s illness. Much to my despair and that of many mothers of autistic people, theories like this have been widely advocated by psychoanalysts and found in almost every literature on autism for a long time. (Cruz, 2008, p. 31).

Although they dedicate different spaces to the issue, in both works, there is a criticism of the professionals who accepted the theories that linked autism and an alleged “bad motherhood”.

Another theme present in the sources analyzed here concerns the absence of services and professionals - mainly from the areas of health and education - specialized in autism and the impacts that the absence of these services has caused in their daily lives. Cleusa mentioned in her book the various moments that Alexandre did not study because she did not find schools that would accept his enrollment and the extent to which staying at home generated setbacks, especially in the matter of sociability. She also reported cases of aggression, including physical, that her son suffered at one of the institutions he attended:

The other day when I went to pay the tuition at school Alexandre started to cry as soon as he saw me. The inspector intervened saying that when the psychologist spoke to him, Alexandre would calm down. Outside I could still hear his loud screams and I thought it was because of my presence at school. When he arrived in the afternoon I asked him why he was crying and he said that the “uncle”, referring to the psychologist, had beaten the ruler on his hands because he had cried. (Szabo, 1988, p. 36).

This excerpt expresses the vulnerability to which autistic children were exposed throughout the 1970s and 1980s. Faced with the refusal of many establishments to accept children with disabilities, many families found themselves at the mercy of institutions that

were not only incapable of providing a service adequate to the needs of their children, but that often subjected them to situations that can be defined as being mistreated.

By participating in ASTECA, Deusina had the opportunity to participate in the project and in the consolidation of the first integrated educational service for autistic people in public schools in Brazil, carried out through a partnership between the Association - which was responsible for guiding the school community about the autism - and the Educational Foundation of the Federal District - responsible for finding a suitable school to receive the pilot project. Felipe was one of the first students to participate in this process of school inclusion, which officially began in 1987 at *Escola Classe 405 Sul* in the pilot plan (Cruz, 2008). About the experience, she made the following description:

We have registered many victories, for example, Felipe's studying in an integrated manner with non-autistic students, but it was also clear the challenge that a proposal like this only succeeds if the school is prepared in advance, if it receives supervision continuously, that it is guaranteed the student the support of other professionals, in addition to proper family guidance. (Cruz, 2008, p. 57).

Despite the positive experience, when he started what would be called Elementary Education II, Felipe had difficulties adapting due to the changes that occurred in this new stage of teaching and the lack of flexibility of some professionals, resulting in what was defined by his mother as a feeling of failure.

If Alexandre and Felipe were denied basic access to education and health services during their childhood, this situation was accentuated in adulthood. Cleusa wrote in a context in which discussions about autism started in Brazil, focusing mainly on children and the difficulty in diagnosing them due to the lack of trained professionals. In her account, it is observed that the more time passed, the more difficulties she found to enroll her son in educational institutions.

Deusina, when writing in 2008, also pointed out the invisibility of the adult autistic person, especially the one who does not have the ability and condition for an independent life. From the age of 14, Felipe had a worsening of his condition, showing signs of another mental disorder in addition to autism. The situation intensified in 2002, when he had what her mother called “[...] a crisis of intense emotional lack of control” (Cruz, 2008, p. 79), requiring psychiatric hospitalization.

In addition to the difficulties related to the experience of hospitalization, the family still had to face the poor quality of services, such as when visiting the boy one day after his hospitalization, they found out that he was no longer at the institution he was admitted to and that they could not say precisely where Felipe was. According to Deusina, only three hours after being informed that her son was not in the hospital, they discovered that “he had been improperly transferred to a clinic in the satellite city of Planaltina/Federal District” (Cruz, 2008, p. 80). The clinic offered care via the Unified Health System and also privately, although, from the mother's perspective, the care and structure offered to patients treated by the Unified Health System were not adequate, which even made the Public Ministry close the public wing of the hospital.

Such experience, associated with professional performance, made Deusina have a clear vision on how public policies aimed at such a group should be outlined:

[Autism] presents varied demands for services that range from basic medical evaluation care, medication use, education, family guidance to more specific demands at various levels of complexity such as psychiatric hospitalizations. When I needed this alternative treatment for my son, I did not find quality services, just a lot of misinformation and prejudice, which further aggravated our problem [...]. (Cruz, 2008, p. 85).

It is important to highlight that not all autistic patients have psychotic conditions, as well as not all need interventions that require hospitalization. However, it is important to reflect on the availability of services that address all the needs expressed by autistic people and their families.

Whitman (2015), when describing the responsibilities of legislators in relation to the theme of autism, establishes four key points: 1) focus on early intervention; 2) establishment of local centers specialized in assisting autistic people and their families; 3) elaboration of research aimed at the design of public policies aimed at this public; and 4) support for basic and applied research on the subject.

In the two analyzed sources, it was observed that such questions were present, although, in the first one - written by Cleusa -, the demand for the State to assume its part in relation to care is not so clear. In view of the moment of publication of the book, in 1988, this timidity can be associated with the very context in which the first steps were taken to build full citizenship. In 2008, not only Deusina already had an accumulation of experience - as a mother, scholar and activist -, but her own activism in autism provided her with an experience capable of visualizing and better defining the responsibility of each subject in relation to autism - family, teachers, health professionals and the State.

## 7 FINAL CONSIDERATIONS

We proposed, in this paper, to analyze how mothers of autistic people perceived and self-represented within a given history of autism. The narratives about their experiences help us to understand the experiences and feelings experienced by these subjects, in addition to the paths followed - within their possibilities - aiming at better living conditions for their children.

The autobiographies, far from being simple maternal outbursts, represent the maternal attempt to assume the role of their individual trajectories and the construction of autism as a phenomenon that deserves the attention of health and education professionals, researchers from different areas of knowledge, media and the State.

We presented the autobiographical writing as a practice of advocacy and political action of the mothers, which, in turn, helped to unveil female protagonism in the fight for rights. We approached the beginning of the first discussions about the phenomenon in Brazil - 1970, when few professionals knew much about autism -, going through the 1980s - the moment of rise of the first pro-autistic associations and the possibility of advocacy on the topic, which includes the writing of Cleusa Barbosa Szabo's (1988) autobiography -, 1990 and 2000, in which a series of legal provisions - such as the Constitution of the Federative Republic

of Brazil (1988) and the Child and Adolescent Statute (Law no. 8,069, of July 13, 1990), for example - guaranteed the status of citizen and subject of law for the autistic person.

Thus, the writing mothers presented their life trajectories at different times: Cleusa in a scenario of democratization of Brazilian politics; Deusina in a context of political stability and advances in discussions on the inclusion of people with disabilities. Although temporally different, we can argue that such mothers viewed, in autobiographical writing, a mechanism to publicly expose their perceptions about the phenomenon and create an articulation between autism, advocacy and maternal activism.

The claim made by these women is part of the recognition of a very specific place of speech, that of the mother of autism, and this identification is a political instrument capable of generating - in those who have no experience in the field of autism - the recognition that their voices deserve to be heard and their demands met.

In recent years, Brazil has experienced significant advances around the issue, the main one being the sanction of Law no. 12,764, of December 27, 2012, also known as Berenice Piana Law. This law represented an important milestone in the history of citizenship of the autistic person, considering him/her, for legal purposes, as a person with disabilities, starting to acquire the same rights legally guaranteed to such group. Its sanction represented an achievement as a result of a long journey which started in the 1980s by mothers and fathers of autistic people.

It is also worth remembering the inclusion of autism in the 2020 Demographic Census, to be carried out by the Brazilian Institute of Geography and Statistics (IBGE). Although access to diagnosis - especially early diagnosis - is not a reality for countless families, for the first time in Brazil there will be access to some data on self-declared autists, which in turn will be fundamental for the design of public policies. These data will be collected due to the political and collective pressure from mothers, fathers and autistic people who mobilized themselves so that the topic was not one of the issues taken from the Census conducted in 2020.

In view of the long political trajectory of mothers of autistic children in Brazil, and the gaps that still exist about the history of these women, we highlight the importance of studies that address the role of these women and explore the multiplicity of experiences, since, although all can be considered “mothers of autistic people”, several issues - such as ethnic-racial, social class, disability, region where they live, etc. - can significantly interfere in the experience of these women in relation to motherhood.

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