

What do family members of autistic people say of the work carried out by the CAPSi?

O que dizem familiares de autistas sobre o trabalho desenvolvido pelos CAPSi?

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Abstract

The child and adolescent mental health policy, implemented in Brazil from the beginning of the 21st century, established the *Centros de Atenção Psicossocial Infantojuvenis* (CAPSi - Psychosocial Care Centers for Children and Adolescent) as strategic services to prioritize more complex cases, with emphasis on autism. This study aims to compare two sources of information on the perception family members of autistic people regarding the work carried out by CAPSi: the first was collected in a 2011 survey, which used focus groups; and the second, from the literature produced on the subject in the following 10 years. The family member's narratives were organized into four thematic axes: perception of the effects of psychosocial care; information sharing; perception about care processes; and demands and claims. Despite the heterogeneity between the studies, the results indicated that the work of the CAPSi produces positive effects, especially regarding socialization. However, this perception is not accompanied by a better understanding of the clinical picture and care processes. The value of treatment is often attributed to the personal attitude of professionals, indicating the lack of sharing and participation by family members. These aspects should encourage the CAPSi to involve family members as partners in care, particularly valuing the transmission of the psychosocial reasoning, its strategies and direction of care.

Keywords: Psychosocial Care Centers; Autism Spectrum Disorder; Family Caregivers; Care Processes.

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Resumo

A política de saúde mental infantojuvenil, implantada no Brasil no início do século XXI, estabeleceu os Centros de Atenção Psicossocial Infantojuvenis (CAPSi) como equipamentos estratégicos para priorizar os casos de maior complexidade, com destaque para os autistas. Este estudo visa cotejar duas fontes de informação sobre a percepção de familiares de autistas acerca do trabalho desenvolvido pelos CAPSi: a primeira foi colhida em pesquisa de 2011, que utilizou grupos focais; e a segunda, a partir da literatura produzida sobre o tema nos 10 anos seguintes. As narrativas foram organizadas em quatro eixos temáticos: percepção sobre os efeitos do trabalho psicossocial; compartilhamento de informações; percepção sobre os processos de cuidado; e demandas e reivindicações. Apesar da heterogeneidade entre os estudos, os resultados indicaram que o trabalho dos CAPSi produz efeitos positivos, principalmente em relação à socialização. Contudo, essa percepção não é acompanhada de melhor entendimento do quadro clínico e dos processos de cuidado. O valor do tratamento é frequentemente atribuído à atitude pessoal dos profissionais, indicando a ausência de compartilhamento e participação dos familiares. Esses aspectos devem instigar os CAPSi a envolver os familiares como parceiros do cuidado, dando atenção especial à transmissão da lógica psicossocial, suas estratégias e direção do cuidado.

Palavras-chave: Centros de Atenção Psicossocial; Transtorno do Espectro Autista; Cuidadores Familiares; Processos de Cuidado.

Introduction

In the early 21st century, with the advent of the child and adolescent mental health policy, the Brazilian State, through the Brazilian National Health System (SUS), allocated financial resources and technical guidance for the implementation of psychosocial care networks for childhood and adolescence, establishing the *Centros de Atenção Psicossocial Infantojuvenis* (CAPSi – Psychosocial Care Centers for Children and Adolescents) as strategic equipment, and territorial networking and intersectoral collaboration as fundamental elements (Brasil, 2002).

When appearing on the national scene, the unprecedented nature of this proposition—which aimed to reach, over time, the countless children and adolescents with mental health needs—established the provision of access and qualified care for the most complex cases as a priority. It was also indicated that users and family members should occupy the place of care partners, as opposed to the passive place of objects of intervention, historically assigned to them in the traditional psychiatric system. In addition to innovating the place occupied by users and family members, the CAPSi were implemented with the responsibility of operating a double mandate—therapeutic and managerial—meaning that they should be able to offer continuous and expanded care to children and adolescents with specific needs and, at the same time, organize the mental health demand of their reference territories (Couto; Delgado, 2015).

At the start of the CAPSi implementation process, in line with the decision to prioritize the more complex cases, users were included as “all those who, due to their mental condition, were unable to maintain or establish social ties” (Brasil, 2004, p. 23; our translation), a category that included autism, among other conditions. The long history of omission, by the public mental health field, of propositions and actions for the care of children and adolescents in intense psychological distress justified the decision, at that time, to provide this clientele with access to the CAPSi, so that they could find within the SUS equipment capable of offering multidisciplinary and territorialized care, capable of developing unique

therapeutic projects, and guided by the ethical principle of social inclusion. Even though care for autistic people should not be restricted to mental health, but rather cover the entire spectrum of life, it was up to the CAPSi, in the early 21st century and on behalf of the SUS, to state that it was also the responsibility of psychosocial care to look after autistic people in situations of suffering, as opposed to the historical lack of care for these people by public mental health care (Couto, 2004).

Since then, autistic people and their families have been present at the CAPSi, although in different proportions, according to clientele characterization studies. Despite methodological differences, the findings of this research suggest a trend towards an increase in autistic people in the CAPSi in recent years, when compared with older surveys (Hoffmann; Santos; Mota, 2008; Delfini et al., 2009) and more recent ones (Teixeira; Jucá, 2014; Lima et al., 2017). Portolese et al. (2017, p. 83) consider this fact an advance, since “this equipment is the most prepared for cases with ASD [autism spectrum disorder].”

Increased access and the growing number of autistic people in the CAPSi do not in themselves guarantee the quality of care for these people in psychosocial facilities. Additional factors that need to be taken into account are: the way of welcoming, of building bonds and partnerships in the care process; coordination with territorial resources to expand support networks; intersectoral collaboration to achieve comprehensive care; the centrality of the therapeutic project in social insertion and expanding citizenship conditions; and the development of sharing strategies between workers and users/family members, so that the care process is meaningful, understandable and aimed at improving the quality of their lives (Couto; Delgado, 2015).

After 20 years of the existence of CAPSi in the public care field, and considering the importance of the participation of autistic people’s family members in the psychosocial process, questions emerge: what is the perception of these family members about the work carried out by the CAPSi and its effects on autistic users? Do they consider that there is sharing of knowledge about the therapeutic project, including diagnosis and care strategies? What do they most often claim from the CAPSi?

In this study, the specific interest in family members’ perception of psychosocial work is related to the growing political activism of family members of autistic people in the Brazilian context, whether or not they are part of the CAPSi, whose agendas revolve around care practices and intervention models, in addition to disputes regarding the ‘place of speech’ and expertise in public policymaking for autistic people (Lugon; Costa Andrada, 2019). Invested as social and political actors and organized through associations of different epistemic and ideological nuances, family activists have guided, in recent decades, many of the paths of national policies for autistic people, some of them in clear opposition to the psychosocial care network (Nunes; Ortega, 2016).

A paradigmatic example of the tensions between a significant part of the family-activist movement and the psychosocial field was the emergence of controversies surrounding Law no. 12,764 of December 27, 2012, which established the National Policy for the Protection of the Rights of People with Autism Spectrum Disorder (Brasil, 2012). Understood as a victory for the political activism of a segment of family activists, its approval gave visibility, in the regulatory process, to an antagonism between this segment—which defended the national assembly of exclusive services for autistic people—and operators in the psychosocial field, critical of this excessive specialization, as it violates the principle of comprehensive health and reinforces the exclusion and stigma experienced by autistic people (Rios; Camargo Júnior, 2019). Illustrative of this antagonism in the regulatory process was the lobbying carried out by family activists, aiming to suppress the reference to qualification and strengthening of the *Rede de Atenção Psicossocial* (RAPS - Psychosocial Care Network) toward the care of people with ASD. Decree 8,368, of December 2, 2014, however, maintained RAPS, alongside the Health Care Network for People with Disabilities, as a strategic network for the care of autistic people (Lugon; Costa Andrada, 2019)

Controversies aside, it is important to highlight the increasingly active role of family members in formulating public policies and organizing care networks, in accordance with the assumptions of participation and social control of health policies

in the SUS. In this sense, knowing how family members of autistic people included in the CAPSi perceive psychosocial work can be an important contribution to the qualification of this field and to strengthening the role of partners assigned to them in psychosocial care.

Considering this context, and taking as a premise the fact that knowing family members' experience and perception about the psychosocial mode of care is key for the planning and advancement of the field, the objective of this study is to compare and analyze two sources of information, collected in different periods, on the perception of family members of autistic people regarding the work developed by the CAPSi, using also different methodological strategies, as described below.

Methodology

This qualitative study was developed from the following guiding question: Do the perceptions about the care process, its sharing and its effects, formulated by family members of autistic children and adolescents about the CAPSi's work in research carried out in 2011, in a context-specific region, resonate or not with studies on the same topic published in the following decade?

Two methodological strategies were used to produce the data. The first concerns the narratives of family members from 14 CAPSi in the metropolitan region of Rio de Janeiro, collected through focus groups (FGs) held in 2011 within the scope of a larger survey, of an evaluative and participatory nature, whose objective was to produce indicators for CAPSi's work with autistic people (Lima et al., 2014). A total of 29 family members participated in this survey, 24 of whom were female and 05 male. In previous articles, other categories extracted from these FGs were analyzed (Lima; Couto, 2020; Lima et al., 2020).

The objective of this study was to highlight and organize in a spreadsheet the FGs' statement related to the category 'understanding of family members of autistic people about the care provided by CAPSi and its effects.' The analysis of this material generated the following thematic axes: a) perception of the effects of psychosocial work; b) perception about the care processes in the CAPSi; c) sharing

of information by the CAPSi; and d) main demands and claims of family members.

The second data collection strategy was a non-systematic review (Adams et al., 2016; Greenhalgh, 2015; Haddaway et al., 2015; Munn et al., 2018) of national scientific literature published between 2011 and 2021 on the topic of 'family members of autistic people and CAPSi,' in order to analyze whether, in the decade following the FGs, studies on the topic have shown advances or maintenance of challenges related to the four thematic axes mentioned above. This methodological choice is justified by the low number of results obtained in a systematic "pilot" search carried out in the scientific databases Electronic Library Online (SciELO) and Virtual Health Library (VHL)/Latin American Caribbean Literature in Health Sciences (LILACS), for their importance in the dissemination of freely accessible national scientific production (Langdon; Foller, 2012). With the keywords "autism/autistic," "family/family/caregivers," and "CAPSi/psychosocial care/mental health service" only two to five articles were found, depending on the combination of search terms.

According to Greenhalgh (2015), for topics on which there are few articles published in journal databases, it is necessary to expand the search strategy beyond them, using tools such as Google Scholar. This perspective aligns with the growing debate about the relevance of using these online search tools for reviews, especially when systematic reviews in indexed journals and databases encounter publication bias, yield few results and/or involve studies whose objects or fields of investigation are made available through gray literature (Adams et al., 2016; Haddaway et al., 2015).

Therefore, a search was carried out with the Portuguese equivalents for the keywords "family members" AND "autism" AND "CAPSi" and the same time frame (between 2011 and 2021) in the Google Scholar tool, with a filter for pages in Portuguese, in an anonymous browser, and 767 results were found. Next, an exhaustive reading of the abstracts visible on the Google Scholar pages was carried out until the point of saturation, indicated by an increasing number of repeated results and/or whose titles clearly indicated "off-topic" texts (Fontanella, Riccas, Turato, 2007). By excluding repetitions, citations, and off-topic results, a selection of 155 results was obtained. The next

stage consisted of reading the titles and abstracts of the 155 references, with the following exclusion criteria: publications outside the theme ‘family members of autistic people and CAPSi’; texts in a foreign language; citations; free format texts; and gray literature. At this point, 44 references were obtained for full reading, in which the inclusion and exclusion criteria were applied. Studies that presented narratives from family members of autistic people compatible with the theme ‘understandings about CAPSi care and its

effects’ were included. The exclusion criteria covered: theoretical studies; literature review articles; studies not conducted in CAPSi; studies conducted in CAPSi on work with autistic people, but which did not address the perspective of family members; inconsistencies between the title/abstract and the content of the article; and previous articles arising from larger research with FGs. This stage reached seven articles, which make up the sample of this study (Figure 1).

The articles analyzed are listed in Table 1.

Figure 1 – Graphic diagram of the non-systematic review

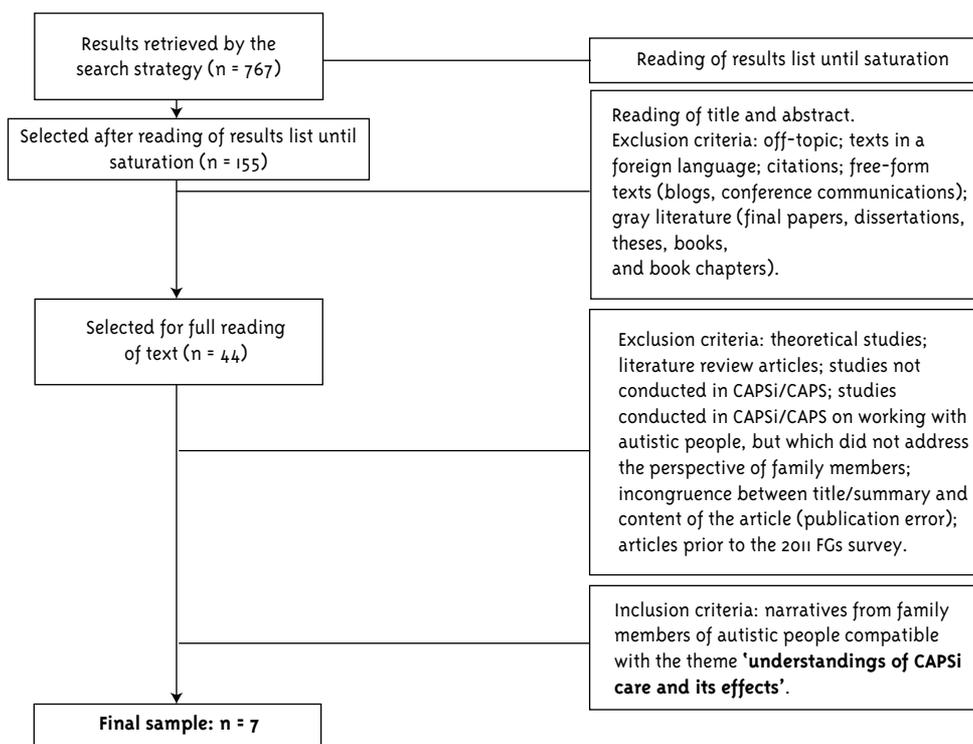


Table 1 – Articles included in the literature review

Study	Year	Location of research	Profile of research informants and methodology used	Study's objectives
Felix; Santos. <i>Infância e atenção psicossocial</i>	2016	Recife PE	19 family members of children using a CAPSi. (interviews and field diaries)	Analyze the challenges in accessing RAPS for children and adolescents
Araújo; Guazina. <i>A percepção de cuidadores sobre os cuidados ofertados para crianças e adolescentes em atendimento no CAPSi</i>	2017	Rio Grande do Sul	5 family members of teenagers using a CAPSi in RS. (interviews)	Elucidate the perception of users' caregivers about the services offered in a CAPSi in a city in the interior of the state of Rio Grande do Sul.

continues...

Table 1 – Continuation.

Study	Year	Location of research	Profile of research informants and methodology used	Study's objectives
Ingrasiotano; Akil; Máximo. <i>O lugar das famílias de usuários do Centro de Atenção Psicossocial Infantil (CAPSi) do município de Itajaí – SC na produção das necessidades de saúde mental</i>	2017	Itajaí/SC	6 families of CAPSi users from Itajaí/SC. (interviews)	Understand how relationships between users' families and CAPSi in Itajaí/SC produce mental health needs and the place of families in these relationships.
Carvalho-Filha et al. <i>Coping e estresse familiar e enfrentamento na perspectiva do transtorno do espectro do autismo</i>	2018	Caxias/MA	32 family members of autistic children assisted by 3 different services: AMA, APAE, and CAPSi (interviews)	Analyze the daily lives of informal caregivers and people on the autism spectrum
Ribeiro; Miranda. <i>Demandas a um CAPSi: o que nos dizem os responsáveis por crianças e adolescentes em situação de sofrimento psicossocial</i>	2019	Unknown	19 family members of users of the only CAPSi in a medium-sized municipality. (group interviews)	Understand the demands that those responsible for children and adolescents address to the CAPSi.
Trindade; Gaudêncio; Santana. <i>A família de crianças e adolescentes com autismo e o trabalho do CAPSi: vivências e experiências</i>	2019	Unknown	11 family members of CAPSi users. (questionnaire and interviews)	Evaluate changes in the family dynamics of autistic children after being monitored at the CAPSi.
Rabelo et al. <i>O papel de cuidadores de crianças usuárias do CAPSi: um estudo de uma cidade do RN</i>	2021	Rio Grande do Norte	7 family members of CAPSi users in a city in the interior of Rio Grande do Norte (focus group)	Assess how caregivers perceive their role as responsible for an atypical child receiving treatment at a CAPSi.

In the seven selected articles, excerpts from family members' statements were analyzed and recategorized according to the four thematic axes extracted from the 2011 FGs, in order to allow a comparison of advances, setbacks or maintenance of problems in CAPSi's work with autistic people.

This study presents some methodological limitations, as in some of the articles analyzed, the universe of interviewees was "family members of CAPSi users" (which included autistic people), without a precise identification of whether or not the excerpts of speech were from family members of autistic people. Furthermore, given the heterogeneity of the methodologies and objectives found in the articles analyzed, and between these and our research, the comparability of the findings

is limited. However, the comparison between the data set from the 2011 FGs and the sample of articles from the following 10 years brought relevant results about the perceptions of autistic people's family members about psychosocial work.

The research was approved by the Research Ethics Committee of the Institute of Psychiatry of the Universidade Federal do Rio de Janeiro - Ipub/UFRJ (opinion no. 81 Liv3- 11) and by the Research Ethics Committee of the Municipal Secretariat of Health and Civil Defense of Rio de Janeiro (CAAE: 0045.0.249.314-11).

All names used in the excerpts of family members' statements referring to the FGs from the 2011 survey are fictitious in order to protect the confidentiality and anonymity of the study participants.

Results and discussion

Perception of the effects of psychosocial work with autistic people

This thematic axis covers family members' perception about changes in autistic users after their inclusion in CAPSi and the correlation of these changes—if any—with the treatment offered by the service. We will seek to articulate the narratives collected in the 2011 FGs and the statements selected in the literature between 2011 and 2021, as presented in the topic on the methodology of this article.

In the FGs, family members pointed out improvements in autistic people's behavior and socialization since they began monitoring at CAPSi, as shown in the following statement:

[...] when Tiago arrived [at CAPSi], he was an extremely agitated child, he wouldn't stop. We had to lock the gate, we had to be careful. And today, if you look, people say: "Wow, your son walks alone?" And I say: "And yours doesn't?" You know? Tiago would be a child who could never be independent. He does handicrafts, swims, he took a computer course and received a diploma from the mayor. Many things happen to him because of CAPSi. Because before CAPSi it didn't happen. (Isabel, FG 2011)

Some reports indicate that the perceived improvements are related to care strategies often used by CAPSi, such as collective or group work designed to expand social ties:

As autistic people have that isolating and a little antisocial side, when you put them in a group that socializes them, this gives a good result, for sure. My son had a lot of good reactions, despite being a calm child, this helped him a lot. (Getúlio, FG 2011)

There is a lot of congruence between the statements from the 2011 FGs and those collected from the literature in the subsequent period concerning the effects of the care offered by the CAPSi. The findings are in line with what was recorded in the study by Trindade, Gaudêncio and Santana (2019), involving interviews with

11 caregivers of autistic users; in the survey carried out by Araújo and Guazina (2017), in which five caregivers of children and adolescents were interviewed (one of them identified as autistic); and in Rabelo et al. (2021), who carried out a focus group with seven caregivers of users (five of them autistic). In these studies, family members highlight the "improvement" of children in the way they interact and communicate, a greater understanding of the environment and social codes, and the willingness to play, based on psychosocial care:

Because with them working with him here like this, it's... at home he didn't like toys, today we buy him toys and he picks up any toy, puts it in his hand, plays with it, lets it go; and before he came to CAPSi, he could have all the most beautiful toys in the world and he wouldn't even look at them [...] (E10). (Trindade; Gaudêncio; Santana, 2019, p. 74)

The improvement is because she is very agitated, she wouldn't play with her sister, with anyone, not even other children. But going there [at CAPSi] she is playing more (Caregiver D). (Araújo; Guazina, 2017, p. 458)

It has improved a little, today he no longer does the things he used to do (putting his head in the hammock strings, talking with his hands, he wanted to kill his sister), but it is still a lot of work (CAREGIVER 02). (Rabelo et al., 2021, p. 5770)

In summary, it can be seen that family members, both in the 2011 FGs and in the literature found in the following decade, tend to evaluate the effects of psychosocial care favorably. However, in the caregivers' statements found in Araújo and Guazina (2017) and Ingrasiotano, Akil and Máximo (2017)—involving interviews with six family members of users, including those with autism—this improvement was strongly associated with a specific aspect of the therapeutic plan: the medication. In these family members' view, this can be a key element in controlling behavior, preventing crises, and ensuring sleep at night:

That she has this problem, sometimes she is fine, sometimes she is very agitated, sometimes she runs away and goes out into the street [...] so when she

takes the medication I can control her, calm and well, but she cannot go without the medication... (Caregiver C). (Araújo; Guazina, 2017, p. 457)

[...] now he takes Ritalin and Risperidone and Fluoxetine... because Fluoxetine was introduced last month. The doctor came because I questioned why he is always very agitated, a mile a minute, I asked the Dr. that when I take fluoxetine, which I do, I feel fine, it takes away this irritation, this agitation, that I feel sometimes I get very irritated, I already feel that it's a lack of my medication, then the doctor realized that if he has the same genetics as mine it could work for him and gave him fluoxetine (EDUARDO'S FAMILY). (Ingrasiotano, Akil; Máximo, 2017, p. 429)

Araújo and Guazina (2017, p. 457) highlight the strength of the biomedical model, which tends to leave family members in a passive position, by relying on medication as an “adaptive resource for children and adolescents in family and school life.” In turn, in the FGs held in 2011, there was no systematic investigation of this topic, which appeared few times in the narratives of family members, who sometimes highlighted the role of psychotropic drugs as the drivers of users’ improvement—as in the statements above—and sometimes highlighted less medication-dependent practices by the CAPSi:

What I like here [CAPSi] is that they don't just throw a bunch of medicines at you, hand you a bunch of medicines. They teach us to trust the treatment! Mine passed... he's now been taking medication for about three years. He's been here for seven years, and he's gone four years without medication! (Iracema, FG 2011)

However, in contrast to Iracema’s statement (FG 2011), Nunes and Ortega (2006) point out that one of the reasons why activist family groups consider the treatment offered to autistic people to be “inadequate” would be the fact that, for them, the CAPSi would be reduced to medication prescription sites. In our larger, evaluative survey, carried out in 2011, 56% of autistic users were using psychiatric medication, according to reports from CAPSi key

informants (managers) (Lima et al., 2017). It is worth mentioning that Law no. 12,764, of December 27, 2012, guarantees the right to access to medicines, among other health actions, and that the Care Line for People with ASD in SUS points out that medication can be part of the singular therapeutic project, but should not be taken as its axis (Brasil, 2013). Given the complexity of the topic, these services should take as their task the clarification and informed consent of family members regarding their children’s treatment—including the use of medication—which is related to the issue of information sharing in these services, as we will see in the next topic.

Information sharing in the CAPSi

When analyzing the perception of family members of autistic people about the sharing of information related to the construction of diagnoses and therapeutic projects by the CAPSi, the comparison between narratives of those who took part in the FGs held in 2011 and those whose statements are recorded in the literature of the subsequent 10 years revealed approximations and discrepancies with what was presented in the previous topic. This is because, while acknowledging the positive effects of CAPSi’s work, family members say they “know nothing about the condition of their child” and have many doubts about what objectively characterizes autism.

It's been more than two years and she didn't give a report. And we don't know what his condition is. Because, in my opinion, I don't know why he is in treatment. Because he gets along with everyone, he plays, he keeps track of everything. I don't think my grandson is autistic. I think he's very agitated, I think he's more hyperactive. (Jurema, FG 2011, emphasis added)

It's... Like... There at the CAPSi we don't talk about that. About such pathologies, understand? They treat you a lot, like that... the children themselves, they do therapy with the children, they talk to their mother, but I miss that, because I want to better understand what my son's condition is. [...] So, I think he has some autistic symptoms, but I wanted to better understand this type of autism,

which I know is associated with something else. I wanted to know the degree and I don't have this information in the CAPSi. (Regina, FG 2011, emphasis added)

To a large extent, this lack of knowledge about the autistic condition expresses a gap in communication between family members and CAPSi teams, which affects key points of the psychosocial project. This because the notion of family members as partners in care (Delgado, 2014), which, along with others, underpins the psychosocial mode of care, implies a radical transformation with regard to the place occupied by family members while the asylum model was in force. In other words, from liabilities and objects of intervention, in psychosocial care families must be taken as active subjects and partners, with clarity about the paths taken in the preparation of diagnoses, care processes and therapeutic projects, requiring workers to provide accessible, comprehensible, well-founded and permanently shared information, so as to enable the sought-after partnership with family members.

The study by Félix and Santos (2016), based on semi-structured interviews with 19 caregivers of children who attend a CAPSi in the Northeast region, corroborates the lack of effective communication between professionals and caregivers, also recording that the latter end up being without access to clinical management and the proposed direction of care. A caregiver's statement clarifies this point:

[...] we are very much at the mercy of what they are going to do, we have no knowledge. I think it should be... It's a support center for both children and families, because I am educated, I read, but other people I see here aren't, they are totally lost, for example, here they do the internal work, of course, but **we don't know everything that's going on** (Alice, mother, 26 years old). (Félix; Santos, 2016, p. 44, emphasis added)

Félix and Santos (2016) state that the direction of care in the CAPSi studied is restricted to specialized knowledge, delegitimizing the knowledge and expertise specific to family members and leaving them with insufficient guidance regarding the work being conducted.

Carvalho Filha et al. (2018, p. 114) also find that caregivers of autistic people "have limited knowledge about ASD," largely determined by the lack of knowledge being shared by professionals. In view of this, they draw attention to the importance of "managers, professionals, and health services being able to act together" (Carvalho Filha et al., 2018, p. 114; our translation) with family members of autistic people, by promoting health education strategies on the topic, which may lead to a better understanding of the autistic condition and greater participation in care pathways.

In another article analyzed, there is a record of a mother's statement that exemplifies the problem mentioned above:

I don't know if all CAPS are like this, but I think it's a very serious flaw, the follow-up with us, you know? I don't think **the doctor should meet only with the professionals, or if she didn't, she should make another professional available to talk to us. Once a month, with the mothers, the fathers, the people who look after them, you know?** It should be like that because here we have little assistance from them. (Marta, mother, 49 years old). (Félix; Santos, 2016, p. 44, emphasis added)

The lack of sharing and consideration for the family member's expertise ends up engendering, according to Nunes (2014, p. 53), a way of searching for information whose "arrival point is a medical report." The expectation of family members for an objective delimitation through reports involves, in addition to the search for clarification regarding the enigmatic condition of their children, more pragmatic aspects, linked to access to rights and social policies. It is through this document, for example, that users or family members are entitled to the Continuous Cash Benefit (BPC), free public transport in some municipalities, and access to the inclusive educational system, among other public policies based on the expansion of social justice and equity.

In psychosocial care, the complexity of situations, the different dimensions of suffering and concrete life difficulties are as crucial to the construction of care processes as the psychopathological phenomenon, and should therefore be considered in dialogue with family

members. Even though there is, on their part, a great expectation of understanding what is happening to their children based on the report/diagnosis, it is necessary to consider that mere medical information does not reach the complexity involved in the demand for reports. This is because, despite offering 'a name'—which is no small thing—for a phenomenon considered by family members to be enigmatic or strange, the report has no intelligibility or meaning directly applied to their complex life experiences. Experiences of social isolation, job loss, physical and emotional overload, the centrality of care in the woman (mother or grandmother), the need for support networks and guidance on how to deal with the child, among many others, are invisible and silenced if the search for a report is taken as an end in itself (Muylatert, Delfini, Reis, 2015).

In this sense, CAPSi must take into account the different elements involved in the request for a report by family members, which may occur on their own request, but also on recommendation from other health services or intersectors. It is necessary to overcome both biomedical reductionism, which takes psychiatric classifications as self-explanatory, and the postponement of issuing a report based on the belief that, in this way, the particularity and complexity of the affected subject would be preserved, without reducing it to a psychiatric designation.

The statements of family members in the 2011 FG help to clarify this last point:

So, the school always asks me “mom, where is the report on this one?” I fight for this at CAPSi. “Guys, the school is always asking me for a report, can you give me this report?” (Janete, FG 2011)

“Ah, because the report is a serious thing!” I know it’s a serious thing, but don’t you know that Matheus has a problem? “Ah, but he’s still a child, he has to grow up!” I know! My greatest delight one day will be taking this card and throwing it away! My greatest happiness will be to see that my son no longer needs this card, but unfortunately, he does. (Tatiana, FG 2011)

When asked to issue a report, CAPSi workers, whether they do so immediately, postpone it or simply refuse, run the risk of declining the psychosocial care operation itself.

The comparison between the FGs’ narratives and the literature shows the persistence of disagreements between family members and CAPSi professionals, with the dispute over the reports as one of its indicators. The ethos of psychosocial care must focus on collective and individual dimensions, considering both the social determinants of health and the unique and socially situated experience of the suffering subject, including the family members’ experience. In this sense, the biomedical and diagnostic dimension should not be disregarded, but this should not be taken as a prerequisite for access to care (Yasui, 2010). Transmitting this ethos to family members and valuing their status as care partners continued to be a challenge for psychosocial care for children and adolescents in the period between 2011 and 2021.

Perception of care processes in the CAPSi

Both the narratives collected in 2011 and the studies published in the following 10 years indicate that psychosocial work processes—especially the welcoming process, building bonds and trust—are perceived by family members of autistic people as innovative strategies in the field of care, because they produce a sense of belonging. Being welcomed, being able to go to the service as often as necessary, receiving the team at home when it is impossible to go to the CAPSi and recognizing the service as a place where it is possible to cry or ‘open up’ suggest welcoming as a relevant psychosocial process. The following statements exemplify this:

And when we come to the CAPSi, the family is supported, there is a parent meeting, there is an individual meeting, it is a great support that we receive here (E4). (Trindade, Gaudêncio; Santana, 2019, p. 75, emphasis added)

We talk, we open up, we have friends, we know who we can cry with. (Antônia, FG 2011, emphasis added)

Welcoming is, to a large extent, associated with the availability of CAPSi professionals, as mentioned in some statements from the 2011 FGs: “it’s the willingness of the professionals that makes the

difference” (Regina, FG 2011), “*at the CAPSi they [workers] are like warriors, even the outsourced workers at the front*” (Roberta, FG 2011). Similar perceptions were recorded in the study by Félix and Santos (2016, p. 43) when the family members interviewed highlighted the “good professional qualifications” of the CAPSi team surveyed, focusing on their dedication:

[...] dedication, attention, good interpersonal relations of all professionals involved, such as security guards, administrative assistants, and other professionals.

However, even considering the value attributed to the dedication and availability of workers, it is not recommended that the difference in psychosocial care be centered on these qualities. After all, the spectrum of transformations inherent to the psychosocial operation is broad, involving not only attitudinal elements of workers, but also changes in the understanding of phenomena, in clinical practice, in the place occupied by users and families, in the inclusion of community and intersectoral resources such as care resources, among many others.

The psychosocial model constitutes a scientifically informed expertise, it has foundations and guidelines capable of guiding new forms of care, focuses on communities and expands the conditions of participation, protagonism and citizenship of all those involved, amalgamating clinical effectiveness and social transformation (Costa-Rosa, 2000). At this point, it is worth asking: Were the CAPSi, in the period from 2011 to 2021, able to operate and transmit to users and their families the reach and coverage of the psychosocial mandate beyond the attentive and available position of the workers? If not, the logic and expertise typical of the psychosocial mode remain enigmatic and unfathomable in the field of hegemonic culture, for which the understanding of mental health needs tends to be individualized and subordinated to biomedical knowledge, as evidenced in the discussion about medication and diagnoses.

Failure to share the psychosocial perspective with users and family members means that the broader understanding of ‘which problem is being treated and cared for’—which should involve the subjects and

the community—remains unanswered or, even, with the same reductionist response that psychosocial care aims to overcome. Furthermore, the difficulty in communication, in addition to weakening the construction of partnerships, can result in demands for “specialized care,” in the form of segregated services, intensive, individualized, and medicalized interventions, as we will see next.

Main demands and claims

In the 2011 FGs, there were many complaints, requests, suggestions and demands made by family members regarding the CAPSi. One of the most common demands was that the entire list of therapies proposed to autistic people, including their schooling, be concentrated in the same space:

I think the CAPSi should integrate everything, the whole. Having the special education part, having the music therapy part, the clay part, the painting part, the doctor part. Having a part where parents could be there without having to spend their idle time: producing something, doing something, to be able to generate income there. Right there, being able to integrate everyone there. (Adriana, FG 2011)

I think it should be all in the CAPSi, why? I take care of my heart in Laranjeiras, my other son takes care of his heart in Humaitá, Lucas takes care of it at CAPSi, Bruno takes care of it at [Instituto] Fernandes Figueira, Lucas used to take care of it at Santa Casa... That's complicated, isn't it? (Regina, FG 2011)

It is possible to see that there are different motivations for these demands, such as the possibility of family members themselves engaging in activities or the reduction of time spent traveling between health and education facilities. What, at first glance, seems to point to the need for a totalizing institution, which would in itself meet all the needs of autistic people, can, in fact, be taken as a demand that calls for the principle of comprehensive care (Oliveira; Andrade; Goya, 2012), reinforcing the need for this comprehensiveness to be the subject of substantial investment by the CAPSi in their territories of operation.

In the articles consulted, this theme appears mainly in the form of requests for some specialties that, despite being provided for in the ordinance that established the CAPSi (Brasil, 2002), are not present in many of them, such as occupational therapy and speech therapy.

[...] what Paulo really needed was an OT, occupational therapy, because he really needed it, ninety percent occupational therapy plus therapy... and here there was hardly any of that and then it started to weaken me a little (Luciana, Paulo's mother). (Ribeiro; Miranda, 2019, p. 56)

Other complaints found in the FGs and in the literature produced between 2011 and 2021 refer to the intensity of care, the frequency of visits to the CAPSi and the length of service, which, in the case of this research, are also associated with the demands for specialties:

So, the time they are out there, pacing back and forth, they become anxious. Like an empty mind, with nothing to do. If there was an occupation, perhaps the hours would even increase. Half an hour for music therapy, half an hour for I don't know what. Forward to multiple segments that day. Even if we spent the whole day. I think we would be satisfied because we would see that they would be in several segments. (Antônia, FG 2011)

The girls stay in there for half an hour, I think it's a short time. We pass by, move around, take 4 buses like in my case, we have to be here at the right time, only to stay for half an hour. Half an hour is very quick (Ana, grandmother, 52 years old). (Félix; Santos, 2016, p. 43)

On the one hand, these narratives contain pertinent complaints, often associated with the precariousness of the CAPSi's work and their limitations in offering more intensive care (Lima et al., 2020)—it is worth highlighting that the CAPSi were the type of CAPS that grew least in the country between 2011 (when there were 149) and 2020 (when there were 278) (Desinstitute, 2021). From another perspective, the narratives are linked to the service's difficulties in transmitting to family members the mode of operation of psychosocial care, as previously

discussed. The demand for specialists is one of these sensitive points, given the prioritization, in the CAPSi, of collective or group spaces—often called “coexistence” or “permanence”—to the detriment of the offer of techniques conducted by specific professionals in individual spaces (Lima et al., 2014). Furthermore, some statements recorded in the literature analyzed associate the issue of frequency and duration of care with what would be the specificities of autism treatment, and relate to a theme also present in the 2011 FGs: the need or not to divide spaces and schedules of CAPSi by diagnosis, separating autistic children from other children, given that the former would require a different kind of work:

I just think there should be more days, if the government encouraged better, because treatment for autism has to be every day, it's not a small thing you coming, and then spending the week at home, the child going to school, the child living at home, or going to other places that are also part of the treatment. It's all they have, right?! For those who are treated for autism in other places it is every day. (E1). (Trindade; Gaudêncio; Santana, 2019, p. 77)

I didn't even know, at the beginning, that the CAPSi was a reference for autism, because it isn't. Excellent service, the professionals are great, everyone there welcomes us very, very well, but there is no work aimed at autistic people, you know, there are several deficiencies, right? (Marina, FG 2011)

This debate, which was present in the 2011FGs and in the literature published in the following decade, suggests the persistence of polarization that led the family movements lobby to propose—unsuccessfully—the suppression of the reference to qualification and strengthening of the psychosocial network in the care of people with ASD (Lugon; Costa Andrada, 2019). The idea that the management of autism requires, in a mandatory and universal way, certain types of therapy and/or a high weekly workload (“in other places it is every day”), or that the CAPSi “have no work aimed at autistic people,” flirts with the technification and segregation of the treatment of these users and constitutes a challenge for the fulfillment of the

psychosocial mandate by the CAPSi in the period covered by this study. Facing this polarization, with its overcoming through intersectoral strategies on the horizon, should be one of the main tasks of psychosocial care for children and adolescents in the coming years.

Final considerations

Based on the guiding question that informed the development of this study and the findings from the strategies for collecting information, we can infer that, in the perception of family members, the work of CAPSi with autistic people produces favorable effects, especially in relation to socialization. However, the recognition of therapeutic resources used for this purpose oscillates between collective care facilities, highlighted in the FGs, and the use of psychotropic drugs, present in reports taken from the literature. More than a difference in understanding, this finding may indicate the existence of fragile sharing of psychosocial processes with family members, a factor that is related to another aspect highlighted in this study, which is that the children's improvement is not accompanied by a better understanding of the family members about what is happening to the children, whether from the point of view of psychopathological phenomena or the care processes used. Another indicator of this problem is the demand for reports, which tends to replace dialogue and center the source of information on the doctor, harming the very transmission of the psychosocial nature of care in the CAPSi.

The value of welcoming, building bonds, and supporting—the basis of work in psychosocial care—is ascribed, to a large extent, to the personal attitude of professionals, producing a gray area over the public mandate of psychosocial services and the innovation they are called to operate in society and within the 'culture of therapies.' Understanding as a personal characteristic that which is of the public order says more about the lack of sharing and participation by family members than about a misunderstanding of the process.

All these highlighted aspects must be taken as a warning to the CAPSi to increase effective actions of participation, sharing, partnership, and transmission of the psychosocial mandate, including users and their families. Psychosocial care is a project of social

transformation that cannot be carried out if it is not shared and collectively agreed upon. Even though the focus of this study was the work of the CAPSi with autistic people, it is necessary to highlight the importance of intersectionality for a comprehensive care. In this sense, advancement in the field of psychosocial care depends heavily on collaboration and co-responsibility between different public sectors, agents, actors, and managers in the territories.

Although this study has limitations of scope in the comparability of its findings, due to the methodology applied and the methodological heterogeneity between the articles that made up the sample and the data from the 2011 FGs, we believe it was possible to compare the narratives and extract results from them that indicate the characteristic challenges of psychosocial care for autistic people in the period between 2011 and 2021, in order to guide the improvement of care for these users. The future of psychosocial care for autistic children and adolescents involves valuing their families as care partners, paying special attention to the circulation of information and strategies for transmitting the psychosocial logic.

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Authors' contributions

Lima, Couto and Costa Andrada participated in the conception and design of the study; analysis and interpretation of data; article writing; critical review and approval of the version to be published.

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