

# Psychosocial Care for Children and Adolescents with Autism in the CAPSi of the Rio de Janeiro Metropolitan Area<sup>1</sup>

Atenção psicossocial a crianças e adolescentes com autismo nos CAPSi da região metropolitana do Rio de Janeiro

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## Abstract

Centers for Child and Adolescent Psychosocial Care (CAPSi) are public institutions for the care of children and adolescents with serious mental health problems, including those with autism spectrum disorders (ASD). A review of the Brazilian literature indicates a lack of systematized information on the treatment offered to such patients. This study presents and discusses data related to psychosocial profiles and therapeutic projects for patients with autism and their families at the CAPSi located in the Rio de Janeiro metropolitan area. Methodology: a descriptive, quantitative study based on questionnaires sent to 14 CAPSi in 2011. Results: 782 patients were diagnosed with autism in the surveyed CAPSi, comprising 1/3 of patients receiving care. The majority were male, aged 10 to 19 years. Most lived with their family in the service's coverage area and received semi-intensive care, with individual and collective assistance, including to family members. About 1/5 were out of school and less than 1/3 received the *Benefício de Prestação Continuada da Lei Orgânica da Assistência Social* (BPC - Loas [Continuous Benefit of the Social Assistance Organic Law]). It was concluded that the CAPSi of the region offered care to a significant number of autistics, requiring, however, investment in intersectorial coordination to expand social inclusion conditions,

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improvement in care information and incentive to use evaluation methodologies to train professionals providing care to autism patients and others.

**Keywords:** Autism; Psychosocial Care; Children and Adolescents; CAPSi.

## Resumo

Os Centros de Atenção Psicossocial Infantojuvenil (CAPSi) são equipamentos públicos destinados ao cuidado de crianças e adolescentes com problemas mentais graves, incluindo aqueles com transtornos do espectro do autismo (TEA). Revisão da literatura nacional indica falta de informações sistematizadas sobre o tratamento oferecido a esta clientela. O artigo apresenta e discute dados referentes a perfil psicossocial e projetos terapêuticos para usuários com autismo e seus familiares, em CAPSi situados na região metropolitana do Rio de Janeiro. Metodologia: estudo descritivo, quantitativo, baseado em questionários enviados a 14 CAPSi em 2011. Resultados: havia 782 usuários com diagnóstico de autismo nos CAPSi pesquisados, constituindo 1/3 dos usuários em atendimento. A maioria era do sexo masculino, na faixa dos 10 aos 19 anos. A maior parte residia com a família, na área de abrangência do serviço, e estava em regime assistencial semi-intensivo, com atendimentos individuais e coletivos, incluindo os familiares. Cerca de 1/5 estava fora da escola e menos de 1/3 recebia o Benefício de Prestação Continuada da Lei Orgânica da Assistência Social (BPC - Loas). Concluiu-se que os CAPSi da região ofereciam cuidado a número expressivo de autistas, requerendo, no entanto, investimento em articulações intersetoriais para ampliar condições de inclusão social, aprimoramento das informações sobre o cuidado oferecido e incentivo para o uso de metodologias avaliativas visando a qualificar a assistência a usuários com autismo e a outros sob seu cuidado.

**Palavras-chave:** Autismo; Atenção Psicossocial; Crianças e Adolescentes; CAPSi.

## Introduction

Centers for Child and Adolescent Psychosocial Care (CAPSi) are regional and community-based services that offer daily attention to children and adolescents afflicted with mental disorders, with priority given to those of a more serious nature. Among the latter, autism spectrum disorders (ASD) stand out for their impact on the establishment of social bonds from the early years of life as well as the burden placed on parents or other caregivers. Despite the magnitude of the problem, only recently has the Brazilian Unified Health System (SUS) started devising strategies to care for this population. Until the end of the 20<sup>th</sup> century, people with autism were mainly cared for by philanthropic institutions (such as APAE and Pestalozzi), family associations, welfare facilities (such as shelters for the “disabled”), special education institutes, or a few outpatient or hospital mental health services (Couto, 2004; Brasil, 2015a). Only after regulation by Ordinance No. 336 of February 19, 2002 (Brasil, 2002) – published in response to the deliberations of the III National Conference on Mental Health, held in 2001 – did SUS develop the first public mental health project to include autism in its scope by setting up CAPSi in the different Brazilian regions (Couto; Delgado, 2015).

However, few studies have focused on investigating the treatment offered to autistic patients in the CAPSi or investigating their psychosocial profile. Some studies already published (Pinto, 2007; Brandão Junior, 2009; Quaresma; Silva; Quaresma, 2010) address autism care in those services according to the theoretical framework of psychoanalysis, generally using the methodology of case discussion combined with theoretical elaboration. Others, such as those by Visani and Rabello (2012), based on surveys of CAPSi medical records, report that the treatment of autistic children starts late due to the absence of early detection initiatives, insecurity, and delay by other health professionals in diagnosing and managing cases of autism (which causes delay in referral to the CAPSi), also pointing to the constant report of family quests for diagnoses and treatments. Couto (2012), following a metanarrative review of the literature on CAPSi published in Bra-

zilian journals between 2002 and 2010, emphasizes that despite the important presence of children and adolescents with ASD in the CAPSi, there is no systematized information on the care offered to them in such facilities. Studies surveying data on the various diagnoses in the CAPSi report a prevalence of developmental disorders (Code F.80, in the 10<sup>th</sup> edition of the WHO International Classification of Diseases - ICD 10), which include autism, of around 14.2% (Hoffman; Santos; Mota, 2008), 16.2% (Delfini et al., 2009) and 27.5% (Ronchi; Avellar, 2010). More recently, Lima et al. (2014), in research carried out in the Rio de Janeiro metropolitan area to produce quality indicators of care for children and adolescents with ASD in the CAPSi, recorded an important gap related to the absence of assessment studies on community services for autistic children.

A survey coordinated by the Brazilian Autism Association (Abra) investigated public services (including CAPSi) and private and philanthropic institutions/NGOs between 2011 and 2012. Of the 106 institutions surveyed, 40 provided exclusive care for people with autism, with 45% of autistic children aged 0 to 5 years; 35.73% aged 6 to 12 years; 26.31% aged 13 to 18 years; and 22.50% aged over 18 years. According to the survey, 47% received care for 20 hours a week or more, while 8% received care for 40 hours a week. There was, however, an uneven distribution of hours of care according to age: a proportionately larger number of autistic children over 18 received more than 20 hours of therapy per week compared to those aged 0 to 5 years. Autism-exclusive institutions offered proportionally less hours of treatment per week, and also had a lower professional/care ratio than other institutions (Mello et al., 2013).

In the international context, most research on autistic services was carried out in the United States, whose health system organization is distinct from Brazil's. A study that investigated the profile of children receiving care in community mental health services in the US between 1994 and 1999 found that 1% of patients had a diagnosis of autism/Asperger syndrome. In this group, more than 80% were male. Approximately 1/4 to 1/3 of the referrals came from the school system, with 40% of patients being referred for disruptive behavior, such as hyperactivity

and aggressiveness, and 12% for social impairment, such as social avoidance and precarious interaction with peers - that is, most were referred because of the "accessory" symptoms and not the "main" symptoms of autism. With regard to psychoactive drugs, 63% had already used them compared to 48% of children with other diagnoses. A small number (6.3% of autistic and 11.8% of Asperger patients) lived in institutions compared to children with other diagnoses (19.4%) (Mandell et al., 2005).

A more recent study, also involving children with autism treated in community mental health facilities in the US, identified a predominance of high functioning autistic children and a frequent provision of behavioral or cognitive behavioral therapies, whereas parent training strategies were less frequent. In addition, it was observed that the therapeutic strategies did not differ much from those used with patients with other diagnoses, and, although consistent with evidence-based data, were used at a lower intensity than recommended. In general, evolution pointed to the improvement of children's symptoms and family functioning (Brookman-Frazee; Taylor; Garland, 2010). In another study by the same research group, the lack of adequate training to care for people with autism was cited by professionals of community mental health clinics in the United States as one of the main challenges faced in everyday life (Brookman-Frazee et al., 2012).

Also in the US, research involving interviews with caregivers evaluated the use of health services for autistic children aged 6 to 17 years across the country. Half of them had been diagnosed after the age of five, and from that age, identification of the condition was done mainly by psychologists and psychiatrists, whereas in the first four years of life it was done typically by pediatricians, family doctors, nurses and psychologists. Sixty-one percent of patients underwent three or more types of treatment, the most common being social skills training and speech/language therapies, followed by occupational therapy (especially for those under 11 years old) and behavioral therapies. Fifty-six percent used psychiatric medication, with a predominance of stimulant drugs, anxiolytics and mood stabilizers (Pringle et al., 2012).

In England, Barrett et al. (2011) evaluated the use of services for preschool autistic children (24 to 60 months of age), with an emphasis on economic costs. The families of 152 children with autism were contacted to investigate the use of services in the six months prior to the interviews. In the health field, 80% of them had undergone speech/language therapies, 60% had contact with community pediatricians, 57% with general practitioners and 48% with health visitors. In the field of education and childcare, 64% attended common nurseries or daycares, and 11% attended specialized nurseries and daycares; 11% were in mainstream schools and 6% in special schools. The authors found an increase in costs with age and in children with more extensive impairment. Finally, they recognized the existence of inequalities in access to services, with some children using high levels of service and others using very low levels, the latter possibly associated with the greater load in family care.

In Australia, early intervention and education strategies are key in care for people with autism. There is a network of NGOs that receive public funds for evaluation, early detection, education, employment, and social skills programs. In addition, each state has government services for people with intellectual disabilities, including autism, involving psychologists and other professionals. Also available, especially in the state capitals, are children's psychiatric clinics, which offer secondary consultation for rural regions (Brereton; Tonge, 2014). In the state of Western Australia, the Disability Services Commission was established in 1997 and is responsible for distributing early intervention government funds to children with ASD. Since 1999 there has been a registration method to monitor the annual number of autism diagnoses, and there is currently a protocol to guide the diagnostic evaluation process (Glasson et al., 2008).

Within the context of gathering qualified information on the offer of autism care in international and Brazilian systems, the objective of this research is to present and discuss general data

related to care offered to children and adolescents with autism in the CAPSi of the Rio de Janeiro metropolitan area, as well as data on the psychosocial profile of this population. In July 2011, there were 132 CAPSi accredited by the Brazilian Ministry of Health (MS) located in large and medium-sized cities in Brazil, 16 of them in the state of Rio de Janeiro (Brasil, 2011a). The last official document published by the MS informs that in December 2014 there were 201 CAPSi throughout the country (Brasil, 2015b). However, there are services in operation that, due to various problems, are not accredited by the MS. In the Rio de Janeiro metropolitan area, in June 2011 there were 14 CAPSi in operation, four of which were not yet accredited. These 14 CAPSi comprised the universe of this study, and at present there are others in operation in the city of Rio de Janeiro<sup>2</sup>. The recent implementation of CAPSi and responsibility of SUS for treating autistic patients requires knowledge of the state of the art in autism care, aiming to improve regional and intersectorial therapeutics and care in order to enhance conditions for social inclusion.

## Methodology

A descriptive study, based on quantitative data, on autistic patients receiving care at the CAPSi of the Rio de Janeiro metropolitan area, carried out within the scope of a broader qualitative-evaluation study involving higher- and middle-level professionals and relatives of autistic patients with the aim of gathering indicators on the care of this population (Lima et al., 2014). The universe of the survey included the 14 CAPSi of the Rio de Janeiro metropolitan area in operation in 2011, involving the municipalities of Rio de Janeiro, Duque de Caxias, Nova Iguaçu, São João de Meriti, Belfort Roxo, Itaguaí, Queimados (Metropolitan Area I), Niterói, São Gonçalo and Itaboraí (Metropolitan Area II). Over approximately eight months, the research team held weekly meetings in which a questionnaire was drafted based on the survey carried out in the CAPS network of the city of Campinas (SP) (Cam-

2 During the research or after its conclusion, other CAPSi started operating in the metropolitan area of Rio de Janeiro, not being included in the 2011 investigation: the Maurício de Souza, Heitor Villa-Lobos and Visconde de Sabugosa CAPSi, all in the city of Rio de Janeiro.

pos et al., 2008) and monitoring instruments used by different levels of mental health management. Following contact by telephone with the mental health coordinators of the 10 municipalities and the directors of the 14 CAPSi involved in the research, and following a visit to the services during the respective team/supervision meetings, an electronic message was sent to each CAPSi director with a questionnaire consisting of general information about the service (such as address, initial date of operation, date of accreditation, etc.) and other 22 items, grouped into three main areas - user profile, therapeutic project and psychosocial data of the autistic patients - with reference to June 2011. Of the 14 CAPSi, nine returned the questionnaire fully completed, four returned it partially completed, and one did not return it.

The survey was approved by the Research Ethics Committee of the proposing institution (Opinion No. 81Liv3-11) and by the Research Ethics Committee of the Municipal Health and Civil Defense Department of Rio de Janeiro (CAAE: 0045.0.249.314-11). No requirements of this process were made by the other municipalities.

## Results

### Overall and sociodemographic characterization

The 13 CAPSi that answered the questionnaire had 2,213 patients in regular care in June 2011, 782 (35%) of whom were identified as autistic. These patients were especially concentrated in the 10 to 14 (32%) and 15 to 19 (32%) age groups, with marked male prevalence (81%) (Table 1). Eighty percent of the autistic patients had used the service for more than 12 months.

**Table 1 – Overall and sociodemographic characterization of autistic patients**

Autism and other diagnoses found at the CAPSi (n=2,213)	Total n (%)
Autism	782 (35%)
Other diagnoses	1,431 (65%)
Total number of patients in care at the CAPSi n (%)	2,213 (100%)

continues...

**Table 1 – Continuation**

Autistic patients by age group (n=782)	Total n (%)
0-4 years	43 (6%)
5-9 years	159 (20%)
10-14 years	254 (32%)
15-19 years	247 (32%)
21 years or over	58 (7%)
No information	21 (3%)
Total number of autistic patients in care at the CAPSi by age group n (%)	782 (100%)

Autistic patients by gender (n=782)	Total n (%)
Female	149 (19%)
Male	633 (81%)
Total number of autistic patients in care at the CAPSi by gender n (%)	782 (100%)

### Psychosocial data

As recorded in Table 2, most autistic patients lived with their family (86%) within the CAPSi coverage area (82%). Regarding schooling, 32% were in special education and 20% in mainstream education, with a significant percentage (20%) out of school. In addition, in 28% of cases the user's schooling situation was not informed.

A little over half (52%) of autistics had free bus transportation and less than a third (31%) received BPC. However, there was a significant lack of information regarding those topics (21% and 26%, respectively, according to Table 2). Another topic with substantial recording loss (42%), and therefore not included in Table 2, was related to autistic patients living in areas covered by *Estratégia de Saúde da Família* (ESF - Family Health Strategy): according to the CAPSi, only 20% of autistics lived in areas with ESF coverage.

**Table 2 – Psychosocial data of autistics at the CAPSi**

Data (n=782)	Total n (%)
<b>Residence</b>	
Family	669 (86%)
Shelter	12 (2%)
Therapeutic residence	3 (0%)

continues...

**Table 2 – Continuation**

Data (n=782)	Total n (%)
Other	1 (0%)
No information	97 (12%)
<b>Total n (%)</b>	<b>782 (100%)</b>
<b>Resident in the CAPSi coverage region</b>	
Lives in the region	642 (82%)
Does not live in the region	140 (18%)
<b>Total n (%)</b>	<b>782 (100%)</b>
<b>Benefits: BPC – LOAS</b>	
Receives the benefit	244 (31%)
Does not receive the benefit	332 (43%)
No information	206 (26%)
<b>Total n (%)</b>	<b>782 (100%)</b>
<b>Benefit: Free travel bus pass</b>	
Receives the benefit	410 (52%)
Does not receive the benefit	207 (27%)
No information	165 (21%)
<b>Total n (%)</b>	<b>782 (100%)</b>
<b>Schooling</b>	
Out of school	153 (20%)
In mainstream education	177 (20%)
In special education	242 (32%)
No information	210 (28%)
<b>Total n (%)</b>	<b>782 (100%)</b>

## Clinical care

According to the categories of *Autorizações de Procedimentos Ambulatoriais de Alta Complexidade* (Apac - Authorization for High Complexity Outpatient Procedures)<sup>3</sup>, 61% of autistic patients were in semi-intensive care, 11% in non-intensive and 16% in intensive care. Just over half (56%) of those patients used psychotropic drugs. In addition, 17% were undergoing concurrent treatment at another institution or with a professional outside the CAPSi (Table 3).

**Table 3 – Autism care at the CAPSi**

Clinical care (n=782)	Total n (%)
<b>Treatment by care intensiveness</b>	
Intensive	127 (16%)
Semi-intensive	475 (61%)
Non-intensive	87 (11%)
No information	93 (12%)
<b>Total number of autistic patients in care at the CAPSi n (%)</b>	<b>782 (100%)</b>
<b>Autistic patients and use of psychotropic drugs</b>	
Use drugs	441 (56%)
Do not use drugs	259 (33%)
No information	82 (11%)
<b>Total number of autistic patients in care at the CAPSi n (%)</b>	<b>782 (100%)</b>
<b>Autistic patients treated in other facilities</b>	
Treated in other facilities	131 (17%)
Treated exclusively at the CAPSi	486 (62%)
No information	165 (21%)
<b>Total number of autistic patients in care at the CAPSi n (%)</b>	<b>782 (100%)</b>

Chart 1 shows the main spaces and activities offered to these patients at the CAPSi: the 13 services reported having individual and collective care spaces (called “coexistence,” “permanence,” “among many,” or “among several,” according to the decision of each CAPSi), eight offered workshops and 11 made home visits to autistics. Twelve CAPSi reported providing assistance to parents or other caregivers (in group or individually), eight reported holding parent/caregiver meetings and none reported holding meetings with patients.

Also regarding the care offered, four services reported having specific schedules, workshops or other spaces and activities for autistic patients (i.e. exclusively for them, not including patients with other conditions), and eight CAPSi reported having schedules and/or spaces according to

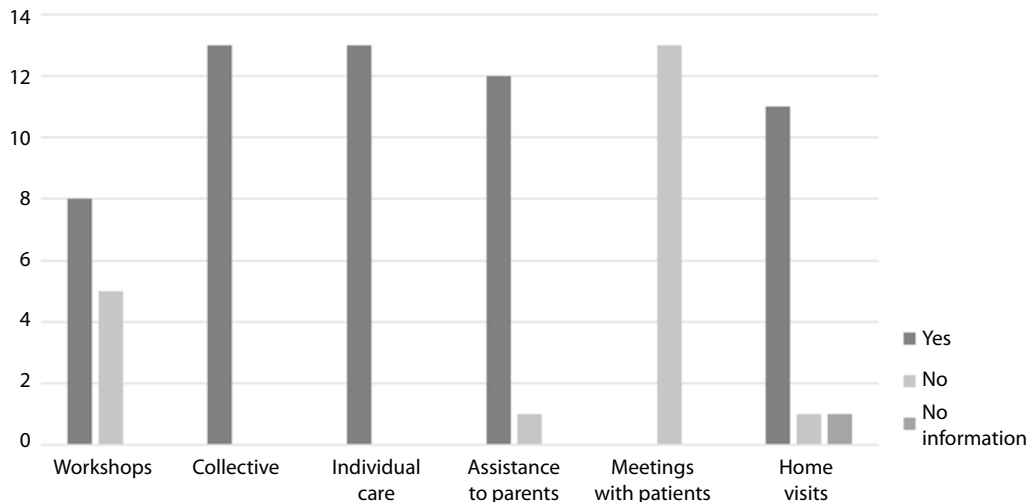
3 Until 2010, registration of care services at CAPS and CAPSi was done through Apac, which was replaced by *Registro das Ações Ambulatoriais da Saúde* (Raas - Outpatient Health Care Registry), in compliance with Ministry Ordinance No. 3,088, dated December 23, 2011.

age, separating autistic children from autistic adolescents.

Regarding relationship with other sectors and social movements, six CAPSi reported having regu-

lar meetings with the schools attended by autistic patients and only two services reported having contact or interacting with an autism family support association (data not included in the tables).

**Chart 1 – Activities offered to autistics at the CAPSi**



## Discussion

The percentage of autistic patients at the CAPSi of the Rio de Janeiro metropolitan area (35%) is higher than that reported by studies carried out in the CAPSi of other regions, where the ASD group varied between 14.2% and 27.5% (Hoffman; Santos; Mota; 2008; Delfini et al., 2009, Ronchi; Avellar, 2010). This suggests that the CAPSi surveyed took responsibility for the care of autistic patients, although in absolute numbers those patients (n=782) represent only a portion of autistics residing in the region<sup>4</sup>, considering the current estimates of ASD prevalence, around 0.66% (Hill; Zuckerman; Fombonne, 2014). Thus, even considering the possibility of families resorting to care resources outside SUS, there still seems to be a significant gap in the care of autistic patients by the public

mental health network in the surveyed region (Lima et al., 2014).

The gender percentage reproduces the ratio of four boys to one girl found in autism prevalence studies (Hill; Zuckerman; Fombonne, 2014) and in previously cited studies of US services (Mandell et al., 2005; Brookman-Frazee; Taylor; Garland, 2010). The majority (64%) of autistics is in the 10 to 19 age group, with a much smaller number of young children in the services. Since 80% of patients had been registered for more than 12 months, it can be deduced that they began treatment in the service at an earlier age than recorded in the study, but information on access to treatment immediately following detection or perception of clinical indications of autistic problems is unknown. Such data is relevant, since the identification of signs of autism risk and early treatment have been associated with

<sup>4</sup> In 2011, the population of the metropolitan area was 10,862,107, 2,804,019 of whom in the 0 to 19 age group. (Source: Portal IBGE Cidades. Available from: <<http://bit.ly/1LH8d4G>>. Accessed on: April 26, 2016.

a better evolution of the condition (Brasil, 2015a; Ibañez; Stone; Coonrod, 2014).

As for psychosocial data, like the US study cited (Mandell et al., 2005), few patients do not live with their families/caregivers. This indicates that only a minority of this population resides in shelters in the Rio de Janeiro metropolitan area, which does not mean that the services should neglect mapping and interacting with institutional sheltering organizations in their regions, aiming to overcome existing modes of exclusion and segregation. The percentage of patients residing outside the CAPSi coverage area is small, suggesting a trend towards regionalization in care, with the proviso that in the region surveyed, the population (and geographic) scope of most CAPSi is above the recommended by ministerial ordinances (Brazil, 2002, 2011c).

Only one in five autistic patients resided in areas covered by ESF (Family Health Program), a ratio that - despite the significant loss of data in this area - is close to ESF coverage in June 2011 in several municipalities of Metropolitan Area I (for example, 22.5% in the city of Rio de Janeiro, 17.35% in Duque de Caxias, 28.46% in Itaguaí and 36.11% in Nova Iguaçu), although the municipalities of Metropolitan Area II showed greater coverage (62.12% in São Gonçalo, 77.02% in Itaboraí and 75.01% in Niterói)<sup>5</sup>. The data do not allow assessing the quality of coordination between the CAPSi and basic care, although the low ESF coverage in most of the metropolitan area in 2011 points to fragility and low impact of this relationship on access and provision of quality care for autistics.

About half of autistic patients (52%) attended school, well below the national average of children and adolescents enrolled in the education system, which was 93% for ages 4 to 17 in 2011<sup>6</sup>. However, due to the absence of information in 28% of cases, the figure may be higher than that recorded in this study. It is noted that there are more autistic patients in special education than in mainstream education, which seems to run counter to *Programa Educação Inclusiva* (Inclusive Education Program)

created in 2003 by the Brazilian Ministry of Education and supported by the 2007 *Plano de Desenvolvimento da Educação* (Education Development Plan) (Brasil, 2015a). However, one must consider that it was only after 2011, with *Plano Nacional dos Direitos da Pessoa com Deficiência - Plano Viver sem Limites* (National Plan for the Rights of Persons with Disabilities - Unrestricted Living Plan), instituted by Decree 7,612 of November 17, 2011 (Brasil, 2011b), that inclusive education gained momentum, with greater investment in “multifunctional resources classrooms,” and the current scenario may be more inclusive than that encountered at the moment of data collection. Less than half of the CAPSi reported having regular meetings with schools, which may be related to the high rate (20%) of autistics out of school, also pointing to the difficulties of the CAPSi in establishing solid, regular and strong relationships with the main public service for children and adolescents: the education sector.

Access to social benefits shows that more patients have free bus transportation than BPC. It is also necessary to stress the rate of loss of information in this question, above 20%. The “free travel pass” is granted upon registration of the diagnosis, but depends on municipal and state legislations, which do not exist in all places surveyed. Access to BPC is national, but involves meeting socioeconomic criteria, besides a psychiatric diagnosis. It was not possible to ascertain from the questionnaire the position of the CAPSi regarding the granting of such benefits, but the context of this study suggested that, on the one hand, the staff of those services recognized the positive impact of BPC on the socioeconomic situation of families, while, on the other, they associated it with greater stigma and even abandonment of treatment, leading many professionals to conclude that the issue should only be evaluated individually, case by case (Lima et al., 2014).

Regarding the care offered at the CAPSi, most autistic patients were included in the semi-intensive regime, which demanded their presence at the ser-

5 These figures are calculated at the address <<http://bit.ly/1PH6o8L>>, selecting “Competências por Unidade Geográfica”, “Municípios”, “Rio de Janeiro” (Estado), and, in “Período”, “junho” and “2011” at the beginning and end, changing only the municipality of choice.

6 This information can be found at <<http://bit.ly/2kqoyy1>>. Accessed on: April 6, 2017.



vice for up to 12 days in the month (Brasil, 2004). Studies that recorded similar information, but covered the totality of CAPSi patients, also pointed to prevalence of semi-intensive care (Hoffman; Santos; Mota, 2008). In practical terms, intensiveness of care, as understood by CAPSi staff, is not restricted to the number of visits, but related to the mobilization of a broad set of resources to address the needs of a case, depending on its complexity and moment in the life of the child or teenager and his or her family. Thus, semi-intensiveness may be consistent with the registered attendance at the service (Apac registry), but not with the potential mobilization of resources by the CAPSi to expand care - an aspect that, however, requires specific investigation to be better evaluated, which was not done in this study. It is necessary to discuss the most appropriate notion of intensiveness for autistic patients, what kind of strategies should be included to expand care, and how to harmonize children's permanence at the service with their permanence in other social spaces, especially school. It is worth noting that both US research (Brookman-Frazer; Taylor; Garland, 2010) and Abra's research (Mello et al., 2013), cited above, also showed a predominance of lower intensiveness (in terms of duration and frequency) than advocated, although the notion of intensiveness in the US and Abra is not the same as that used at or proposed for the CAPSi.

It was observed that all services offer individual and collective spaces for care and, to a lesser extent, structured spaces such as workshops. The minority of services (n=4) offers exclusive spaces or schedules for autistics, with separation by age group being more common (n=8).

Despite the variation in services, the average number of autistic patients who use psychotropic drugs at the CAPSi is in the same range of studies carried out in US services (Mandell et al., 2005; Pringle et al., 2012), described above. On the other hand, the percentage of patients treated simultaneously at the CAPSi and by other professionals or services is low (17%), whereas in the same US research the majority (61%) underwent three or more treatments simultaneously. However, one must take into account the differences in the concept of multi-professional treatment between Brazil and the US

when comparing data in both countries. In England, as cited above (Barrett et al., 2011), there is a predominance of speech and language therapies for autistic patients, and it is necessary to investigate whether such data is repeated in Brazil. In addition, since the data is based on information provided by the directors of the services, there may possibly be children and adolescents with autism whose simultaneous treatment with other professionals or at other institutions was not communicated to the CAPSi by their relatives.

Almost all the CAPSi reported offering individual or group assistance to family members, but only eight reported holding meetings with them, which shows a predominance of traditional clinical approaches to the detriment of expanded care strategies involving the participation and co-responsibility of parents and caregivers in making decisions on the daily practice of services and the exercise of citizenship in health, fundamental principles of psychosocial care as Brazilian public policy. In this sense, it is relevant to note that the vast majority of services also reported having no interaction with autism family support associations. These associations are not always present in areas covered by the CAPSi, but have gained political relevance in recent years, both nationally and in the metropolitan area of Rio (Oliveira, 2015; Rios; Andrada, 2015).

It was not possible, within the scope of this study, to analyze the differences in data between the various services, municipalities and metropolitan areas covered by the research, which should be the subject of future work. The absence or loss of information on a number of topics, especially those linked to psychosocial data, also limited the analysis of information. However, despite the limitations of the study - addressing a specific region and using only secondary sources of information provided by service managers, with a limited number of assessment items and lack of response in many of them - it was considered important to share the findings to contribute to the debate on the need to advance evaluation strategies that address psychosocial care for people with autism in SUS, and on the need for the CAPSi and mental health managers to invest in the production of qualified information on service, patients, care regimes, effectiveness of care and

other topics related to the commitment of SUS in offering the best care possible to the population.

## Final remarks

The care and assistance provided to children and adolescents with autism and their families has improved in recent years at the CAPSi of the investigated region. The offer of different care regimes, individual and collective, home visits, assistance to families and others comprised the scope of psychosocial care provided to autistics by the psychosocial care network in 2011. Systematic partnerships with other regional sectors or resources for the joint development of care strategies and expansion of care and social inclusion conditions for autistics were rarely mentioned by the services, and it is not possible, from the data gathered in this research, to establish the determining factors of this phenomenon. This may have contributed to the existence of structural problems, which create real obstacles to the full development of the psychosocial network, such as the deterioration of the physical space of the CAPSi, the insufficient number of professionals, the fragility of employment relations - worsened by the trend towards outsourcing - and the absence of regular strategies to train workers for psychosocial action, among others (Couto; Delgado, 2015; Lima et al., 2014). Without consistent investment by different levels of public mental health management in qualification and provision of minimum working conditions, the innovative CAPSi project may be compromised in its effectiveness, failing to positively change the history of care for autistics and other patients with serious mental problems, who for decades have been neglected by the public mental health system.

In the researched CAPSi, the scarcity of consolidated information on autism care strategies indicates the need for greater investment in the production of qualified data capable of assisting collective evaluations to improve care. Commitment at all levels of mental health management within SUS - federal, state and municipal - is urgently needed to improve the information generated by the CAPSi, which should be incorporated into the routine of those services as a means to qualify care, and not as a

mere bureaucratic requirement. Transforming staff, patients and families into producers of knowledge, based on jointly produced and analyzed information, can make a difference in rewriting the history of mental health care for children and adolescents in Brazil, especially the care of autistic children, which for decades has segregated the services managed by families from those provided by the public mental health system (Oliveira, 2015, Rios and Andrada, 2015). The growing relevance of autism in the past decades requires the definition of clear strategies in the field of psychosocial care, with intersectorial action and the CAPSi as the fundamental means of implementation and development.

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## Authors' contribution

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