

# **Beyond controversies in child mental health: Negotiating Autism and ADHD diagnosis in France and Brazil**

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## **Abstract**

This article explores the local forms that global controversies around autism and ADHD have taken in France and Brazil. Inquiring into the social and historical features of the two contexts makes the abstract, globally circulating ideas meaningful in particular forms, and helps to transcend dichotomies (global/local, biological/relational, mental suffering/disability) through their pragmatic negotiations and integration into the everyday experience of those affected by the conditions.

Our research is based on policy reports and regulations, interviews with policy makers, care and school professionals, families, and observations in mental health care services.

We first present inflamed debates in both countries: while autism wars caused the legitimacy of psychoanalysis to be challenged, debates around ADHD focused on the medicalization of social problems. Both controversies impacted policy orientations, the organization of mental health care, and professional knowledge and practices. We discuss the similarities and differences in these transformations in the two countries. We then examine how these controversies unfolded in local configurations of actors and resources. Finally, we call for reflection on how processes of globalization in mental health and local contexts mutually shape each other.

## Introduction

In the last few decades, autism and ADHD have been constituted as “problematic categories” (Rosenberg, 2006) and “contested illnesses” (Brown, Morello-Frosch and Zavestoski, 2011), the ontological status and boundaries of which are challenged. Both psychiatric categories have been exposed to public negotiations by actors inside and outside the medical system in many countries. In both cases, debates and controversies expanded to the public sphere and have involved professionals, parents, self-advocates, lawyers and virtual social networks.

Many of these debates have occurred in the arena of Global Mental Health (GMH) in the past fifteen years, as autism and ADHD became priorities. In 2008, Autism Speaks launched the Global Autism Public Health Initiative (GAPH) to facilitate the development of systematic and sustainable solutions for enhancing awareness, research, training, and service delivery for Autism Spectrum Disorder (ASD) at a global level. More recently, in 2017, the journal *Autism* published a special issue on “Global Autism Research” (Rice and Lee 2017; Rosanoff, Daniels, and Shih 2015). While ADHD diagnosis and the use of medication for the condition remained limited to a few countries until the 1990s, diagnosis and treatment now occur at large scale in many parts of the world, leading to the “globalization” of the disorder (Singh et al. 2013; Conrad & Bergey, 2014).

As GMH initiatives developed, the framing of the autism and ADHD categories within which they operate gained influence. They became a powerful narrative not only in low- and middle-income countries, where GMH interventions are mainly implemented, but also in high-income countries, where they sparked heated debates and controversies.

GMH provides a comprehensive, global definition of autism and ADHD as neurobiological disorders; one that goes hand in hand with biomedicalization and defines an appropriate treatment. This framing generated strong tensions around the status of local diagnosis and treatment practices, thus reviving an old debate in psychiatry about the universality or cultural specificity of mental disorders and their treatment. Such is the case with ADHD, as global mental health initiatives argue that it affects all individuals equally across cultural contexts, hence justifying the scalability and generalizability of the use of psychostimulants as well as the exportation of Western psychiatric expertise and standardized care packages to the Global South (Mills, 2014). Critics counter that such approaches to ADHD promote one-size-fit all interventions and therefore disregard markers of difference such as gender or culture. The result has been a rapid spread of the diagnosis and pharmaceutical solutions – the ‘McDonaldization of children’s health’ (Timimi, 2010; Mills, 2014).

As it appears in the universal vs culture-specific debate, the controversies that have arisen in various countries about the GMH framing of the autism and ADHD categories have tended to aim at the epistemic level. They focus on the contours, the origins, the etiology of the diagnosis, as well as on its treatment, thus opposing other, alternative framings. As they unfold in particular social structures, though, these controversies regarding mental health categories take various forms. For example, the metaphor of the McDonaldization of ADHD hides profound differences in the ways diverse countries have approached the condition. While some countries, such as the US, rapidly accepted the biomedical model for ADHD, and consequently have diagnosed and prescribed psychostimulants to large parts of their population, other countries, France and Brazil among them, have resisted that route (Smith, 2017).

In this article, we examine the process through which controversies incorporate, and are incorporated into, local contexts and are put to specific uses. Our focus is on autism and ADHD in the French and the Brazilian cases. Our rationale for this focus is twofold.

First, although the two conditions differ in crucial ways<sup>1</sup>, strong parallels exist in the unfolding of the controversies around them in the two countries. While autism and ADHD are ‘officially’ described as neurobiological disorders, their etiology remains unclear. Extensive research has not yielded any convincing, well replicated biomarkers with clinical utility for both conditions (Anderson, 2015; Singh, 2016; Walsh et al. 2011; Visser & Jehan, 2009; Freedman & Honkasilta, 2017). Moreover, there is no consensus regarding treatments and best forms of care. Autism and ADHD are thus challenged as regards their legitimacy and medical, social, epistemic, and ontological status. In several countries, disputes about autism and ADHD have generated legal arguments, administrative categorizations, and legislative maneuvers. Individuals living with the disorder, as well as their families and medical professionals frequently become activists, mobilizing facts to support the condition’s legitimacy and forming groups through which they share their experiences and fight for rights (Ortega, Zorzanelli and Rios, 2016). These proximities, along with the similar timeframe of the controversies, lead us to consider the debates that unfolded around autism and ADHD as a set of 'related-controversies'.

Second, we argue that the specific arrangement of similarities and divergences offered by France and Brazil has proved to be a heuristic tool for understanding how processes of globalization in mental health and local contexts mutually shape each other. Both

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<sup>1</sup> While ADHD remains a highly contested illness – it is, in this sense, an "illness you have to fight to get" (Dumit, 2006) –, its actual existence is rarely called into question. Instead, how it should be understood or "treated" is what constitutes a field of contestation. We thank one of the anonymous reviewers for calling our attention to this fundamental difference.

autism and ADHD fueled heated debates in the two countries when family organizations and certain professionals introduced the GMH discourse, while vehemently attacking psychoanalytic-oriented mental health services. The two countries share strong similarities in their recent epistemic and institutional mental health history. A majority of mental health professionals in France and Brazil have been trained in psychoanalysis, which has dominated scientific discourse and practices since the second half of the 20th century (for France, see Laurent, 2012 and Fansten, 2018; for Brazil, see Ortega, Zorzanelli and Rios, 2016). In both countries, the state has been involved in child mental health, through the implementation of extended public mental health services associated with public policy and regulations.

Although the GMH agenda is primarily intended for low-income countries, and therefore excludes specific GMH interventions for those conditions in Brazil in France, GMH arguments and metrics have been taken up by health professionals and family organizations in both countries to advance biomedical and behavioral approaches to autism and ADHD. The GMH rhetoric and methods are used to justify and legitimize a certain view on diagnosis, treatments and service organization, and to dismiss psychoanalysis for a lack of 'scientificity'. Yet, in each country, the biosocial fields of autism and ADHD are far from encompassing homogeneous groups holding neatly antagonistic positions; these fields include discourses, individuals and groups that, while opposed in some respects, overlap or support one another in other respects. For example, in the strongly polarized biosocial field of autism, parent organizations and self-advocates have conflictual relationships in the US, UK and Australia, whereas in France, until very recently, autistic self-advocacy remained under the influence of parent organizations (Chamak, 2008). Comparing the debates in Brazil and France helps

to shed light on the various ways in which GMH discourse participates in shaping controversies in national contexts.

It is crucial to examine the controversies beyond the discursive and epistemic levels, so as to include the way they affect institutions and actors. In both countries these two controversies have had numerous impacts on policy orientations, the organization of mental health care, and professional knowledge, as well as on care practices. Here, the significant differences in France and Brazil's social structure and health care system, among many others, allow for a stimulating comparison.

To that effect, we first discuss the multifaceted consequences that the autism and ADHD controversies have had in both countries. We show that, although they were similarly framed as a war between neuro-cognitive and psychoanalytic approaches, they resulted in diverging institutional and social reorganizations. We then turn to smaller, local configurations of actors and resources, where practical constraints and the social context become central to understand the pragmatic uses that are made of these categories. Through this rather uncommon juxtaposing of varying analytical foci, we want to draw attention to the importance of considering the two levels –policy and practices –, in order to produce a meaningful comparison.

The results presented in this article are based on an analysis of research material that we collected during various investigations on issues related to autism and ADHD in France and in Brazil. XX investigated the social use of categories linked to “agitated children” in France – including ADHD –, in schools as well as in mental health care services (XX, YEAR). XX's research focused on the development of policies and services to address severe forms of autism in France in the context of strong political activism (XX,

YEAR). XX investigated the effect of autism and ADHD controversies on child mental health care policies in Brazil (XX, YEAR).

These investigations were guided by similar methodological approaches. We used policy reports and regulations, as well as interviews with policy makers, advocates and health care providers in the two countries to compare the controversies and their effects. The description of care practices and specific situations is based on ethnographic surveys in care services and with families, interviews with health care providers, school teachers and families, and participant observation in mental health care services in both countries.

To compare this material, two issues needed to be considered: (i) how to articulate material collected in different research protocols, and (ii) how to carefully compare case studies from distinct national contexts? We developed a reflexive approach and distinguished different levels of comparison. At a macro-social level, we analyzed the construction of public policies and the interactions between groups of actors (parent organizations, professional groups). At this level, we reconstructed and then compared the chronological sequences peculiar to each country, to understand the differentiated articulations between transformations in health policies and the development of controversies around autism and ADHD (Part 1). On the other hand, at a micro-social level, we examined practices and interactions between individuals in care centers and family groups. To make the comparison meaningful, we situated each interview and each case study in its general context (the one described at the first level of analysis) and in its particular context: we considered the social structure of the neighborhood, the configuration of local care services, and social relations between professionals, patients and families (Part 2).

## **Part 1 - Autism and ADHD controversies: deciphering the effects on health care organization and public policies**

In this first part, we successively consider how the autism and ADHD controversies unfolded in France and in Brazil (see figure 1), before comparing their most salient effects on public policies and health care organization.

### **France: The psychoanalysis vs neuro-cognitive care dichotomy as a mean to criticize public mental health care**

In France, autism was defined until the 1990s as a form of severe psychosis by psychiatrists who opposed DSM-based diagnostic criteria. When parent associations gained visibility in the 1980s, creating private structures that offered day or residential care specifically designed for children with autism, as well as training programs in behavioral methods (Chamak, 2005), they were not rejecting mental health services. They simply distanced themselves from the definition of autism as psychosis, and advocated for change. Parent associations' pressure rose sharply in the 1990s, turning into passionate activism against psychoanalytically-oriented psychiatrists. From the mid-1990s parent mobilization and the heated debates around psychoanalysis' legitimacy led to the framing of autism as a political problem (Struk, 2017). Several public reports raised concerns about the lack of sufficient and adequate care, emphasizing that parents should be more closely involved (Borelle, 2013; Chamak, 2005). As a result, early diagnosis, wider diagnostic criteria and educational and behavioral approaches were introduced, as well as a non-psychiatric research agenda for autism (Akrich et al., 2009). The official recognition of autism as a disability in 1996 ushered in more changes: children with autism were included in school inclusion policies, with the strong support of parent associations, while their access to disability

services was facilitated. In 1999, publicly-funded new regional centers, *Centres Ressources Autisme* (CRA), were introduced to offer information, diagnosis, and services for parents of autistic children. The CRAs were independent from child mental health services and the psychiatric hospital they were administratively affiliated with, as well as from social services. Their national implementation followed in 2005 and played a key role in institutionalizing autism as a particular diagnosis requiring specific treatment (Borelle, 2013). Some professionals, mainly psychoanalysts, continued to refuse these new diagnostic practices and behavioral treatments. However, parent associations, public policies, international psychiatry and the media all converged, thus exerting strong pressure on the mental health field that prompted most French psychiatrists to adopt these changes (Chamak & Bonniau, 2013; Chamak, 2008). Parent associations' positions are currently polarized between a total rejection of psychiatry and psychoanalysis, and a critical posture amenable to collaborations with professionals from those disciplines. In any case, a major aftermath of the controversy has been to make autism a public health issue that has defied the domain of child psychiatry and been incorporated into disability policy (Borelle, 2013).

The dissemination and consolidation of the ADHD diagnosis in the French public space was highly controversial as well. In 2005, a collective report advocated for early detection of "conduct disorder" in children (INSERM, 2005), sparked a wide movement of protest among mental health and education professionals. They criticized the excessive "medicalization" of childhood, pointing to assessment and diagnosis as tools of social control on children, and defending psychoanalytically-oriented practices as more respectful of children's rights. This mobilization was articulated to the debates generated by the drafting of the 2005 law that recognized ADHD as a disability and

granted access to financial and human assistance. Psychoanalysts considered that this law emphasized symptoms rather than causes, and thus implied the risk of “freezing” situations.

In practice, at that time, many public mental health centers were reluctant to diagnose ADHD and focused rather on agitation, which they linked to the child’s emotional history and family dynamics. Professionals in these centers rarely prescribed medication and promoted psychosocial interventions (Béliard et al. 2019). The situation has changed over the past 15 years. Media coverage shifted between 1998 and 2004, from initial doubts about the diagnosis and treatment of ADHD to the endorsement of the neurobiological description of the condition after 2005. Parents of hyperactive children contributed to consolidating the recognition of hyperactivity as a disorder in its own right, through collective mobilization supported by some professionals (Jupille, 2011). Methylphenidate consumption also increased from 2004 (Akrich and Rabeharisoa, 2018). In 2014, the guidelines published by the Haute Autorité de Santé marked a milestone in the recognition of ADHD. Moreover, and although diagnosis and follow-up of ADHD are supposed to be offered widely, specialized centers remain relatively difficult to access, so that treatment still largely takes place in public mental health facilities or with private practitioners.

It is significant that in France, autism and ADHD controversies occurred successively. Thus, parent associations’ and psychiatrists’ positions regarding ADHD restated and reinforced conflicting standpoints consolidated during the “Autism wars”. In this sense, criticism of the ADHD category and methylphenidate treatments afforded a new opportunity for psychoanalysis-oriented professionals to defend their ideas and practices (Borelle et al. 2019). Nevertheless, it also meant that when the ADHD controversy

started, in 2005, the legitimacy of neurobiological approaches was stronger in France than it had been in the 1990s during the “Autism wars”. This might account for the less intense conflict around ADHD. Moreover, the issue of social control pointed to the role of schools,<sup>2</sup> while the concern about excessive and early medicalization of children’s behaviors challenged biomedical approaches in psychiatry rather than psychoanalysis, which could appear as a protection against social control implemented through schools. This historical context might also account for the relatively smooth resolution of division among professionals with regard to ADHD. The current diversity of practices includes many intermediate, hybrid positions (Beliard et al. 2018), such as an explicit call for integrating psychodynamic and neurobiological approaches, which was unthinkable when the autism controversy was at its height.

### **Brazil: competing discourses of inclusion and a strong division between public and private mental health care systems**

In Brazil, the battle over autism at the level of public mental health discourses and policies has revolved around two understandings of the condition: as ‘mental suffering’ or as ‘disability’. The first view is advanced by public mental health professionals and is associated with resistance to diagnosis and specific services provision for autistic individuals. Parent associations, on the other hand, defend autism as a disability and

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<sup>2</sup> In this article we do not focus specifically on education, although this is the field in which many of the differences in understandings and treatment of these two conditions play out. We are nonetheless aware of the relevance of the field and we do mention it several times in the article, without examining the issue in depth. As our focus here is on the mental health field and the negotiation of autism and ADHD diagnosis in this area, it is beyond the scope of the article to focus on education as a site of comparison. On the educational implication of autism diagnosis and policies in Brazil see, for autism, Cascio et al 2018; Guareschi, Alves and Naujorks, 2016; Lima et al. 2018; Nascimento, Cruz, and Braun, 2017; and for ADHD, Beltrame, Gesser and Souza, 2019S. V. Cruz, Okamoto and Ferrazza, 2016; Leonardo and Suzuki, 2016. On the educational implication of autism and ADHD diagnosis and policies in France see Bailleul et al., 2008; Akrich and Rabeharisoa, 2014; Mazereau, 2016.

favor diagnosis-specific services and evidence-based treatments, while criticizing psychoanalytic-oriented services and treatments (Ortega, 2018).

Psychosocial Care Centers (*Centros de Atenção Psicossocial* – CAPS) are community mental health services that provide outpatient care or partial hospitalization for patients with severe mental illness. They collaborate with primary care units to coordinate psychiatric care in a defined catchment area (Mateus et al. 2008). The CAPS system opposes the framing of mental health policies according to specific disorders and the creation of specialized services for different diagnoses (Biehl, 2005: 134; Ministério de Saúde, 2004). Diagnoses at CAPS and CAPSi (specific form of CAPS for children and adolescents) constitute an ongoing process and are re-evaluated throughout the 'care strategy' which may involve psychotherapy, rehabilitation and medication. At the center is the 'singularity' of the child, her history, family and everyday life (Couto, 2004, 2012; Couto, Duarte and Delgado, 2008).

Most parent associations oppose CAPSi principles of not organizing services according to specific diagnoses. They demand specialized services for autistic children and the political involvement of the associations, and criticize the limited connection to other sectors such as education and social assistance (Nunes and Ortega, 2016). Moreover, they also strongly disagree with psychoanalytic treatments for autistic children. Despite claims of multi-disciplinarity, several CAPSi, particularly in the State of Rio de Janeiro, have a psychoanalytic orientation (Lima et al. 2014; 2017).

In recent years family associations and several specialists have fought to expand policy definitions of disability in order to provide individuals living with autism with the civil rights and protections available to 'disability' groups (Block and Cavalcante, 2014). Owing to the pressure exerted by parent associations, a law was passed in 2012 to

protect the rights of individuals with an autistic spectrum disorder (Law 12.764, known as the 'Autism Law'). An individual with autism is considered to be a "person with a disability for all legal intents and purposes".

Alongside these developments there have been several critiques of psychoanalytic treatment of autism in Brazilian public services. The rationale was that “psychoanalysis-based services do not possess proven efficacy” (Ortega, Zorzanelli and Rios, 2016). In April 2014 the National Council for the Rights of Persons with Disabilities (Conselho Nacional dos Direitos da Pessoa com Deficiência – CONADE) presented the regulatory decree for the Autism Law, which provided for the treatment of autistic individuals in CAPS.<sup>3</sup> This issue divided parent associations and several considered it as a 'betrayal'. They initiated an online petition against the decree, which they considered to be "the worst that could be offered to our children". The CAPS, they wrote, "is not the place for our autistic children"; they were created to "treat people with severe mental disorders such as schizophrenia, or addicted to crack, alcohol, licit and illicit drugs addicts."<sup>4</sup> The presence of antagonistic understandings hampered serious discussions and cooperation between mental health professionals and parent associations. It divided already scarce resources earmarked for the same public, between two different networks (mental health and disability) with almost no interaction between them (Ortega, 2018; Souza Lima, 2017).

With regard to ADHD, in Brazil the acceptance of a biomedical cause is still controversial and has given rise to several disputes. The predominance of psychoanalysis and critical, anti-psychiatry perspectives in mental health services, along with the influence of “constructivism,” in the education system – whereby behavioral

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<sup>3</sup> [www.pessoacomdeficiencia.gov.br/app/node/888](http://www.pessoacomdeficiencia.gov.br/app/node/888)

<sup>4</sup> [www.peticaopublica.com.br/pview.aspx?pi=BR72114](http://www.peticaopublica.com.br/pview.aspx?pi=BR72114)

problems are not seen as symptoms of underlying pathological conditions – explain the resistance to biomedical perspectives (Conrad and Bergey, 2014; Hinshaw et al. 2011). Current academic and professional tensions in the country regarding ADHD reflect the conflicting biomedical and medicalization discourse. The former is promoted by the Brazilian association of psychiatry and other medical and professional organizations which argue that the condition is under-diagnosed (Mattos, Rohde, and Polanczyk, 2012). They stress the need to popularize and disseminate information among the general public, schools, and parents, and facilitate access to diagnosis and treatment when needed. This standpoint is defended by physicians and professionals from the social sciences and humanities who express a concern over the over-medicalization. They argue for a broader approach to learning difficulties and inattention, and the adoption of multidisciplinary and psychosocial methods that leave medication for severe cases (Ortega, Zorzanelli and Portugal, 2018).

Strong criticism has been voiced over the fact that the country does not have a specific treatment policy for ADHD, which has resulted in a series of complex procedures for low-income patients to obtain methylphenidate through the Unified Health System (by lawsuits or through an administrative process beset by red tape) (Maia et al. 2015). Critics also disagree with the idea of sending patients with ADHD to CAPSi, in compliance with a directive issued by Secretaria Municipal de Saúde of São Paulo in 2014 (Portaria No. 986/2014, 2014). As a reaction to the directive, the Associação Brasileira de Psiquiatria (ABP) published an open letter (titled “Carta Aberta a População” [“Letter to the People”]) in which it opposed the São Paulo regulation, claiming that the measure “positions itself against scientific systematization in a mystifying, disrespectful way”, and constitutes “an abusive barrier to access to pharmacological treatment by people with a low income, and places restrictions on the

full practice and autonomy of Brazilian medicine and science” (ABP, 2014; see also Ortega, Zorzanelli and Portugal, 2018).

In Brazil, methylphenidate requires a specific prescription for narcotics and psychotropic medication. Several Brazilian physicians strongly disagree with those regulations and argue that the notification procedure for its prescription is excessive and disproportionate to the potential risks, and that the notification process intimidates many patients (Carlini et al. 2003)

As in France, autism and ADHD are also immersed in intense debates and controversies in Brazil regarding etiology, diagnosis, treatments, policies and organization of care. Psychoanalysis is a key factor in these debates, where its representatives vehemently refuse biomedical models and interventions. Parent and professional associations have embraced the disability model which has been granted in the case of autism through the 'Autism law', but not in the case of ADHD, considered as a 'dysfunction' and not a 'disability'.<sup>5</sup> The notion of autism-as-a-disability opened the possibility to make demands for “specialized treatments,” through the Health Care to the Person with Disability Network, as well as social and educational inclusion. It also challenges the universal logic of public health care that structures the model of public health in the country.

As in France, the ADHD controversy in Brazil followed the autism controversy – albeit more closely –, and its intensity was lower, which can be related to the organization of care. Professionals in child mental health services generally attend to severe conditions,

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<sup>5</sup> <https://tdah.org.br/tirando-duvidas-direito-das-pessoas-com-tdah>

such as autism, much more than conditions such as ADHD, for which they favor non-medical strategies. Few services, public or private, specialize in children with ADHD.

### **Family associations, diagnosis, therapeutic orientation and service organization**

The autism and ADHD controversies raised issues about diagnosis and treatment, and about service organization, leading in the former case to the so-called “Autism wars”, and in the latter to accusations of excessive medicalization of childhood. As a result, in both countries the categories were shifted from mental health to disability policy, which led to the creation of specific care policies, diagnosis and treatment centers, and guidelines. Examining simultaneously how these processes converge and diverge in France and in Brazil affords a fruitful understanding of the ways in which the local and the global mutually shape each other.

First, the recent histories of autism and ADHD illustrate how patient or family activism became a “mode of public action”, involving interventions on the organization of care, as well as the production of knowledge in the medical field<sup>6</sup>. In both countries, family associations strongly opposed professionals in the political arena, while securing alliances with policy-makers. As a result, they were involved in the organization of alternative care services, especially in France where they opened cognitively-oriented

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<sup>6</sup> We opted in this article for leaving out the issue of self-advocacy in both countries since the arc of advocacy in France and Brazil has not leaned heavily toward the self-advocacy model found in countries like the US or the UK. There is an incipient autism self-advocacy community in Brazil, but they have not been as actively involved in defining policy, education or inclusion rights as elsewhere. In France, self-advocacy is also relatively weak, although an association of autistic people participated in the preparation of the 2005 law. Moreover, Brazil and France do not present the same fierce opposition between autism self-advocacy and parent-led advocacy as we find in other countries (e.g. the US and the UK). The preferred form of activism in both countries is parent-led (Antunes and Dhoest, 2018; Chakmak, 2008; Lima et al. 2018; Nunes and Ortega, 2016). As to ADHD, in France mobilizations are mainly parent-led (Rabeharisoa, Moreira and Akrich, 2014). In Brazil there is advocacy led by adults living with ADHD but it is heavily aligned with the biomedical model, disseminating knowledge about the condition and health and education policies, and advancing advocacy and the fight for social and educational inclusion (Ortega and Müller, 2020).

therapy training and care centers. In the process of advocating for specialized centers, they also targeted the universal logic that structures the model of public health care in both countries. Through their participation in drawing up guidelines for professional practice (Akrich, Rabeharisoa, 2014; Oliveira et al. 2017; Lima et al. 2018), they succeeded in marginalizing psychoanalysis as a legitimate therapy, on both scientific and ethical grounds. Overall, their struggle to secure public resources as well as symbolic capital was successful, especially in the domain of autism.

Second, the existing organization of public and private services in each country influenced the consequences of the controversies. As noted above, with the inclusion of autism and ADHD in disability policy, specialized services that excluded or marginalized psychoanalysis were developed, with rather different outcomes. French public mental health care services cover conditions with a wide range of severity, including autism and ADHD (Nakamura, Planche and Ehrenberg, 2018; Tibi-Levy, 2020), and attend to families from wide range of social backgrounds. Two main features affect children's care trajectories: first, given that access to services is residence-based, the type of care a child will receive is contingent on the service's therapeutic orientation. Second, children most often attend both public and private care services, either alternatively or simultaneously. In this context, the alternative structures developed by family associations have diversified available treatments, even for children receiving public care. On the other hand, it has paid more attention to the parents' ability to understand the complex landscape of services in the child's access to care.

In Brazil, even though access to public mental health services (CAPSi) is universal, it is taken up mostly by low-income families. As a result of the recent economic crisis, they

were joined by part of the middle class who lost their private insurance. As CAPSi prioritize severe mental disorders, autistic children constitute most of the population receiving care in these institutions. Besides the assistance offered by family associations, such as the *Associação de amigos do autista* - AMA (charity and non-profit institution), there are very few private services for autistic children. As to ADHD, many professionals are harsh critics of the disorder and promote non-medical strategies to deal with issues of hyperactivity and attention deficit. Some parent and psychiatric associations have criticized the lack of specialized services for children with ADHD, given that CAPSi usually consider them not to be severe enough. It is uncommon to have specialized services (in fact, there are very few) within the National Health Service (SUS) or even in the private sector. It could thus be said that while the French services that emerged were private and parallel to public mental health services, Brazilian services were public and seldom focused on ADHD.

Finally, even though the issues, and actors, of the debates were peculiar to each national arena, they led to a similar confrontation of psychoanalysis with GMH discourse. As we have seen, psychoanalysis was a key player in the autism and ADHD controversies in France and Brazil. Historically, it had constituted a predominant theoretical explanation as well as a widely used therapeutic approach within community mental health services in both countries. The recognition of autism and ADHD as disabilities exacerbated criticism of psychoanalysis that had been rising in both countries in the previous two decades. In their arguments, parents' associations and professionals relied on GMH discourses and its metrics (Global Burden of Disease – GBD, and disability-adjusted life years – DALYs) to substantiate the scientificity and evidence base of biomedical

and behavioral approaches, as well as the lack of scientificity and evidence base of psychoanalysis.

It has been argued that global mental health policy is “enacted in situ”, and that the located uses “enable mental health research and policy to go global” (Lovell, Read, & Lang, 2019: 537). As a result, the relationship between the local and the global should be considered to circulate both ways. Located spaces always contain elements of the global, and “the global in situ is always itself a local phenomenon” (Adams, Burke, & Whitmarsh, 2014: 184).<sup>7</sup> The case of autism and ADHD in France and Brazil illustrates such a “looping effect” between local uses and global categories and policies, as local actors, here parents and professionals, referred to “Global” discourse to legitimate their claims for specific services and policies for autism and ADHD. Besides leading to the creation of new treatment options and the reorganizing of mental health services at national level, such use of global categories also participated in weakening psychoanalysis, thus consolidating the universality of GMH categories

## **Part 2 - What do controversies produce in local configurations?**

Leaving the level of public policy and care organization, we now examine what controversies produce in local configurations of actors and resources. Controversies about autism and ADHD polarized positions about the boundaries and ontological status of the categories, leading to confrontation between family associations and psychiatrists, as well as among psychiatrists. Considering actual care situations helps to understand how these polarized positions evolved, as actors needed to engage in a

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<sup>7</sup> Recent anthropological research moves beyond the global/local divide, as evidenced in Escobar’s notion of “glocality” (2001) or in Tsing’s “friction” (2005) to describe zones of global/local engagement (Bemme & D’souza, 2014).

pragmatic negotiation that took into account practical constraints as well as elements of the social context. The positions of professionals and parents in relation to these controversies were constructed by the articulation between a set of heterogeneous elements: not only the theoretical frameworks mobilized in the different professional approaches, but also the practical issues related to local care systems, and the social relationships in which specific stakes for professionals and families were rooted, depending on their place in society. In the following we examine three dimensions that are particularly salient in our research conducted in France and Brazil.

### **Pragmatic attitudes in care centers and negotiations between parents and professionals**

Professionals' approaches to care and diagnosis are not as rigid in practice as the controversies seem to suggest<sup>8</sup>. Research conducted in French public mental health centers shows that professionals endorse diverse and nuanced positions; oppositions in discourses are less clear-cut in practice. In some services, professionals strongly engaged in public controversies; they saw the research as an opportunity to defend their psychodynamic practice (Borelle et al., 2019). However, even in these services, the care practices we observed articulated and hybridized different approaches. Psychoanalytic-oriented professionals could partner with schools regarding ADHD issues. A child psychiatrist with psychodynamic training and who opposed the ADHD diagnosis explained that she was "ready to prescribe Ritalin" when agitation became too problematic, in order to "calm down the school a little". In another example, in a neuro-

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<sup>8</sup> In the case of diagnostic consultations, Céline Borelle (2017) showed that professionals take into account not only the clinical "truth" of a diagnosis but also its practical implications, such as the parents' ability to accept a diagnosis, or the implications of the diagnosis in terms of clinical research.

and behavior-oriented center, drug treatment was not systematic, and follow-up could be psychotherapeutic as well as cognitive-behavioral.

An *a priori* homogeneous approach can thus hide distinctions and oppositions. For example, among defenders of the ADHD category, appropriate treatment could strongly diverge: for or against medication, as a first step or not, integrated with other therapies or not (XX, YEAR).

Situations of care for children with autism and severe behavioral problems provide another compelling illustration of the need to balance convictions with practical constraints. In a context of extremely heated debates between family associations and public psychiatrists in France, marked with calls for boycotts and accusations of torture, a special hospital unit was created to address situations of children with autism excluded from care centers because of their behavior. In these units, parents actively involved politically in the fight against psychoanalysis agreed to collaborate with the same professionals that they opposed publicly, in the hope of finding an adequate way of dealing with their child's situation (XX, YEAR).

In Brazil, despite their opposition to diagnosis-specific services and specialized centers as advocated for by parent associations, CAPSi professionals frequently displayed a pragmatic attitude toward those institutional and ontological stances. A good illustration is their tendency to group children together in collective activities using age groups and loose criteria of "children's profile", which in practice frequently result in diagnostically homogeneous groups and activities (Lima et al. 2018).

The same pragmatic attitude characterized parents' requests to CAPSi professionals for medical reports (*laudos*) and diagnosis in order to get the disability compensation to which they are entitled under the new Autism Law. Professionals often hesitated. On the

one hand, they recognized the positive impact of disability compensations on the socioeconomic status of families while, on the other, they associated diagnosis and medical reports with greater stigma and even treatment abandonment. This led many professionals to consider that the issue should be assessed on a case-by-case basis only (Lima et al. 2014: 2017). “I think you have to be careful, yes. You have to do something else before you give the diagnosis, but I also think the team takes too long,” commented a CAPSi professional interviewed by Souza Lima (2017: 94). He added:

“Parents talked a lot about it: 'I understand that you don't want to label, but the world requires labeling. For you to enter a school you need an ICD diagnosis. If you don't not take the ICD, the school won't accept it.' So, well, they need it. You can't be there for a year and keep saying 'we don't want to label your child.' Okay, you have to be careful, but you have to understand that the school is asking for such things" (Ibid.).

Mental health professionals in Brazil recognize that medical reports alongside an autism diagnosis are a parent's right, according to the legislation. For families living in conditions of extreme social vulnerability, frequently far from the CAPSi and with no or very little money for public transportation, this is important.

### **The moral connotations of diagnosis in family lives**

Our research also highlights the role played by the social representations and value systems that shape the social meaning of the diagnoses in each context. Historically, multiple meanings and ambivalent moral connotations have been attached to both autism and ADHD diagnosis. Autism as a neurobiological condition was first

recognized in the latter half of the 20th century. It was most often related to early-onset difficulties in the relationship of the mother to her infant, and it was common to hold the mother responsible for her child's problems. By the end of the century family associations vehemently opposed this attitude, and the prevailing narrative was progressively replaced by an organic and neuro-developmental view of the disorder. Therapy now consists largely in behaving adequately with the child, which professionals expect parents to do, as collaborators in the provision of care. Instead of being responsible for their child's condition, parents are now supposed to be active and responsible for taking appropriate care of their child (Borelle, 2017).

The diagnosis of ADHD is morally connoted as well. As it applies to children identified through their misbehavior, it comes as a relief to some parents. Yet, in practice, the ADHD diagnosis rarely exonerates parents from their responsibility in educating their child. As Ilina Singh (2004) shows, mothers attempt to apply "the no-fault model of behavior" when interacting with their child, suggesting that ADHD reinforces the ideology of the good mother, a mother who is loving, caring and able to recognize and solve her child's problem.

Moralizing the diagnosis takes specific forms, depending on social conditions and available resources. In the case of ADHD in Brazil, in contexts of extreme poverty and social vulnerability, pharmaceutical treatments are not foregrounded. As Beatriz Chagas describes in her ethnography conducted in Nova Iguaçu, one of the poorest municipalities of the Rio de Janeiro Metropolitan Region, pharmacological treatments are not central partly because methylphenidate is excluded from the essential medicines of the municipality (and therefore of free dispensation). As a result, families with scarce resources are unable to afford it. Moreover, in those contexts, professionals have

emphasized social aspects of ADHD, such as violence, poverty, and a lack of parental authority and of healthy leisure activities (Chagas, 2017). Mothers, on the other hand, have been found to have accepted the existence of the condition and to have acknowledged the positive results of their children's drug therapy. At the same time, they still insist on their own responsibility and on the impact of family and community relationships on the severity of the symptoms. The child's improvement was likewise associated with contextual factors. Medication is not only regarded as a "luxury" item but also as one that will not target the root cause of the problem (Chagas, 2017: 123).

Parents interviewed in Chagas' ethnography did not classify their children's behavior as a pathological condition and, even if they admit some beneficial effects of the medication, they did not consider drug therapy to be the solution. "It's hard to put up with him because the mess goes overboard", commented Joana, the mother of Caim, a child diagnosed with ADHD, "but I don't think that giving medicine will be good for him, it may be for me because he gets out of my face, but not for him. I feel sorry" (Ibid., 161). Many of those families frequent neo-Pentecostal churches and for them the emphasis on drug therapy will exempt parents from responsibility for the moral education and from the management of their sins. As Maysa, mother of Nicodemus, a child diagnosed with ADHD, explained: "I think my duty as a mother is to educate my son, to teach him that his mess has to be controlled, that there is time for everything. The church helps me.... Nicodemus is a gift from God, and if he has something, it's me who has to help because I'm his mother" (Chagas, 2017: 162, 163). However, some mothers complain of the pressure exerted on them by the church: "The pastor speaks as if it were easy, you know? I know I have obligations because I'm a mother but it's also not easy to take care of two children alone. Then it seems that if something goes wrong it's my fault, but it's not. Everything is the mother, for better or for worse!" (ibid., 163).

To understand what the diagnosis means for the child and their parents, it is therefore necessary to take into account the family's configuration and social situation. During research in France on children considered to be "agitated", we asked parents to narrate their child's story, educational trajectory, and care pathway, as well as their family history. One of our interviewees, Mrs Kaluba, was born in Cameroon and lives in Paris with her ten-year-old son Sydney and his two siblings. She arrived in France shortly before Sydney was born, and now works as a home help for the elderly. During Sydney's early years, Mrs. Kaluba and her children lived in a working-class neighborhood with a high proportion of immigrant families. At school, teachers found Sydney's behavior strange and disturbing. When he was three years old, he started therapy with a psychologist at a public mental health center. Ms. Kaluba and her children were then relocated to a social housing unit in a wealthier neighborhood, where Sydney attended a new public mental health center. There, Sydney's problems were approached differently: he received medical check-ups, administrative recognition of disability, day hospital care, drug treatment, which for Mrs. Kaluba represented "effective" care, whereas the previous center had done "nothing". To us, she described Sydney's problems in professional terms, yet "language problems" was the term she used when she preferred to remain discreet, for instance with the extended family. With school professionals and administrations, she mentioned what she considered to be her son's main diagnosis, autism, which a professional announced to Ms. Kaluba when Sydney was 9 years old. Mrs Kaluba hoped the diagnosis of autism would allow her son to be accepted into a special class. Previously, other terms had been used, such as hyperactivity, but Ms. Kaluba did not seek a diagnosis of ADHD and gave little importance to the term "hyperactivity". Unlike autism, which suggested a serious

problem and a "real" disability, in her mind hyperactivity did not mean a specific disorder or diagnosis; it seemed too close to the common-sense idea that her child moves around too much and disturbs the others. On the contrary, she tried to present her son as "kind", "serious" and "rule-abiding", not "violent". She described herself as a respectable mother, mobilized for her son, deserving the support of institutions. This concern made sense in Sydney's family's living context: as one of the few black and poor families in a privileged neighborhood, they were frequently associated with the so-called immigrant and single-parent families, suspected of giving their children an inadequate upbringing. In this context, the moral connotations linked to the diagnosis of autism were more acceptable for Ms Kaluba than those associated with ADHD. It allowed her to distinguish herself from the social groups and meanings with which she and her son risked being associated: children considered as a "problem" and parents who were deemed to be in failure (Béliard et al. 2018). This example suggests some of the ways in which the moral connotations associated with various diagnoses guide parents' positioning, and take on specific meanings according to the issues related to their place and trajectory in society.

The previous two examples underline the network of representations and values that shape the engagement of families with diagnoses and controversies. The "moral economy" (Fassin and Eideliman, 2012) that surrounds the issue of children's behavioral problems is peculiar to each context. In both countries, parents deal with moral representations and judgments that associate their children's behavioral problems with "failing" parents, considered to be incapable of raising their children because of the social conditions in which they live (poverty, violent environment, lack of cultural activities, and educational deficiencies). Mothers in particular are targeted, as they are

subjected to injunctions to be responsible and active in the education and care of their children. The two examples shed light on the way mothers interpret and deal with diagnoses, assert their educational role despite the medication – like the mothers described by Chagas –, or take charge of schooling, medical, and administrative procedures, like Mrs. Kaluba.

Differences are also revealed through a comparison between mothers in the two countries. First, the sources of respectability they choose vary according to the legitimate institutions in a given environment. Religion was central for Nova Iguaçu mothers, whereas Mrs. Kaluga, like many parents in the French context, relied on institutions – health care services and school – to affirm her engagement as a mother. Second, the neighborhood's social stratification influences the mothers' strategy. In a poor municipality such as the one described by Chagas, the mothers face representations which target the neighborhood as a whole. In Ms Kaluba's Parisian neighborhoods, where heterogeneous social classes coexist, the mother attempts to distinguish herself from the most dominated social groups within the neighborhood. Thus, parents' appropriation of their child's diagnosis depends on local moral economies, that is, on particular arrangements of meanings associated with the different diagnoses in each context. The positions taken by professionals and parents, and the relationships established between them, are not only linked to ideologies about disorder and treatment; they are also grounded in concrete situations, depend on several constraints, and are immersed in social relationships and practices such as parental educational practices and socialization processes.

## **Relationships with care providers embedded in parents' social trajectory and socialization**

Case studies also show that the socialization and social trajectories of parents shape their relationship to the conceptions and practices of professionals. Because of their living conditions and the constraints that they have to come to terms with, some parents develop a pragmatic understanding of treatment and service organization. For many parents in Brazil – specifically those in the lower classes – the request for specialized services for autism stems not from their opposition to the universal logic of public health care in the country, but from a pragmatic understanding of treatments and service organization. As one mother of a child with autism explained in Costa Andrada's ethnography of autism services in a poor municipality of the state of Rio de Janeiro, "We keep going back and forth with these kids... For us, it's very tiring... Can you imagine how it is for the autists? We take the child to school in one place, a psychologist in another, the speech therapist is far away, CAPSi once a week... All these professionals are in different places! So, if we had all of them in one place, it would be much simpler" (Costa Andrada 2017).

In contexts of extreme vulnerability and structural violence, as the one where Costa Andrada's fieldwork was conducted, some parents of autistic children take up the community-based CAPSi approach as well as more structured therapies from the rehabilitation centers. A mother whose son received care from both kinds of services commented:

"Why not both? There are so few places where I can take my son... you know, in one place they fix one part of my son's problems, and in the other place, they take care of the other problems...." (Costa Andrada 2017: 139; see also Cascio, Costa Andrada and Bezerra 2018). Beyond the need for a stronger articulation between services and health

policies, such a pragmatic attitude overcomes hard binaries and oppositions, showing how controversies and disputes are negotiated in the everyday life of those involved in caring for individuals with autism.

Furthermore, in cases where parents pay attention to the controversies and to the different professional approaches, we can see how the various alliances or distances between parents and professionals are linked to convergences or divergences concerning social and educational norms. Thus, in the French context, upper-class parents are divided between two positions regarding children that are considered “agitated”. On the one hand, some parents reject psychodynamic approaches and mobilize to get diagnoses, like ADHD; they rely on their social network and their financial resources to access diagnostic consultations, often in private practices when the delay is too long in public centers. The diagnosis of ADHD allows them to obtain a prescription for medication and recognition of disability in order to keep their child in the most normal academic trajectory possible, and to seek academic success. On the other hand, other parents – often from a more intellectual background, with socialization and values similar to those of child psychiatrists and psychoanalysts – adhere to psychodynamic approaches. These approaches involve care practices compatible with their own educational conceptions and moral and political values, such as valuing dialogue with the child, and distance from the disciplinary requirements of the school, among others. Thus, for these parents, psychodynamic interpretations of their child's difficulties represent an approach that is consistent with their intellectual and moral values (XX, YEAR).

These examples show that, regarding their children's mental health, parents do not perceive care practices from an exclusively therapeutic perspective, separate from other spheres of life. Rather, they need to articulate those practices – whether they involve

medication, psychotherapy or educational advice – with their social and educational norms and values. How they conceive of the “right way to educate a child”, the emphasis they place on discipline and schoolwork, and the importance they give to dialogue, all participate in shaping their position in mental health controversies.

Thus, while the analysis of controversies frequently overlooks social stratification, the examination of care practices and uses of medical conceptions highlights the importance of social contexts and social class relations. The pragmatic uses of categories, which depend locally on the organization of the health care system and the distribution of resources, challenge binary representations of controversies. The relations between professionals and families are embedded in phenomena of moralization of diagnoses which, in turn, depend on the social norms concerning children's behavior, peculiar to each context, , as well as parental practices and family relations.

## **Conclusion**

As global mental health and discontent with it have recently been under scrutiny, this article delves into the links between global and local. Our research examines the formulation and effects of controversies over two diagnoses in Brazil and France, autism and ADHD. Common themes emerge: polarization of debates in binary approaches; criticism of the legitimacy of psychoanalytic approaches; and challenging of the role of public psychiatry. However, the historical and social transformations peculiar to each country influenced the way in which the controversies were formulated. For example, the debates around autism and ADHD followed distinct chronologies in

Brazil and France and as a result played a different role in the process of reform of the care systems, which in turn oriented the debates differently.

Additionally, at local level, we examined the uses of medical conceptions and diagnoses embedded in care practices and relationships between actors. Binary controversies as they unfolded in the public sphere and in the media gave way to pragmatic negotiations that revealed a more complex landscape. At this local level, the effects of social norms and inequalities also became more visible. By articulating the local and the global level, our analysis reveals controversies as complex phenomena, depending both on the historical and political context and on the relations between socially situated actors. Thus, the form taken by the critique of psychoanalytical approaches in each country depends on its place in the health care system, on political transformations, and on the social positions of the actors who use this approach in health care relationships.

Comparing diagnoses of autism and ADHD is instructive in several respects. Historically, these categories have given rise to recurrent controversies with lasting echoes. Although these two categories cover realities that often differ in their severity and form, both feature as options to label people with behavioral problems. Yet, their moral connotations differ, as well as the management options they open up. This highlights the importance of local negotiations in the qualification process of problematic situations.

The controversies surrounding these two categories have also played a key part in redefining the hierarchy between therapeutic approaches, especially regarding psychoanalysis. This calls for reconsideration of the Global Mental Health approach to both “local traditions and epistemologies”. As noted above, GMH has been criticized for favoring a Western, biomedical model of illness and treatments, and of thus

expanding the influence of the Pharma industry while neglecting practitioners of traditional therapies and local healing modalities (Summerfield, 2012; Kirmayer and Swartz, 2014; Ortega & Wenceslau, 2020). Critics also argue that existing mental healthcare alternatives and 'counter-clinics' are ignored, or their scientificity is challenged, within the boundaries of evidence-based treatments and practices (Lovell, Read and Lang, 2019; Davis, 2018). This frequent criticism has been refuted by some GMH advocates who stress their engagement with local communities and healing traditions and practitioners (Patel, 2014).

Since most GMH interventions are located in the Global South (specially in African countries and in India), when local healing traditions and practitioners are invoked, they mainly refer to traditional healers and local healing practices and epistemics, such as shamanic, ritual and religious healing practices, indigenous medicines, and herbal treatments, among others (Sax, 2014; Sood, 2016; Green and Colucci, 2020). Brazil and France differ regarding such healing practices. Brazil has a strong presence of indigenous and traditional healing forms: shamanic as well as religious healing practices from indigenous, Afro-Brazilian and Neo-Pentecostal origin (Ortega and Wenceslau, 2021). Their presence is mostly located in regions with strong indigenous populations and in the poorer neighborhoods of many Brazilian cities. XX has described the marginal role of cultural and religious beliefs and practices within mental health services in the country, as the 'silencing of culture' (XX, YEAR). This 'silencing' also accounts for the limited role of transcultural psychiatry and ethno-psychiatry in Brazil, especially within mental health services. In France, transcultural psychiatry and ethno-psychiatry have developed separately from mainstream psychiatry (Fassin, 1999; Fassin & Rechtman, 2005), while traditional and religious healing practices remain marginal.

Alternative medicine is widely used but remains unofficial and largely hidden from institutions (Ramsey, 1999).

Despite Brazil being a middle-income and France a high-income country, both have universal public health systems that integrate community mental health care into primary care. In both countries, psychoanalysis has historically been a key player in mental health care. Integrated into public mental health services and widely used for the treatment of autism and ADHD, it is perceived as an alternative and a form of resistance to global bio-psychiatry. Thus, although from a GMH perspective psychoanalysis suffers from the same criticisms of lack of scientificity and evidence as traditional and religious forms of healing (Khan et al. 2012), it differs from these healing traditions on social, cultural, political, epistemic, institutional, and therapeutic grounds. Psychoanalytic treatments and practices have been severely undermined in recent years, particularly with the diffusion of a global mental health discourse. Their impact nevertheless still exceeds that of traditional and alternative medicines and is integrated into standard medical care in these two countries. Moreover, psychoanalysis cannot be reduced to a medical discourse, which prevails in certain contexts. It also constitutes a social and power structure that includes professionals, care organizations, practices, and institutional arrangements.

The criticism that psychoanalysis underwent in recent years mobilized arguments from the Global North, such as the Global Mental Health agenda. Psychoanalysis was depicted as outdated and non-scientific. In this and other examples, the “global” was effectively equated with the realm of policy-making underpinned by the ideals and expertise of countries of the Global North, often officially endorsed by the WHO, while the “local” was equated to on-the-ground experiences in the Global South which

typically fail to live up to global policy aims and standards (Ortega and Behague, 2020). Yet psychoanalysis emerged and became influential in the Global North as well as in the Global South, where it is still powerful. Thus, the case of psychoanalysis calls for a disentangling of the traditional versus modern medicine divide along the same lines as the South versus North divide in which Global Mental Health is based. We also argue that Global Mental Health should focus on entanglements between local and global as a way to avoid thinking in terms of these divides.

### **Conflict of Interest**

On behalf of all the authors, the corresponding author states that there is no conflict of interest.

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