

## Online Collective Identities for Autism: The Perspective of Brazilian Parents

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The importance of online communities for parents of people with disabilities has been discussed by many scholars in the fields of Digital and Disability Studies, showing, for instance, the importance of social support and the formation of social ties. In order to contribute to this scholarship, this paper explores how collective identity models are built and circulated by parents of autistic people in one of the biggest Brazilian online communities about the subject, ‘Sou autista... conheça o meu mundo’ (I am autistic...get to know my world). The results were obtained through a digital ethnography, based on participant observation and an exchange of information with the members of the community studied. Based on the data collected, the study concludes that the collective identity models that circulate in this community can be grouped into legitimising, resistant, and project identities, as postulated by Castells (2010). The different views reflect how parents see autism and represent the ways it is treated in Brazilian society.

**Keywords:** Autism; Brazil; Social Media; Parents; Collective Identities

### Introduction

While parents of children with disabilities are often stigmatised and excluded from social life, through social media they are able to foster relationships and find a sense of belonging, which is frequently denied to them in the offline realm (Avery, 1998; Clifford, 2011; Engel, 2016). When parents get together and form online groups connected to disability, they take part in social interactions that can build and circulate different identity models.

This paper aims to better understand the role of social media in the definition and spread of views on autism in Brazil. To do so, it explores the identities adopted by parents of autistic people in one of the biggest Brazilian online communities about the subject on Facebook, ‘Sou autista... conheça o meu mundo’ (I am autistic... get to know my world), whose members are mostly parents, mainly mothers of autistic people.

Before moving to the practical aspects, we want to justify our language choices, as we understand that language matters and carries ideologies. We chose to use ‘autistic’ instead of

‘people with autism’ in respect for those who have been battling for an autistic identity and who emphasize the need for a more positive and assertive language, preferring to be called in an identity first-language instead of in a person-first language (Kenny et al., 2016). The identity-first language considers autism as an inextricable part of one’s identity, not as an impairment, but as a difference.

For this analysis, data was collected through digital ethnography, which implies participant observation in online spaces. The interpretation of the data was guided by thematic analysis grounded in the idea of collective identity models (Castells, 2010), as well as other research in Media and Disability Studies. This methodology allowed an effective exchange of information between researcher and participants, giving the latter a voice and valuing their perspectives, a crucial point when it comes to groups which are stigmatised in society and frequently even in academic research.

Understanding the construction and circulation of collective identity models adopted by parents of autistic people, allows us to comprehend how different views of autism coexist and influence people in Brazil, a country that barely appears in research devoted to Disability Studies especially when compared to other countries in the global South (Meekosha, 2011). Moreover, the views on autism that circulate among parents are transmitted to autistic children at an early age and lay the foundation of how they will identify and present themselves in the future. Additionally, as Goffman (1990) points out, people directly connected to individuals with disabilities carry part of the stigma that marks disability in ableist societies, which the author calls ‘courtesy stigma’. Hence, the experience of parents is not only based on how their sons and daughters are treated by society, but also on their lives as parents of people with disabilities.

As to the effects of the digital realm on representations of autism, we can see that it contributes to the propagation of information and facilitates the formation of groups, as online there are no geographical barriers. Consequently, these representations have a more far-reaching impact than those maintained in isolated geographical communities, which becomes even more important in a huge country like Brazil. Carter (2009) and Clifford (2011) also point out that online presence is of great importance to parents of autistic people as they suffer from a higher level of social isolation than parents of people with other disabilities.

In the next sections we first deal with the theoretical approaches used in this research, starting by presenting the idea of collective identities proposed by Castells (2010), moving on to the different views of disability and autism, and then the role of social media to discuss such topics. We then present the methodological aspects guiding this research. Subsequently, we analyse the collective identities which are articulated in relation to autism, based on the

empirical data gathered during the digital ethnography. Finally, we discuss how those identities can possibly affect the symbolic realm of participants in the community studied.

### **Collective identities**

Identities can be understood through a constructionist approach, considering them as products of the relationships of individuals with each other and their environment. In Hall's (2006) view, this goes against the idea that people have one fixed identity, and that instead, they may have multiple coexisting identities. Rather than being determined by biological or structural constraints, identities are seen as invented, created, and reformulated socially (Snow, 2001).

Some scholars affirm that identities are usually connected to oppressed groups, who, when able to escape oppression, would no longer need a collective identity (Lawler, 2014). Still, studying identities remains necessary as we are far from living in a society in which oppressed groups are properly represented. Moreover, Alcoff (2003) says that understanding the identities of oppressed groups is an important instrument to provide them with the tools to contest the roots of their oppression. Siebers (2008), who deals with disabled identities, adds that the formation of collective and political identities is the best way to promote social representations that can shift the paradigms of contemporary society that stigmatise people with disabilities. The dominant social paradigm is that of ableism, which 'produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully-human. Disability, then, is cast as a diminished state of being 'human' (Campbell, 2009). This ideology reduces people with disabilities to an inferior status as human beings, considering them as people in need of a cure or at least some sort of correction, adopting a position in which only what is defined as 'normal' is socially acceptable.

Identities work at the individual as well as the social level. In this paper we focus on the circulation of collective identities, as the Internet facilitates the creation of groups through processes of identification and may be able to strengthen their voices for representation and articulation.

Usually, online groups are sustained by a shared identity among members. However, this does not mean that only one identity will be in circulation in the group, as members can use other sources to build sub-identities related to the shared one. In the group in question, there is a socially shared identity defined by the social role of members as parents of autistic people (Snow, 2001). Nonetheless, when we analyse socio-political articulations, other identities appear, depending on members' position in relation to autism. These positions can be understood by drawing on the three models of collective identity proposed by Castells (2010).

According to Castells (2010: 6), identity is ‘the process of construction of meaning on the basis of a cultural attribute, or a related set of cultural attributes that is given priority over other sources of meaning. For a given individual, or for a collective actor, there may be a plurality of identities. Based on this definition, Castells (2010) divides collective identities into ‘legitimising’, ‘resistance’, and ‘project’ identities. Legitimising identities are identities sustaining mainstream views which are disseminated by powerful and traditional ideological apparatuses and often treated as normal or the most common in contemporary society. Identities of resistance are observed in groups that do not fit what is considered normal and, for this reason, come together to form networks of social support, resisting the pressures of mainstream ideologies and providing support to each other. Project identities actively contest current ideologies and paradigms by voicing dissent and creating and promoting new paradigms. In our analysis, these three identity models will be used to discuss views on autism.

### **Perspectives on disability and autism**

For a long time, disability was framed according to a medical perspective, mostly defined as a pathology in need of a cure or removal from society. However, in the middle of the twentieth century, the field of disability studies along with activists with disabilities developed a social constructionist approach to disability, arguing that it is the product of social interactions between a person with an impairment and a non-accommodating environment. As Goodley (2011) points out, this approach separates impairment, the functional limitation occasioned by a physical, cognitive or sensorial impairment from disability, that is the loss or limitation of opportunities because of social and physical barriers.

Such views on disability have an impact on the understanding of autism. The medical view is still dominant, with two institutions disseminating the most popular classifications of autism: on the one hand the International Classification of Diseases 10 (ICD-10) published by the World Health Organisation (WHO); and on the other the Diagnostic and Statistical Manual of Mental Disorder 5 (DSM-5), published by the American Psychiatric Association. The ICD-10 defines autism as a Pervasive Developmental Disorder, marked by cognitive impairments in social interactions and communication, as well as the development of restrictive and repetitive patterns of interest. The document divides autism into Childhood Autism, Atypical Autism and Asperger Syndrome, adopting different terminologies not only to specify the degree of impairment but also the age at which they are identified. However, this division is currently discussed, and future versions of the ICD might be similar to how autism is seen by the DSM-5, which states that the characteristics of autism vary along a spectrum, going from mild to severe, and differ between people, depending on the environment that surrounds them. Although the DSM-5 takes into consideration the influence of social factors to

determine autism, it still uses the medical perspective for diagnosis and cares little about the social aspects of disability. Its main function is to provide a set of diagnostic criteria, focusing more on the limitations of autism than on the differentiated characteristics of the autistic mind.

The diagnosis promoted by the two manuals, are often criticised. Recent updates have broadened the criteria, and some scholars acknowledge that this may be one of the causes of the increase in the number of diagnoses (Timimi and McCabe, 2016). Moreover, treating autism through the medical view implies that notions of normalcy are applied to the lives of autistic people. The idea of the normal, as explained by Davis (2006), implies that everybody who deviates from a curve accepted as normal, is treated differently by society. The imposition of normalcy was also discussed by Foucault (2003) and the idea of disciplined bodies and abnormality, all showing the pervasiveness of norms. In other words, autistic people are expected to reach similar milestones as those who are considered 'normals', without acknowledging the positive value of differences.

When we leave the medical view and turn to the social one, we find the idea of neurodiversity, a term coined by Singer (1999) and currently used by many autistic people and their supporters. From the neurodiversity perspective, people on the Autism Spectrum have a different way of processing the world that surrounds them, and this difference associated with the fact that mainstream society is tailored for the neurotypical (those with a mainstream brain), creates most of the disabling conditions for autistic people (Armstrong, 2011). Ortega (2009: 426) states that neurodiversity 'must be understood within the context of the diffusion of neuroscientific claims beyond the laboratory and their penetration in different domains of life in contemporary biomedicalised society..., influencing the ways we think about ourselves and relate to others, favouring forms of neurological or cerebral subjectivation'. Thus, neurodiversity opens doors to re-define autism not as a pathological condition, but as a cerebral difference which offers challenges as well as opportunities.

Regarding the view of parents on autism, Langan (2011), states that their voices inside the autism community have always been diverse. She observes three distinct phases. In the first phase, from 1960 to the 1980s, autism was considered as an obscure condition, resulting in stigma. At this time, parents' focus was on social support, although they also played a role in discrediting professionals who said that autism was a result of bad parenting. In a second stage, in the 1990s, autism became more popular, and parents, supported by media, spread the message that autism was caused by external conditions such as vaccines. In the current stage, starting in 2010, there is a wave of parents supporting autistic diversity and moving away from the medical model.

Apart from these global perspectives framing perceptions of autism, it is also worth considering local influences (Meekosha, 2011). For instance, Kim (2012) compares

perspectives on autism in Korea, Nicaragua, and Canada, concluding that each country shaped autism according to its cultural norms. While in Korea autism is perceived negatively and often denied or treated as an individual or family problem, Nicaraguans do not see autism as a disease or disability, but as an individual need that should be accommodated by society. Meanwhile, Canada offers a better structure than the other countries and facilitates access to knowledge. In a similar study, O'Dell et al. (2016) affirm that different cultural contexts influence perspectives on autism.

Acknowledging the importance of the socio-cultural context to understand autism and other disabilities, we should also consider the relationship between inequality and disability in the global South. Although more research is still needed, scholars point out that poverty and disability are intertwined in complex ways, one feeding into the other. In the case of Brazil, the limitations brought along by autism may be more salient in high-income families who expect more of their children, while at the same time those families also have more access to services and therapies to attempt to normalise or improve the skills of their autistic children. On the other side of the social spectrum, we have families living in disadvantaged areas who might not even have access to diagnostic tools, let alone therapies. Additionally, Assis et al. (2009) in a study conducted in Brazil, show that behavioural and intellectual issues are correlated to low-income and socio-structural problems, so those characteristics, if not addressed properly, may be mistaken for mental illnesses. These studies confirm the need for research such as ours, taking into account both broadly circulating perspectives on autism, as well as perspectives rooted in concrete socio-cultural contexts.

### **The role of social media**

Baym (2010) states that online groups are shared spaces allowing for the formulation, negotiation, and application of social rules and shared behaviours. As there are no geographical boundaries, these groups are created mostly based on a process of identification. Moreover, members of digital communities are able to produce and exchange information without the need of a mediator, which, according to Benkler (2006), provides particular ways of interpreting the world that can foster public debates and dissenting perspectives.

In the case of autism, both the social and medical views can be transferred to the online environment. However, the appearance of digital and social media, was not just able to transpose the offline to the online, but also helped to strengthen these perspectives as it allowed the formation of communities including previously isolated people.

Online groups were usually created by parents of autistic people and autistic people themselves, with a small presence of professionals, caregivers, and other family members. The importance of contact among autistic people themselves is emphasised by Bagatell

(2007), who says that it is through this proximity that they can share and learn to accept their experiences as autistic people. As a consequence, the Internet has been essential to promote the neurodiversity movement, mostly in the English speaking community, because many autistic people use online platforms for self-advocacy and collective articulation. Communication among each other and with neurotypicals is facilitated by the affordances of online tools, such as the dominance of written communication (Nelson, 2004; Dekker, 2006). Parents also benefit from online communication, which helps to reduce their social isolation and offers possibilities of social support, representation, and socio-political articulation.

Research about social media usage among parents of people with disabilities, has investigated questions regarding social support and the formation of social ties. In a seminal study of online groups for parents of children with disabilities, Avery (1998) mentions that being part of a virtual community with other parents sharing the same experience, provides a sense of belonging and gives parents the chance to freely talk about their emotions. In another study, Carter (2009) concludes that participating in online groups reduces the loneliness and stress of parents, making them more visible. She also affirms that the main benefits of social media for parents of autistic people are easy access to information, social support, the sense of belonging, and possibilities of identity formation and socio-political articulation. In our study, we aim to build on this scholarship by focusing in particular on parents of children with autism.

### **Methodology: digital ethnography in the study of minority groups**

Based on the theories discussed above, we used digital ethnography to analyse the identities circulating in the online autism community proposed. Digital ethnography is the transposition of ethnographic methods to the digital environment (Kozinets, 2010), which is seen as a place that allows for cultural exchange and ties ‘texts to particular circumstances of production and consumption’ (Hine, 2001:52). Ethnographic methods consist of ‘a researcher spending an extended period of time immersed in a field setting, taking account of the relationships and understandings of those in the setting and participating in those processes’ (Hine, 2005:4-5). According to Boellstorff (2013:54), digital ethnography ‘combine[s] elicitation methods (like interviews and focus groups) with participant observation, which, as a method not predicated on elicitation, allows us to study the differences between what people say they do and what they do’.

This methodology is particularly suited here as it provides inclusive tools to promote a better comprehension of socially marginalised groups without oppressing their voices. Generally speaking, ethnographic research aims to observe and, subsequently, interpret the cultural aspects of a certain group. Culture is understood here as the meanings people give to their actions and symbolic interactions, which must be interpreted within their social context

(Geertz, 2008). Transposing these ideas to online environments, Bell (2008) states that digital cultures encompass forms of representation, concepts, and images that are created and replicated through the use of digital media and that are able to change one's perception of the world.

The analysis presented in this paper was based on data collected by the first author from October 2014 until December 2015, focusing on a single Brazilian online community, 'Sou autista... conheça meu mundo' (further referred as SACM). The data was thematically analysed, which allows for the identification of themes emerging in the community (Bran and Clarke, 2006). We approached our data with an analyst-driven approach guided by the collective identity models proposed by Castells (2010), as these could embrace the different models of disability, medical and social, and also the question of social support. Thus, the emerging patterns were clustered into one or more identity models.

It is not a coincidence that a Facebook group was chosen, as Facebook is the most popular social media platform in Brazil. In fact, in a digital ethnography about social media usage in Brazil, Spyer (2013) states that 'in Brazil, Facebook is the Internet' due to its enormous popularity. This particular Facebook group was selected because it presents a high level of engagement and constant social interaction among its members, so it was relevant in terms of representation as well as rich data, important factors when considering the cultural aspects of an online group. During the entrance period, other groups were observed, but this particular one was selected because it was the most active, and because parents present in other groups were usually also active users of 'SACM'. By the time the research was conducted, the group had around 20,000 members.

Samples of online interaction in this group were collected and thematically analysed through a qualitative approach based on observations and annotations about what was happening in the community and emerging patterns. Rather than indiscriminately archiving all the content circulated on the page during participant observation, only limited random samples were collected as the posts of the page remain available online, and once the patterns were observed, it was possible to go back to the archives by using keywords and common expressions (for example, the word 'desabafo' (outburst) was constantly used when parents wanted to share a difficult moment).

As highlighted earlier, the thematic analysis was theoretically guided by the three identity models proposed by Castells (2010): legitimising, resistance and project identities. The topics and annotations that led to representations of these three kinds of collective identities, were put together in order to observe how these identities were articulated, and which subjects were discussed in these contexts. For instance, subjects connected to a pathological view of autism, use of medication, and diagnostic criteria were classified under the legitimising category; social support and shared experiences (both negative and positive) were classified

as resistance, while sources of pride and shifting paradigms were classified under the project identity model. Many utterances were classified under different identity models, which indeed were fluid and overlapped. For instance, mothers sharing experiences regarding the use of medicines were linked to both the legitimising and the resistance model.

Regarding ethical procedures, it was impossible to collect consent from all members of the community, so the administrator was asked for permission, and members were publicly informed through various posts in the group; they welcomed the research and were willing to participate. Nonetheless, as we understand that participants may not be fully aware of the implications of academic research, in this article, the names of participants are not provided and all the quotes were translated from Portuguese without literal quotation, avoiding the use of search engines to track them. The quotes presented in this paper, were stripped of any personal and other identifying details such as names, locations, institutions and dates.

The main author also had to deal with issues regarding presentation and she chose to present herself as a supporter instead of taking the academic role of a neutral subject. For instance, talking specifically about autism, Emerald and Carpenter (2015:747) shared how they were affected by their research with mothers of autistic children, adding that, although emotional involvement is seen as the opposite of academic rationality, ‘our personal experiences can lend understanding to the social/cultural/political context’. Thus, this choice was made based on the intimate nature of the community studied, and also because we acknowledge that Disability Studies is not a field which you approach neutrally, but as a supporter. The full research was also approved by the ethical board of the University of Antwerp.

To conclude this methodology section, it is important to reflect on the strengths and limitations of this research. On the one hand, using digital ethnography to understand the identities adopted by parents of autistic children and their views on autism, allows the research to go deeper than simply using surveys or interviews, as people can be heard and observed acting naturally, without over-thinking possible answers. On the other hand, the digital space cannot be analysed in its totality, so in order to make data manageable, only one platform and group was chosen. While the selection criteria we adopted aimed to get a good sample of what was happening on social media in Brazil, we do realise that what we found may not be representative of the whole Brazilian cyberspace. Moreover, we understand the limitations of analytically approaching data, as we tend to fit the categories into already established theories, which may leave other aspects out of the discussion. Nonetheless, we tried to discuss the nuances between the models in our analysis by discussing that people may sustain more than one identity model.

## **Findings**

### **Collective identity models in ‘Sou Autista... Conheça Meu Mundo’**

The first thing to take into consideration when observing the group SACM is its national and cultural context. As a Brazilian group, most people there tend to have been first introduced to autism through the medical view presented by ICD-10, as this is the classification currently used in Brazil. Nonetheless, the views on autism promoted by the DSM-V are becoming increasingly popular among Brazilians. As discussed earlier, both documents are rather problematic when removing mental health from the context in which they were originally created— rich western countries. While the worldwide increase in the number of diagnoses also affected Brazil, professionals are concerned that issues caused by socio-economic and structural problems may be labelled as ‘mental illnesses’ in countries in the global South (Mills, 2015). Specifically in the case of Brazil, Rios and Costa Andrada (2015) state that ‘a common concern was the risk of treating as autistic those children who showed symptoms of autism due to life circumstances other than an individualized organic problem’, which adds a layer of complexity to the diagnosis of autism in Brazil.

It is also important to observe that social media in Brazil is considered one of the most important venues for the creation and presentation of a digital culture (Hayashi and Baranauskas, 2008), so the articulations of autism observed there, are representative of broader discussions in Brazilian society. However, it is important to remember that even though the number of people with access to the Internet has been growing in the past years, mainly thanks to mobile communication, access is still uneven. For instance, De Santana et al. (2009) mention that social media is not explored fully because of the lack of digital literacy and limited knowledge of English. Moreover, access is uneven among social classes, as people with a disability in Brazil often live in harsh economic conditions because of ableism and they also suffer from digital exclusion and illiteracy (Neri et al., 2003). In the group we studied, many mothers had to quit their jobs to care for their children as government and institutions do not provide enough social support.

However, it is important to remember that as social media allows other forms of communication than written speech such as images, even parents with limited literacy can share their stories. For instance, it is common to see pictures of children posted by mothers when they accomplish something, such as going to school for the first time or eating by themselves, or on the contrary, when they are having a hard time. For this particular research, we did not focus on a visual analysis of the images circulating in the communities, but as they can contribute to other categories of analyses, we acknowledge their importance for further studies.

In the following subsections, we analyse the community according to the collective identity models as well as the intersections among them.

*The medical view and the legitimising identity model*

Analysing the community using the categories proposed by Castells (2010), it quickly became clear that the medical view is still the most salient one among parents of autistic people, as illustrated by the large number of posts regarding medical treatments and medication. In typical interactions among members of the group, parents often ask about the reactions to some medicines and the advantages and drawbacks of some sorts of treatment in relation to others. A common example is the medicine Risperidone, often prescribed for autistic people in Brazil, and which is frequently mentioned in conversations. For instance, parents say that their children have calmed down thanks to the medicine, while others are worried about the side effects. One mother posted: ‘my son is taking Risperidone and is gaining weight and is always hungry, I want to know if the same is happening to your kid’, to which other parents replied that it was normal. Some parents said that they stopped the medication for that reason, while others said they were hiding food or controlling their children’s diet.

Posts about alternative medical treatments are also popular among members, leading to a high number of dialogic and reactive interactions. One parent once asked ‘Can someone give me an over the counter alternative to calm down my son?’ and parents suggested a range of supplements such as methyl b12, omega 3, herbs, melatonin, and a gluten free diet. Another parent asked whether it was better to talk to his doctor, to which other parents replied saying that doctors did not live their realities and often did not know all the alternatives to help their children. As an example, many parents said that they had to talk to their children’s doctor about melatonin because they read about it in the group first and only then they got a prescription. This is the kind of communication Benkler (2006) discusses, stating that in online communities, ordinary people can access and share the knowledge that was formerly only available to experts. The unequal access to treatment can also be observed here, as some families have access to better professionals, while others just have social media to find information. For instance, in Brazil services addressing mental issues are still concentrated in the capital cities, while the countryside suffers from a lack of services (Mateus et al., 2008).

Another recurrent subject corroborating the medical view of autism is the observation of diagnostic criteria involving questions about how autistic people behave and the attempt to classify such behaviours, mainly related to sensorial, social, and motor skills according to the criteria provided by medical guides. In an illustrative example, one parent posted:

I would like to ask mothers who have teenagers, how do you behave when they isolate themselves? Is this, part of their personality, or is there something wrong? I feel helpless and worried when my son isolates himself.

Another mother also asked about motor skill:

How are the motor skills of your kid? My son drops everything he tries to catch.

The strong presence of posts about medication and characteristics connected to diagnostic criteria can be understood as part of Castells' category of *legitimising identity*, as the sources used to build this identity are based on mainstream and powerful institutions such as medical organisations and the pervasive ideology of ableism, which enforces normalcy upon the lives of people with disabilities. The discussions observed in the group, usually deal with forms of correcting behaviours so that they fit into what mainstream society considers as normal, instead of valuing the differences offered by autism. Hence, these discussions show a clear signal of the pathologisation of autism, which Gil (2015) emphasises, ignores that autism is not a disease per se, but a confirmation of the enormous diversity of human beings.

The legitimising identity model also embraces discursive practices that enforce normalcy. As mentioned above, it is common to see pictures or posts of children achieving the milestones enforced by society (i.e. going to school, eating independently, using the toilet). These show how parents are putting effort into making their kids fit into what is considered normal.

### *Social support and the resistance identity model*

In the middle ground between the medical and social view, we can situate the fact that most people who joined the group were looking for some sort of social support, and, thus, share a *resistance identity*. The discourses and interactions that surround resistance identities tend to deal with sharing negative or positive experiences and the search for friendly support. Those attempts often result in empathy and religious advice, as Brazilian society is highly religious. It is rare to find practical responses to the negative narratives members are confronted with, but they do exist. At some point, one of the members started a crowdfunding campaign to support the father of a severely autistic man who was going through economic troubles. It is also common to see discourses of self-blame, mainly by mothers, who online, can find some comfort when realising that they are not alone. Some parents have even remarked how the group is important as a source of social support:

Here we can talk about our bad moments and find some support, the group offers some sort of therapy. We can cry and give motivation to each other. There are bad days and good days.

I'm really happy that now I have this group to share my life with.

Resistance can also be found in reports of prejudice and discrimination, mainly inside schools which are supposed to be inclusive according to the Brazilian judicial system. For instance, some parents related cases of abuse inside regular schools or even the rejection of autistic children. One mother recounted how her son:

...was humiliated by the teacher because of his behaviours, [the teacher] said he sits on the ground, he stims [repetitive moments commonly used by autistic people] and he has a lot of problems.

Other parents proceeded to talk about how schools were not prepared for inclusion because teachers did not know how to treat autistic children, and that the problem were not the children, but the ignorance of teachers. This kind of experience is usually shared by many parents who feel a sense of hopelessness with the educational system. Although most of the reports are passive, others do result in concrete actions such as protests and formal lawsuits against schools which failed to accept autistic children. Those reactions are important to give other members the feeling that they can also take a more active position when faced with discrimination, and that resistance is not restricted to emotional and social support. Generally speaking, resistance identities do not reject the perspectives adopted by the other two groups, legitimising and project identities, so they can work as a mechanism of cohesion, keeping the group together despite other diverging views.

#### *Paradigm changes and the project identity model*

The third group of identities described by Castells (2010), *project identities*, can be observed among parents who accept autism as a matter of neurological difference, creating and promoting ideas that value autism while trying to shift the mainstream ableist view of autism as a social burden and disease. As an example, one mother said:

In the past, I used to explain my child's behaviour to everybody, but now I understand that my child has the same rights as all children, and everybody should accept the differences. If someone does not accept it, it is because this person does not know how to live in society.

Although this view, under the scope of the neurodiversity movement, has gained force worldwide, it is still limited among parents in Brazil, and is more common among groups where the majority of members are autistic. One of the reasons that may explain the lack of access to the neurodiversity view in Brazilian society, is that much of the material published

is only available in English. Moreover, the Internet is the venue for neurodiversity and there is still a great digital divide in the country, not so much in terms of Internet access, but more in terms of digital literacy, which limits how people use the Internet, often constrained to a couple of popular websites, mostly social media.

Furthermore, we can observe the neurodiversity perspective in the community studied, although not in really popular posts. Subjects related to neurodiversity can be found in topics that show parents who are proud of their children and say that they are learning valuable life lessons because of their child's autism. A father said:

While we think we are teaching them, they are teaching us.

In a longer post, another parent questioned the idea of normalcy by saying:

We are used to always see the 'normal' to the point of forming our patterns of beauty and ignoring the differences. Seeing a child speak naturally, learning to talk at a 'normal' age, eating alone, being independent, are things that don't come naturally when autism is involved. It might be scary at the first moment, difficult, painful, unacceptable. However, if we let it go, we can see how [autistic children] are strong when they can do all those things. Of course I wanted him to be able to fully communicate, to not stim, to be able to run and play as all other 'normal' kids. However, even though he doesn't have all these skills, we are proud of his characteristics. Every step he walks is celebrated, we are grateful for having him.

There are also a few parents, usually highly educated and engaged with disability activism, who regularly promote the social view of autism. Some parents have written about the subject and contributed to the promotion of a positive view of autism in Brazilian society, such as Deusina Lopes da Cruz (2008), Manuel Vasquez Gil (2015), and Andrea Werner (2016), all active social media users in relation to autism. Although these people are influential and articulate, there is still a long way to go in order to make the neurodiversity movement more popular in Brazil. For now, even the online practices that are somewhat connected to the neurodiversity movement barely move to the kind of socio-political articulation that is able to question the current paradigms. Despite the potential presented by social media to empower people and to form dissenting identities, the presence of such a group is still limited. However, the exposure to new information online can foster future changes towards more positive views of autism.

### *Intersecting identity models*

Not all the identities circulated in SACM can be strictly categorised under one of the three groups proposed by Castells (2010). For instance, posts about the sense of tragedy that besets

a family after an autism diagnosis, usually come in the form of grievance narratives, supporting the view of autism as a social burden and disease, and also justifying a claim for social support. These discourses are often about personal and family tragedies of dealing with autism on a daily basis. Common examples are about children who have meltdowns in public or cannot accomplish tasks considered basic according to social norms and standards. Parents relate feelings of powerlessness in dealing with autism. One mother stated how:

If my child were not autistic, it would be really good. There are some moments in which I get desperate; I am tired and tired of fighting against this damn autism. [...] Are mothers of autistic people condemned to suffer?

Another said:

I couldn't stop looking at those [neurotypical] kids in the classroom and asking 'why not my child?' A feeling of powerlessness and self-blame [...] I didn't know that being a mother could be so painful, not because [my child] is autistic, but because of the uncertainties along the way.

These narratives show how parents embody old views of autism that tended to present the mother as responsible for their child's autism, such as the theory of the refrigerator mother, which assumes that autism is caused by the emotional coldness of the mother (Silberman, 2015). Despite presenting a negative perspective of autism, these narratives deserve further attention as a form of social support, as they combine components of legitimising and resistance identities, since people tend to act with empathy towards such subjects and offer their help.

## **Discussion**

Much of the research about social media in relation to oppressed groups focuses on its emancipatory powers and potential to be a democratic venue for public participation. However, the reality of SACM shows that this opportunity is barely used as a way to promote ideological shifts. Even so, the role played by social media among parents of autistic people in Brazil is noticeable. It is through social media that they create ties with others who live the same experience so they can share their daily lives among equals, without the constraints of what society considers normal and the fear of being judged, even if discourses of normalcy still permeate the discussions in the group. They can also narrate their grievance and be accepted and cheered on, showing the importance of resistance identities. This is essential for all members as it creates a sense of family and belonging, at least in the group studied, which is fundamental for parents who carry a courtesy stigma and, hence, are often subjected to social exclusion. It may be even more important in the case of autism, as this condition is

often invisible to people who do not know it, but which can heavily affect the behaviour of autistic people, who in turn may come across as badly educated and their parents irresponsible. Evidence collected from the group shows that, in many instances, parents are mistreated because people do not understand that their children have an invisible disability.

Overall, most discussions we witnessed in SACM expressed legitimising and resistance identities. Despite the frequent posts complaining about the lack of knowledge about autism, which leads to prejudice and lack of acceptance, many members seem not to be aware of the neurodiversity movement as a means of contesting ableism and changing how society sees autism. The frequent appearance of these two identity models can be explained by the fact that the medical view of autism is the first to be offered to parents through the diagnosis of their children, when they are submerged in a universe of medical information while getting little information on the social aspects of disability. The medical view is also the one most promoted by mainstream media and institutions, strongly affecting the minds of people who do not have or are not able to find other sources of information. The strong presence of the resistance identity model is explained by the fact that parents of autistic individuals join online groups about autism mainly to find social support and exchange information. Stigmatised people typically form groups of resistance to help each other to face the challenges of life in a society which values only what is considered normal.

Although the strong presence of the legitimising identity model can be seen as evidence of the power of ableism and normalcy, it can also be understood as an important carrier of social capital through the exchange of medical information which may be difficult to access for some people, given that Brazil is a huge country marked by profound inequalities. Inside SACM, information is exchanged among peers, without requiring the presence of a professional in a superior position, turning the exchange into one that is more affective and empowering (Benkler, 2006) as parents can understand each other's perspective. Moreover, even parents who adopt a legitimising perspective, take part in collective actions to advance how autistic people are treated, a position highlighted by Carter (2009) as a positive outcome of social media usage. Obviously, such actions do not promote paradigm shifts, as they are often more aimed towards medical treatments.

When it comes to improving treatments and accessibility, the legitimising and resistance identity models can also be observed together. As an example, one of the posts observed during participant observation shows a video of a mother complaining about the medical treatment given to her son and mentioning the power of the online community, stating that it has more than ten thousand members who will see what happened to her child as well as the face of the doctor responsible for denying treatment. In such situations, the shared social identity of parents of autistic children and the resistance identity are stronger than all the others and support is given immediately, in the form of both words and practical actions, as

people who lived nearby got in touch to ask for an effective answer from government and to expose the situation.

The offline consequences of the identities perceived in the online environment are another important aspect to discuss. Firstly, just by providing a comfortable venue for parents, social media is able to reduce the stress of dealing with an ableist society and, as already said, helps to strengthen resilience, which is mentioned by parents in the group. Moreover, the exchange of information gives parents tools to better deal with autism as well as professionals who sometimes also lack information and are not prepared to take care of the overwhelming amount of autism diagnoses. Alternative ways of treatment are also effectively shared and used by groups representing all identity models as they neither pathologise autism nor ignore the medical view, and therefore constitute a neutral intervention. For instance, many parents relate good experiences with diet changes and the use of vitamins, influencing other members of SACM to do the same and even leading to the creation of other online groups just to discuss aspects such as specific diets for autistic people. Moreover, the social ties established online often extend beyond the digital environment, as many parents promote local events or even create associations based on people they meet in the group.

In future research, other directions should be taken into consideration when studying autism and social media, including the formation and exchange of social capital, the use and appropriation of the affordances of each platform, and the formation of ties among parents. Social media has also been used by Brazilian autistic people themselves, and their voices should also be studied, as the Internet is seen by autistic people as empowering, comparable to what sign language means for the deaf (Dekker, 2006).

Finally, the social construction of autism in Brazil is still to be adequately explored by scholars. It is worth addressing how the huge inequalities of the country may affect diagnosis and the meaning of ‘autism’, a word that has been widely questioned by critical autism studies even in the context of the global North, where the criteria to define autism usually emerge from. We hope that the perspectives we observed online may help other scholars to grasp the broader direction the construction of autism is taking in Brazil.

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