

Autism ‘Super Mums’

Affectivity as political capital in special mothering and autism advocacy

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Received: 10 January 2020; Accepted: 14 October 2020; Published: 23 April 2021

Abstract

From the refrigerator mother theory to more recent comparisons to ‘warrior-heroes’, mothers of children with autism spectrum disorders have been historically categorised as emotionally remarkable. Drawing on my ethnographic fieldwork in Portugal, I explore in this article how mothers politically mobilise emotions, characteristics, and acts usually associated with good mothering, such as maternal love, dedication, and sacrifice. While these socially expected phenomena have been addressed as instruments of the relegation of women to motherhood and care labour, I propose a novel look at the value of affectivity in discourses and practices of care and advocacy. I argue that mothers strategically embody and employ their affectivity as political capital to validate their role as expert caregivers and advocates, creating new opportunities to access leading positions within the autism advocacy movement.

Keywords

Advocacy, Affectivity, Autism spectrum disorders, Special mothering, Portugal.

Introduction

Ideologies of motherhood have long placed women in roles and social positions oriented to reproduction and childcare, contributing to the reinforcement of a gendered division of labour (Chodorow 1978, 11; Leskošek 2011). An alleged innately feminine caring attitude, for instance, has been employed to describe women as being naturally drawn to motherhood (Apple 2006; Bassin, Honey, and Kaplan 1994), and ideals of 'good mothering' (Thurer 1994) and 'intensive care' (Hays 1996) have dictated mothers' identities by requiring them to selflessly devote themselves to their children. Disability scholars have further explored this topic and pointed out that mothers of children with disabilities are judged far more harshly than mothers of typical children with regards to their mothering skills (Ryan and Runswick-Cole 2008). Not surprisingly, literature on mothering children diagnosed with autism spectrum disorders (ASDs) features topics like chronic maternal stress (Davis and Carter 2008; Pottie and Ingram 2008; Tehee, Honan, and Hevey 2009), depression (Benson and Karlof 2009; Osborne and Reed 2010), and mother-blaming and social stigma (Gray 1993; McDonnell 1991).

In this article, I explore mothers' experiences of living with, taking care of, and campaigning for their autistic children in Portugal and show how they construct scripts of motherhood and advocacy commitment. My argument is that, while rejecting the long-lasting blaming beliefs to which they have been subjected (Caplan 1998), mothers navigate and reframe the manifold facets of the good-mother ideal and strategically mobilise a new archetype known as 'warrior-hero mother' (Sousa 2011). In their narratives of caregiving and advocacy dedication, these mothers ground their resilience and strength in their unconditional love for their children. Love fuels their special mothering and autism advocacy journey. By addressing emotions through the theoretical framework of the 'affective turn' (Clough and Halley 2007; Gregg and Seigworth 2010), I suggest that mothers intentionally employ an affective lexicon as political capital in order to be publicly recognised as loving and skilful caregivers and to legitimise and reinforce their role as autism experts. Moreover, thanks to social media, mothers now play a more active role in shaping the debate over disability issues. This increased involvement in the public arena foresees, in my view, a greater access to leading roles within the Portuguese autism advocacy movement. Considering the current state of the Portuguese disability rights movement, I argue that this circumstance is crucial. Beginning in 1933, the *Estado Novo* dictatorship prevented the development of any form of political activity or social movement until its fall in 1974; the following 'systematic lack of coherent legislative change' resulted in disabled people's social exclusion and poor health conditions (Fontes, Sena Martins, and Hespanha 2014, 7–8). After 1974, the revolutionary climate and the abolition of legal constraints on collective action fostered the birth of diverse grassroots initiatives such as the

Associação dos Deficientes das Forças Armadas (ADFA) [Armed Forces Disabled Veterans Association], the first disabled people's association that emerged in response to a huge number of wounded soldiers returning from colonial wars on the African continent (1961–1974). While the Portuguese disability movement has so far fought for so-called 'first-level demands' (Fontes 2014, 1403), namely basic rights such as health and education, the movement has recently succeeded in turning disability 'from a private and family issue into a public issue and to inaugurate a new culture of rights as an alternative to the culture of pity and charity that had dominated most disabled people's lives' (idem, 1407). My work tries to capture the development of this new phase of 'second-level demands', more targeted toward and attentive to disabled people's social and political rights.

Before developing my argument, I will describe my fieldwork in order to help readers contextualise the presented data. This paper emerges from my PhD research project on the parent-led autism advocacy movement in Portugal, in which I carried out 14 months of fieldwork in Portugal among 19 disability rights activists (15 mothers and four fathers). All my interlocutors were Portuguese citizens in their late 30s and 40s, and mainly hailed from the working-class and tertiary milieus. I met my interlocutors in different ways: via the *Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo* (APPDA) [Portuguese Association for Developmental Disorders and Autism]; through parents suggesting other potential subjects from among their acquaintances (so-called 'chain-sampling'); and, since most autism support and advocacy communities are hosted by social media platforms like Facebook (Clifford and Minnes 2013), I also conducted a netnography (Kozinets 2010) of online Portuguese-speaking groups led by parents. I created a specific Facebook profile using my real name that clearly stated that I was an anthropologist working on autism advocacy. In addition to contact through follow-up chats and online interactions (Hine 2015), my interlocutors and I met in person during autism events (e.g., conferences and celebrations), public gatherings, and in their private houses. I also participated in numerous advocacy-related actions, such as marches and through parliamentary questions. I have conducted non-structured and in-depth interviews during both face-to-face encounters and computer-mediated interactions (Bowler 2010), for which interlocutors granted me explicit consent; their participation was voluntary and their names are hereby pseudonymised to secure their anonymity.

In the sections below, I will first address how the aforementioned 'warrior-hero mother' trope first emerged and then illustrate how mothers of autistic children mobilise their affectivity as a driving force in both their special mothering and advocacy commitment.

From bad to hero: the changing face of mothering ideologies

The birth of parent-led autism advocacy during the 1960s and 1970s played a crucial role in the emergence of different explanatory theories of autism (Feinstein 2010). Parents harshly criticised the psychoanalytic approach, which understood autism as a child's defence against a rejecting mother (Bettelheim 1972), for spreading mother-blaming assumptions and in turn presented themselves instead as loving caregivers and experts about their children's condition. Through their advocacy campaigning, they also succeeded in implementing childcare services and early intervention programs. Indeed, up until the 1960s, in many western countries children with physical, sensory, and developmental disabilities were either placed in private residential institutions or kept at home with no professional care provision. In Portugal, where my study is based, the first autism organisation, the *Associação para a Protecção às Crianças Autistas* (APPCA) [Association for the Protection of Autistic Children] was founded in 1971 by parents who supported a biomedical understanding of autism over the psychoanalytic explanation and who fought to secure their children's basic education through the creation of special education schools and programs (Lo Bosco 2018).

Overall, the establishment of autism advocacy organisations and the intense parental criticism of the psychogenic origin of autism, together with the growth of epidemiological and statistical studies in child psychiatry (Evans 2013), have contributed to the emergence of a biomedical understanding of autism. By addressing the impact of parental advocacy in scientific research, scholars have pointed out how families have often anticipated paradigmatic shifts in the understanding of autism (Silverman and Brosco 2007) and, thanks to their monetary support, fostered in the late 1980s the later reappraisal of autism as a highly variable neurodevelopmental condition (Grinker 2007). The attribution of a biomedical aetiology had a crucial impact on the implementation of behavioural and developmental therapies, for such therapies are precisely based on the idea that, through therapy, autistic children can improve their social, adaptive, and behavioural skills (Ospina et al. 2008). In this regard, both approaches emphasise the influence of familiar, affective, and social environments in improving children's autistic symptoms and traits. Mothers' love and emotional involvement were thus turned into therapeutic tools *par excellence* and key features of so-called 'special parenting' (Silverman 2012). Engaged in full-time, expert, intensive parenting, 'bad mothers' finally became brave and good mothers (Knight 2013).

Considering autism's aetiological path, the biomedical epistemological shift described above has undoubtedly had a huge positive impact on mothers, who had historically been blamed for their children's autism (it was presumed they had

poor parenting skills). However, this change did not entirely free mothers from being the targets of surveillance or from being judged as not good enough. Behaviourist and developmental approaches target the mothers of autistic children by arguing they must do more to develop healthy and affective relationships with their children. Called upon to devote unlimited time to their children's needs and rights while disregarding all self-interest (Knight 2013; Landsman 2009), mothers are frequently portrayed by media as 'tireless campaigners [...] with resilient determination' (Kingston 2007, 16). From these societal expectations regarding mothers' intensive and long-term commitment to 'expert parenting' has ultimately emerged a new archetype known as the 'warrior-hero mother' (Sousa 2011) or 'child-saving hero' (Waltz 2015). According to this new ideal, mothers of children with disabilities are seen as solely responsible for their children's wellbeing and are expected to be like 'soldiers with expert, specialised knowledge in varied medical and nonmedical fields, including law, education, behaviour analysis, pharmacology, sensory integration, motor therapies, and bureaucratic minutia. These represent divergent skills sets that require sizable commitment of time, money, and education' (Sousa 2011, 239). Mothers' guilt for having been considered the source of their children's autism has then been replaced by the crushing responsibility for their children's development. Now more than ever, mothers are compelled to prove their mothering skills, to work tirelessly, and to selflessly take care of their children:

No longer the abjected 'refrigerator-mother,' today's 'autism mom' is supposed to be a child-saving hero, expected and encouraged to do anything and everything in pursuit of normalcy, from special diets to special schools, from medications to therapeutic toys. The discourse, however, remains one of covert parental guilt: if your child becomes an autistic adult, it's your fault because you failed to do enough to save him or her. The autism mom must position herself as a heroine (Waltz 2015, 355).

Whilst helping discredit the blaming imagery of the 'cold' and unaffected mother described in the 20th-century psychogenic theory of autism (Bettelheim 1972; Kanner 1943; 1949), the new heroine-mother ideal is anything but emancipatory as it reproduces the same good-mothering expectations. Instead of disappearing, the mother-blaming discourse, so persistently intertwined with the history of autism, takes on a more subtle shape by shifting its charge from the etiological to the therapeutic sphere and exposing mothers to a wider scrutiny as their care skills, parenting expertise, and advocacy involvement have gained more visibility through mass media platforms (Sousa 2011, 239). In this regard, social networks and the internet, while acting as sources of information, mutual support, and empowerment, may also contribute to the spread and reinforcement of oppressive gender-based stereotypes (Madge and O'Connor 2006). Considering all these

aspects, in what follows I will illustrate mothers' caring and advocacy experiences and highlight how, in their narratives, they *strategically* employ an affective lexicon, which refers in part to this new 'heroic nuance' of the good-mothering ideology. While this trend is certainly a consequence of the enforcing of good-mothering expectations, I suggest looking at how women actively navigate the demands of this oppressive ideal and manage their everyday parental responsibilities within disabling environments.

About mothers' strength and self-confidence

Most of the women I encountered during my research spoke about their journeys of raising autistic children by recalling the moments of diagnosis. Diagnosis represents a common significant moment of these women's narratives, and seemed to have had a profound impact on their subjectivity, parenthood, and expectations of family life. Indeed, although the explanatory models they were offered regarding the causes and traits of their children's autism diverged in significant ways, each of the mothers referred to the moment of diagnosis as a 'turning point' in their life and recalled it with mixed feelings ranging from grief to relief. For instance, some of the mothers welcomed the diagnosis as a blame-free explanation of their child's unusual behaviours or as the final proof of their intuition, while others remembered it with anguish and worry. Nevertheless, moments of diagnosis for the majority of women interviewed ultimately translated into an opportunity for personal growth. Consider my first meeting with Barbara, mother of 14-year-old teenager Eduardo and a very proactive user of *Os Amantes de Saturno* [Saturn's Lovers], one of the main Facebook-based autism advocacy and mutual support communities for parents, which I attended during my nethnography. Within this online community, Barbara was the one who, more than anyone else, posted motivational quotes for parents who asked for support and guidance after having recently learned their child(ren) had autism. When I met her in person, she wanted to be sure that I heard the story of her motherhood journey with Eduardo from the beginning. She described the diagnosis moment as a 'dramatic plot twist':

A long time has passed since then and I still feel that tingling sensation. [After the diagnosis] you gradually start to see the reality and heal from the disenchantment of not having got that cute and beautiful baby that all mothers want and after this mourning ... well, mothers are strong and that's why we finally start fighting for our real child! It's like an epiphany!

Sitting in a coffee shop and enjoying orange juice while waiting for Eduardo, who would shortly get out of school, Barbara spoke with a fierceness in her eyes about several episodes in which she'd had to replan her life to accommodate her son's

needs. For instance, she'd moved to a smaller apartment in a neighbourhood with a 'safe school' for her son. She wanted people to know that 'being a mother of an autistic child is not easy' so that they understood how much effort she had put into raising her son and how she would continue to do it for the rest of her life. By mobilising a narrative that highlights her strength in facing reality and in embracing her child's autism, Barbara presented a version of herself that could reasonably expect to be recognised for her special knowledge, care abilities, and commitment, as well as for her resilience in adjusting her daily routines and life plans according to Eduardo's changing needs.

Raising a child with special needs also entails learning to manage the tangled bureaucracies of the public welfare and healthcare systems, as well as how to navigate learning programs and special education services. While this represents a demanding and time-consuming process, it is often described by mothers as an opportunity to build self-confidence and for personal growth. Laura, for instance, a young woman who I first met thanks to a mutual friend, opened up about her tough journey of mothering Oscar, a five-year-old non-verbal autistic child who, at the time of my research, was suffering from meltdowns caused by sensory overload:

Being Oscar's mother is a life-long learning [journey] because everything is changing and science comes up with something new every day [...] Sometimes I'm literally locked in front of my computer doing my research, scheduling medical examinations, chatting with my son's speech therapist, but behind all this stress I like to know how things work, learn about medicine, for example— all this made me a smarter woman.

Laura eventually opted for a part-time job and enrolled in a postgraduate evening course in child psychotherapy. She wanted to capitalise on her knowledge and experience in order to develop her career and learn more about Oscar's challenging behaviours.

Meltdowns are a common occurrence in autistic children but are still misunderstood as simple tantrums or bad manners, which mothers are often judged for. Like Laura, Irene is struggling with her son's manifestations of outward distress. She stopped hanging out with friends and tells me she feels embarrassed in public spaces for her son's screaming and stomping. She feels powerless to bear strangers 'who dare give advice or judge' her mothering skills. Irene's feelings are similar to those of many mothers I encountered during my fieldwork and reveal how many mothers have internalised good-mothering expectations, which can be especially painful when they have to handle their children's defiant behaviours in public. While the judgments of others often evoke feelings of shame, guilt, and self-doubt, mothers told me they had also experienced feelings of 'superiority to others'; Irene, for example, told me about an episode in which she openly reacted to

people's scrutinising stares: 'It's like Western movies. I looked straight into their eyes. You have to understand me! I don't yield to people's ignorance. It's not me who is going away this time, if my child's screams and weird noises are bothering you ... so look for another place!'

This open deployment of emotions can also have a significant impact on the relationships between mothers and health professionals. In many of my interviews, mothers complained that doctors underestimated their perspectives on autism or accused them of being excessively anxious. This lack of recognition and appraisal can lead to some tensions. Silverman (2012, 17–18) argued that parents' affective investment in autism knowledge 'can bolster and at the same time weaken claims of objectivity and knowledge. Parent activist groups find the scientific work that they support marginalised because of their non-objective, non-neutral position. Their work nonetheless suggests that partiality and objectivity are techniques that are not always in conflict'. Laura's experience in this matter is quite interesting as she argued that the feeling of been constantly scrutinised by her son's doctor ended up pushing her to acquire new information about autism and utilise it:

Now, with the internet, you can say to doctors, 'No, you're wrong because I read this and that.' It's an act of rebellion because Portuguese people are not used to complain[ing] nor confront[ing] doctors [...] I know things because I feel them, but also because I study! Mothers study, read, and learn, they understand things, so doctors are no longer feeling so omnipotent now! [...] My fears have been guiding me [...] You need the love and care that only mothers have [in order] to really understand.

Drawing on different information sources (such as scientific papers, blogs, YouTube videos, scientific sites, and forums), which are now more easily available thanks to the internet, mothers are able to develop authoritative voices and resist being unquestioningly compliant in the face of professional expertise. On one hand, confronting doctors' knowledge and competing with their authority could be seen as a positive way of empowering patient's families against medical paternalism; but, on the other, building up cooperative relationships with doctors is important for providing the best healthcare possible. Aware of the tension inherent in her claims to authority, Laura's purpose is to highlight how mothers' opinions have been for a long time belittled for being allegedly emotionally grounded and thus unreliable. In response, Laura interprets her emotions as a 'way of knowing' (Silverman 2012, 3) and as a valid tool of expertise to which she appeals to prove her ability to identify and appropriately respond to her child's needs.

Considering these ethnographic cases, I suggest that mothers attribute a positive value to their emotions in order to take back into their own hands that same affective lexicon that has been widely used against them. Silverman has also

addressed the use of love in the context of autism research as 'the source of specific, focused and committed knowledge', despite it having been seen in the past 'as a liability or a barrier to reliable knowledge' (ibid.). By exploring how parents fight to be counted on to speak about autism and contribute to its understanding, the author argues that 'parents and their allies say that emotional knowledge enables them to observe and attend to their children in the right way, guides them in medical decisions, and helps them make the right choices for the person whom they love' (ibid.). The case studies I have reported also illustrate how mothering a child with special needs presents a range of unusual and demanding requirements; it is often described by mothers as a path studded with new challenges. In this respect, I agree with Knight (2013), who suggests that mothers of children with disabilities are expected to have dedication, patience, strength, and resilience, and to perform their caring role with tireless energy. In my analysis, mothers also experience the burdensome effects of these social expectations as part of a process that eventually strengthens their determination and self-confidence as activists. In other words, they understood their intense affective labour as an integral part of a personal and passionate commitment to the autism cause. According to Laura, for instance, mothers' dedication to their children and their efforts to adapt and accommodate their children's needs are bound to their advocacy commitment insofar as:

being an attentive and loving caregiver is already being an activist. While we [mothers] love and care [for our children], we act to change things, we *capitalise* every occasion, so that there are no frontiers between the ways in which we love, we care and we advocate for our children's rights. [Italics mine.]

In the next section, I will explore in more detail what mothers *do* as autism advocates and how they employ their affective labour as a driving force for political action.

I love, I care, I advocate

The discrimination faced by people with disabilities is embedded in a complex and interwoven web of educational, social, and personal barriers that prevent disabled people's full, effective, and equal participation in society. Mothers typically said it was after being confronted by society's disabling environments that they first came across local advocacy associations. Through such associations they were able to get in contact with other parents who shared similar concerns and campaigned for their children's rights after having witnessed similar discriminatory episodes. During my fieldwork, I attended different advocacy events and helped publicise them, especially through social media and my network of contacts. On May 2015, I took part in the solidarity walk organised every year by the *Associação*

Portuguesa para as Perturbações do Desenvolvimento e Autismo (APPDA) [Portuguese Association for Developmental Disorders and Autism] to collect funds for its future activities. That year, at least 30 people joined the walk inside the Monsanto Forest Park, the largest green patch in Lisbon. I enjoyed walking the trails and talking to many different people—parents, educators, teachers—until the laughs of a group of parents eventually caught my attention. When I approached them, I found out that they were laughing about some jokes they had made during a picnic they had organised with their respective children a few days before. After I introduced myself and talked a bit about my work on autism advocacy, they pointed almost in unison to a woman in her early forties, whom they described as a ‘natural-born warrior’. And indeed, Raquel was truly fierce; she first approached a parent advocacy group after her son, Fernando—who, at the time of my research, was 14 years old—was prevented from joining in with his school’s summer activities:

My son didn’t join his classmates for the summer camp because the principal argued that it was better to find one [summer camp] for kids with special needs—you know, one of those ghettos where our children are isolated from their peers [...] So I said to myself, ‘If love makes me so strong to bear what society does to our children, then I can do something for this society!’

Dissatisfied with the responses of formal institutions, such as the National Institute of Rehabilitation and the APPDA (whose activities, however, she has continued to take part), she in 2009 co-founded a parent association called *Dar Resposta* [Give an Answer] whose goal was to promote equal opportunities for people diagnosed with autism and/or other disabilities. Thanks to her engagement in *Dar Resposta*, she soon became the representative spokesperson of the group during interactions with the political establishment, national television, and newspapers. At the time of my research, she was already a well-recognised figure in Portugal’s parent-led autism advocacy movement. Over the years, she has promoted the publication of several autism guides for parents and informative pamphlets to raise public awareness about the disregard, social discrimination, and exclusion that people with disabilities are still suffering in Portugal. Among many other activities, members of *Dar Resposta* participate in study and discussion groups.

Some of the parents who I first met through the *Os Amantes de Saturno* [Saturn’s Lovers] online community also belonged to *Dar Resposta*, including Barbara. Here, she was responsible for collecting parents’ complaints and proposals and for drawing up an annual report to send to education boards, the health commission, and other local government bodies charged with implementing social policies for autistic people. According to her, parents’ first-hand experiences with their autistic children’s health and education issues can crucially contribute to more

comprehensive and effective institutional responses to the different needs that such parents and their children may face.

Online petitions represent another instrument used by parents to seek public attention and mobilise potential supporters. On *Dar Resposta's* website, for instance, there is a specific section where parents can find a list of petitions asking for a law or policy change. Slogans like 'be part of the change' or 'the time has now come' aim to encourage people to commit themselves to change their society into a more inclusive, compassionate, and just place for autistic people. As Raquel and Barbara explained while we were on the subway on our way to a meeting of activist parents (to which I was also invited), petitions are also an important way to evaluate a society's responsiveness to a cause and to draw attention to specific problems faced by disabled people or concerns currently overlooked by the local government. Autistic children, for instance, are particularly vulnerable to bullying in national schools, where discrimination practices become easily normalised (Rowley et al. 2012). This issue was initially raised within the *Os Amantes de Saturno* group by Olga, an activist mother, who later described me a specific episode experienced by her child:

Some mean guys at school spat on my son because he was trying to interact with them, they have crossed the line! [...] What made me mad is *why* did they do this? for fun? none of their parents ever called me, this hurts me, but I'm stronger than ever!

This awful episode prompted her to collate similar stories shared by other parents regarding the psychological impact of bullying and run a petition requesting the Portuguese parliament to finally pass an anti-bullying law. Despite generating a huge media debate, the petition failed to achieve the minimum quota of 4000 signatures required for parliament to convene a plenary session and discuss a bill.¹

A different outcome occurred in January 2015, when *the Plataforma— Associação de Pais pela Inclusão* [Platform—Association of Parents for the Inclusion] ran a petition for the revision of a 2012 ordinance² that stated that students over 15 years old with special educational needs (SEN) who had attended primary school with an adapted curriculum were only entitled to attend high school for no more than five hours per week. The remaining 20 hours per week were to be dedicated to programs of vocational training provided by public or private institutions. A few weeks after the launch of the petition, the Portuguese teachers' union FENPROF announced its support, which led to a significant increase in the number of

1 Article 52 of the Portuguese Republic's Constitution and Article 232 of the Portuguese Parliament's Procedures Rules.

2 Ordinance no. 275-A/2012 of the Portuguese Ministry of Science and Education
<https://data.dre.pt/eli/port/275-a/2012/09/11/p/dre/pt/html>.

signatures. On the day of the plenary session, I met Olga, Barbara, and Raquel together with other mothers in front of the neoclassical São Bento Palace, the seat of the Portuguese parliament. After passing through a security checkpoint, we entered a central hall filled with deputies' seats. From there, we went to the upper gallery, which consisted of three circular sections of benches. The session eventually resulted in the revocation of the ordinance for having denied students with SEN equal opportunities in achieving their academic potential. At the end of the day, sitting at a cafe to celebrate the victory, I expressed to all of them my admiration for their determination in denouncing the 'countless, pervasive, and hidden injustices', as Barbara said, that their children still experienced in society. Pleased by my appraisal, Raquel argued that society should recognise the ways in which mothers' love for their children pushes through crucial societal changes that every citizen benefits from:

I have my personal force [...] the love for my child and the absolute will to fight for his rights; this is what drives me to be an activist [...] You know, discrimination has multiple facets, from mockery to indifference [...] advocacy is an everyday practice and ultimately concerns all human relationships. It affects everyone.

Despite the huge steps taken, social changes usually occur over a very long period of time. In May 2015, a report from the Disability and Human Rights Observatory, which aims to 'follow-up disability policy development in Portugal and to promote participatory processes of disability rights monitoring and implementation', denounced the failure of current policies on inclusive education and the substantial lack of material and human resources for students with SEN in public schools (ODDH 2015). The coordinator of the Observatory, Dr Paula Campos Pinto, declared on national TV that Portugal's 'institutionalised resistance' to the social inclusion of people with disabilities was irremediably compromising the futures of younger generations (RTP News 2015). This dramatic situation arose to a great extent due to the austerity measures that the Portuguese government adopted to pay back the huge financial loans offered by the International Monetary Fund, the European Central Bank, and the European Union to avert bankruptcy and the insolvency of the state following the global financial crisis of 2007–2008.³ The impact of the public sector reforms of that period—from housing and labour markets to pension, education, and healthcare systems—on families' social and economic conditions resonate today. However, disability scholars have argued that even before the economic crisis, the Portuguese welfare system showed 'structural inadequacy' in providing special education and healthcare services for

3 At the end of 2009, the Greek economy faced one of its most severe government debt crises, as did Ireland in 2010, Portugal in May 2011, and Cyprus in April 2013. In the following years, Spain and Italy were also forced into austerity through reforms and financial measures.

children with disabilities, which eventually led to lower levels of education, employability, and labour income (Portugal et al. 2011, 277). The austerity policies following the financial crash further exacerbated already-entrenched socioeconomic disparities by introducing budget cuts in the areas of health, education, employment, and social assistance. For this reason, 'families have been urged to assume responsibility for care, which accentuates their economic and social vulnerability, reinforcing the dependent role of people with disabilities in the family and in society' (Pinto and Teixeira 2012, 26). In light of this, activists like Irene have publicly condemned the widespread and misleading idea that parents of children with disabilities benefit from a wide range of public services: 'Families bear almost entirely the costs [related to ASDs services],' Irene told me, 'and I even know parents who cannot afford to pay for their children's speech and occupational therapy.' According to the last national study on the quality of life of families living with autistic people up to 25 years old, families spend an average of €371 per month on healthcare (medicines and therapies), of which less than half is eventually refunded by the state (Cottinelli Telmo 2013). Moreover, the study addressed the lifetime social costs associated with autism (such as family's leisure activities and parents' employment); 23% of parents are forced to work part-time and 70%, mainly women, have had to resign from a job in order to care for their children. This data openly discredits the idea that people with disabilities are a burden on the public budget and that, as Irene pointed out, families take advantage 'shamelessly' of welfare services: 'In response to this kind of discriminatory and stereotyped assumptions and to the blatant violation of the human rights in this country,' she said, 'mothers should now fight more than ever for their children.'

Beyond giving support to parents' claims regarding disability-related issues, Irene engages in autism advocacy to 'bring knowledge to the community' so that other mothers might benefit. On several occasions, she invited me to take part some of her activities. For example, we attended a training course on how to file a discrimination complaint at the National Institute of Rehabilitation (INR). Our plan was to share all the information we gathered with the *Os Amantes de Saturno* community. We then wrote a *vade mecum* containing the list of paperwork to fill in, the names of the public institutions appointed to receive the trials (i.e., the Ministry of Education and the General Inspection of Education or an ombudsman), as well as the legislative measures to mention in the complaint (i.e., the Non-Discrimination Law 46/2006, the Special Education Law, and the Dispatch 7-B/2015 on compulsory schools' enrolment conditions and class formation⁴).

4 For more on the Non-Discrimination Law (Law 46/2006), see https://www.inr.pt/bibliopac/diplomas/lei_46_2006.htm; for the Special Education Law (Law 3/2008), see http://www.inr.pt/bibliopac/diplomas/dl_3_2008.htm; and for Dispatch 7-B/2015, see https://www.portaldasescolas.pt/imageserver/plumtree/portal/matnet/DespachoNormativo_7B_2015.pdf.

Mentoring is one of Irene's advocacy areas, as she recognises her role in inspiring other mothers to become change-makers and part of a collective voice:

I know how hard mothering a child with autism is and I want to help mothers to feel confident—and why not?—to turn themselves into influential women! I'm glad if I can make a difference, especially because you need time and nerve to understand bureaucracy and a lot of creativity [laughs]; my friends say that I like to study the legislation, you know, to learn those horrific bureaucratic processes but ... I mean, I need to know this stuff if I want to fight for my child [...] I need to be strong, and he [Osvaldo, her son] gives me the strength to go forward, I love him unconditionally.

Irene's case—much like those of the other women I discussed previously—shows what mothers are capable of when responding to the social discrimination, marginalisation, and unequal treatment experienced by their children in society. They show not only dedication to intensive care and special mothering, but also to engagement in autism advocacy, itself articulated through a narrative that refers consistently to emotions and unconditional love and highlights the affective grounds of their advocacy commitment.

About affective labour and (un)disciplined subjects

So far, I have emphasised how mothers refer to emotions to explain, relate, and provide accounts of their care and advocacy practices. I argue that mothers employ their affectivity as political capital; that is, as a resource fostering their agency as parents, caregivers, and committed advocates. Following the approach known as 'affective turn' (Clough and Halley 2007; Gregg and Seigworth 2010), which highlights the productive and generative roles of affects, my aim is to acknowledge mothers' emotions as motives or 'forces' able to affect their capacity to act upon the world and to be 'moved by and to move others' with regards to the issues that they draw into view (see Athanasiou, Hantzaroula, and Yannakopoulos 2008 for a review). Scholars have already explored the wider political entanglements of emotions within different research contexts related to autism; for instance, Belek has explored how autistic self-advocates use emotional rhetoric as a 'political act' (2017, 62) in order to promote a positive understanding of autism and to restructure the power gap by claiming the autism label in opposition to those who claim to speak on autistic people's behalf. In a different context, Fitzgerald (2013) has addressed the emotional narratives of researchers working on the neurobiology of autism to highlight how research practice—beyond its laboratory-based and conceptual work—implies a relevant form of emotional labour and commitment. This body of scholarship shows how affectivity is always tangled up in the socio-political contexts subjects live in. We perform and materialise emotions

in our everyday discourses and actions, revealing the 'affective nature' of our interests and concerns (Ahmed 2004). Indeed, emotions shape our motivations and inform our positions regarding societal issues. With this in mind, my attentiveness towards emotions lies exactly on what they do; that is, how they move people to act and change. Affectivity is deeply connected with the idea of transformation (Massumi 2002); it triggers processes of transformation of the self, as well as of people's intentions and interests. My focus on mothers' everyday practices aims to precisely capture the affective and transformative nature of their actions and experiences, a reading that echoes Antonio Gramsci's definition of the 'political' as a process of 'molecular transformation of subjectivity' in social interactions (1994, 258–59).

The ethnographic field is an arena for intersubjective interaction, transformation, and self-questioning as well. Combining participant observation with in-depth interviews allowed me to build and maintain engaged and emotionally grounded relationships with the people I met in the field. Attending to and actively participating in most of the steps mothers took to care and campaign for their children evoked in me a sense of esteem and admiration that has increased over time. However, I was deeply aware of how the demands of special mothering and advocacy commitment represent an unpaid workload that compound the exploitation and underestimation of women's labour force (McDowell 2009). In our conversations, mothers complained that they had been unemployed for too long or forced to resign from their jobs or accept part-time contracts in order to devote their time to childcare. On this matter, Hardt (2007) proposed the term 'affective labour' to refer to 'gendered forms of labour that involve the affects in a central way, such as emotional labour, care, kin work, or maternal work [and] engages at once with rational intelligence and with the passions or feeling' (idem, XI). Analogously, care and advocacy represent examples of so called 'zero-work' (Staples 2007) that is, activities that, despite producing knowledge, relationships, and affectivity, fall outside of wage work (idem, 119). Incorporated into the sphere of gratuitousness, the affective labour inherent in these activities is not regarded as a form of social production (Ryan and Runswick-Cole 2009, 52) but is naturalised as a feminine duty. For these reasons, 20th-century feminist studies have interpreted 'intensive mothering' ideology—a way of living motherhood that is self-consciously committed to child-rearing (Hays 1996)—as a form of violent accomplishment of a gendered system of domesticity (Williams 2000) aimed at swallowing up women's desires, pleasures, and personal purposes. Since the publication of Hays's work, scholars have suggested how parenting cultures are multiple and have very different implications for parents (see Lee et al. 2014 for a review). In this regard, Faircloth (2013) has illustrated how mothers who advocate for long-term breastfeeding consider their 'choice' as 'the natural thing to do'. While they naturalise the gendered divisions of care labour implied in so-called

'attachment parenting' (a style of parenting which involves long-term care), they also claim breastfeeding is a practice that positively affects their identity as mothers. Looking back at my fieldwork, I recall that Raquel explained the prevalence of mothers as both primary caregivers and advocates as a consequence of the gender disparities inherent in cultural conceptions of families. While critical of mothers 'voluntarily' adhering to these cultural gender norms, she nevertheless defined as 'typical' some of the skills that are generally attributed to them, such as resilience and devotion.

Following these theoretical hints, I acknowledge that women are gendered individuals subject to diverse regimes of motherisation, themselves based on biomedical knowledge, patriarchal ideology, societal assumptions, and the family itself, which represents another key institution through which the state reinforces its control over women's bodies (Foucault 1965, 1977). Despite being incorporated by women in ways that are often silent and subtle, these disciplinary regimes have a fluid and transformative character: their target 'is not the production of subjects whose behaviours express internalized social norms; rather, [their] control aims at a never-ending modulation of moods, capacities, affects, and potentialities' (Clough 2007, 19). In my analysis, mothers both comply with and resist this corpus of biopolitical strategies in that they both embody and disobey any attempt of behaviour codification. Feminist scholars have recently developed a theory of care and motherhood which neither romanticises these experiences nor reads them as forms of self-sacrifice (Green 2011; Rogers and Weller 2012, 5). I then suggest that mothers of autistic children are (un)disciplined subjects because they navigate in their own ways the social and cultural ideologies of good mothering and the moral values attributed to it. Their supposed compliance with the complex of disciplinary practices that surrounds the mothering ideal is, actually, circumvented, resisted, or even subverted by their everyday behaviours, attitudes, choices, and practices. In a sense, being a mother is a 'way of doing' to the extent that, like gender (West and Zimmerman 2002), it takes place in social interactions and through performative acts (Butler 1988, 519). If ethnography helps researchers understand why and especially what moves people to do what they do (D'Andrade and Strauss 1992), I then acknowledge that in my fieldwork mothers are shown to internalise and simultaneously reject the mothering myths from which they build their own expectations of motherhood. They do not represent mere replicas of sociocultural models or 'a direct precipitate of cultural constructs' (Strauss 1992, 1–2) and nor do they represent themselves as mere instruments of their children's needs. There are also mothers who do not or cannot succumb to the high demands of special mothering. In my analysis, while they criticise society for its wrong or outdated expectations, mothers still try to do all they can to be the 'best mother possible', an ethos exemplified by Irene's words:

You know, we will always fall short of what people demand of us, so we have to choose: we can suffer from these pressures or we can decide that some aspects [of the 'perfect mother' ideal] are impossible to attain or are even outdated [...] No one today is willing to give up one's personal freedom or aspirations and motherhood is also funny and we must enjoy the good aspects as well ... so when I feel sad or guilty, I think that maybe these feelings come from wrong expectations or old ways [of looking] at a mother's work.

Although fitting in their own ways to a model of childcare and advocacy engagement, mothers are also acutely aware of being subject to gendered social expectations, unpaid labour exploitation, and arrangements that position their 'heroism'—as Barbara argued—as the flipside of the state's inability to provide healthcare and educational services for people with disabilities. Similarly, mothering and campaigning for an autistic child is described by Raquel not just as a parental duty but also as a personal and political commitment before a disabling society that still fails to recognise autistic children as citizens of equal worth. While the warrior-hero archetype intensifies mothers' moral and social responsibilities regarding their children's rights, mothers strategically mobilise that heroism (itself defined by full-time involvement, dedication, and love) to portray themselves as 'models' and 'fighters'. This archetype is, in other words, actively employed, especially in the public sphere, to reinforce mothers' social roles and increase their opportunities in the political and parent advocacy spheres, as Raquel's case shows. Mothers also claim to be the ones who have authentic knowledge about their children's condition because of their parent-child relationship and emotional proximity. In this case, they draw on the affectivity lexicon to ground the distinctiveness of their abilities and validate their role as caregivers and autism experts. The public deployment of love as a distinctive element of their expertise is especially significant if we consider how, since the late 19th century, mothers' expertise in child-rearing has been gradually delegitimised; in their place have come psychiatrists, psychologists, and paediatricians (Apple 2006). By reassessing childcare as an acquired and elaborate set of competencies, mothers are nowadays helping to demystify and subvert any attempt to romanticise 'mothering' as a 'natural attitude' to rearing and behaving in certain ways. Less inclined to accept biomedical professional expertise as unquestionable fact, mothers trust in their intuition and gut feelings; they instead present and trust modes of knowledge gained from experience and from spending time with their children.

In light of this, I suggest that the affective lexicon represents a strategic narrative thanks to which mothers eventually access the public sphere as 'active social agents' (Ribbens 1994, 205–6) and not as mere victims of motherhood ideology. Mothers' roles as caregivers and autism advocates are certainly bound up in wider

forms of gender inequality, but despite these challenging circumstances, mothers continuously construct their own scripts of motherhood through a 'social activist position' (McDonnell 1991, 73) that allows them to turn their struggles into a collective call for social change. As Ryan and Runswick-Cole have pointed out, the 'high level of advocacy' of mothers of children with disabilities translates into a form of collective activism, which is itself 'a mechanism for expressing, in a "selfless" way, the mothers' aspirations and needs [and allows them] to ask for help while at the same time managing their image as the "selfless carer"' (2009, 51). This reading promotes, in my view, an image of mothers as engaged social agents, and acknowledges an understanding of motherhood in line with the perspective of critical feminism (Green 2006, 2011). In this respect, besides its positive impact on the disability rights movement, parent-led advocacy has also contributed to destabilising normative prescriptions related to women's roles in society. The positive interlacing of affectivity, care labour, and advocacy commitment subverts, to a certain extent, the traditional gendered roles of a public father and a private mother. No longer confined to the intimacy of the domestic space, mothering, care, and advocacy become fields of knowledge that contribute to a new sense of feminine assertiveness (Johnson 2015; Morrison 2011). By positively embracing the duty of campaigning for their children's rights, for instance, mothers push for a form of social change that intersects with their own goals as good citizens. I remember, in this regard, Irene's emphatic words in describing the value of her heroism for society at large:

My friends say that I'm a warrior because I've never been afraid to give my voice for disabled people's rights in this country [...] A mother is undoubtedly a fighter for her child and I have been a spokesperson for other mothers too, but my fight is also for the good of all of us, [for us] to have a better society and be better citizens.

Conclusion

My fieldwork on parent-led autism advocacy in Portugal shows that mothers have gained a stronger position in the national disability movement and that their campaigns on behalf of their children eventually articulate so-called 'second-level demands' for people with disabilities, namely social equality and citizenship rights. Through the use of social media platforms, they succeeded in bringing greater visibility to current disability issues and in spreading their call for a more inclusive society. My research also shows that the Portuguese autism advocacy movement is built by a plethora of offline and online associations and communities. Compared to autism-related institutional associations (such as the APPDA or the INR), online communities are much more open (teachers, educators, and researcher like me can access them) and allow for information to be easily exchanged and events and

advocacy initiatives to be more easily and inclusively organised. In my view, online communities help also to circumvent geographical boundaries and physical distance, a crucial benefit for those parents who may not have access to local support groups in their residential areas. Overall, if the parent-led autism advocacy movement in Portugal has gained a role in decision-making processes about disability policies, it is thanks to those mothers who have been able to politicise their struggles and call for collective engagement.

Mothering a child diagnosed with ASDs and campaigning for their rights requires a long-term and intensive commitment. Scholars have explored how special mothering and advocacy commitments have resulted in an intensification of 'good-mothering' demands (Caplan 1998; Sousa 2011; Waltz 2015) or, on the contrary, how intensive mothering can be central to the construction of women's identities (Faircloth 2013). In this article, I have instead illustrated how mothers actively navigate the moral demands of fitting into the good-mothering ideology, highlighting how their practices and narratives of special mothering, intensive care, and advocacy commitment play a powerful role in shaping their subjectivity as caregivers and advocates without necessitating the abandonment of their own aspirations. Intensive mothering and advocacy commitment can represent powerful loci wherein mothers construct their own scripts of mothering and engaging as citizens. In particular, I have explored how mothers refer to their affectivity as the driving force for their care and political actions. The affective lexicon informs the complex emotional transformations of their parental subjectivity; it is positively employed to reaffirm their expertise as caregivers and is finally used in the public space and on social media platforms to reinforce their roles as advocates and to bring to the attention of broader society the social inequalities, stigma, and discrimination that people with disabilities still suffer today. My article, therefore, proposes a novel look at how mothers mobilise their affective labour for political purposes and how contemporary forms of mother-based activism can be considered active and transformative ways of acting in the public space. The focus on the political value of mothers' affective labour can bring, in my opinion, greater visibility to their roles within academia and a new understanding of childcare and advocacy as political experiences.

Acknowledgements

I wish to thank all the advocate mothers of autistic children I encountered during my fieldwork in Lisbon who shared with me their life stories in the hopes of communicating their experiences and concerns to a wider audience. I would like to thank my colleagues at the Institute of Social Sciences at the University of Lisbon for comments on an early draft of this article and my partner for his incisive

feedback and support. I am also grateful for the insightful comments generously offered by *MAT's* anonymous reviewers and for the support of the editorial staff. This article is based on research supported by the Fundação Ciência e Tecnologia, Portugal (scholarship grant no. SFRH/BD/84969/2012).

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